

Written evidence

Memorandum submitted by Contact a Family

Contact a Family provides support, advice and information to families with disabled children across the UK. Each year, our helpline and information services assist over 18,000 parents.

Of our enquiries around 1,500 each year concern Special Educational Needs. Contact a Family does not take a particular stance on the mainstream vs. special school debate, but seeks to advise and assist parents in an impartial manner to obtain whatever kind of placement they believe will best meet their child's particular needs.

We also seek to enable parents' voices to be heard by policy makers and to report to policy makers on the concerns that parents express to us. In this way we hope to have a positive influence on legislation and practice.

As part of this, we regularly undertake surveys and research with parents to inform our policy work. In January 2003, Contact a Family carried out a web based survey of parents visiting the Contact a Family website and invited them to tell us about their experiences of the education system and whether they felt that their children had been discriminated against at all.

In total 1,688 parents visiting the Contact a Family website completed the questionnaire. The results are as follows:

What sort of school is attended?

Child at mainstream school	52%
Child at special school	22%
Child at special unit	5%
Child in residential school	3%
Other/not given	18%

Age of child

3-5	20%
6-8	19%
9-11	21%
12-16	24%
17-19	5%
Not Given	11%

How satisfied are you with the overall quality of your child's education?

Very satisfied	25%
Quite satisfied	27%
Not sure/not given	29%
Quite dissatisfied	11%
Very dissatisfied	8%

How well does your child's teacher understand your child's needs?

Very well	26%
Quite well	24%
Not sure/not given	23%
Not very well	18%
Not at all	9%

Does your child get all the extra help they need to make the most of schooling?

Definitely yes	23%
Probably yes	21%
Not sure/not given	21%
Probably not	22%
Definitely not	13%

Has your child been discriminated against in the education system?

Definitely yes	17%
Probably yes	17%
Not sure/not given	30%
Probably not	19%
Definitely not	16%

How aware do you think you are about disability discrimination laws in education?

Very aware	17%
Quite aware	20%
Not sure/not given	27%
Not very aware	24%
Very unaware	12%

It is disappointing, but perhaps not surprising, that only a third of parents could describe themselves as very or quite aware of laws around disability discrimination in education and that a third felt that their child had probably or definitely been discriminated against at school.

We also undertook an exercise to look at all enquiries on education which have been made to the helpline this year January–August 2005 in order to be able to inform the Committee what the current issues for parents are. The Committee needs to bear in mind that parents would not telephone a helpline to report that all was going well with their child's education. The cases reported below are therefore only representative of those parents who are in some form of difficulty with their child's education.

Total associations between enquiries and keywords (within date range)

Education general	183
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Choosing A School	28
Disability Discrimination and Education	17
Education Maintenance Allowance (EMA)	18
Educational Assessment	47
Exclusion From School	12
Funding	9
Further Education	4
Gifted Children	1
Home Based Education	12
Hospital Education	0
Inclusive Education	4
Parent Partnerships	80
Portage	1
Post 16 Transition in Scotland (factsheet)	9
SEN-England (factsheet)	131
SEN-Scotland (factsheet)	9
SEN-Wales (factsheet)	6
Sencos	0
Special Educational Needs Tribunals	13
Special Schools/Special Education	56
Statementing/Record Of Needs	41
Teaching Methods	0
Transition (Education)	16
Transition in England and Wales (factsheet)	47
Total enquiries for Education	744

Of the 744 enquiries for education, we looked in more detail at 94 enquiries where a detailed response was required and we have more complete information in the form of a case record.

20 of these concerned getting insufficient support at mainstream school

For example: A 12-year-old with ADHD was finding his parents' separation difficult to cope with. There had been a history of domestic violence and the mother had fled to a refuge. The son missed quite a bit of school and is now finding it very hard to settle back in to school. Mother has asked the school for support for him but the school aren't even prepared to listen, let alone do anything to help the son. Mother is now seeking an assessment

Four getting insufficient help at special school

For example: A 13-year-old boy at special school has been told he is "too large" to go swimming with the other school children unless his dad comes to put him in the hoist as he is too heavy to lift. Parents are very concerned as he is a wheelchair user and this is the only exercise he gets.

10 cases where the LEA refused to issue a statement

For example: A five-year-old girl was displaying severe behavioural difficulties, lighting fires, cutting through electric cables at home and was disruptive and aggressive at school and violent towards both children and adults. Parents have tried using behaviour strategies but to no effect. Mother dreads going to pick her up from school for fear of being told of yet another incident. There was a discussion with the school about a referral to educational psychology but nothing has happened yet. Despite all these issues, a statement has so far been refused. The family are considering an appeal.

10 cases where the parent was looking for funding for a private placement

For example: daughter with learning difficulties had been attending mainstream, LEA were considering statementing and parents decide she would be better in an independent school. The family are paying an additional amount on top of the fee for additional learning support. This is a struggle and parent wanted advice about whether there were any funding streams which would contribute towards the costs of this.

Nine cases where the parent had not understanding the statementing process

For example: A family were moving from Northern Ireland to the East Midlands. In Northern Ireland they were getting excellent support for their daughter who has visual impairment and other physical disabilities including arthritis. The new school they had chosen had said they could meet her needs. However the LEA have now said that in their opinion the daughter has no additional support needs and can manage perfectly well without assistance. Family are unaware of English law and practice regarding statementing process and wanted information about appeals.

Five cases of severe bullying

For example: A single father bringing up a son with autism. He was attending a mainstream school and moved up to the local comprehensive at age 11. He was being bullied several times a day and was taken to accident and emergency on one occasion. His psychologist wrote to the school to ask them to intervene but the school still denied there was a problem. The child attempted suicide mid way through year 7. The child received no education for over a year and now receives one day per week home tuition.

Three cases where the school was lacking information on dealing with a disability or medical condition

For example: A school requested information on a condition which causes delayed toilet training. The school had been minded to refuse entry to the child until she was toilet trained, unless her mother would come to the school to clean and change her whenever required, and only agreed to reconsider when we pointed out that this may well be viewed as disability discrimination.

Three cases where the parent was considering or undertaking home schooling or tuition

For example: Mother phoned up about a teenage daughter in London with systemic lupus. She receives home tuition combined with part time attendance at school as she is sometimes very ill. She is flourishing on this system and expects to get good GCSE grades. Home tuition will finish at the end of GCSE year and the LEA say they do not provide it for 16–18 year olds under any circumstances. Contact a Family subsequently confirmed with the LEA that this is indeed their position. Daughter wants to continue in education until at least age 18. Parents want to challenge the LEA as this in effect means that seriously ill pupils cannot receive an A level education.

10 cases where the child had been excluded, or was under threat of exclusion

For example: An 11-year-old boy in Greater Manchester with ADHD had been excluded five times since transferring to secondary school. The transition seems to have unsettled him, as he had never been excluded from primary school. He is currently on a four week exclusion. He is statemented and receives 17 hours of support per week but school want more support. The LEA refused and the school said he cannot come back without the additional hours of support they think he needs.

Two enquiries about the availability of particular courses

For example: A young deaf woman with moderate learning difficulties had been doing a drama course at 6th form which she was enjoying. The course was cancelled and as a result the young woman had started to self harm and express suicidal thoughts.

Six cases about home school travel

For example: A parent rang concerning her son's taxi journey to school. The same firm has been taking him for six years and he has developed a good relationship with the staff. The LEA has put the contract up for competitive tender and the mother has been told by the taxi firm that they did not get the contract. Mother has heard nothing from LEA, has not been consulted and the school term is due to end in a couple of weeks, leaving her uncertain what will happen after the summer. Her son is on his third school in eight years—the other two having been closed and this is the one aspect of his schooling that has some consistency.

12 cases of parents struggling to choose between mainstream or special school or having difficulties with moving between schools

For example: A family in the South West were very concerned about making a choice as to where their child went to school. They do not have a clear understanding of what the differences might be between a mainstream school and a special school and what kind of support and help their child would receive in each. They said that the mainstream teachers seemed terrified of their son and when they were shown the "special needs department" it appeared to be two very dark rooms in the basement. But then an educational psychologist said that they were veering towards choosing mainstream for their own benefit, "to feel that their child was normal". Parents are now very confused and unsure what is the best option.

All of these examples illustrate the kinds of problems which parents have with the complex processes around Special Educational Needs. In many cases, the parent simply does not understand the process, what their rights are and the timescales which need to be adhered to. Contact a Family produces information factsheets for parents which explain the law and the processes which apply. Samples are enclosed for the Committee's information.

In other cases, parents say that they find the school or the LEA obstructive, trying to save money and certainly not thinking creatively about how they could meet the child's needs. It will doubtless be some considerable time before the provisions of the Disability Discrimination Act are understood and the culture of disability equality is firmly embedded in everything that is done for a child and his or her family.

In other cases, lack of staff means long waits for appointments such as Educational Psychology or Speech Therapy. Parents feel very anxious that early chances for their child's behaviour or language to improve are slipping away as the months go on.

The evidence from our helpline is that the current drive to move away from statements is not welcomed by parents who value having set out what their child's rights are. We feel that on the evidence from our helpline it will be a long time before parents feel confident enough in the goodwill of the school and LEA not to feel the need to have a statement.

When we talk to parents at support groups, social events and workshops they give us the following key messages:

They strongly feel that the emphasis should be on the potential and achievements of pupils with disabilities. There are educational, social and moral grounds for educating disabled children alongside their peers but inclusion needs to be properly supported. Statementing doesn't always deliver the specialist support their children need. This often has to be hard-fought for and parents describe constant battles with authority and bureaucracy. There is some concern that special schools can't offer a broad curriculum, have limited academic focus and are isolated and isolating, over protective and stigmatising.

Some parents feel that special schools provide an environment that is more able to deliver health and intimate personal care and more tolerant of behaviour difficulties. Smaller class sizes are very important to some parents who feel that their child would not, or has not been able to cope, in the larger and busier environment of a mainstream school. Some have found that staff in mainstream schools have negative attitudes. Some parents believe that league tables may affect mainstream schools attitudes to pupils with SEN. They also tell us that schools are reluctant to accept children without statements. Statements are seen as a "dowry". Some parents also tell us of horrific examples of bullying of pupils who are "different".

Placements certainly need to be flexible and support the return to mainstream school when appropriate. Most parents agree that some places need to be reserved for intensive intervention and some those with the most complex needs.

September 2005

Memorandum submitted by GA Architects

GA Architects is a firm specialising in this field. For many years, we have been closely involved in refurbishment and new build projects for adults and children with special educational needs. We have designed and delivered projects for children and young people with autistic spectrum disorder, severe learning difficulties and other areas of special needs, including physical and mental disability. We have worked on both residential and educational projects in assisting clients in terms of brief writing,

development planning and building design and construction. GA Architects is currently working with Kent County Council as our practice is on the panel of the special needs schools review. One project is a refurbishment and new build at Rowhill, a school for 96 children with learning and behavioural difficulties.

Due to this in-depth experience, we are acutely aware of the impact of architecture and environmental design on the learning abilities for people with special educational needs. Furthermore, we understand how successful design helps people with special educational needs raise their standard of achievement.

We are aware that this is not a specific issue being investigated by the Committee, however, expect that the area of architecture and learning environment will naturally arise during the investigation. GA Architects would be willing to submit oral evidence or the Committee to assist with the inquiry. Furthermore, we would happily support the work of the Committee in alternative ways, for example attending relevant meetings or sub-committees, if it is felt that our experience would be of value.

September 2005

Memorandum submitted by South East Region Special Educational Needs Partnership (SERSEN)

The system of statements of need for SEN pupils ("the statementing process")

INTRODUCTION

The SEN Regional Partnerships were set up in response to the 1997 Government report "Excellence for All Children" which highlighted the need to make standards of SEN provision more consistent across England. The SERSEN partnership represents the Local Authorities of Brighton and Hove, East Sussex, Kent, Medway, Surrey and West Sussex. This submission comes from specialist officers within the LAs who have a responsibility for SEN and form the Management Team of the Regional Partnership. These views do not necessarily represent those of the individual local authorities.

FACTUAL BACKGROUND INFORMATION

NUMBERS OF PUPILS ATTENDING SPECIAL SCHOOLS—ENGLAND

	2002		2005	
	<i>Number</i>	<i>% of those pupils who have statements of SEN</i>	<i>Number</i>	<i>% of those pupils who have statements of SEN</i>
Maintained special	86,610	32.7%	83,130	32.8%
Non-maintained special	3,780	1.4%	3,700	1.5%
Independent special	6,300	2.4%	6,290	2.5%
Total	96,690	36.50%	93,120	36.80%

Source: DfES Statistical First Release June 2005 SFR24/2005.

NUMBER OF STATUTORY ASSESSMENTS UNDERTAKEN—ENGLAND

2002	2004
32,110	27,290

Source: DfES Statistical First Release June 2005 SFR24/2005.

APPEALS REGISTERED WITH THE SPECIAL EDUCATIONAL NEEDS AND DISABILITY TRIBUNAL (SENDIST)

1999–2000	2000–01	2001–02	2002–03	2003–04
2,463	2,728	3,048	3,532	3,354

Source: SENDIST Annual Report 2003/2004 December 2004.

THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (“THE STATEMENTING PROCESS”)

1. The legislative system providing for statements of SEN to be issued and maintained by local authorities has, in our view, some strengths but many serious weaknesses.

2. The strengths include:

- (a) formal recognition and summary of a child’s educational needs which many parents value;
- (b) reassurance to parents that their child will receive the provision he or she needs;
- (c) can add rigour to the planning to meet the needs of individual children and pressure to ensure all agencies work together;
- (d) promotes closer monitoring by the school and careful planning for transitions;
- (e) offer parents a mechanism for redress through SENDIST; and
- (f) provides a mechanism for the provision of additional resources for children requiring very high levels of support.

3. The weaknesses are:

- (a) extremely costly and bureaucratic process to administer;
- (b) diverts key professionals from working with pupils and teachers;
- (c) slow and unresponsive system;
- (d) statutory assessment seldom reveals new information;
- (e) stressful and alienating to parents;
- (f) little assurance to parents;
- (g) hold local authorities responsible for provision over which they have little or no control;
- (h) varying rates of issuing statements nationally;
- (i) tribunal decisions lead to some very high-cost placements which impact on a local authority’s ability to provide for other children, including those with similar levels of need;
- (j) does not support early intervention by schools;
- (k) makes the local authority responsible for arranging provision to meet a child’s needs, which can detract from the school’s sense of responsibility;
- (l) focuses resources on the individual child, which can set them apart from their peers; and
- (m) statements have the effect of “labelling” a child, defining them by reference to their difficulties.

4. It is our belief that the Government should implement the recommendation of the Audit Commission with urgency:

“The Government should establish a high level independent review to consider options for future reform (of the statementing system) engaging all key stakeholders.” Audit Commission SEN Policy Focus Paper June 2002, para 81

5. The Audit Commission (op cit) calculated the cost of issuing a statement in 2002 as £2,500. In 2004 there 27,290 assessments were undertaken in England. At 2002 prices this amounts to more than £68 million. At current prices the figure would be much higher. We maintain that this cannot be a good use of public resources.

6. Figures published by the DfES (op cit) show that there were more than 250,000 statements maintained by English local authorities in January 2005. Each one of these pupils is entitled to an annual review of the statements and this adds a further costs and bureaucratic burden on schools, local authorities and key professionals such as educational psychologists diverting them away from providing support to the child/school.

7. We would support the view of the Audit Commission when it said in its report “SEN: A Mainstream Issue”, November 2002:

“LEAs” responsibilities towards children with statements may also be limiting their scope for investing in wider preventative work”, para 38

8. The Audit Commission (op cit) also recommended that health and social services be held to account for their part in meeting children’s special educational needs. This has in part been achieved through the duty to co-operate enshrined in the recent Children’s Act but it is only LEAs who can be held legally to account for the provision in a child’s statement. Other professions are not required to ensure that they provide what they recommend.

9. It is our belief that the weaknesses in the system considerably outweigh the benefits and that the costs, bureaucracy and diversion of key support professionals away from providing support to children and teachers is unsustainable.

10. The system is frustrating and alienating to parents, who feel they have to fight to have their child’s needs met. It too frequently results in an appeal to SENDIST despite the best efforts of local authorities and schools to avoid this. SENDIST was established to provide an informal, independent mechanism for

resolving disputes in relation to the statutory process between parents and local authorities. In 2003–04 23% of parents and 10% of local authorities were legally represented at SENDIST hearings, 53 appeals against a SENDIST decision were lodged with the High Court and a small number went to the Court of Appeal.

11. The SENDIST Annual Report 2003–04 (op cit) shows that in just over 62% of appeals parents were able to obtain an order for the school of their choice. Of these, in mainstream, about 33% were independent schools. In special schools, 40% were independent and 27% were non-maintained. These decisions can result in local authorities facing very high fee levels for many years to come. These individual decisions seriously impact on the local authorities' ability to meet the needs of other children who often have similar or greater levels of need.

12. The report of the SEN Regional Partnerships on Out of Authority placements 2005 indicates that in England there were 161 pupils whose placement in out of authority schools costs exceed £200,000 per annum (with four placements costing over £500,000). The report shows that there appears to be a rising trend in the proportion of high cost placements over £100K per annum. The report estimates that in 2004–05 more than £500 million was spent by local authorities on out of authority placements. This is equivalent to nearly £41 for every child aged 0–19. The average cost of out of authority placements is nearly £50,000 per child per year.

13. It is also important to note that the proportion of children and young people attending special schools has not reduced as might have been expected (and is widely believed) through the inclusion of the right to a mainstream placement in the 2001 Act. Many parents continue to believe that a specialist placement is the most appropriate one for their children and do not seek to pursue a mainstream placement.

RECOMMENDATION TO THE COMMITTEE

14. We believe that the current system is overdue for radical reform and that the benefits of the system could be achieved in other less costly, bureaucratic and alienating ways. We would strongly argue that the Government should act on the 2002 Audit Commission recommendation for a wide ranging independent review of the system involving all key stakeholders.

THERAPY PROVISION

15. It is widely accepted that there is a national shortage of paediatric speech and language therapists. Currently public funding for speech and language therapy is given to the Primary Care Trusts (PCTs) of the National Health Service. Too often there is insufficient therapy funded by the PCTs to meet the need of the children with special educational needs. Often local authorities are directed by SENDIST to make one to one direct therapy provision for children. This is not available through the health service and the shortage of therapists generally means that the local authority finds it extremely difficult and very costly to meet the directions.

16. The issues are similar although not yet as intense for occupational therapy and physiotherapy.

17. The establishment of Children's Trusts may go some way to alleviating this situation but unless there is more availability of the therapists themselves and more funding to employ them it is unlikely that the demands on the local authorities will abate.

18. The allocation of School Health Service responsibilities to local authorities must not, however, happen without the necessary national funding being provided to meet identified needs, something which the DoH has consistently failed to address since the Lancashire Judgement of 1989. This shift may be the only way long term of gaining coherent support for children. However, it is essential that it is not be accompanied by the funding and staffing shortfalls which already leave the LA exposed as the perceived "agency of ultimate resort/blame".

RECOMMENDATION TO THE COMMITTEE

19. The Government should consider removing the funding for therapy from the NHS and allocating it to the local authorities.

20. The Government should urgently ensure that more training places are available to paediatric therapists, especially speech and language therapists.

REFERENCES

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September 2005

Memorandum submitted by Visual Dyslexia

SEN MODELS

We have a major concern as to the efficacy of the current SEN model and to a potential model that places too high an emphasis on the ability of the teacher to recognize, assess and take appropriate action in what is a highly complex area. Currently the ability of the average class teacher to recognize when a child has vision linked stress syndrome is minimal. In recent trials (completed in June 2005) with a Scottish LEA we demonstrated that at least 30% of children have 10 or more symptoms consistent with vision linked stress syndrome (to the complete surprise of the class teachers). The Scottish LEA has indicated that it wishes to contact the Scottish executive with the findings.

THE EFFECTS OF VISION LINKED STRESS SYNDROME

Vision linked stress syndrome is the name for a group of symptoms produced by inappropriate lighting, the visual aspects of work presentation or the visual environment. Symptoms found form a continuum with most people experiencing some effects but it is only of importance in education if it either reduces performance significantly or produces symptoms which are distressing or unpleasant to the student. It is often misdiagnosed as laziness, lack of concentration, dyslexia, attention difficulties or dyspraxia.

Inappropriate responses of current educational professionals is almost universal, they try to resolve visual difficulties using educational techniques, with resultant poor results.

Examination underachievement is inevitable and there is evidence to suggest that current educational techniques and the classroom itself provokes problems!

EDUCATIONAL AND PSYCHOLOGICAL TESTING MAY BE FLAWED

There is evidence to suggest that it may be impossible to rely on current educational assessment methods and that cognitive processing testing may be unreliable unless Vision Linked Stress Syndrome is taken into account. Indeed, in other trials it was clear that the arousal levels in the brain could be compromised by an inappropriate environment. Examinations may well be challenged in courts in the future. VLSS is however not addressed by an eye test, by medical or psychological assessments at this time although a 20 week post graduate diploma course is imminent.

CURRENT TESTING METHODS

Generally speaking they are non existent although some teachers may try to use coloured overlays and some optical practices will use colorimetry. These techniques are inadequate as both will inevitably miss a high proportion of those with problems and what is more they will often miss the most extreme cases. The disability act applies in this case. It is also incumbent to demonstrate that duty of care has been fulfilled and we believe that it is unlikely that these methods could be considered sufficient. Health and Safety issues may also apply.

THE MODEL WE WOULD PROPOSE

All children are screened for VLSS at seven and if a class teacher/parent/psychologist or other responsible person requests. The screening should be in two parts:

1. the class teacher—recognition that a problem may be present (one day teacher training necessary)
2. a specialist teacher—confirm whether full VLSS assessment is necessary (one week intensive training necessary, equipment required a PAT light and diagnostic tests)

In addition those believed to be suffering from dyslexia, dyspraxia, ADD, ADHD, ASD should be screened by a specialist teacher before an educational psychologist is consulted as this will stop unnecessary referrals.

Those that show significant symptoms and respond positively should be referred to an appropriately trained specialist in VLSS who would treat problems and alleviate symptoms immediately.

RESULTS

The value of this would massively exceed the cost by a factor of around 50 (figures presented by at invited meeting at HOC). However, it is believed that a large scale pilot scheme is essential to determine the optimum delivery method and we propose that this takes place ASAP.

ORTHOSCOPICS

Orthoscopes are a new innovative company which has developed new assessment techniques with help from the UK Government, large multinationals companies and extraordinary individuals. They are currently undertaking a number of clinical trials on the effects of VLSS with health authorities, universities and medical specialists. They have a unique range of instruments and testing techniques that are the first in the world that can address the range of visual problems caused by inappropriate visual stimulus and have designed and produced lenses which have no peer. Dynamic lighting can also be used and is often more appropriate than spectacles or overlays.

September 2005

Memorandum submitted by LOOK London

LOOK London is a voluntary body run by parents of visually impaired children. LOOK London aims to help families with blind or partially sighted children gain appropriate education and support for their children. In this written submission we are particularly mindful of the importance of the five outcomes from “Every Child Matters” and how these impact on the role of parents and access to provision. We are also willing to give oral evidence if required.

Our evidence is based on case studies gathered from our involvement with families and the issues which arise from their experiences. Visual impairment is a low incidence disability with a rate of just two per thousand. An increasing percentage of visually impaired children have additional and complex needs. The parents who approach us do so because they feel the system is not working and are often angry and frustrated because they feel no-one is listening to them. Parents can also feel very isolated because of the low-incidence of their child’s disability and the subsequent difficulty in finding others with similar experiences.

THE ISSUES

All of the families who contact us have visually impaired children, many with significant, additional, health problems. One example is the case of a blind child with a rare skin disorder living in cramped conditions in a deprived area of London. The family was desperately trying to gain a school place for their child but the child needed access to both onsite medical care and teaching staff trained to provide curriculum access through non-visual means.

Even with support from the LOOK London key worker, the family had great difficulty getting any help from statutory bodies involved in providing housing or social care. The promised links across services were non-existent because of staff shortages, rapid turnover of staff and enormous bureaucracy. Eventually the family was successful in gaining a school place and somewhere larger to live though worries remain over the number of cars parked around the housing estate and the lack of safe play space for a blind child (or indeed any child).

Other cases illustrate the lack of choice available to parents and children—particularly when a visually impaired child has additional needs—and the problems with gaining access to joint funding from health, education and social services for residential provision or access to after school clubs or opportunities for social and independence training. Equipment for use at home is also an ongoing issue with some authorities offering support whilst others refuse.

WHAT SHOULD BE DONE?

- LOOK London was set up with a key aim to focus on education but increasingly we have become involved in helping parents to fill in forms to claim various benefits such as the Disability Living Allowance (DLA). At times our key worker has had to help desperate families with bedding and other resources for their home. Parents should not have to rely on organizations such as ours and should have easy access to practical advice and support. This is especially important when families are new to England and do not understand the English system and when children have visual impairments and associated multiple disabilities.
- A seamless link, from the earliest age possible, should be provided which helps families with children who have ongoing health needs and severe visual impairment/blindness to gain access to services which address the implications for the whole family.
- There is a danger that in the wake of integrated services, responsibility will be unclear or disrupted by inadequate levels of staffing. Communication is critical across all aspects of Children's Services. Funding arrangements for pupils needing residential placement should be transparent with due attention given to the social and emotional needs of the child and the well-being of the whole family.
- Whilst an emphasis on inclusion and mainstream provision is to be welcomed parents should feel there is a choice and, quite appropriately, some parents may wish to choose special school provision. These wishes should be recognized and respected.
- Statutory assessment procedures are invariably stressful, confrontational and lengthy, due to their complex nature. Any revised process should aim to reduce the adversarial nature of the current system especially in relation to LEA appeals and SEN tribunals.

September 2005

**Memorandum submitted by Disability, Inclusion and Special Needs (DISN) Research Group,
School of Education, University of Birmingham**

BACKGROUND

The group submitting this evidence comprises around 35 academic staff, representing a unique and specialised centre for research and teaching concerning children and young people having diverse needs.

Research-oriented links with policy-makers are reflected in our extensive government-sponsored research, a series of policy seminars involving key national policy-makers (see reports on our web site) and major literature reviews. These critiques and research include a focus on special schools; special educational needs (SEN) policy and provision evaluations; activity around leadership and management of inclusive education; conceptual critiques of "special" pedagogies; the promotion of inclusion through multi-disciplinary working; pupils with emotional, mental health and behaviour problems; educational interventions for children with autistic spectrum disorders; and the educational achievements of deaf children. Some 150 doctoral research students (including students on well-established Education Doctorates in the field), of whom around one sixth are international students, are currently based here in DISN at the University of Birmingham.

Teaching activities include undergraduate, postgraduate professional training in educational psychology, and innovative continuing professional development (CPD) programmes (linked with SEN/disability foci primarily for people working in education [mainly teachers but also support staff, health and psychology professionals, special educational needs coordinators (SENCOs) and headteachers]). The School is unique in having Teacher Training Agency (TTA) approval for mandatory qualifications training in all three of the recognised areas (visual impairment, hearing impairment and deaf blindness). Our CPD activities encompass a diverse range of flexible modes of delivery, patterns of training and levels, involving locally based tutors who are aware of pertinent issues and the specific contexts in which the impact of CPD is measured. This work includes a range of programmes developed and run at all stages (design and planning, teaching, tutorial support and evaluation) in collaboration with regional or national partners (particularly LEAs and charities).

The professional relevance of work by members of DISN is fostered through well-established links with practitioners working in schools, services and other educational settings, parent groups and over 40 organisations. The group is also represented on the editorial boards of around 20 major journals in the field.

KEY POINTS*1. Focus of the inquiry*

1.1 We welcome the breadth of the inquiry as this will increase the likelihood of a helpful and comprehensive examination of issues.

2. *Nature of SEN/disability*

2.1 There is confusion in the field between the language of disability and the language of SEN (Miller, Keil and Cobb 2005; Clarke 2005). This is most stark in the contrast between the Disability Discrimination Act and the language of statementing/School Action. The disparities are likely to become increasingly problematic as agencies with different orientations work together (eg under Children's Services/Trusts and the widening policy differences between Scotland/England/Wales (see 3.3. and 5.1 below) are played out. Clarification on this issue would be welcome but we would not wish to see retrograde steps taken, of the kind which institutionalise categories of need. A review of the Scottish approach to this matter (from "categories to circumstances") and now reflected in legislation, policy and practice would be timely.

2.2 There is extensive evidence of the overlap between education and social/economic needs (Dyson 2001; Emerson and Hatton 2005). This evidence is well-documented and sustained over time (eg Tomlinson 1982). "SEN" policies need to explicitly address these overlapping sets of needs.

2.3 The social model of disability has been helpful in redressing an over-emphasis on "within child" factors in disability/SEN. However, it now needs to evolve into a model which balances prevention with identification and the individual with the social (Billington and Pommerantz 2004, Dewsbury et al 2004) informed by a practice-research synergy.

SUMMARY

The implications of an "expanded" concept of needs (Warnock, 2005) should be given specific consideration in relation to the development of all aspects of policy, practice and provision.

3. *Curriculum*

3.1 There has been a series of comprehensive reviews into the validity or otherwise of concepts of "SEN pedagogy" (Davies and Florian 2004, Moore et al 2004; TTA 2004, Dyson et al 2002.). On balance, the conclusions do not support SEN-specific teaching strategies (by SEN group) but they do support the need for individualised teaching strategies informed by disability-specific knowledge (Lewis and Norwich 2001, 2004; Norwich and Lewis 2001).

3.2 Around 9% of five–15 year olds are estimated to have mental health problems (Meltzer et al 2000). Whether this percentage is increasing is a matter of debate although the balance of evidence suggests that this is the case, particularly among older children and boys. Curbing this incidence and growth requires both a social/cultural response (eg changing a culture in which children are demonised "feral children"/"hoodies" etc), redressing an over-emphasis on a narrow curriculum (see 3.3). A review of aspects of the culture, policies and practices of schools (and concomitant training needs) which promote mental health or, conversely, exacerbate risks for vulnerable children and young people is needed (Ofsted, 2005). Linked with this, pre-service and post-qualification training for teachers and other school staff are required to equip these personnel to fulfil their responsibilities as "Tier 1" child and adolescent mental health service providers (HAS 1995; Hawton et al, 2002).

3.3 There is good evidence that all children benefit from a broad curriculum which (as intended in the 1988 Education Act) includes substantial attention to children's social, emotional and spiritual needs. (See, for example, striking evidence from the 20 year follow up of children with learning difficulties who had attended the Frostig Centre in the US, Raskind et al, 1999). In this connection, recent legislative and policy developments in Scotland and Wales warrant review. Recent changes in Scotland concerning curriculum provision generally, and provision for pupils with additional support needs specifically, have taken place simultaneously (Scottish Executive 2004a, 2005a, 2005b). This approach has, implicitly and explicitly, involved a re-conceptualisation of inclusive education and a careful consideration of the implications for practice. Further, the approach has taken significant steps towards reducing tensions in educational policy which emphasise high standards of academic achievement on the one hand (sometimes characterised by an overemphasis on "league table performance") and open access on the other (Scottish Executive Education Department 2004b).

3.4 The judicious use of P scales in mainstream schools, avoiding an inappropriate focus on fragmented and narrow targets, is crucial. Failure to do this is likely to have negative outcomes (for children, parents and schools) and run counter to evidence about the importance of a broad curriculum (see 3.3).

3.5 The growing emphasis on both "participation" and "protective factors" in research on social policy (eg Edwards 2005) underlines the need for, and value of, a broad curriculum in which the development of citizenship skills (referenced not to the self alone but also to the wider community), advocacy and self-advocacy are central.

3.6 A clear strategy concerning the use of ICT is needed, based on systematic research evidence. This strategy, referenced to demonstrably useful, not token use of, ICT should incorporate appropriate financial underpinning and continuing support. Such a strategy should also be seen as integral to the Future Schooling agenda in which ICT could be woven into new modes of personalised teaching and learning, rather than being seen as an "add on".

SUMMARY

Curriculum provision for children and young people with SEN and disabilities needs careful review, to ensure that its focus is on learning rather than on assessment, and is both challenging and personalised.

4. *Staffing, support structures and resources*

4.1 Many recent initiatives support professionals' development in the SEN context (notably the recent *Removing Barriers to Achievement: the Government's strategy for SEN*, DFES 2004). However, training programmes have tended to be fragmented in terms of level, geography, provider and focus as well as of very variable quality. A review of CPD in the SEN/disability context is needed to address (1) the varying needs of personnel at different levels, (2) the patchy quality of some CPD work (3) the growth of unregulated providers whose main motivation is income generation not quality or relevance (4) the lack of coherent progression for individuals (5) the lack of coherent progression at school, LEA and national levels (6) the future of mandatory training (7) the roles of a spectrum of providers including National College for School Leadership (NCSL) and the TTA (now the Teacher Development Agency) within the whole system. Such a review should also be linked to addressing concerns highlighted by the Audit Commission (2002), about the age profile of personnel working in the special school sector.

4.2 The SENCO role has evolved as a successful and valuable role, often emulated in overseas education systems. There has been considerable progress in recognising the time and workload demands of the role (Cabinet Office 2004) but the SENCO is often still not part of the Senior Management Team and there are problems of isolation, noted at the outset but still not resolved (Lewis et al 1996,1997; NUT, 2004). The SENCO forum, run by BECTA, provides a well-researched model of effective support for SENCOs and others working with children with SEN (Lewis and Ogilvie 2003). However, a thorough review of the SENCO role is needed (Layton 2005, Layton and Robertson 2005). The TTA Standards for SENCO Training have not been updated since their inception in 1998 and the SENCO role remains undefined or ill-defined (Cheminais 2005, Cole 2005, Cowne 2005, Cowne and Robertson 2005). Such a review needs to be placed within the changing context to which the inquiry relates, including workplace reform (Thomas et al 2004, Butt and Gunter 2004) and the development of integrated children's services, with a special focus on professional status and training. The review should also take into account recent research into collaborative key working (Gerschel et al, 2005) and its implications for the development of interconnected support systems for children and young people with SEN and disabilities.

The Training and Development Agency for Schools (TDA) will be reviewing the overall framework of occupational and professional standards used by the school workforce in 2005–06. In this connection, the Standards for SENCOs should be given a high priority, and take account of recommendations made in *Removing Barriers to Achievement: the Government's strategy for SEN* (DfES 2004), particularly those which emphasise the importance of strategic and leadership aspects of the SENCO role. The TDA review should also take account of the conceptual framework for professional development outlined in *Removing Barriers to Achievement*. This framework applies to the wide range of professionals involved in supporting children and young people with SEN and disabilities, and the contexts in which this support is provided.

4.3 Decisive strategies are needed to grow the highest levels of expertise and understanding in the field (see HMI 2005). The decline in the numbers of SEN advisory support services and local/national SEN inspectors (including Ofsted) plus the closure or fragmentation of dedicated university groups/departments concerning SEN means that valuable specialist expertise is being lost. Specific strategies such as support for clearly defined/recognised/funded specialist (ideally cross departmental) university centres for high level training and research, secondments (as in the James Report model) and a national programme of teacher researchers at doctoral level would be valuable in taking the field forward in the new contexts. We note that support services and special educational provision have been severely neglected in terms of CPD concerning leadership/ management roles. The further development of such services as part of a support network is crucial for the realisation of a flexible and inclusive educational community.

4.4 The community infrastructure of support around children with special needs and disabilities is crucial (Lewis, Robertson and Parsons 2005). The impact of the extended schools policy on children with SEN needs to be closely monitored; it is vital that extended schools ensure that pupils with special needs and disabilities are included in activities. The implications of this are likely to be significant.

4.5 There is a good case for a targeted programme to develop disabled young people as mentors to other disabled children/young people.

SUMMARY

There is an urgent need to ensure that more effective support is made available to children and young people with SEN and disabilities. This necessitates the harnessing of established evidence about the nature of good practice. It also requires the implementation of an initial/continuing professional development policy that has optimum impact on the school workforce.

5. Patterns of provision

5.1 The evolving differences between SEN policies and practice across England, Scotland and Wales indicate that devolution issues concerning SEN need to be scrutinised and lessons learned.

5.2 The value of early intervention concerning children with SEN has been well documented over many years (most recently, the EPPE (2004) project). The DfES-funded Early Support Programme for children with disabilities is providing useful illustrations of guidance bridging different agencies (health, social services and education) as well as spanning statutory and voluntary services.

Within this, the role of an early years SENCO warrants greater scrutiny in order to share discussion of effective practice across diverse contexts.

5.3 Children's Services/Children's Trusts are potentially in a very good position to foster inter-agency working. The role of key workers for some children with SEN (Greco et al 2005) is likely to emerge as significant. New ways of working need to be explored, evaluated and disseminated. A crucial issue will be determining who takes on key worker responsibilities (Gerschel et al, 2005). SENCOs are more likely than ever to be involved in working with teams of colleagues, both within and beyond school settings. However, there is a danger that too much will be expected of them and that they will be overstretched. Recent research (Greco et al 2005) highlights the importance of defining the parameters of the key worker's role if it is to contribute to better outcomes for children and families.

5.4 The current DfES-commissioned independent review of low incidence needs is likely to be an important document informing future regionalisation concerning low incidence SEN, including specifically the future of the SEN Regional Partnerships. These need to be considered alongside other evidence (eg about outreach and support services). Failure to do this may lead to the development of overlapping systems of support and provision. In this connection, the roles of voluntary bodies and independent special schools need scrutiny. Further, the increasing incidence of children's multiple (especially medical) needs and consequent multiple medication warrant clear thinking about professional roles and the wider application of good practice (Farrell and Harris, 2003)

5.5 There is evidence for the value of special schools/units as part of parent choice within a plural system (Porter et al 2002). This position is consistent with personalised learning (Leadbeater 2005) and, seen through this lens, is not merely a rebranding of a status quo. However, personalised learning, and the experience of this through access to a variety of connected educational provision warrants careful monitoring and evaluation.

5.6 There is a need for systematic evidence about practice and impact of home education for disabled/SEN children (Lewis, Robertson and Parsons 2005). Education, and even schooling, need not be construed solely in terms of binary distinctions in provision (mainstream/special, inclusive/segregated) (see 5.5). Furthermore, this important growth in home education may need reappraising in terms of how it reflects the positive application of principles associated with the concept of personalisation in education.

SUMMARY

Moves towards the integration of children's services should be underpinned by systematic planning to ensure that personalised opportunities and the support to access these are genuinely coherent and flexible.

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September 2005

Memorandum submitted by the Pre-school Learning Alliance

INTRODUCTION

1. The Pre-school Learning Alliance is a leading educational charity specialising in early years, with over 40 years experience of working with children and families. The Alliance provides practical support to over 15,000 early years settings and makes a positive contribution to the care and education of over 500,000 young children and their families each year. We encourage and actively promote parental involvement and partnership-working in all aspects of our work.

2. The Alliance is the largest voluntary sector provider of Neighbourhood Nurseries and Children's Centres, having opened 29 new nurseries in the last two years, of which 22 are designated as Children's Centres. The charity is a major employer of early years professionals within the sector and aims to be involved in 100 Children's Centres by 2008.

3. The Alliance has always been inclusive in its practice, providing help and support to early years settings. Since the Mary Warnock Report in 1978, the Alliance has formerly recognised the benefits of specifically trained early years workers for children with special educational needs. SEN co-ordinators (SENCOs) visit and support groups on a regular basis, advising them on legislation and best practice. This is supported by publications for early years settings, outlining clear guidance for early years professionals and support staff. The charity also provides a range of key products and services including publications, childcare consultancy, information and advice, quality assurance, research, training and family programmes.

4. The Alliance welcomes the opportunity to submit evidence to the Committee on the SEN inquiry. The Alliance recognises the need to define a specific set of guidelines for the early years sector, distinct from primary education. It is important that children under five with SEN are recognised as having complex and often distinct needs to children of statutory school age.

DEFINITIONS OF SPECIAL EDUCATIONAL NEEDS

5. The 2001 Special Educational Needs Code Of Practice (SENCOP) encouraged the move away from 'statementing' and separate provision for children with SEN. It was intended that this would give parents more choice about the best setting for their child's individual needs. However, many parents have found the statementing process demoralising and have experienced difficulties accessing the help they need from their local authorities despite the supporting documentation.

6. Peter Farrell states in his 2001, "Special education in the last twenty years: have things really got better?" (British Journal of Special Education, 28 (1):3-9) "... parents have a much louder voice, there are more mechanisms to support them and they have far greater rights of appeal but perhaps more important are the continued problems associated with the bureaucratic and cumbersome statutory assessment procedures which, despite proposed changes in the new draft Code, still seem to be a millstone round the necks of all those involved in striving to provide the best quality education to pupils with SEN and their families."

7. If a system of statements is to be continued, there needs to be an easier way for this to happen. Definitions of SEN and disabilities can be confusing. Anecdotal evidence from early years providers suggests that uncertainties exist as to what constituted or defined an SEN or a disability, which appeared to cause confusion in their duty of care. The 2001 SEN Code of Practice uses the terms for a special educational need from the Education Act 1993 and a disability from the 1989 Children Act/1995 Disability Discrimination Act.

8. With the new Disability Discrimination Act (2005) in place, it would be beneficial if government created a process that clearly defines what characterises a child with SEN or a disability. This should be communicated clearly so that all early years providers and professionals in voluntary, private and maintained sectors can be consistent.

INCLUSION

9. The Alliance supports a move towards inclusion for children with special needs in to mainstream schools. However, adequate funding must be provided if we are to realise this objective. Funding will be required to train early years professionals in delivering effective inclusive practice and to provide the extra facilities needed to provide a high quality learning experience for the child. The Alliance does not believe that Special Schools are advantageous, as they can foster a culture of separation, which directly contradicts the philosophy of inclusive practice. However, it would be ill judged to undertake a process of dismantling all Special Schools without putting the appropriate infrastructure and resources in place for genuine inclusion.

10. Children with SEN have different needs according to their type of condition or disability. Early years professionals will therefore need access to specialist inclusion training. Children with profound special educational needs or disabilities require individual and specific attention to benefit fully from any inclusive form of education. These children should not be segregated from their peers. A process of inclusion is the best way to provide good learning outcomes for children and also supports their individual rights. By ratifying the United Nations Convention on the Rights of Child in 1991, the UK Government accepted the obligations set out by the Convention and agrees to be responsible for implementing its principles.

11. Raising standards of achievement for SEN pupils is an important objective. However, funding needs to be provided for key staff to follow the correct policies and specialist staff need training on how to follow procedures (as defined in the 2001 Special Educational Needs Code of Practice and other relevant legislation).

PARENTAL INVOLVEMENT

12. The Alliance welcomes the Committee's decision to highlight the important role of parents. Parental involvement underpins the Alliance's work. Parents and carers are a child's first and primary educator. For children with special educational needs, a parent is the first informer of their child's needs and/or disability. Parental involvement can only work with good communication between the early years professional and the parent. Experience shows that Alliance member groups have found it very beneficial to involve parents in all aspects of their child's early development and learning, parents welcome the support. This enhances a child's educational experience and the parents also benefit from the support and advice given by the early years professional.

LEGISLATIVE FRAMEWORK

13. Feedback suggests the legislative framework for SEN provision is very confusing for early years providers. The 1995 Disability Discrimination Act (DDA) not only applied to pre-schools (with or without educational funding), but also applied to other service providers such as restaurants and petrol stations etc. Evidence provided by the Alliance's local SENCos, suggests that some early years providers were unclear about how to comply, until a year after the Special Educational Needs & Disability Act of 2001 (SENDA). The SENDA and part 4 of the Disability Discrimination Act was only applicable to maintained nurseries, schools and post 16 providers. This caused confusion within the sector. It would have been more helpful to have a clear guidance specifically for the early years sector before the new legislation was enacted.

14. Unfortunately, clear guidance on duties for educationally funded early years settings did not come in until 2002, with the production of the SEN Code of Practice (SENCOP) and for the whole sector in 2003 with the joint guidance from the Sure Start/NCB/CDC–Early Years and the Disability Discrimination Act 1995, what service providers need to know. Generally the process is considered by early years professionals as too bureaucratic, complicated and time consuming.

15. The Alliance supports the Government's move to establish a legislative framework to specifically address the process of inclusion for children with special educational need and/or disabilities.

The process has been difficult both for individual childcare providers and for organisations to interpret legislation and support their members. The Alliance has consistently urged government to provide a clear and concise set of guidelines specifically for early years settings.

CONCLUSIONS

16. It is clear that the legislative framework for children with Special Educational Needs has been fragmented and non-cohesive in the past. To move forward and build upon past experiences, the Alliance recommends that the Committee consider the following:

- Wherever possible children with SEN should be educated in mainstream settings, providing there is adequate funding and resources to support this. It is clear that more funding is needed to specifically address any transition from special schools to inclusion in mainstream settings.
- Special Schools by their very definition do not promote inclusive practice and in some cases can isolate children. However, the specific expertise of those within special schools should be utilised within the mainstream sector.
- Standards will only be raised for SEN pupils if the early years workers receive appropriate training.
- Clearer guidance for educational establishments needs to be available for those settings who have children with SEN, including a clear definition of what constitutes a SEN or a Disability.

September 2005

Memorandum submitted by Save Thornchace Intervention Committee 2 (STIC2)

I am writing to you to comment on the revised proposal to close Thornchace Special School in Merrow. The County have now put forward the structure for two new centres which would replace the school thus maintaining the provision for the current girls and allowing girls with and without statements of special needs to attend.

On the face of it, it would appear that these proposals are adequate to meet the needs of such vulnerable girls and it is acknowledged that officers have recognised the need for single sex provision.

However I have the following concerns:

- Girls attending these new centres will not be offered the full range of GCSEs and Entry Level certificates currently available at Thornchace due to the fact that each centre will only employ two full-time teachers. This is particularly relevant to the seven girls who are currently at Thornchace, some of whom are capable of achieving a number of good results and are not on roll at any other school.
- The County envisage the girls having a mixture of centre-based work, local secondary school provision, college and work experience as their "curriculum diet". The staffing ratios proposed for the eight to 10 girls (two full-time teachers and two learning support assistants) would make the logistics of transporting and accompanying girls very complex. The workload for the Head of Centre and teacher with a "significant" teaching time-table would be too onerous for one person and from discussions with officers it is expected that staff will prepare lunches, taxi the girls around and perform child minding duties rather than educate the girls.
- The proposed Chertsey location has limited in-door and NO outdoor space and needs approximately £100,000–£150,000 spending on it to bring it up to standard.

- Girls with BESD will not have access to boarding facilities and boys with similar needs will. This is an equal opportunities issue, which still has not been addressed. Indeed recently a brand new boarding facility was opened at Wishmore Cross, the boy's equivalent BESD school.

If the county is a active participant of the "Every Child Matters" framework, something that ALL partners have signed up to, it is ironic every child matters, it would seem, except when you are female and have social, behavioural and emotional needs and live in Surrey.

September 2005

Memorandum submitted by Bristol Dyslexia Centre

We are the Directors of the Bristol Dyslexia Centre and would very much like to contribute to the Select Committee inquiry into special educational needs. We both have a professional and personal interest in the SEN field. Pat is a mother of two dyslexic sons and founder of the Bristol Dyslexia Centre and Belgrave School. Over the past 35 years she has taught and lectured widely. Michael is dyslexic, a law graduate and has taught SpLD students for 10 years.

The Bristol Dyslexia Centre has over 300 students and 30 teaching staff. The Centre has been established since 1989 and during this period has firmly established a reputation for excellence by successfully transforming thousands of struggling students from academic failures into pass grade candidates, with many attaining exceptional A grade results. The Centre incorporates Belgrave School, providing full-time education for dyslexics and school phobics for ages six to 12 years, an Assessment Centre that caters for five independent chartered educational psychologists, and three floors of the building are dedicated to part-time specialist tuition for adults and school-age students. We have also developed our own approach to learning which has been incorporated into two software titles, the Nessy Learning Programme, a phonic-based learning programme for dyslexics and BrainBooster, study skills for the ages 13 to adult.

We would like you to consider the Nessy Learning Programme when examining the need for SEN resources, expertise and provision in mainstream schools. Nessy has achieved outstanding results from a recent study of students using the programme (please refer to supplementary materials). Following this success, the school using the programme expanded use of the software to the whole school.

- The Nessy programme differs from others in several key aspects. One key aspect of Nessy is the structured game-based learning. We believe that learning should be fun as we all learn best when we are enjoying ourselves and that this approach should not be restricted to the Foundation stages of education but become a general principle even at secondary level. The Nessy game-based learning is effective because it is set in the context of a structured programme of incremental and cumulative learning. The Nessy programme advocates learning to read, spell and write through games, both computer and paper based card/board games, and the results of a recent survey demonstrate that this multi-sensory approach is successful and inspiring. Effective phonic-based learning is necessarily repetitive and SEN students in particular need stimulation to become motivated and engaged.
- Another key difference is the extensive range of ability covered by the Nessy programme. By addressing abilities from five to 16 years this programme allows students to maintain learning consistency during the transition from Primary to Secondary education. Programs addressing SEN at secondary level has often been poorly resourced.
- The Nessy programme has been successfully used by LSAs and NQTs who lack specialist experience. They have found it an invaluable resource because Nessy includes all the reading and spelling rules with supporting paper based activities in 1,500 printable pages.
- Experienced specialist teachers, rather than academics have developed Nessy over many years. This means it uses unique learning strategies that have already proved effective in the classroom. These strategies capitalise upon dyslexic learning strengths in areas of creativity and by associating concrete meaning with intangible learning concepts that are otherwise difficult to grasp eg the prefix-root-suffix becomes a head-body-tail of a word.

Other aspects that we feel the Committee should investigate are the inconsistencies in teacher training for the recognition and addressing specific learning difficulties in the classroom and the inadequacies of the assessment process. Many teachers lack the training or ability to identify dyslexia let, alone incorporate effective classroom strategies. In 90% of our enquiries by email and telephone it is the parents who identify their children as at risk and not the professionals. This is surely a poor indictment of the current teacher-training curriculum and many NQTs that we encounter still find that their courses include only a token and arbitrary mention of dyslexia. In our experience many teachers feel defensive and do not like to admit a lack of knowledge when approached by concerned parents.

This is the situation in our LEA and I am sure in many others. It can take anything up to two years to be assessed by an educational psychologist and then the child needs to be functioning at several years behind their actual age to qualify for funding support. As reading assessments begin at a level of five to six years in practice this means that only the most dyslexic children are assisted and then not helped until nine to 10 years when

the secondary problems of low self-esteem, frustration and disenchantment with school learning are entrenched, often with lifelong detrimental consequences. The usual standard of proof for identification of dyslexia is an assessment by an educational psychologist. Parents desperate to halt this destruction to their children's personality seek private help. The assessment process takes about 2½ hours and costs in excess of £300. The end result is a report which is often unintelligible to anyone but the most experienced specialist teacher and must be renewed after two years, yet this is the standard of proof required by official bodies such as universities, tribunals, examination boards, LEAs and schools etc Surely government could endorse an assessment which was quick and cost effective but that focused upon practical remediation and jargon-free language.

We hope that you will consider the points raised in this submission and would be delighted to supplement these comments if you consider they include areas of relevance to the inquiry.

September 2005

READING AND SPELLING ASSESSMENT SCORES

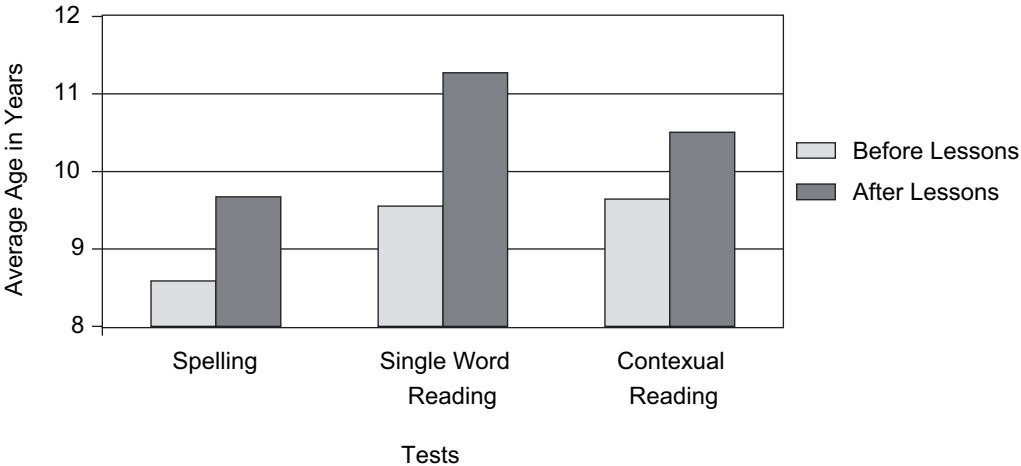
<i>Student</i>	<i>Nov-04 Sp Age spelling</i>	<i>June-05</i>	<i>progress 18 hours</i>	<i>Nov-04 R Age reading</i>	<i>June-05 (single)</i>	<i>progress 18 hours</i>	<i>Nov-04 R Age Reading</i>	<i>June-05 (context)</i>	<i>progress 18 hours</i>	<i>Nov-03 C A age</i>	<i>June-05 C A</i>
A	6y 5m	6y 10m	5m	6y 4m	7y 5m	13m	6y 6m	7y 0m	6m	6y 5m	7y 0m
B	6y 4m	6y 10m	6m	6y 8m	8y 9m	2y 1m	6y 9m	8y 3m	1y 6m	8y 3m	8y 10m
C	6y 10m	7y 0m	2m	6y 4m	7y 3m	11m	6y 9m	9m	8y 4m	8y 4m	8y 10m
D	7y 0m	7y 8m	8m	6y 9m	7y 9m	12m	7y 0m	8y 0m	12m	8y 5m	9y 0m
E	7y 7m	8y 2m	7m	7y 2m	8y 0m	10m	7y 0m	8y 0m	12m	8y 5m	9y 0m
F	7y 0m	7y 5m	5m	7y 5m	8y 0m	7m	7y 9m	8y 0m	3m	8y 6m	9y 1m
G	7y 7m	8y 6m	11m	8y 0m	10y 0m	2y 0m	8y 6m	9y 3m	9m	8y 7m	9y 2m
H	8y 2m	9y 10m	1y 8m	10y 0m	9y 9m	(3m)	9y 0m	9y 9m	9m	8y 8m	9y 3m
I	8y 6m	9y 0m	6m	9y 7m	10y 3m	8m	8y 8m	9y 6m	12m	9y 4m	9y 10m
J	8y 6m	9y 4m	10m	10y 7m	11y 0m	5m	9y 0m	9y 6m	6m	9y 5m	10y 0m
K	9y 2m	10y 1m	11m	9y 0m	9y 9m	9m	8y 6m	9y 0m	6m	9y 6m	10y 1m
L	11y 2m	12y 1m	11m	10y 6m	12y 6m	2y 0m	11y 0m	12y 0m	12m	9y 6m	10y 1m
M	7y 1m	8y 8m	1y 7m	8y 9m	9y 7m	10m	10y 3m	11y 6m	1y 3m	9y 10m	10y 4m
N	9y 8m	11y 4m	1y 8m	12y 6m	16y 0m	3y 6m	10y 4m	11y 4m	12m	9y 10m	10y 3m
O	9y 2m	10y 5m	1y 3m	10y 6m	12y 6m	2y 0m	8y 9m	11y 3m	2y 6m	9y 11m	10y 6m
P	8y 8m	9y 6m	10m	11y 0m	15y 0m	5y 0m	13y 0m	14y 8m	1y 8m	10y 2m	10y 10m
Q	7y 10m	9y 4m	1y 6m	9y 4m	10y 6m	12m	9y 6m	9y 9m	3m	10y 5m	11y 0m
R	8y 2m	9y 6m	1y 4m	8y 3m	10y 6m	2y 3m	10y 3m	11y 3m	12m	10y 7m	11y 2m
S	11y 2m	12y 4m	1y 2m	12y 6m	14y 0m	2y 3m	9y 9m	10y 3m	6m	11y 6m	12y 1m
T	11y 6m	12y 4m	10m	11y 0m	13y 0m	6m	12y 0m	15y 4m	3y 4m	11y 1m	11y 8m
U	8y 2m	9y 8m	1y 6m	12y 9m	11y 0m	0m	11y 3m	11y 3m	0m	11y 2m	11y 8m
V	10y 3m	10y 8m	5m	12y 9m	16y 0m	3y 3m	13y 0m	15y 4m	2y 4m	12y 2m	12y 9m
W	8y 10m	9y 9m	11m	11y 9m	12y 9m	12m	10y 6m	10y 9m	3m	12y 5m	13y 0m
X	11y 8m	12y 4m	12y 10m	12y 10m	16y 0m	3y 2m	13y 4m	8m	12y 10m	12y 10m	13y 5m
Y	11y 2m	11y 8m	10y 9m	10y 9m	14y 8m	3y 11m	12y 3m	12m	13y 5m	13y 5m	14y 0m
Z	11y 2m	13y 0m	10y 0m	10y 0m	13y 0m	3y 0m	13y 0m	1y 8m	15y 10m	15y 10m	16y 5m
Average improvement			1y 1m			1y 9m			10m		

Assessment information—

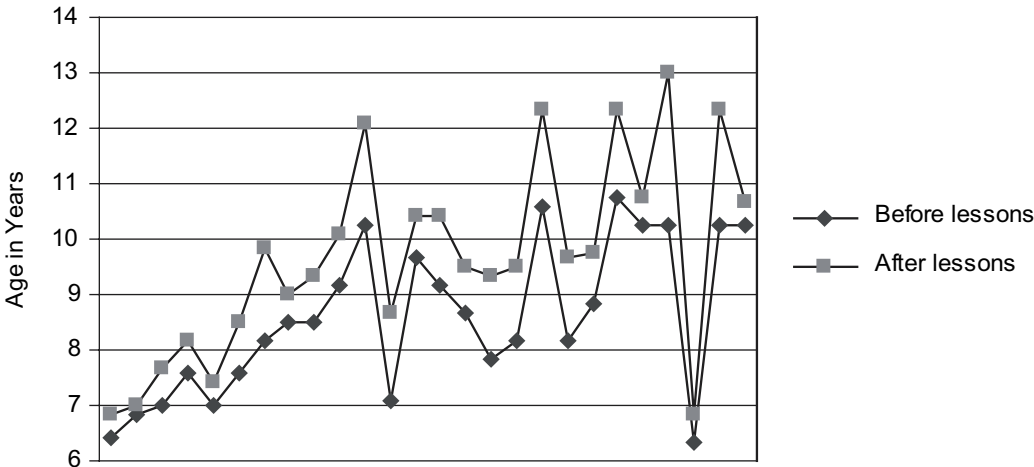
Vernon single word spelling, WRAT single word reading (decoding skills), Holborn sentence reading (up to 13 years), *Kirkless contextual reading and vocabulary

These assessments show results attained at the Bristol Dyslexia Centre using an age range of students covered by the programme. Results were taken before and after 18 hours of using the Nessy Learning Programme over a period of six months from the end of November 2004 to the beginning of June 2005. All students are dyslexic.

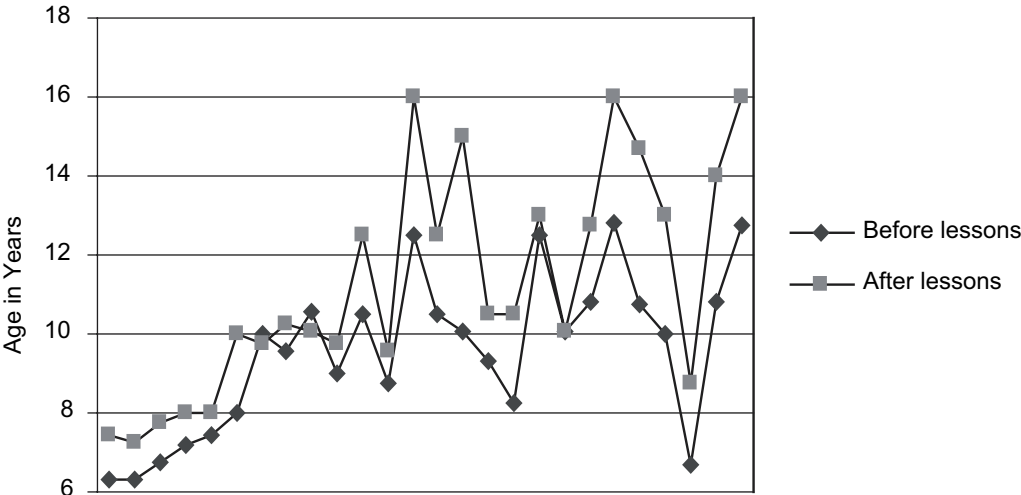
Average Change In Reading Age in Different Tests

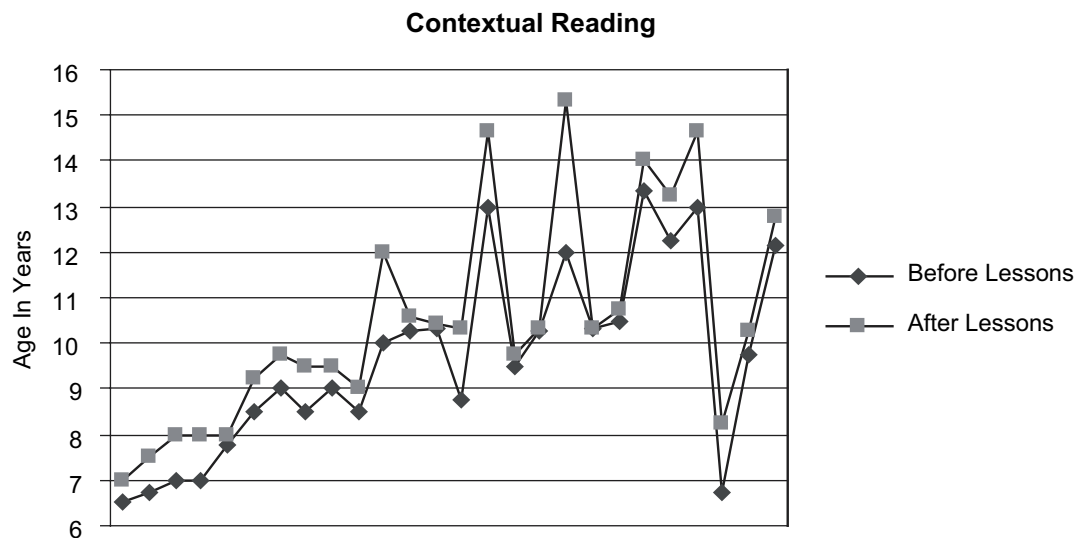


Spelling



Single Word Reading





**READING AND SPELLING ASSESSMENT SCORES FOR FLAX BOURTON PRIMARY
SCHOOL YEAR 6 JUNE 2004**

<i>Student</i>	<i>Reading Comprehension Age September 2003</i>	<i>Reading Age Comprehension June 2004</i>	<i>Increase in Reading Comprehension Age</i>	<i>Spelling Age September 2003</i>	<i>Spelling Age June 2004</i>	<i>Increase in Spelling Age</i>
A	8 yrs 6 mths	9 yrs 3 mths	9 mths	8 yrs 3 mths	10 yrs 5 mths	2 yrs 2 mths
B	8 yrs 6 mths			9 yrs 7 mths	10 yrs 2 mths	1yr 7 mths
C	7 yrs 9 mths			5 yrs 10 mths	7 yrs 1 mths	2 yrs 0 mths
D	9 yrs 0 mths	9 yrs 9 mths	9 mths	12 yrs 0 mths	12 yrs 4 mths	4 mths
E	9 yrs 6 mths	12 yrs 0 mths	2 yrs 6 mths	12 yrs 0 mths	12 yrs 9 mths	9 mths
F	8 yrs 9 mths	10 yrs 8 mths	1yr 11 mths	9 yrs 2 mths	11 yrs 2 mths	2 yrs 0 mths
G	7 yrs 6 mths	9 yrs 7 mths	2 yrs 1mth	7 yrs 1 mths	9 yrs 8 mths	2 yrs 7 mths
H	8 yrs 0 mths	9 yrs 3 mths	1yr 3 mths	8 yrs 3 mths	11 yrs 8 mths	3 yrs 5 mths

June tests were administered by Backwell Comp. The June reading Test was a different and more difficult test to that used in September. The same spelling test was administered in both September and June.

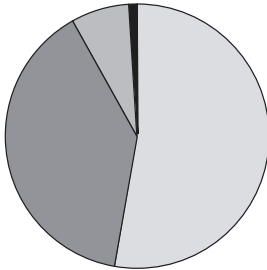
Tickenham Primary School PANDA report has shown improvement since introducing Nessy.

During the trial Nessy has been used extensively in Jersey as part of the curriculum rather than as an exclusive resource with monitored results in a comparative study. Feedback from teachers and children has been outstanding (see endorsements).

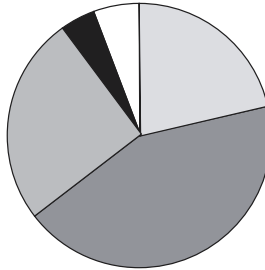
Results from a survey of 101 dyslexic students (June 2005), aged between 6
16yrs, using the Nesy Learning Programme

86% said Nesy is fun to play
64% thought Nesy boosted their confidence
69% said Nesy made them want to learn more
86% said the games are great
55% said they wanted to use Nesy all the time when learning at school
84% said Nesy made learning fun
87% said Nesy helped them to learn
75% thought Nesy helped them with their other school work
76% said that Nesy is the best learning programme that they had used

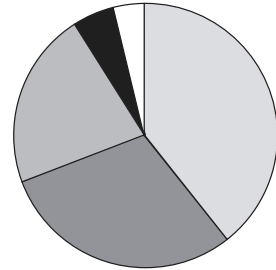
Nesy is fun to play



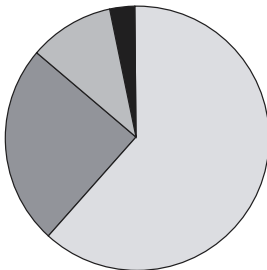
Nesy has boosted
my confidence



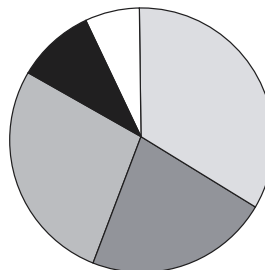
Nesy makes me
want to learn more



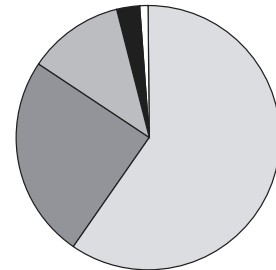
The Nesy games are great



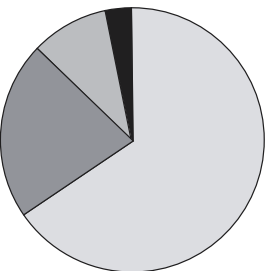
I want to use Nesy all the time
when learning at school



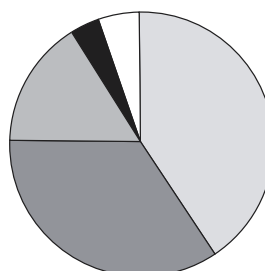
Nesy makes learning fun



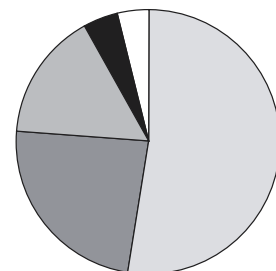
Nesy helps me learn



Nesy helps me with
my other school work



Nesy is the best learning
programme I know



Key

	Agree Strongly
	Agree
	Not Sure
	Disagree Slightly
	Disagree Strongly

Memorandum submitted by the Centre for Studies on Inclusive Education

1. INFORMATION ABOUT CSIE

1.1 The Centre for Studies on Inclusive Education (CSIE) was established in 1982 to promote the education of disabled and non-disabled children together in mainstream schools and the gradual ending of the practice of educating disabled children separately in “special” schools. In collaboration with schools, local education authorities (LEAs), organisations of disabled people, parents and academics it has developed expertise on inclusive education, including the development and evaluation of practical tools for implementing inclusive education in schools and early years settings. CSIE closely monitors the development of inclusive education at national and international levels, both in practice and in the interpretation of the UN Convention on the Rights of the Child by the Committee on the Rights of the Child, and is participating in the drafting of the new UN Convention on the rights of disabled people.

1.2 Copies of some of the Centre’s most recent publications are provided as evidence for this inquiry and outlined in this Memorandum. Further information about the full range of CSIE’s work can be found on the CSIE website (csie.org.uk) as can links to other voluntary organisations pursuing similar aims and work.

2. GENERAL STATEMENT

2.1 The Special Educational Needs and Disability Act (2001) requires schools and colleges in England to make reasonable adjustments so that disabled students are not disadvantaged. From 2006 schools are also required to promote disability equality. Internationally, inclusive education is promoted in key human rights instruments, notably UNESCO’s Salamanca Statement (1994) and the UN Convention on the Rights of the Child (1989). A new Convention on the rights of disabled people currently being drafted at the UN is on the way to agreeing inclusive education as an entitlement for all.

2.2 The Government’s strategy for special educational needs, *Removing Barriers to Achievement*, and the effective examples and work towards inclusion taking place in many schools, represent progress towards inclusive development. But CSIE is deeply concerned that only two years into this strategy and despite the promising examples of inclusion working, there are renewed calls for segregated “special” provision. In CSIE’s view, it is unacceptable to rely on segregated schooling as a solution to discrimination which still exists in some mainstream schools and to difficulties in the early stages of a long-overdue restructuring of mainstream education to become more inclusive. Resorting to segregation and responding to discrimination and difficulties with further discrimination is not a proper response from a human rights perspective and undermines those efforts which are being made in mainstream to uphold rights and develop inclusive provision.

2.3 The evidence presented in this Memorandum covers a number of the issues identified by the Committee, and is organised under the following themes:

- inclusive education as a pressing human rights concern (section 4)
- statistical evidence of variations between LEAs in effecting inclusive education and of poor
- overall progress towards inclusion (section 5)
- positive developments in inclusive education (section 6)
- the damage caused by segregating pupils into “special” schools (section 7)
- children and young peoples’ views supporting inclusive education (section 8)
- problems with the concept and definition of “special educational needs” (section 9)

3. RECOMMENDATIONS

3.1 In light of the evidence presented, CSIE hopes that the Committee will endorse the goal of inclusive education for all children and young people and recommend that the Government:

- honour the human rights aspects of inclusion and renew its commitment to ensuring inclusive education for all children and young people;
- focus on identifying the further steps necessary to continue building the capacity of mainstream schools to support the full diversity of pupils;
- increase efforts and resources for awareness raising and training for inclusion, eg to tackle gaps that have been identified by Ofsted;
- continue awareness raising on legislative requirements to include children and young people and ensure their implementation; and
- halt the building of new “special” schools and ensure the effective transfer of resources from existing ones to mainstream schools.

4. HUMAN RIGHTS IMPERATIVE

4.1 There are compelling human rights reasons for reducing segregation of children and young people “with special educational needs” and ensuring inclusive education for them all, without exception. An examination of international human rights agreements and standards as they relate to inclusive education was commissioned by CSIE and published in 2002 (*Social and Educational Justice—the human rights framework for inclusion*, written by Sharon Rustemier). As discussed in the report:

4.1.1 The UN Convention on the Rights of the Child (1989), the UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) and the UNESCO Salamanca Statement and Framework for Action (1994) recognise the rights of all children and young people to fully supported inclusive education and the responsibilities of governments to provide it.

4.1.2 Segregated schooling violates children’s right to inclusive education and breaches all four principles underpinning the Convention on the Rights of Child—the principles of non-discrimination, the best interests of the child, optimal development, and listening to the voice of the child.

4.1.3 The existence of separate “special” schools is seen in international human rights agreements only as an interim measure until mainstream schools have developed the capacity to accept all children.

4.1.4 Following its General Discussion on the rights of children with disabilities in October 1997, the Committee on the Rights of the Child, which monitors implementation of the Convention on the Rights of the Child, specifically stated that legislation that segregates disabled children into separate institutions “for care, treatment or education” was “not compatible with the principles and provisions of the Convention”. And in a General Comment in 2001 on the aims of education the Committee made clear that denying disabled children mainstream education alongside their non-disabled peers falls far short of human rights standards.

4.1.5 According to international human rights standards, parental choice in relation to their children’s education is limited by children’s rights and the state is expected to constrain parental choice when it violates the rights and best interests of the child. A human rights based commitment to full inclusion is incompatible with a view that parents should be allowed to choose segregated education in “special” schools

4.2 Further evidence of the ongoing commitment of the UN to inclusive education as a human rights issue is demonstrated in the Concluding Observations of the Committee on the Rights of the Child which are published three times a year to report the results of the CRC’s examinations of governments’ progress in implementing children’s rights. Analysis by CSIE of these assessments clearly demonstrates the Committee’s ongoing concern with educating disabled children in appropriately supported mainstream settings rather than in segregated “special” provision.

4.3 The UN Ad Hoc Committee responsible for the drafting of the new Convention on the rights of disabled people completed its sixth session in August 2005 and expects to finish its work at two further sessions in 2006. So far negotiations on Article 17 (education) have shown agreement on inclusive education as a human right for disabled pupils, although debate continues on the extent to which education in separate groups should also be an entitlement for some disabled pupils and what form, if any, it might take. CSIE has submitted a series of position papers as part of the ongoing discussions and these are available on the Centre’s website.

5. VARIATIONS IN INCLUSIVE PRACTICE

5.1 CSIE has for many years monitored the percentages of children and young people placed in “special” schools in LEAs across England, based on figures provided by the Government, and has consistently found large variations between LEAs, despite being bound by the same national Government policy on inclusion and placement. Its most recent analysis covers placements of pupils aged 0–19 in “special” schools and other segregated settings during the period 2002–04 (*Segregation trends—LEAs in England 2002–04 Placement of pupils with statements in special schools and other segregated settings*, written by Dr Sharon Rustemier and Mark Vaughan OBE). The analysis again showed that the practice of inclusive education is unacceptably varied across England, with wide variations in LEAs’ placement of pupils with statements of special educational needs in mainstream and segregated settings.

5.2 By way of illustration of this variation in practice, the latest analysis found that the five LEAs with the lowest percentage of pupils segregated in England in 2004 were Newham (0.06%), Rutland (0.23%), Nottinghamshire (0.45%), Nottingham (0.47%) and Cumbria (0.49%). In contrast, LEAs with the highest percentage pupils segregated were South Tyneside (1.46%), Wirral (1.34%), Halton and Knowlsey (both 1.32%), Stoke-on-Trent (1.23%), and Birmingham and Lewisham (both 1.21%). This means that in 2004 pupils with statements of special educational needs in South Tyneside were 24 times more likely to receive a segregated education than those in Newham, London.

5.3 The analysis also revealed that the national percentage of 0-19-year-olds given a statement in “special” schools and other segregated settings in England fell only marginally from 0.84% in 2002 (103,721 pupils) to 0.82% in 2004 (101,612 pupils). One third of LEAs in England actually increased segregation of disabled pupils over the three years under review. These findings should be seen against a backdrop of legislative reform which supposedly *increased* children’s right to mainstream schooling.

6. POSITIVE DEVELOPMENTS IN INCLUSION

6.1 Over the years, CSIE publications and conferences have provided examples of inclusion working well in practice. Work by other voluntary organisations and increasingly by academic, government and other institutions, nationally and internationally, has also shown how effective practice can be achieved. The most recent work on inclusive practice by CSIE involved a two year research study into the use of the *Index for Inclusion*, a set of materials to help mainstream schools reduce barriers to learning and participation written by Tony Booth and Mel Ainscow and first published by CSIE in 2000. In 2005, CSIE published the results of this study in *Learning about the Index in Use*, written by Sharon Rustemier and Tony Booth, which illustrates how the *Index* is being used and what can be learned from these experiences in terms of the five phases of the *Index* process—getting started with the *Index*, finding out about the school; producing an inclusive school development plan; implementing priorities and supporting development and reviewing the *Index* process. The authors selected examples of inclusive development using the *Index* from hundreds of positive examples collected from primary and secondary schools across England.

6.2 In addition, one of the briefing papers prepared by CSIE for the sixth session of the Ad Hoc Committee drafting the new Disability Convention gives information about examples of inclusive education from countries across the world (*Briefing (2) from the Centre for Studies on Inclusive Education (CSIE) July 2005, Ending Segregation and Developing Inclusive Education—A Worldwide Movement*). The briefing gives access information and a brief summary of relevant content for nine different websites. *The Inclusion Week Magazine*, published in 2002 as part of CSIE's Inclusion Week from 11–15 November, which saw more than 250 inclusion events, also contains positive examples of inclusive development in schools across the UK and overseas.

7. DAMAGE OF SEGREGATION

7.1 A 2003 report from CSIE illustrates the damage of segregation to individuals and society, drawing on the substantial bodies of educational and social psychological evidence. *The Case Against Segregation Into Special Schools, A Look At The Evidence*, by Dr Sharon Rustemier, shows how segregated schooling is linked with stigma, stereotyping, prejudice and discrimination—the very conditions which disabled adults identify as among the biggest barriers to respect, participation and a full life.

7.2 This analysis of research shows that segregated “special” schooling has been associated with impoverished social experiences, abilities and outcomes; reduced academic experiences in terms of curriculum provision, outcomes, examination opportunities and accreditation; lower student aspirations and teacher expectations; high absence rates; difficulty in re-integrating into mainstream; poverty in adulthood; and poor preparation for adult life. Negative consequences for segregated pupils identified in the research also include depression, abuse, lack of autonomy and choice, dependency, lack of self-esteem and status, alienation, isolation, fewer friends, more restrictive interpersonal relationships, bullying and limited life-styles.

8. CHILDREN'S AND YOUNG PEOPLES' VIEWS SUPPORTING INCLUSION

8.1 CSIE has made efforts over the years to include the views of children and young people in its publications and conferences. Although this is not an area which is part of the Committee's terms of reference for this inquiry, we suggest it is, nevertheless, an important area for consideration when investigating special educational needs. When young peoples' views have been sought as part of educational research and in other forums they have spoken out against segregation and put forward a vision of an inclusive school as their preferred choice of learning environment.

8.2 As a project for Inclusion Week (see paragraph 6.2), CSIE summarised and amalgamated its work and that of other bodies so that young peoples' views could be presented in a *Young Voices* feature throughout the *Inclusion Week Magazine*.

9. PROBLEMS WITH THE DEFINITION OF “SPECIAL EDUCATIONAL NEEDS”

9.1 CSIE's experience indicates there are considerable limitations with the practice of identifying and labelling some children as having “special educational needs” and selecting them for separate treatment within mainstream or in separate “special” schools. The root of these problems is the association of a definition of “special educational needs” with a medical view of disability and difficulty in learning as resulting from personal deficit and difference. Such an association is not only disrespectful and hurtful to the young people themselves but has repercussions for the way they are supported to learn.

9.2 Using a label of “special educational needs” and a medical model of disability when educational difficulties occur deflects attention from barriers in the environment such as inaccessible buildings, inflexible curricula, teaching and learning approaches, and school organisation and policy. The responsibilities of schools and other institutions in these situations are considerably weakened. A “special educational needs”

label can also lead to lower expectations by teachers of pupils' potential and, together with other group headings such as "ethnic minority", "gifted and talented" and "English as an additional language", contributes to a fragmentation of schools' efforts to respond to the full diversity of students.

9.3 An alternative way of approaching disability and educational difficulty is through a social model which views the problems children and young people experience in school not as stemming primarily from their impairments, whether cognitive or physical, or from their social and economic circumstances, but from barriers to learning and participation inherent in the school setting itself or arising from interactions between students and their schools. Inclusive education can be understood as the practical outcome of a social model approach to disability and difficulty in learning and it is this approach which is adopted in the *Index for Inclusion* referred to in paragraph 6.1.

9.4 A medical or individual model of disability and educational difficulty with its categorisation of difference as "special educational need" is still embedded in Government policy and legislation and is operating in schools alongside a social model. This creates considerable problems for all those trying to pursue inclusive education. The social model and the medical model are radically different approaches with the potential to produce radically different experiences for pupils. A social model approach looks towards making resources available in mainstream settings and adapts and restructures mainstream curricula and classrooms to respond to the full diversity of children. A medical model, on the other hand, focuses on diagnosis, labelling and segregation into "special" services and settings. Such a gulf in understanding means that trying to operate both at the same time or to amalgamate them risks conceptual incoherence and forces a moral dilemma on school staff.

9.5 This short review of problems with the definition of "special educational needs" completes CSIE's memorandum of evidence to the Committee.

September 2005

Memorandum submitted by Mobility and Independence Specialists in Education (MISE)

I am writing as Chair of the Mobility and Independence Specialists in Education group (MISE). This is a national, curriculum group of over 150 members who provide Mobility and Independence (M&I) Education, for children and young people with a visual impairment. These professionals work in a variety of contexts such as Local Education Authorities, Special Schools and Social Service departments.

The aim of a M&I programme is to provide children and young people with the skills and strategies that will help them to maximise their potential to lead independent lives in the future.

It is every child's right to have physical access to their educational environment, as well as in the wider world. For those with a visual impairment, this can only happen if they have access to a M&I specialist who will assess their need at various stages of the child's life, particularly when in transition. The child may then need a M&I programme to cover a range of skills and strategies, from the development of their compensatory senses and concept development, to long cane training depending on their age, ability and level of residual vision.

There are many issues concerning the provision of M&I Education, not least the variable nature of services across the country as a whole. This is both a training and funding issue as well as a lack of Quality Standards across the profession. The result is that children and young people with a visual impairment are often unable to access even an initial assessment or ongoing M&I training. This is a particular issue for those children who have additional special educational needs who are placed in generic special schools. Many of these issues are supported by the research project "Steps to Independence" (RNIB 2002).

The extension of the Disability Discrimination Act into the Education sector should have raised awareness of disability access in general, however most schools and Colleges have focussed on access for people who use wheelchairs and do not have the expertise to assess for those with a visual impairment.

It is the view of myself and many of my colleagues that until there is official recognition of the profession and the a Standard training required for people new to the profession, as well as quality standards concerning service provision, we will continue to fail children and young people with a visual impairment.

Without M&I Education, many children and young people will be unable to fully access their educational opportunities. The current agenda of "Every Child Matters" has great relevance to M&I Education which is directly linked to each of the five outcomes.

As chair of MISE and a practising professional for over 18 years, I am happy to support the work of the inquiry in any way.

September 2005

Memorandum submitted by South Gloucestershire Council

LOCAL CONTEXT

South Gloucestershire has historically been a relatively inclusive authority compared to many other local authorities in the country. We have an inclusion policy and under 1% of the resident school population is in special schools. In a recent inspection by Ofsted the provision for SEN in South Gloucestershire was deemed to be good in relation to SEN Strategy and the use of resources. Support Services and Outreach from special schools conform to the best practice as identified in the Ofsted Report on those services published in July 2005.

ISSUES

Provision for SEN Pupils "In Mainstream Schools"

1. Current regulations give a blanket right to parents to request mainstream education for pupils with special educational needs. We would suggest that this is not practical in each and every case as it may not be appropriate for that individual pupil, be to the detriment of other pupils in the school and not be an efficient use of resources. We try to place children in mainstream schools whenever possible, as our record shows, but there is a concern about what this type of provision can practically deliver for some children.

2. The specialist resources available to mainstream schools from both the Education Service and the Health Service have been diluted by the policy of including children in mainstream schools. Every mainstream school cannot have expertise with the full range of very severe special educational needs, especially where the cognitive ability of the pupil is not in the normal range. We would contrast the appropriate efforts to include pupils with severe physical disabilities, with what is possible under the current legislation where parents could ask for children with Profound and Multiple Learning difficulties to be included in mainstream school. Whilst we have managed to include some pupils with Severe Learning Difficulties in mainstream school the Profound and Multiple Learning difficulties group would be very much more difficult indeed.

3. We have developed a number of Resource Bases as part of mainstream schools and these do produce a better concentration of resources. However, there is a penalty in that pupils have to travel from a much wider area and are not able to be included with their local peer group. This does produce a better use of education support services and can concentrate available Health Service provision. Some parents do not want their children placed in Resource Bases but want them placed in local schools with local peers. Individual placement in the local school may not provide the best possible education for their child or allow scarce resources to be concentrated. A continuum of provision is necessary but cannot be adequately funded if resources are dissipated.

4. The Health Service has not adequately resourced its community services for inclusion. There seems to have been a lack of joint planning between the DfES and DH with regard to providing the resources from Health to support the policies of inclusion taken forward by the DfES. Inclusion is currently held back by the resources available to community paediatrics, school nursing and therapies.

5. There is a conflict in the new education budget structure between the need to have adequate resources in central support services (see Ofsted Report July 2005) and the requirement on local authorities to ensure maximum delegation of resources to schools. Our latest concern is that the Government's drive to allow planning and preparation time for teachers, without providing enough resource for school budgets may have produced an anti inclusion pressure. Schools are free to reduce the amount of time that the SENCO had to spend on SEN and reallocate that time to providing planning and preparation time for other teachers. Alternatively time available for Teaching Assistants on SEN matters could be reallocated to enable classes to be covered to provide planning and preparation time. The current SEN information regulations are not sufficiently strong to allow Local Authorities to insist that schools declare their SEN expenditure to the Local authority or to parents. Ofsted reports are not sufficiently detailed to allow this sort of issue to be picked up. Consequently these regulations need to be revised and Ofsted needs to be more rigorous over SEN issues in schools.

6. There has been a distortion in the use of resources over the last few years as Local Authorities have been forced to divert resources from providing support and advice to schools to providing posts to deal with the increasing demands of the statutory processes in SEN and the Tribunal system. Schools have had to spend time administering Statements when the staff time could have been spent with the pupils.

Provision for SEN Pupils in Special Schools

7. The drive towards inclusion nationally has resulted in lower investment in special school buildings in local authorities, as the future of the special schools was not always clear. In this local authority we have invested in a high quality core of special school provision but are currently having difficulty in raising the capital to allow us to finish this programme. Currently the only way to raise this capital is as a Targeted Capital Fund Bid which is in competition with mainstream schools. If this bid to the DfES fails in one year then there is no prospect of being able to bid again for two years. In an authority where there is a growing

shortfall of special school places this means that, through no fault of our own, we may have no places for some children needing special school places in the medium term. The previous system of separate special school capital funding did allow for major special school schemes to be funded without competition from mainstream school projects.

8. In various policy documents the DfES has been clear that it expects a balance of special school and inclusive provision in a local authority. However, this is not reflected in the wording of the SEN Code of Practice which gives an almost unfettered right for parents to request provision in mainstream school. There seems to be a discontinuity here between policy and the statutory obligations that have been placed on local authorities. This would seem to be creating conflicts in the system.

Raising Standards of Achievement of SEN Pupils

9. Before we can look at raising achievement of SEN pupils it is necessary to be clear about their levels of attainment and have monitoring data available. We are developing processes for more detailed monitoring of pupil achievement and restructured our Inclusion Support Service to provide targeted advice to schools on SEN issues. Achievement of SEN pupils has been looked at within the context of the achievement of vulnerable pupils as a whole. Links are being developed between this work and the support and challenge that the Local authority provides to schools. At the moment it is not clear as to whether this sort of development can be followed through in the new School Improvement Partner structure that is being developed by the DfES at the moment.

Statements of Special Educational Needs

10. The Statutory Assessment and Statement system is now out of date and is not helping the inclusion of pupils. Schools often see pupils with Statements as being the local authority's responsibility rather than their own. Maintaining this statutory system does not reflect the Government's drive to devolve responsibility to the school. The presence of statements has created an "industry" in doing unnecessary formal assessments, legal involvement and expertise Tribunals. In South Gloucestershire we have made major strides in reducing the number of statutory assessments completed but it will be very difficult to reduce this further without a change in the law. The Government drive against bureaucracy in SEN cannot progress further whilst Statutory Assessments and Statements remain.

11. There is a considerable waste of resources in the SEN statutory system, which has penalties for school and local authority budgets along with the Legal Aid Budget. The presence of the Special Educational Needs and Disability Tribunal is part of an over legalistic system. The Tribunal was conceived to be a place where parents and local authorities could represent themselves, but increasingly parents have employed barristers and local authorities are being forced to also employ barristers. SENDIST does not publish the costs of its decisions in its annual report or go back to monitor whether its placements are successful. It seems ironic in a system where outcomes are monitored at every level that SENDIST doesn't have to also monitor in this way. Placements made by SENDIST are causing a considerable and ever increasing drain on local authority resources. These resources could be better employed in meeting the needs of special needs children in general, rather than concentrating on a few cases that go to SENDIST. SENDIST outcomes are often having a contra effect on policy making locally to central Government policy direction. The DfES will need to consider whether it wants that situation to continue. The SENDIST regulations as currently interpreted are unfair to local authorities. If a parent is represented by a barrister there is no stipulation that a parent cannot attend the actual hearing, but if an LEA instructs a barrister the instructing officer, as a party, cannot attend as well. This means that the Local Authority is at an immediate disadvantage and must be contrary to natural justice. Whilst we have managed to reduce the number of cases that have resulted in appeals to SENDIST, the cases that still go forward for decision mainly involve an unnecessary use of resources and distortion of the continuum of provision.

Provision for Different Types and Levels of SEN

12. The needs of most pupils with SEN can and should be met in mainstream schools, with varying degrees and types of support, including for some pupils, provision in a resource base. Special schools are still required to meet the needs of a small number of pupils, especially those whose needs are hardest to meet in curriculum terms in a mainstream school. It may be useful to think of this as being where the mainstream curriculum cannot be any further differentiated and a separate curriculum is necessary for an individual child. Again the distinction between pupils with physical disabilities and profound and multiple learning difficulties is a helpful one. Additionally special schools are necessary for pupils where care needs are at a very high level. Currently South Gloucestershire maintains special schools for pupils with:

- Severe Learning Difficulties.
- Profound and Multiple Learning Difficulties.
- Complex Learning Difficulties.

Often pupils attend the school for Complex Learning Difficulties when they have been in mainstream school and this has not proved appropriate. The pupils in the special schools are often those who have secondary needs which make for considerable complexity and possibly preclude education in the mainstream classroom. SENDIST places many pupils with specific learning difficulties (dyslexia) in specialist residential provision. This is unnecessary as these pupils can have their curriculum needs met in a mainstream school and considerable work has been done in recent years to improve the provision that can be made. Consequently placements by SENDIST for a variety of pupil needs show an inefficient use of resources through:

- Tribunal members possibly not all having an up to date understanding of inclusion issues;
- the Tribunal looking at the individual case and not viewing it in the context of the provision made for SEN pupils as a whole;
- some parents, who are able to work through the legalistic SEN framework gain a disproportionate amount of resources;
- a major distortion of the SEN system; and
- resources being channelled away from the majority of SEN pupils.

13. Provision in a residential school is only needed in a few cases and usually where there are considerable care needs. Increasingly this is confined to pupils who have Severe Learning Difficulties and Autistic Spectrum Disorders along with Challenging Behaviour, or Behaviour, Emotional and Social Difficulties. Historically BESD schools have found it difficult to be successful but this may be due to difficulties with organisational structure and a lack of staffing resources. Subject to the availability of capital from central government we would want to develop a high quality day school for pupils with Behaviour, Emotional and Social Difficulties. This must be integrated with childrens' services locally and will need considerable investment in buildings and staffing. We have identified that high quality leadership and management would be essential for this school and have identified that it may be necessary to pay what is in effect a recruitment and retention premium to attract the best people. Multi-agency support is crucial but difficult to guarantee.

Legislative Framework

14. There are a number of potential conflicts within the Government's intentions for the organisation of schools and making efficient provision for pupils with special educational needs.

Maximum delegation	V	Maintaining Core local authority SEN Services
School Improvement Partners	V	Co-ordination with local authority SEN Support and Challenge
Under-funded PPA time	V	Pressure on SEN resources in schools
Delegation of responsibilities to schools	V	Statutory responsibilities for SEN remains with the local authority
Separation of local authority and Schools Budgets to reduce local authority central expenditure	V	Local authorities are centrally under resourced to support schools and parents and meet the statutory responsibilities in SEN
Code of Practice on local authority/schools relations	V	The SEN Code of Practice.
The Statutory SEN system and statements are a route cause of conflict	V	Disagreement resolution system created to reduce Tribunals
Local authority power to name a school	V	City Academy principals can activate their own disagreement resolution mechanism. This group of schools is being treated differently to other state funded establishments.
Every Child Matters	V	SENDIST could place a child in a residential school against the wishes of Childrens' Social Services
Health Service has prime responsibility and budget to support the local authority	V	If the Health Service chooses not to prioritise support for SEN then the Local Authority has the ultimate responsibility.

The largest area of conflicts in the current system is the confusing legal situation with regard to the provision of health services in the support of the education service. The primary responsibility for therapy provision rests with the Health Service but if it decides that it does not have the resources to support the education service then the ultimate responsibility then falls on the local authority. This is the source of a great deal of conflict within the system and can give rise to considerable differences in provision around the country. It needs to be clarified in law as to what the Health Service and the local authority statutory responsibilities are. It has seemed to observers that the DfES and DH are reluctant to do this.

15. The Speech and Language Therapy Action Forum (DfES/DH) has made little progress on dealing with the responsibility issue in what is probably one of the most contentious areas of SEN provision. Whilst the issues being dealt with by this group will be helpful, they have not dealt with the central issue of who is the responsible agency.

It is clear from the way that this group has been established that the DfES and the DH are not prepared to deal with the root cause of the conflicts over therapies provision and other support to education ie to clarify and simplify where the budgets and responsibilities for making provision lie. The only solution to this is to change legislation and either put the ultimate responsibility on the Health Service or transfer the budgets and the responsibility for the child health services to schools into the Local Authority or a children's trust. This would link in with the Every Child Matters agenda but would require Government to be bolder in its legislative programme and not rely on the nebulous concept of partnership working.

16. Our recent experience of a case in which a parent involved the Disability Rights Commission has left us with concerns about how this agency is working. A school was unjustifiably taken to DRC by a parent after it had taken every reasonable step to meet the child's needs. The parent was informed that the DRC did not intend to take the case further but the school was not so informed. On enquiring of the DRC we were informed that it was not their policy to do so. We were concerned that this sort of attitude would potentially make supporters of inclusion disaffected because they had been treated in this way.

Fears

17. Currently the bureaucratic structures and conflicts within the SEN system are discouraging people from entering the SEN field. This is of particular concern as staff turnover is high because of the stressful and demanding nature of the work. This cannot be to the benefit of SEN pupils as a whole. Local authorities have difficulty recruiting to posts in SEN and in some cases posts have remained vacant on a long-term basis. It is clear that many candidates of quality do not choose SEN as a first choice. The work is relentless, extremely demanding, stressful and not acknowledged for what it is. Consequently it is not a high status area of work in Education. The shortage of quality candidates has reached a point where strategic development and planning is affected in some LAs where the deadlines for SENDIST responses have first priority on the experienced officer time available. It cannot be to the benefit of SEN children as a whole that so much scarce management resource is wasted on a sterile distorted process.

18. Former Minister Baroness Cathy Ashton publicly stated in a meeting in Bristol that the DfES did not propose to change the Statutory SEN system as the legislation required cannot be steered through the House of Lords.

Resourcing

19. The Select Committee may wish to look at an emerging national issue ie the increase in the number of pre term babies that are being successfully resuscitated. The number that subsequently leave hospital with considerable disability has increased pressure in the SEN system. The number of children surviving with current levels of disability has increased in recent years. This has created pressures on the school system as well as other community services. These pressures are best summarised as:

- Increased demand for SLD/PMLD school places.
- Increased number of pupils with physical disabilities in mainstream schools.
- Increased pressure on already stretched LA SEN budgets.
- Nursing support to schools is inadequate to provide support, particularly in relation to the use of oxygen and invasive procedures on school premises.
- The availability of Speech and Language Therapy, Occupational Therapy and Physiotherapy support to schools is now totally inadequate.
- In order to meet the needs of the most disabled, therapy support has been prioritised away from those children who historically would have had this support. Consequently this has created the possibility of more appeals to SENDIST.

20. There has been an increase in the demand for resources from pupils with Autistic Spectrum Disorders and Behavioural, Emotional and Social Difficulties. When viewed in conjunction with the increased demand for places for pupils with Profound and Multiple Learning Difficulties and Physical Disability this is a major budget pressure which does not seem to have been allowed for in education budgets nationally. In particular the strategic question has to be asked ie if the nation is making available resources for intensive care beds for pre term babies then, why isn't it making available the resource to provide the community services and school places for those children at a later stage? Additionally the country will need to provide resources in the future for adult social services to meet the needs of these children as they grow into adulthood. As a country we need to determine whether we are prepared to put the resources into the system to meet these children's needs as they go through the Education system and into adult life. Is it appropriate to make the resources available for intensive care and resuscitations without making resources available for later support?

Conclusion

21. The legislative framework and structure prevents rational resource management in special educational needs. There have been no new resources to meet changes in society and increased pressure from the number of pupils entering school with considerable disability. Consequently this is having a distorting effect on the resources available in education, and along with the statutory context has created a situation where conflict with parents is inevitable. Only major structural change can reduce the amount of conflict in the future.

September 2005

Memorandum submitted by the National Deafblind and Rubella Association

ABOUT SENSE

Sense is a family led national organisation that supports people with deafblindness and associated disabilities. It has pioneered early intervention with deafblind children and their families and supports specialist teachers and support staff in developing their skills and knowledge.

DEAFBLINDNESS

Deafblindness is a distinct disability that is more than simply vision loss and hearing loss. The combined effects of not seeing or hearing clearly are experienced uniquely by each deafblind person. Whether they are born with dual loss or acquire it as they start to grow up their lives are profoundly affected.

THE EDUCATIONAL CHALLENGE

Children who are born deafblind face enormous challenges. Vision and hearing are our two most important senses. At least 85% of all we learn comes from eyes and ears. The “incidental learning” from birth, that most of us take for granted, is denied to these children. Finding out about the world around them, learning to communicate and forming relationships are immensely more difficult for them. Also, many deafblind children have additional physical or learning disabilities or medical conditions, which often means that their deafblindness is not recognised immediately and support is slow to be provided. Deafblind children require highly specialist intervention in order to access learning opportunities, whether this is in a mainstream or a special school. Wherever deafblind children are educated, the most significant factor in their progress is the support they receive from qualified and experienced staff after assessment of their needs.

COMMUNICATION IS THE KEY

Deafblind children need to receive information in a way that is accessible to them, so standard teaching methods will not be effective.

Deafblind children and young people whose first language is British Sign Language will benefit from being taught in their first language. They also need a deaf peer group to mix with, whether this is in a mainstream or special school. The use of sign language is a valuable part of deaf and deafblind culture.

Similarly, blind and deafblind children should be offered the opportunity to develop their communication skills in appropriate ways, such as learning Braille or Moon.

For children with no formal language skills, a total communication approach is required.

IDENTIFICATION OF DEAFBLIND CHILDREN

The number of deafblind children, who have additional disabilities, including complex health needs, is growing. The aetiology of the children is changing and premature birth and genetic causes are now two of the key reasons for referral to Sense Family Services. But, in spite of this growing trend, congenitally deafblind children are still very rare in the population. Being born with a condition that is rare and complex presents a challenge, not just to the child and family, but to schools and services as well. There are few (if any) specialist professionals at a local level with sufficient detailed knowledge and experience to identify needs and then provide the right level of support. As a result, getting a good or a poor service, not surprisingly, is a “post code lottery” for families. Many spend hours searching for the “right” person in the LEA to help them. They feel they are a nuisance and get worn out and frustrated trying to get action.

It is largely because of the “gap” in skilled support locally that children with low incidence needs do not get a fair deal at present. The whole issue of providing expert and timely services to meet the specific needs of this most vulnerable group requires a more imaginative and anticipative approach.

Children are still under reported. However, the DES Policy Statement ensured that deafblind children are recognised as a distinct group. Since its original publication DfES, QCA and TTA have all included reference to the needs of deafblind and multi-sensory-impaired children in their documents and Local Authorities have interpreted this statement to the benefit of many children. Deafblind children are

“a heterogeneous group who may suffer from varying degrees of visual and hearing impairment, perhaps combined with learning difficulties and physical disabilities which can cause severe communication, development and educational problems. A precise description is difficult because the degrees of deafness and blindness, possibly combined with different degrees of other disabilities, are not uniform, and the educational needs of each child will have to be decided individually.”¹

This statement also recognises that there is a continuum of deafblind children, some of whom will choose to be educated in mainstream schools, some in resource-bases, and some in full-time provision catering specifically for their dual sensory impairment. Sense supports this policy.

THE STATEMENT OF NEEDS

Having a statement is of huge value to deafblind children and their families. It has helped to transform the lives of children who, in the past, have had to fight to convince others of their ability to learn, because usual teaching methods exclude them. A statement provides entitlement to a thorough assessment, which looks at every aspect of development. It requires a view from multi-disciplinary professionals and gives the family a chance to add their, most valuable, comments. Best practice indicates the assessment should be undertaken by a qualified and experienced person(s) who can also offer advice/insights and make suggestions that relate to practical working with the child, so the value of the assessment can be spread more widely.

Without this proper legal process, deafblind children, in some parts of the UK, would not be identified at all. Their specific needs would not be formally acknowledged. The children would be described by general terms, like having “severe learning difficulties”—which offers no real help to teachers. With the statementing process, families know exactly what they can expect, how the process should be conducted and most importantly, that they are protected by the law. Sense would oppose any change that would reduce families’ rights in this respect.

“Without a clear and cohesive insight into a child’s disability, developmental potential and his or her optimal learning conditions it is not possible to set up a programme for deafblind children.”—(Parent)

We agree the process needs to be made to work more effectively. In spite of a very clear framework parents experience endless local variation in the way the system is administered, with very mixed results.

SENDA

The Special Educational Needs and Disability Act 2001 enhanced the rights of pupils with SEN to a mainstream education. It signalled that where parents want a mainstream education for their child, everything possible should be done to provide this. A parent’s wish to have their child educated in the mainstream can only be refused if the child’s inclusion would be incompatible with the efficient education of other children and there are no reasonable steps which the school and the local education authority can take to overcome this.

The Special Educational Needs and Disability Act 2001 also brought schools within the scope of the Disability Discrimination Act 1995, giving them new duties not to treat disabled pupils less favourably than others and to make “reasonable adjustments” to ensure that they were not disadvantaged.

Sense very much welcomed the Special Educational Needs and Disability Act as a step forward for all children. Sense was also among the many organisations that called for schools to be included in the list of public sector bodies that were given a specific and anticipatory duty to promote disability equality as a result of the Disability Discrimination Act 2005.

THE LEGISLATION IN PRACTICE

In 2003, Ofsted reported on good practice in including pupils with SEN in mainstream primary and secondary schools.² The report concluded that on balance, the schools examined were doing well by their pupils. However, the report also stated that best practice in relation to children with visual or hearing impairment often involved a weekly visit by a specialist teacher of the visually or hearing impaired. This suggests that many children with visual or hearing impairments receive support from a specialist teacher less frequently than once a week. For children with sensory impairments qualified teachers of the deaf, blind and deafblind are essential. If children are to attend mainstream schools, it is vital not only that they have access

¹ DES policy statement of 9 March 1989: *Educational Provision for Deaf-Blind Children*.

² *Special educational needs in the mainstream*, Ofsted 2003.

to specialist teaching themselves but that their teachers also have specialist support to make the curriculum accessible. In the past this support has come from the LEA Advisory Service (often called Sensory Support Services) employing experienced teachers of sensory impaired children. These teachers have a caseload of children, covering all kinds of schools across the authority. But, recently, government has called for a reduction in centrally held budgets (from which this service is funded) to give the money directly to schools. This threatens a very cost effective and efficient use of specialist skills in effectively supporting low incidence children and their teachers.

The Ofsted report also found that pupils with SEN made better progress in learning in primary schools than secondary schools, and that provision at Key Stage 4 and above became much more difficult to manage. Primary schools were also better than secondary schools at identifying suitable targets for pupils.

The structure of secondary schools can be a barrier to the inclusion of deafblind children. Factors that influence this include:

- the structure of the timetable;
- the increasing orientation towards examinations;
- large buildings, leading to difficulties with orientation and the transport of equipment;
- the possibility of an very noisy atmosphere, which can be with a barrier to learning for children with sensory impairments; and
- the lack of staff with experience of low incidence disabilities such as deafblindness.

A further Ofsted report into SEN in mainstream schools in 2004³ found that teaching for pupils with SEN in mainstream education continued to be of varying quality, with a high proportion of lessons having shortcomings.

Although it is possible to differentiate the mainstream curriculum, or to disapply some of its elements, or both, there is a limit to how far this can be achieved. The more a child needs to have large parts of the curriculum differentiated or disapplied, the more difficult it can become to meet their needs in a mainstream school. A child who cannot follow a mainstream curriculum with others in the school may not experience positive feelings about their progress. This will not necessarily promote a sense of belonging, and may even be a barrier to inclusion. All children are different; for some it will work and for others it may not.

“How we measure the success of a school should not depend exclusively upon exam results but should also take account of the ways in which it develops pupils’ social, life and communication skills, and effective transition into adult life.”—(Parent)

RANGE OF PROVISION AND CHOICE FOR FAMILIES

For many parents, choosing the school their child will attend is a decision that causes some anxiety. For parents of children with a low incidence and complex disability such as deafblindness, this anxiety can be very much increased.

Sense believes that every parent and deafblind child should have access to high-quality education and the opportunity to choose a school that best meets their child’s needs whether this is in a special school, a mainstream school, or some combination of the two. Parents tell us that they want choice and they want the same opportunities for choice as they have for their other children. They want clear information about schools of all kinds and then they want respect for their decision when they have made it. A range of options need to be available for all children with SEN and disability, including those with low incidence complex needs who do not fit easily into the system.

“We really benefited from having a genuine choice of schools. With an excellent sensory support service, a good special school and a welcoming mainstream school we experienced what many parents don’t have—a real choice.”—(Parent)

Parents of deafblind children tell us they are looking for a school that feels right for their child. They are not looking at labels, like special or mainstream, so much as the specific areas of support that the school can offer their child. When thinking about their child’s education they are not focused on other children’s needs or what might benefit children in the future. They are in the “here and now” with their child and a very difficult decision ahead of them.

Parents are looking for a school that has a friendly and welcoming approach to their child as well having:

- access to specialist trained teachers of MSI children (VI and HI);
- one to one support to facilitate learning and social participation;
- individualised curriculum;
- differentiated materials to meet their individual needs;
- an appropriate learning environment;
- learning at a pace that takes account of the dual loss;

³ *Special Educational Needs and disability: towards inclusive schools*, Ofsted 2004.

- equipment to facilitate learning and social participation; and
 - peers who can communicate.
- “Children with severe special educational needs require a protected and imaginatively designed environment, a high level of financial and functional support and provision and a high ratio of skilled and motivated support staff.”—(Parent)

INDEPENDENT SPECIAL SCHOOLS

Whilst there has been an increase in the number of children with SEN educated in mainstream schools, there has also been a 10% increase since 2001 in the number of pupils placed in independent special schools by local authorities. According to Ofsted,⁴ this trend is at least in part because of the difficulties that mainstream and some special schools have in meeting severe or complex needs. For deafblind and multi-sensory-impaired children the independent charitable sector has been very significant. It was the non-maintained sector schools that led the way in identifying the children and developing approaches to their very special needs as far back as the 1950s. The “low incidence” factor is at work again here. In these specialist schools families find that their child’s needs are recognised immediately, their communication methods acknowledged and supported and the therapeutic support (so essential for a growing number of children) is more easily integrated into their school day. These schools are valued very highly by parents. They have confidence that the whole school understands the needs of their child, whereas often in both local mainstream and some special schools too, there is a knowledge gap.

In our sector, we have not seen a growth in referrals, which has resulted in a number of closures and mergers of non-maintained schools over the past six years.

MAINSTREAM EDUCATION = INCLUSION?

Sense is concerned that the Government is coming under pressure to interpret the concept of inclusion as ensuring that every child attends a mainstream school. Some of this pressure may arise from the fact that, in the past, many disabled children and children with SEN who could have benefited from being educated in mainstream schools were effectively excluded from them and discouraged from taking public examinations. However, happily, there have been significant changes to policy in recent years. The Special Educational Needs and Disability Act 2001 means that schools now have to make significant changes to staff training and the curriculum, and to plan positively to include a wider range of pupils including children with all types of learning disability. All schools must now have an accessibility plan. There is extra funding for schools to help them do this and Ofsted is monitoring their progress. Nevertheless, as has already been stated, there is still some way to go with proper implementation of the Act, and the DfES and Ofsted should take steps to promote its implementation in all schools.

An argument used in favour of all children with SEN attending mainstream schools is that children who attend special schools are less likely to be entered for formal examinations than children who attend mainstream schools. Research by the Institute of Employment Studies⁵ found that “formal qualifications were more likely to have been achieved by people without statements and those from mainstream schools, than by those with statements or those who had been to a special school”. However, these statistics reflect the fact that it is the children with the most profound disabilities, including deafblind and multi-sensory impaired children, who are more likely to attend special schools. Children who are able to take public examinations should be given every opportunity and encouragement to do so. However, the measure of success for some children is not examination results, and a child with no formal language skills will require a very different curriculum and a different set of measures for successful outcomes to school life.

True inclusion is not necessarily achieved by every child with special needs being on the roll of a mainstream school, particularly if that school is not equipped to meet all the child’s needs. Rather, real inclusion means that every child has access to high-quality education that meets his or her needs.

In recognising the individuality of deafblind children some have dual registration, attending a mainstream school for part of the week. Other children who are being educated in mainstream schools have certain parts of the curriculum disappplied in order that they can spend more time on other subjects, or receive training in communication or mobility skills. Some children attend special schools. It is essential that this range of provision continues if all children are to have their needs met.

CONCLUSION AND RECOMMENDATIONS

Sense warmly welcomes the fact that many children with SEN are now able to attend mainstream schools. With good planning and appropriate support deafblind children are making this choice too. However, a one-size-fits-all policy of “inclusion” in mainstream schools denies parental choice and could actually lead to some children being denied the education that is most appropriate for them.

⁴ *Special educational needs and disability: towards inclusive schools*, Ofsted 2004.

⁵ *Post-16 Transitions: a Longitudinal Study of Young People with Special Educational Needs (Wave Two)* Dewson S, Aston J, Bates P, Ritchie H, Dyson Prof A. DfES Research Report RR582 2004.

Sense believes that:

- there should be a range of educational provision for children with special educational needs;
- every child should receive the education that is most appropriate for them, whether this is in a mainstream school with appropriate support, a special school, or some combination of the two;
- parents should have the best possible information in order to be able to make an informed choice about the education of their child;
- deafblind children should receive a comprehensive assessment by a qualified and experienced person, leading to a detailed statement of their educational needs;
- deafblind children need support from appropriately qualified and experienced teachers and other staff in order to be able to access the curriculum and the social life of the school; and
- more teachers should be encouraged and incentivised to specialise in the teaching of children with special educational needs, particularly sensory impairment.

September 2005

Memorandum submitted by Graiseley Primary School

1. Graiseley Primary welcomes the opportunity to present this written submission to the Committee. We are a small inner city primary school in Wolverhampton with a Resource Base for up to 17 children with statements for Special Needs. We also have a very high percentage of children on free school meals, children who have English as an additional language and pupils who have Special Needs, but are not statemented. Due to the very low socio-economic nature of the area, mobility is high; the area is ranked first for unemployment, third for crime in the City; negative destinations are extremely high for school leavers; there is a shorter life expectancy and the housing market is extremely weak.

2. These issues affect the pupils with Special Needs, making their educational attainment even more difficult to match the required national standards. The children may have some or all of these major barriers to learning to contend with. We successfully minimise them, regarding them as challenges.

3. Our Ofsted report, which was published in January of this year cited us as “a very good school, with several outstanding features”.

We received grade ones for:

- How inclusive the school is;
- Pupils’ attitudes, values and other personal qualities (ethos);
- Pupils’ spiritual, moral, social and cultural development;
- How well the curriculum meets pupils’ needs;
- Enrichment of the curriculum, including out of school activities; and
- Leadership.

They judged provision for Special Needs as very good, with invaluable support; the children make very good progress. They noted that “every child does indeed matter” and that we are dedicated to reaching for high standards and instilling a love of education that will inspire pupils to become lifelong learners. The report also stated that the children are very well prepared for life beyond school; “pupils with special educational needs are fully integrated into the life and work of the school and have very good attitudes to learning”.

4. The difficulty for children with Special Needs arises is when they are working at the bottom of level 3; children working at level 2 or below do not sit the test. These children cannot access the standards of the tests, as they are not differentiated. This leads to significant damage to their confidence and self esteem. They quickly realise that they are not on a par with the rest of their class and so do their parents.

5. Data shows that some children with special needs who have attended our school from Nursery or Reception right the way through to Year 6 can reach level 4 in Science and/or Maths because of the concentrated effort over time. However, we have a very high percentage of SEN children who come to us late during the school year and late in their school career. English is very difficult for them with the added challenge that it is not their first language.

6. The League tables do not support children with Special Needs. The data is often over-looked and not interpreted specifically. This leads to schools with a high proportion of SEN pupils being penalised in the view of “standards”. It leads to crude comparisons from school to school. The SEN children who do not take the test and the SEN children who do have to sit the test are still included in the overall percentage marks obtained. We always publish results that don’t include the children with SEN to staff and Governors. These results are constantly in the very high eighties or nineties.

7. A parent governor with a child with Special Needs was very concerned that the children's results did not show the great amount of progress that they had made and that these children's results deflated the school's success in the present climate. It made her feel "very uncomfortable". Our Ofsted report gave us a grade 2 for "achievement" but had to give us a grade 5 for standards because we do not obtain high results—the only group who do not perform to "national standards" are the SEN children.

8. Schools with a high proportion of SEN pupils, especially with a Resource Base are at a distinct disadvantage.

9. Recommendations to be considered would be to take the SEN children's results out altogether and use a teacher assessment which is not matched against the National Curriculum as these children are not on a level playing field. This would still reflect the standard they were reaching and the value added in their progress, which could be equated to the quality of provision, or

10. Have a separate league table of schools with high proportions of SEN pupils.

11. The threshold at level 3 to sit the SATs tests be raised to level 4 with a separate assessment altogether for level 3.

12. This would give a more accurate picture of the excellent progress made by the children and achieve the Government's targets.

13. The children who cannot access level 4 could then go on to work on a practical skills certificate/award at Secondary school to leave school with qualifications for the world of work.

14. Pupils with SEN take the SATs when they are ready at Secondary school as part of the above award to give an English, Maths, Science standard for employers.

September 2005

Memorandum submitted by the National Autistic Society

1. PROVISION FOR SEN PUPILS IN MAINSTREAM SCHOOLS. AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

At present, some pupils with SEN who do not have Statements are not properly supported, due in part to teachers and LSAs not having sufficient time and resources, but also to what appears to be lack of training and awareness of autistic spectrum disorders.

All staff in contact with pupils should have training to recognise and deal with children who have special educational needs (not only the teachers and LSAs, but also other school staff who have contact with the pupils). This should include improved communication and sharing of knowledge between the various members of staff within schools, leading to a higher level of expertise and understanding all round and therefore an improved capacity to provide for pupils who have SEN.

To better utilise the knowledge and experience of staff who work in special schools/Centres of Excellence by creating outreach facilities and support for their counterparts in mainstream schools. There are 12 "Trailblazer" schools in England that already do this, and the scheme should be extended nationwide.

To explore the different models of provision, and share and incorporate examples of "best practice" between those models.

2. PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

Special Schools have a vital role to play in that there are a number of children whose needs are so complex, specific and severe that their needs cannot be fully met in a mainstream setting. These schools need support and expansion to become Centres of Excellence, with specialisation in certain areas of SEN, eg: autistic spectrum disorders, severe speech and language disorders, complex and multiple learning difficulties. These SEN Centres of Excellence, as well as assisting mainstream schools would also become centres of nurture and therapy for certain pupils who have SEN attending mainstream schools, but who need therapies and help over and above that which their home school can provide.

This extra help could be on a part-time basis and obviously designed to meet each child's individual need. Even when specified within Part 3 of a pupil's Statement, it has been our experience that the provision of speech and language therapy, occupational therapy and physiotherapy can be very limited, even within LEA controlled special schools. The measures described above would help to address this shortcoming.

3. RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

All pupils need to be educated in an environment that enables them to fulfil their potential, whether this be in a mainstream or special school, and there also needs to be improved early recognition of those children who show signs of having SEN. Rapid intervention and support is also vital once a child's SEN has been recognised. The curriculum must be differentiated to the individual needs of the pupil; adhering to the

principle of SMART targets (Specific, Measurable, Attainable, Realistic, Time-bound). The use of both adult and peer group learning mentors to support and encourage children, especially once those children access secondary and tertiary education.

Children's education must be adapted to their different learning styles; as an example, a lot of children who have autism are visual thinkers, whilst other children learn better with a "hands on", practical approach.

Parents who home educate their children must be supported and trained and given access to suitable teaching materials; maybe in the form of an educational "lending library". At present, parents who are home SEN teachers receive no official support or advice, yet are expected to fulfil the targets of the National Curriculum. Like their counterparts in schools, these parental home teachers are entitled to mentoring and on-going training to enable them to educate their children to the best of their ability.

4. THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (THE STATEMENTING PROCESS)

A Statement of Needs is a legal document that should ensure that a child's needs are properly met and their provision is safeguarded. Any prospective changes in the way SEN budgets are managed must not jeopardise any child's provision.

It has been our experience that Statements do not always fully and accurately reflect a pupil's ability and level of need, and there have been reported to us cases where out-of-date Statements have been sent to schools, Statements altered in a manner bearing no regard to what had been agreed by school staff, educational psychologist and parents at an Annual Review, as well as inaccuracies in their content, eg: another child's name being inserted into the reports. Delays in returning phone calls and general slowness in the overall administrative process are common problems.

Drastic improvement in communication needs to be made between all agencies involved in this process parents, LEAs, Health Services, Social Services, etc The use of "joined up services" and Person Centred Planning would facilitate this process and hopefully reduce the amount of red tape. Transparency of action from all agencies involved is also urgently needed. To ensure that the pupil's provision is first and foremost needs led, followed by the financial consideration. At the moment, it is felt that "best value policy" is being misinterpreted by certain LEAs to mean the cheapest provision overall, rather than the most economic provision that does properly meet the pupils' needs.

5. THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

Over the past five years, we as a group have initiated dialogue with various members of the LEA regarding our concerns, have offered constructive suggestions, and have been prepared to work in partnership with them, but there has been very little response to our overtures. Parents are potentially an invaluable resource and source of information, know their children better than anyone else, and need to be consulted fully every step of the way. At present, our experience is that parents are not generally treated in this way, and we feel that this needs to be urgently addressed.

This could be achieved through opportunities for parental representatives to consult with their LEA; to share their experiences and voice their opinions and concerns, so that the LEA and parents would have a better understanding of each other, and improve communication and the pupils' provision accordingly. It would be possible to do this in the form of a Consultation Group; feeding back the input from the meetings to the rest of the local Council.

Parents need to be treated as partners in education, rather than (as appears to be in a lot of cases) adversaries. Clear, concise and prompt communication is essential, as lack of this is anxiety provoking, disrespectful and can lead to unnecessary bad feeling and hostility. This is certainly true during the Statementing process, searching for suitable educational provision and for those parents whose children are in mainstream, getting adequate understanding and support.

6. HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

According to the SEN Code of Practice, children have SEN if they have a learning difficulty which calls for SEN provision to be made for them. Children are considered to have a learning difficulty if they have a significant greater difficulty in learning than the majority of children of the same age, or have a disability which prevents or hinders them from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the LEA.

There are, however, a number of "lost children" whose needs at present are not properly met, as they don't fall within the remit of the above definition, so they do not necessarily get the support they require. An example of this scenario would be a child with Asperger's Syndrome, who is very bright cognitively, but whose sensory problems, as well as the associated social and communication problems means he or she has difficulty understanding what the teaching staff require of him or her, as well as being side-lined and possibly bullied by his or her peers.

A wider remit and definition of what constitutes special educational needs is needed to cover the more subtle and high functioning conditions. To do so would prevent such children falling through the “educational net” and hopefully reduce the number of disaffected children who due to unrecognised special needs present as “difficult” pupils who sometimes truant, and often end up being excluded. Education should encompass more than just a child’s cognitive ability and include their other needs, eg: their social and communication needs and motor skills.

September 2005

Memorandum submitted by RESCARE

1. In representing thousands of families having a child with severe learning disabilities (formerly mental handicap) and/or autism we seek to promote the Government’s key principle of Choice in Education inclusive of properly resourced mainstream, special day and residential schools. It is in this context and on their behalf that we welcome the opportunity to contribute to the Committee’s deliberations.

2. We are deeply concerned at the policies being practiced at local level leading to the unwarranted closure of special schools in contradiction of Government stated intent.

3. The Department for Education and Skills (DfES) stated (2002) “Inclusion is not an agenda for the closure of special schools”, a policy assurance confirmed by Prime Minister (2004)—but closing they are with the choice option being denied at local level.

4. In operating imposed budgets LEA’s and Government should understand that for a system to be “more expensive” does not mean it is “too expensive”.

5. Increasing numbers of children are received into special schools through the Tribunal Appeals system and not referred direct by a local authority.

6. DfES figures School year 2002–03. From 1,076 registered tribunal appeals 689/64% sought special schools and 387/36% mainstream. From 236 Tribunal appeals wanting special schools named in statements 132/56% were upheld.

7. In what can only be considered an experiment in social engineering the use of “inclusion” as the ideological inducement to close special schools is a total misrepresentation of Government policy for those parents whose children have a multiplicity of educational and care needs to be met requiring specialist input in an environment conducive to such a delivery.

8. It is not a question of one type of educational process versus another but a comprehensive service with each area of expertise having a part to play, the quality of outcome for each individual being the ultimate criterion not the process.

9. There is a strong case for DfES issuing a circular reminding local authorities that they have a duty to provide a range of options for pupils with SEN needs including special schools.

10. Special schools are an essential part in delivering an inclusive education service by doing what Government wants, and should continue to be vibrant in order to meet the needs of those who do require them, while supporting entry into mainstream schools where appropriate.

11. With 3% of children nationally having needs that justify a statement, these should name special schools and/or dual special and mainstream options.

12. Also of concern is the increasing numbers of learning disabled school leavers being unnecessarily placed into the sectioning process. The undersigned having had personal experience of this with one of our four male family members suffering learning disability as a result of the fragile X syndrome.

13. HM Government and the DfES should take steps to have considered “The Report of the Special Schools Working Group” published by the DfES 2003 but which has hardly seen the light of day since. It is positive in supporting parents and in recognising the unique understanding and knowledge of their children. We ask that the Committee does likewise by endorsing the Government’s key principle of Real Choice for such families across a properly resourced range of options inclusive of mainstream special day and residential schools.

September 2005

Memorandum submitted by Epilepsy Action

Epilepsy Action is the UK’s largest member-led epilepsy charity. It provides support and advice for people with epilepsy and their families; and campaigns to improve the quality of statutory services in the education, health and social care sectors.

The following is a summary of Epilepsy Action’s submission of evidence highlighting the current shortfall in appropriate special educational needs provision (SEN) for children and young people with epilepsy:

Epilepsy is a very common condition affecting 60,000 children and young people in the UK. There is emphatic international evidence showing that large number of these children experience SEN as a consequence of their epilepsy. Despite this evidence, provision for children and young people with epilepsy in mainstream and special schools is wholly inadequate. The submission suggests that key reasons for this include: no statutory epilepsy training provided to pre-service or in-service teachers; failure to include epilepsy in the Government's SEN strategy; inadequate information in the Government's SEN Code of Practice; and a too narrow definition of "SEN" in government policy. The submission concludes by making a series of recommendations in line with Epilepsy Action's policy statement Epilepsy and Inclusive Education: a policy for change.

The submission's recommendations include:

- strengthen the existing SEN Code of Practice by adding extra information in the section covering medical conditions to include medical conditions that are more likely to cause SEN;
- add a new category of medical conditions that are more likely to cause SEN to the existing document Data Collection by Type of SEN. This is currently used by the Government to gather prevalence data about children with SEN. It must be amended in line with the proposed changes to the Code of Practice outlined above;
- implement epilepsy training for pre and in-service teachers and other education professionals about epilepsy and its SEN and health impacts on the child. The DfES must also encourage its SEN Regional Partnerships to include epilepsy as part of their continuing professional development training. This could be carried out in partnership with voluntary sector organisations such as Epilepsy Action; and
- commission research to identify effective learning and teaching strategies for children and young people with epilepsy. This research must be disseminated to pre and in-service teachers and other relevant education professionals to inform working practices. It must also be sent to local authorities, governors and school heads to inform their SEN policies.

Epilepsy Action would welcome the opportunity to expand on this evidence and present oral evidence to the Committee.

INTRODUCTION

1. Epilepsy Action is the UK's largest member-led epilepsy charity. It provides support and advice for people with epilepsy and their families; and campaigns to improve the quality of statutory services in the education, health and social care sectors.

2. Epilepsy Action believes that successive governments have neglected the provision of special educational needs (SEN) education for children and young people with epilepsy.

3. Therefore, it welcomes the opportunity to present evidence to the Education and Skills Select Committee about epilepsy and the lack of appropriate support for the large number of children and young people with the condition.

4. This document presents some key background information about epilepsy and SEN and then addresses the following areas for investigation by the Committee:

- Provision for SEN pupils in "mainstream" schools;
- Provision for SEN pupils in Special Schools;
- How special needs are defined;
- The "statementing process" for SEN pupils; and
- Raising achievement for SEN pupils.

The submission concludes with a series of urgent recommendations Epilepsy Action would like the Government to address.

EPILEPSY AND SEN

5. Epilepsy affects one in 242 children and young people of school age. This means that there are approximately 60,000 children and young people with epilepsy in UK schools.⁶ About 80% of these children are educated in mainstream schools.⁷ An average mainstream secondary school will have about 10–12 students with the condition.

6. Epilepsy is one of the most common neurological conditions in the UK. People with epilepsy experience recurrent seizures, unless the seizures are controlled by medicine. There are approximately 40 different seizure types and at present, only 52% of all people with epilepsy have their seizures controlled. A seizure occurs when the nerve cells in the brain, which affect the way we think and behave, stop working in harmony. When this happens the brain becomes overloaded for a short time. It is important to note that

⁶ Epilepsy prevalence, incidence and other statistics. Joint Epilepsy Council: Leeds. 2005.

⁷ Managing Medicines in Schools and Early Years Settings. DfES: Nottingham. 2005.

not all seizures are obvious to observers, including education professionals. Some, such as tonic clonic seizures are and their impact on the child's education may, at least in part, be obvious. Others, such as absence seizures may be much less obvious but still significantly impact on learning ability. There is also increasing concern about the effects of sub-clinical seizures where there is no obvious physical manifestation but still cognitive disturbance.

7. There is a strong international evidence-base of the types of SEN children and young people with epilepsy experience:

- A 2003 Irish study shows that half (51%) of parents stated their child was experiencing educational difficulties in school. Concentration difficulties were identified as the most prevalent problem (52.3% of parents); followed by memory difficulties (38.5%); and keeping up in general (35.4%).⁸
- The same study shows that about a third of children and young people are immediately sent home following a seizure at school.⁹
- Another UK study has demonstrated that over two-thirds of young people recovered from their seizures within an hour.¹⁰
- A 1997 Swiss study found that children with epilepsy in mainstream schools had significantly poorer school performance compared to siblings attending the same schools without the condition. Specific difficulties encountered, include: poor concentration; low self-confidence; and poor relationships with peers.¹¹
- A 1992 study in Finland found that nearly a quarter (23%) of children with epilepsy encountered specific learning difficulties.¹²
- A 1986 US study shows that children with epilepsy make less academic progress than expected for their age and IQ level. Specific difficulties were encountered with: mathematics; spelling; reading; comprehension and word recognition.¹³
- A 1974 English study shows that over two-thirds (69%) of children and young people with epilepsy in mainstream schools underachieve academically in relation to their actual intellectual level.¹⁴
- A child or young person experiencing a seizure in school or class is at risk of missing some or all of a lesson or activity. One of the most common seizure types in children is absence seizures where the child regularly loses consciousness for brief periods of time. This is very difficult to recognise and is often overlooked by staff causing significant problems with learning.¹⁵

8. Children and young people with epilepsy routinely experience potential health, learning, behavioural and emotional needs as a direct or indirect result of their condition. Worryingly these needs are unmet by current SEN guidelines and legislation, contrary to the international body of evidence.

9. Epilepsy Action would like the Committee to acknowledge the following areas where children and young people with epilepsy encounter educational difficulties and seek to rectify them as a matter of urgency.

PROVISION FOR SEN PUPILS IN "MAINSTREAM" SCHOOLS

10. The current provision for children and young people with epilepsy in mainstream schools is extremely deficient.

11. Despite the overwhelming evidence base given above there is currently little, or no, structured support for children and young people with epilepsy. One of the key reasons for this is an acute lack of statutory and non-statutory epilepsy training for education professionals:

- A study of teachers in England showed that only 2% had received training on epilepsy, although the majority said they would like to receive training.¹⁶
- Epilepsy is not covered at any stage of the Initial Teacher Training programme for pre-service teachers.
- Not one of the Department for Education and Skills' (DfES) SEN Regional Partnerships offer epilepsy training as part of their drive to improve professional awareness of SEN issues.

⁸ Senior, J. Educational, Medical and Advisory Provision for Children with Epilepsy in Ireland. Brainwave, Dublin. 2003.

⁹ Senior, J. Educational, Medical and Advisory Provision for Children with Epilepsy in Ireland. Brainwave, Dublin. 2003.

¹⁰ Wardle, I. Epilepsy and Education. Epilepsy Today 67. Leeds, Epilepsy Action. 2004.

¹¹ Schuler, M et al. School performance and social integration. Paper presented at European Congress of Epilepsy. Dublin. 1997.

¹² Sillanpaa, M. Epilepsy in children: prevalence, disability and handicap. Epilepsia 33. 1992. 444-449.

¹³ Seidenberg, M et al. Academic achievement of children with epilepsy. Epilepsia 27. 1986. 753-759.

¹⁴ Holdsworth, L and Whitmore, K. A study of children with epilepsy attending ordinary schools. 1: their seizure patterns, progress and behaviour in school. Developmental Medicine and Child Neurology 16. 1974. 746-758.

¹⁵ Radley, R. Education attainment of children and young people with epilepsy. In: Epilepsy and Education (Eds J Oxley and G Stores). London, Education in Practice, 1987.

¹⁶ Bannon, M J, Wilding, C and Jones, PW Teachers' perceptions of epilepsy. Archives of Disease in Childhood, 67. 1992.

- The European White Paper on Epilepsy presented to the European Parliament in 2001 clearly states: “Steps should be taken, as a matter of urgency, to provide courses on epilepsy at both initial and in-service levels [for teachers].”¹⁷

12. This lack of epilepsy awareness results in the failure of education settings to provide an appropriate level of support for children and young people with the condition. Due to this, children and young people with epilepsy are being overlooked by current SEN guidance and legislation.

13. Furthermore, the current situation means that children and young people with epilepsy are at risk of not meeting several of the Government’s national priorities within its Every Child Matters: Change for Children programme. Specifically, these targets include:

- Improve the academic achievement of seven to 16-year-olds.
- Cut the number of half-day absences.
- Reduce the percentage of 16–18-year-olds not in education, employment and training.

14. Training is vital to improve education professionals’ epilepsy awareness and prepare them to deal with the health, learning and behavioural impact of the condition. In turn this would help education settings and local authorities meet their Every Child Matters targets.

15. Epilepsy Action believes that epilepsy’s impact on a child and young person’s education combined with a lack of basic awareness in education settings is a recipe for disaster. Tackling these issues is vital as the Government moves towards an inter-agency model of working and the development of children’s services.

PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

16. The situation for children and young people with epilepsy is similar to that in “mainstream” settings. The key difference is that children and young people in Special School settings are more likely to have complex health and education needs. This often results in Special School settings focussing on the medical management of the condition and overlooking a child’s educational needs. It is vital for staff in Special Schools to have the same, if not greater, understanding of epilepsy’s educational impact on learning and behaviour in order to give children and young people with epilepsy the appropriate support.

HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

17. Epilepsy is not recognised by the DfES as a condition that causes SEN. This is despite the overwhelming evidence of its impact on learning and behaviour outlined above.

18. The DfES currently defines epilepsy as a purely medical condition as opposed to a condition that specifically causes SEN. The department gives a definition of epilepsy in its medicines management guidance. It states: “Children with epilepsy have repeated seizures that start in the brain.”¹⁸ Note the DfES does recognise other medical conditions as having educational/learning implications and has actually issued guidance (jointly with the Department of Health regarding Autistic Spectrum Disorders)—Autistic Spectrum Disorders/Good Practice Guidance: DfES/597/2002.

19. As a result, epilepsy is not included in the department’s key SEN documents, The Special Educational Needs Code of Practice and Removing Barriers to Achievement:

20. The Special Educational Needs Code of Practice devotes only four paragraphs within its 10 chapters to medical conditions. Paragraph 7.64 states: “A medical diagnosis or a disability does not necessarily imply SEN. It may not be necessary for a child or young person with any particular diagnosis or medical condition to have a statement, or to need any form of additional educational provision at any phase of education. It is the child’s educational needs rather than a medical diagnosis that must be considered”.¹⁹

21. This statement risks implying that it is possible to identify children as having either medical needs or SEN. In reality children with medical conditions, such as epilepsy, are more likely to experience learning difficulties as a direct and indirect result of their condition. In order to give a child with epilepsy the appropriate support it is vital to recognise that a child’s epilepsy is likely to cause SEN and that their SEN and health needs are closely inter-related.

22. One solution proposed by Epilepsy Action is to amend the section on medical conditions in the Code of Practice to include an additional paragraph stressing that while a medical diagnosis may not imply SEN, there are some medical diagnoses, such as epilepsy, which make it more likely that a child will experience SEN.

¹⁷ European White Paper on Epilepsy. Brussels 2001.

¹⁸ Managing Medicines in Schools and Early Years Settings. DfES: Nottingham. 2005

¹⁹ Special Educational Needs Code of Practice. DfES: Nottingham. 2001.

23. Similarly, the DfES's 2004 SEN strategy, *Removing Barriers to Achievement*, does not acknowledge epilepsy as a condition that causes learning, behavioural and emotional problems for children and young people. The introduction to *Removing Barriers to Achievement* sets out the Government's strategy as being one that "provides clear national leadership supported by an ambitious programme of sustained action and review, nationally and locally, over a number of years, in four key areas:

- Early intervention.
- Removing barriers to learning.
- Raising expectations and achievement.
- Delivering improvements in partnership".²⁰

24. One of the core initiatives currently being developed by the DfES as part of *Removing Barriers to Achievement* is the Inclusion Development Programme (IDP). The IDP aims to "help schools develop effective inclusive practice by bringing together education, health, social care and the voluntary sector".

25. While this seems the perfect opportunity to develop effective SEN support and best practice for children and young with epilepsy, the DfES has informed Epilepsy Action that epilepsy does not qualify for inclusion within the IDP because of its status as a medical condition and not a condition of SEN.

26. The fact that epilepsy, and its impact on a child's learning and behaviour, has not made it onto the department's SEN agenda are worrying for two key reasons:

27. Firstly, without epilepsy being acknowledged by the Government as a condition that affects a child's learning and behaviour, it is difficult for education professionals to accept that SEN encountered by a child with epilepsy are caused by their condition.

28. This often means that learning or behavioural difficulties displayed by children with epilepsy are often dismissed as simply bad behaviour or low intellectual ability. More detail about these problems will be provided in the next section, "The 'statementing process' for SEN pupils".

29. Secondly, the absence of epilepsy from the Government's SEN strategy has enormous implications for its long-term children's services agenda. As documented above, the Government is currently rolling out its *Change for Children* programme. This programme is designed to implement the policies and practices for children's services outlined in the Green Paper, *Every Child Matters*. These policies and practices were in turn developed from recommendations of the 2003 Laming Inquiry into the tragic death of Victoria Climbié.

30. One of the fundamental changes the Green Paper proposed was a unification of children's services resulting in joined-up support for children and young people with additional needs. Although this programme of measures is well under way, current policy and procedure is entirely at odds with ensuring children and young people with epilepsy receive the appropriate support set out in *Every Child Matters*.

31. At present there exists an over-simplistic divide in the assessment and support for a child with SEN and a child with medical needs. This divide is highlighted in the extract from the Code of Practice quoted above. In reality this divide rarely exists. It would be better if the document highlighted the fact that while a medical diagnosis may not imply SEN in some cases, in others a medical diagnosis may make SEN more likely.

32. Accepting that epilepsy is a medical condition more likely to cause SEN is a vital step for the Government to take if it is to provide the appropriate support for children and young people with the condition.

33. Failure to adequately address these problems will persist until the Government's SEN policy and strategy overtly acknowledges the relationship between epilepsy and SEN and a comprehensive plan is implemented to tackle this issue.

34. Until this happens children and young people with epilepsy will continue to fall between the two statutory frameworks and as a result be offered inadequate, or no, help in the classroom.

THE "STATEMENTING PROCESS" FOR SEN PUPILS

35. Getting a statutory assessment and statement of needs is one of the most specific problems encountered by children and young people with epilepsy. A major factor in this difficulty is caused by epilepsy not being recognised as a condition of SEN.

36. One of the biggest hurdles in obtaining an assessment and statement is caused by epilepsy not being included in the DfES document *Data Collection by Type of Special Educational Needs*.²¹ This document is used in schools in England and Wales and has two main purposes. Firstly it is used by the Government to collate and review the types of SEN encountered in schools. Secondly it is used by education professionals to help identify particular conditions of SEN in their students.

²⁰ *Removing Barriers to Achievement: The Government's Strategy for SEN*. DfES: Nottingham. 2004.

²¹ *Data Collection by Type of Special Educational Needs*. DfES: Nottingham. 2003.

37. Because epilepsy is not included in this document, when a child with the condition displays the specific learning and behavioural needs listed above, there is no clear link made in official guidance. This makes it very difficult for staff to link these needs with the child's epilepsy. In turn, this causes two acute problems.

38. Firstly, it makes it difficult for staff to identify and understand the underlying cause of the child's SEN. This makes it even more difficult for the child to receive the appropriate support or referral to the correct professional or service and for effective multi-agency working to take place.

39. Secondly, this omission of epilepsy from the Data Collection document means that there is no link between epilepsy and SEN in official documents. This means that parents often struggle to convince education professionals that their child's epilepsy is the cause of their SEN.

40. If the Government is to amend the Code of Practice to enable education professionals to identify children with medical diagnoses that put them at a greater risk of developing SEN it is important that this is reflected in its data collection methods. This would address both of the problems identified above.

RAISING ACHIEVEMENT FOR SEN PUPILS

41. Raising the achievement of children and young people with epilepsy is vital to ensure that they receive the same opportunities as their classmates without the condition. As well as underachieving academically (see evidence above), unemployment in children and young people with epilepsy is two to three times more common than in other school-leavers without epilepsy.²²

42. There are several key steps the Government needs to take if it is to raise achievement in children and young people with epilepsy:

- Recognise epilepsy as a medical condition that is more likely to cause SEN in the Code of Practice.
- Include this new category of SEN in the school census document, Data Collection by Type of Special Education Needs.
- Provide pre-service and ongoing in-service training about epilepsy and SEN for education professionals.
- Commission research into effective teaching and learning strategies for children and young people with epilepsy.

CONCLUSIONS AND RECOMMENDATIONS

43. Following on from the steps outlined above, Epilepsy Action has identified several key areas for urgent attention by the Government. Its policy statement: *Epilepsy and Inclusive Education: a policy for change* contains detailed information about the issues outlined in this submission. Epilepsy Action believes that the current shortfall in appropriate SEN support for children and young people with epilepsy can start to be tackled through the following action:

SEN Code of Practice

44. Epilepsy Action believes that the current SEN Code of Practice should be amended to include extra information on SEN and medical conditions. At paragraph 7.64 the existing Code of Practice stresses: "a medical diagnosis does not necessarily imply SEN". An extra paragraph needs to be added after 7.64 emphasising the reverse situation whereby some medical diagnoses make it more likely that a child may encounter SEN. Epilepsy is an example of this situation.

Data Collection by Type of Special Educational Need

45. Following on from this strengthening of the Code of Practice's information about SEN and medical conditions it is vital that prevalence data is collected about children with epilepsy and other medical conditions that are more likely to cause SEN. As suggested above, a new category needs to be added to the existing version of Data Collection by Type of Special Educational Needs that allows education professionals to identify and record the number of children with medical conditions that are more likely to cause SEN.

²² Elwes, R D, Marshall, J, Beattie, A and Newman, P K Epilepsy and employment. A community based survey in an area of high unemployment. *Journal of Neurology, Neurosurgery and Psychiatry*, 54. 1991.

Teacher training

46. To ensure that the amended Code of Practice and Data Collection documents are introduced and implemented successfully, the Government must make it a priority for pre and in-service teachers and other education professionals to receive training about epilepsy and its SEN and health impacts on the child. It must also provide comprehensive continuing professional development (CPD) training on epilepsy for in-service staff. This is all the more important as the Teacher Training Agency is currently being rebranded as the Teacher Training and Development Agency, taking responsibility for providing professional development training for education professionals.

47. The DfES must also encourage its SEN Regional Partnerships to include epilepsy as part of their CPD training. This could be carried out in partnership with voluntary sector organisations such as Epilepsy Action.

48. Following on from the inclusion of information in the Code of Practice and Data Collection document about medical conditions more likely to cause SEN, the DfES must commission research to identify effective learning and teaching strategies for children and young people with epilepsy.

49. To ensure that this new information is implemented effectively, the results of this research must be disseminated to pre and in-service teachers and other relevant education professionals to inform their working practices; it must also be sent to local authorities, governors and school heads to inform their SEN policies.

50. It is vital for the Government to recognise epilepsy as a medical condition that is more likely to cause SEN for two reasons. Firstly, this will help education professionals working with children and young people with SEN to identify better the specific needs of children and young people with epilepsy and provide appropriate support. Secondly, it will allow epilepsy to be fully included in the DfES's SEN strategy and its related initiatives.

51. If the Government is to take raising the achievement of children and young people with SEN seriously and commit itself to tackling the national priority targets for the Every Child Matters: Change for Children programme it must take account of the 60,000 children and young people with epilepsy many of whom are currently experiencing SEN and are being neglected by the current SEN provision in England and Wales.

52. By tackling these issues head on, and in partnership with the voluntary sector where necessary, school staff in the classroom will be better able to give children and young people with epilepsy the correct support. At the same time local authorities and school heads will be able to raise their school achievement and reach national targets more effectively.

53. Epilepsy Action hopes that the Committee will recognise the important issues raised in this submission. It also hopes that the current shortfall in SEN provision for children and young people with epilepsy is brought to the Government's attention and action taken as a matter of urgency.

54. Epilepsy Action would welcome the opportunity to expand on this evidence and present oral evidence to the Committee.

September 2005

Memorandum submitted by the Royal London Society for the Blind

1. INTRODUCTION

1.1 The Royal London Society for the Blind is committed to empowering people with a visual impairment to lead independent lives through the provision of high quality education, training and employment services. Since 1954 Dorton House School has been a centre of education and learning for blind and partially sighted children. Dorton House School is a Non-maintained Special School, part of the Royal London Society for the Blind and located in Seal near Sevenoaks in Kent. We are committed to the most progressive approaches to the education of visually impaired children. The staff team has developed a school that seeks partnership and collaboration with their colleagues in mainstream to develop an effective model of truly inclusive education. We do this by meeting individual needs and giving pupils the necessary skills to take a full part in learning, social and leisure activities, at school and in their local area.

1.2 We are a regional resource, offering training, advice and support to families with blind and partially sighted children and professionals who work with them. We use our specialist staff resources and facilities to enable children who are based in mainstream to benefit from holiday and weekend activities designed to increase their learning, independence and social skills.

2. PROVISION FOR SEN IN SPECIAL SCHOOLS

2.1 The high quality and value for money of our specialist provision is evidenced in our most recent Ofsted and CSCi reports. We are particularly mindful of the importance of the five outcomes from “Every Child Matters” and how these impact on the child with visual impairment, their families, access to provision and fulfilling potential.

2.2 Dorton House School is a regional provider of very specialist provision for children with visual impairment. The majority of children with a visual impairment are placed in mainstream schools and with the right support, do very well academically and socially. However, there are some children who need the specialist environment and the intensive support of Dorton House School, in order to be fully included and achieve their potential but are unable to access it, even though their parents wish it. LEAs are very reluctant to make “Out of Authority” placements on both financial and ideological grounds and many parents feel that they are forced to appeal to the SEN and Disability Tribunal. This is a very confrontational, stressful and expensive process and parents feel angry and frustrated with the LEA and the SEN “system” and feel that no one is listening to them.

2.3 Although non-maintained and independent special schools have a vital part to play in the continuum of provision for pupils with SEN, they are perceived as being “outside the system” when placement decisions are made. Dorton House School offers part time and short term placements together with support in re-including a child in local provision. The funding system is not flexible enough to support the School in playing a fuller regional role in supporting children both within the school and within mainstream. There are no funding mechanisms in place that would underpin the further development of Dorton House as a regional resource. With fewer children being placed, the unique expertise, resources and facilities of Dorton House in a very low incidence disability, visual impairment, are being underused and are in great danger of being lost altogether.

2.4 There are relatively few teachers training each year for the specialist qualification in visual impairment and the average age of qualified teachers is high. There will be an increasing shortage of qualified and experienced staff in this field. Dorton House School provided a regional resource of qualified and experienced staff, specialist resources and facilities that could be used more widely to support and train mainstream staff and schools.

3. AVAILABILITY OF RESOURCES AND EXPERTISE/DIFFERENT MODELS OF PROVISION

3.1 The School’s innovative and successful partnership with our Local Education Authority, Kent, is a case study in “Removing Barriers to Achievement”, the Government’s Strategy for SEN, illustrating building local capacity to meet low incidence needs. Within this Partnership, the School is developing a joint assessment process with a range of agencies, including education, health and other voluntary organisations, under the title of “Shared Vision”. The aim is to give children and families across Kent, a first class, seamless service by sharing expertise and resources and to improve communication and information sharing. Staff from Dorton House are working with their colleagues in Kent mainstream and special schools and Kent staff are accessing joint training opportunities at Dorton House.

3.2 We are working closely with the South East Regional SEN Partnership, supporting a range of Government initiatives for low incidence disability within the wider SEN and school achievement agenda and addressing regional differences in the services available for children and young people with sensory impairment. By developing different models of provision in partnership with a range of other agencies that are flexible, responsive, effective and efficient, Dorton House is contributing on a regional basis to the increased availability of resources and expertise in this very low incidence disability and the building of local capacity.

3.3 There now needs to be a supportive framework, underpinned by appropriate funding mechanisms to support this work and to enhance the quality and standards of provision for all children with visual impairment, wherever they live in the country.

4. ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN’S EDUCATION AND THE STATEMENTING PROCESS

4.1 Visual impairment is very often a life long disability and one that impacts on every part of a child’s life. The isolating nature of the disability means that many children have difficulties in developing the appropriate social and independence skills necessary for full inclusion in society. Resources and teaching strategies need to be highly differentiated to enable a child with little or no vision to access the curriculum and other learning and social opportunities. Children need a high level of individual support whilst learning essential skills such as braille. Many have low self esteem and have poor social and independence skills and are vulnerable to bullying and social exclusion.

4.2 Parents are very anxious that their children are being well-supported and feel that they need the “protection” of a Statement to ensure that their needs are met. They need to have greater confidence in the ability of mainstream schools to meet their child’s individual needs and have had the sometimes negative

experiences of confrontation with the LEA in order to achieve adequate support for their child. They may also have experienced fragmented or non-existent services within health and social services and desperately need a co-ordinated and multi-agency response to their extensive needs.

4.3 Dorton House School is seeking to support mainstream in meeting the needs of children with visual impairment by working in partnership with LEAs and other voluntary and statutory agencies. The “Shared Vision” joint assessment process is already contributing to increasing parental confidence through improved communication and information sharing, joint working and family support. By engaging positively with parents and making placement and support decisions on clear, transparent and evidence-based grounds, tensions between LEAs and parents could be reduced and confidence in the system increased.

4.4 Some LEAs refuse to consider a parent’s preference for a placement within a specialist non-maintained school such as Dorton House and the parent has no alternative but to go to Tribunal. In some areas this seems to be a “blanket decision” regardless of individual need. Parental choice is important and needs to be considered alongside the efficient use of resources by the LEA and a more productive dialogue established. Short term and flexible placements within the specialist school could also support the acquisition of essential skills such as braille and the successful inclusion of the child into mainstream within a fixed period of time.

September 2005

Memorandum submitted by Afasic

INTRODUCTION

1. Afasic is the UK-wide charity representing children and young people with speech and language impairments. Afasic welcomes the opportunity to make a submission to this inquiry.

2. Afasic primarily represents children with specific speech and language impairments, that is to say their impairment is not caused by a physical or sensory disability, such as hearing impairment or cerebral palsy, and their intelligence is within the “normal” range.

3. Speech and language may be impaired in any or all of the following ways:

- The child may have difficulty articulating speech clearly.
- The child may have difficulty understanding language.
- The child may have difficulty learning and remembering words, and putting words together to make sentences and paragraphs.
- The child may have difficulty using language appropriately in context.

4. Speech and language impairments may be associated with other cognitive impairments, including:

- Poor memory.
- Difficulties with social interaction and relating normally to other people.
- Poor organisational skills.
- Poor reasoning skills.
- Difficulties with generalising knowledge and learning from experience.
- Poor predictive skills.
- Difficulty understanding cause and effect.

5. As a result, although they are of normal intelligence, children with speech and language impairments often function and perform at quite low levels and have real difficulty with many aspects of daily life and learning, including acquiring literacy and numeracy skills.

6. Speech and language impairments affect 6% of school-aged children. The majority of these will be at the lower end of the age range, as most children’s speech and language skills improve as they get older, especially if they are given appropriate support by speech and language therapists and teaching staff. However, even where a clinical diagnosis of speech and language impairment is no longer appropriate, children and young people may still have any or all of the cognitive difficulties described above which will affect their learning and performance at school. It should also be noted that 1 in 500 children has a persistent, life-long speech and language impairment, which will affect them throughout their time at school and beyond.

GENERAL POINTS

7. There are a number of problems with the SEN system, as the Committee has implicitly acknowledged by conducting this inquiry. There are many reasons for this, most of which will be discussed later in this submission. One important issue, though, which this inquiry only serves to illustrate, is that SEN is nearly always discussed in isolation, rather than within the context of education policy as a whole. It is important

to realise that SEN is not a stand-alone issue. It affects and is affected by all other initiatives within education. Yet, the impact on SEN services and children with SEN seems often to be just an afterthought, rather than form an integral part of the planning of new policies. Even where SEN is mentioned, it usually seems to have been considered in a very superficial way. The complexities of the issues involved cannot be overestimated, and it is important that everyone undertaking policy work develops a thorough understanding of SEN. There are numerous examples of initiatives that have failed to take SEN properly into account, but it is probably sufficient to cite just a few:

- The 14–19 white paper makes very little mention of SEN. There are some references to entry level qualifications and a few paragraphs about “learning difficulties”. One gets no sense, though, that those writing the document had any real awareness of the complexities of SEN.
- The move towards more autonomy for schools is happening with no mention or apparent consideration of how this will affect support for children with SEN. In particular, the City Academy programme seems to be forging ahead, with no real consideration of the impact that their greater freedom in admissions and curriculum may have on children with SEN.
- The current emphasis on reducing disruptive behaviour in schools fails to consider the extent to which this is associated with unmet SEN. The Audit Commission in its report *Special Educational Needs: a Mainstream Issue* stated that the vast majority of permanent exclusions involved children with known SEN (87% of those excluded from primary schools; 60% of those excluded from secondary schools). In common with other organisations working in the field of SEN, we know of many children with unidentified SEN who have been excluded. So SEN appears to play a really important part in this issue, yet is rarely mentioned when the subject is discussed.
- The speaking and listening guidance (*Speaking, Listening, Learning: Working with Children in KS1 and KS2*) made no mention of children with SEN at all. Although this oversight was later amended in part by the publication of the excellent guidelines for children with SEN, no guidance was issued on how to integrate the two different programmes of learning, reinforcing the notion that SEN is something separate from mainstream.

8. Fundamentally, the education service is designed to suit the “normal” or “average” child (or in some cases the slightly above-average child). The needs of the child with SEN appears only ever to be an afterthought, for whom the standard provision has to be “tweaked”.

9. If this is to change, those in charge of education must move away from this “one-size-fits-all” mentality, and start from the specific needs of individual children. This should then mean that policy formation and service delivery will take into account the needs of children with various types of SEN. It is important that children with SEN are not “lumped together” as the label refers to a very heterogeneous group of children with very different abilities and disabilities.

PROVISION FOR SEN PUPILS IN MAINSTREAM SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

10. Most mainstream schools struggle to meet the needs of children with speech and language impairments. There are a number of reasons for this as outlined below:

11. Ordinary teachers are not trained to identify children with speech and language impairments. It is perhaps not realised how difficult it is to do this without considerable experience or training. Children with speech and language impairments usually look no different to anyone else and their difficulties are often quite subtle. Only a very small minority do not talk at all or have completely incomprehensible speech. Many children with speech and language impairments do not have their needs recognised at all. In other cases, teachers may wrongly attribute a child’s difficulties to some other cause, such as learning difficulties or a behavioural problem. Often the only way to tell the difference with any certainty is through detailed cognitive testing, such as is carried out by an educational psychologist. A speech and language therapist must also assess the child’s language abilities. Teachers are not qualified to do this, may not realise when it is necessary to seek further assessment, or may not be able to access it, as both the speech and language therapy service and the educational psychology service are very stretched. If teachers are to be expected to identify possible cases of speech and language impairment in children, they must be given training to do this.

12. Ordinary teachers are not trained to teach children with speech and language difficulties (or indeed any SEN), so unless they develop an interest in the subject, attend further training or acquire relevant experience, they are likely to be at a loss if a child with a speech or language impairment joins their class. They may seek the help of a specialist, such as a speech and language therapist, an advisory teacher who specialises in teaching children with speech and language impairments or an educational psychologist. These services are, however, very stretched and not every area provides a team of advisory teachers.

13. Teachers and feedback to our helpline tell us that the resources available to most mainstream schools for SEN are quite inadequate, and so schools are under pressure to spread what funding they have as thinly as possible. As a result they tend to use it to buy as much classroom assistant time as they can. While classroom assistants do what they can, they may have little training and experience, and most teachers do not have the expertise to guide them. Even if children have statements, schools often use the funding they bring to buy classroom assistant time which is often then used to support not only the statemented child,

but other children with SEN in his or her class. (If a child's statement is written in accordance with the law, specifying clearly what support will be given, it is not possible to do this, but most statements are very vague about what support the child will receive.) Many children with speech and language impairments would benefit more from high-quality provision delivered by speech and language therapists and specialist teachers. The reality is, though, that the local services providing such support are very stretched and can often provide very little help. Theoretically, schools could use their SEN funding to purchase specialist support, but very few do this, partly because there is no real tradition of schools, especially primary schools, buying in support from external agencies. However, even if schools wanted to, they might struggle to find professionals with the right expertise, given the national shortage of speech and language therapists, and small number of specialist teachers in existence. Schools also find it hard to justify spending a lot of money on high-quality support for a small number of children, and then being unable to provide much, if any, help for children with SEN but without statements. (Their SEN may be milder, but not necessarily. It may be that their parents have not fought to secure them the statement they really need.) This situation will not improve until funding for SEN increases and the level of expertise is raised.

14. The set-up and curriculum of mainstream schools is not designed for children with SEN, and it is very difficult for teachers to change the environment significantly without impacting on the education of the other children at the school. For example, large classes of approximately 30 children are fine for most school pupils but may mean too many distractions for children with speech and language impairments. Children with speech and language impairments may also need teachers to use modified language in the classroom, and to offer frequent reinforcement of new work covered. It is extremely hard for a teacher to do this and also provide work that stretches the rest of the class who do not have the same problems with learning. Inevitably, what tends to happen is that teachers generally pitch their lessons at the "average" child for the class. She may be able to include some "extension" work for the more able children, but is very unlikely to be able to give the time and make the adaptations that are essential for the child with significant speech and language impairments. The time and effort required in enabling a child with a severe speech and language impairment to understand what is being said, or express what he or she wishes to say cannot be overestimated. The odd 10 minutes here and there when the teacher can spare the time is simply not enough. A competent learning support assistant may be able to help, if available, but having assistance to keep pace with the rest of the class is not the same as having teaching designed to meet your needs in the first place. In any case, many learning support assistants, as I have said before, lack expertise, and they need to be guided by the class teacher, who probably knows very little about teaching children with speech and language impairments.

15. Afasic knows of some schools and teachers who have made considerable efforts to provide good packages of support to children with speech and language impairments, but, sadly, this is all too rare. The impact of the various factors outlined above mean that children with speech and language impairments, if they are recognised as having SEN at all, are more often than not lumped together with other slower learners in "the SEN group", and given generic rather than specialised support (ie programmes of work that specifically address their language needs). This generic support often consists just of easier versions of the work done by the rest of the class, done with the help of a classroom assistant who may or may not have any relevant experience or expertise. Too few children with speech and language impairments receive enough support which targets their specific difficulties and helps them develop the skills they will need to improve their ability to communicate, learn and socialise with their peers.

Language Units

16. Historically, language units have provided an efficient and effective form of support for children with severe speech and language impairments, offering specialist teaching and intensive speech and language therapy within a mainstream context so providing an excellent example of inclusive provision. In recent years, however, there has been a trend for the support offered by language units (which are also sometimes called "bases" or "resources") to be "watered-down", particularly in terms of the speech and language therapy they provide and few now comply with the recommendations of the Suggested Guidelines for language units published by Ican in 1988. The result of this is that many language units are not now able to meet the needs of children with severe speech and language difficulties. Having said this, some language units do continue to offer high-quality support to children with severe speech and language impairments. Some LEAs, though, appear to be increasingly reluctant to place children in language units, leading to suspicions that there is a hidden agenda to close them. Afasic is extremely concerned by this, and I include a copy of a recent report we wrote on this issue.

17. The level of language unit provision also varies considerably from area to area, resulting in a postcode lottery for families. While most local authorities have units for children at reception and KS1, and many also at KS2, they are much less common at nursery and secondary school level. As a result, many children whose needs were met reasonably well at primary level often face a difficult choice at secondary level between the local secondary school with, usually, inadequate or inappropriate support or a placement in a special school, which, if it is a local special school probably caters mainly for children with learning difficulties or EBSD and does not provide appropriate support for children with speech and language impairments, or living away from home at a special school for children with speech and language impairments. There are only a small number of these high-quality specialist provisions in the UK.

18. The lack of appropriate provision for children with speech and language impairments at secondary level in particular means that children leaving language units to go to mainstream or local special schools are often “re-classified” or no longer described as having speech and language impairments. Depending on their presentation and the type of school they go to, they are often from this point categorised as having learning difficulties or behavioural difficulties, or just general SEN. This means that speech and language impairments tend to disappear off the radar of services for adolescents and adults. This reinforces the already widespread notion that speech and language difficulties is a problem affecting young children which disappears as children grow up. This is not necessarily the case, and this misconception means that it is virtually impossible for the young people we represent to access appropriate support.

19. Recommendation Afacic would like to see there being an obligation on all local authorities to have high-quality, properly-resourced units for children with severe speech and language impairments across all ages from nursery right through school and at 16+, in schools and FE Colleges. Some children with speech and language impairments will require specialist support right through their education and into adulthood.

20. The legal status of language units/bases also causes problems. They are rarely constituted as a separate provider of education, which means that LEAs do not have to carry out any formal consultations on any changes they plan to make to units or any proposals to close them. As a result, some parents do not know about planned changes practically until they happen, and are not offered the opportunity to comment on them. The uncertain legal status of units also means that parents do not have the right to ask for units to be named in part 4 of statements, nor can they appeal to SENDIST for a placement at a unit. This causes some difficulties for parents.

21. At the moment, the availability of support generally in mainstream schools means that many children with milder difficulties may not have their needs recognised at all. Children with mild-moderate needs often receive inappropriate generic support, and children with more severe needs may receive an insufficiently intensive level of support more suited to children with moderate needs.

22. Recommendation Afacic would like to see all staff working in mainstream schools trained to identify and support children with speech and language impairments. They should also be able to access sufficient speech and language therapy, educational psychology and specialist teacher support for children who need a higher level of support. This could perhaps be delivered as outreach from the language units we would like to see in all areas. However, units would need to be given sufficient resources to be able to do this without adversely affecting the education of their own pupils.

PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

23. There are very few special schools specifically for children with speech and language impairments. Their, generally, high-quality provision not only benefits the children attending the schools, but also sets the standard for other provision for children with speech and language impairments.

24. Generally speaking, these special schools cater for children with the most severe and complex speech and language difficulties, who need a highly modified education that cannot be delivered in a mainstream context. Many of them need a 24-hour curriculum to master the fundamental communication skills most of us take for granted. It is, however, also the case that some of the children attending these schools could have their needs met in a language unit, if there were a unit in their area, or, in some cases, a unit offering sufficiently intensive or specialised support. As a placement at a special school often means weekly or termly boarding, it would be cheaper and preferable for most families if children could live at home and go to school locally.

25. Most special schools for children with speech and language impairments are non-maintained schools. This means that parents cannot request a place for their children there, but can only “make representations”. LEAs are, understandably, reluctant to fund residential placements at out-of-county schools, so parents are often forced into emotionally exhausting Tribunal cases to win places at special schools for their children, if there is no suitable provision locally. Fighting such Tribunal cases is usually very costly, as parents have to buy independent reports, because LEA-commissioned reports rarely recommend this level of support.

26. If LEAs agree that a mainstream placement is inappropriate, they will often name a local special school. Unfortunately, most LEA-run special schools are aimed at children with learning difficulties or EBSD. They are unable to provide a curriculum modified to suit the needs of children with speech and language impairments or the level of speech and language therapy they require. It is hard to avoid the conclusion that, so far as many LEAs are concerned, the pressure to limit expenditure takes precedence over the obligation to ensure that children’s needs are met. If children are placed in provision that is not designed specifically for children with speech and language impairments, their needs are often “re-categorised” at this stage as some other sort of disability.

27. Recommendation Afacic would like to see a special school for children with severe and complex speech and language difficulties between the ages of 7 and 19 in all regions. As well as providing an education for its pupils, it could be funded to serve as a regional centre of excellence providing training and outreach for parents and professionals throughout the region.

RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

28. Children with specific speech and language impairments have normal intelligence levels and so, given the right support, should be capable of attainments within the normal range. The successes of some children who attend or have attended special units or schools shows what can be achieved. Having said that, some children with speech and language impairments have such a complex profile of cognitive impairments that their attainment levels will be depressed. Measuring whether children are achieving at their optimal levels requires careful assessment of their cognitive profile and potential, and detailed measurement of their progress. In some cases, this needs to be done quite frequently, at annual reviews and perhaps at other times.

29. Unfortunately, those whose duty it is to carry out these reviews are the same people who deliver the support, the availability of which is subject to financial constraints. This makes it difficult for the reviews to focus purely on the needs of the child. In practice, the outcomes often seem to be resource-led rather than needs-led. As I have said before, there is a national shortage of speech and language therapists and specialist teachers. It might help if there were an obligation for annual reviews to be conducted by an external expert, rather than the child's headteacher. As it is, many teachers do seem to think that a label of SEN automatically means that a child will under-achieve. This should not be an assumption.

30. Achievement should not only be seen in terms of academic attainment. There are many more aspects involved in growing-up and becoming an adult. These include social and interaction skills, and independence and life skills (eg using public transport and managing money). Most young people just pick these up, from their parents and the world around them, but many young people with speech and language impairments have real difficulty acquiring these skills and need to be taught them explicitly. Otherwise they will have real difficulty coping with adult life. While some special schools make an effort to teach social and life skills, most mainstream schools do not, not seeing it as their role. The consequence of this is that many of our young people have some GCSEs, but are nevertheless unemployable, because they lack the necessary social, communication and organisational skills to cope with the world of work. It is essential that all schools teaching children with speech and language impairments take a more holistic view of their needs and provide an education that will equip them fully for adult life. This should include enabling them to succeed at something, and maintaining their self-esteem. Too many of our young people leave school considering themselves to be failures and incapable of achieving anything worthwhile.

THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (THE "STATEMENTING PROCESS")

31. In Afasic's view, there is no intrinsic problem with the "statementing process". Indeed, if the needs of children with SEN are to be met, there must be a mechanism whereby their needs are assessed and expert recommendations made about the level and type of support they require to meet their needs and the "statementing process" provides this mechanism. While its name, and some minor details, could be changed, the basic process would still be needed. Speech and language difficulties may not be recognised without such a detailed assessment, and so there is an argument for extending this process to all children suspected of having SEN. We do not know at the moment how many children are not receiving the right support because their needs have not been recognised or have been mis-labelled. Where problems with the "statementing process" arise, this is not because of shortcomings in the process itself, but in the way the process is implemented.

32. The "statementing process" is conducted by the LEA. Many LEA staff have little direct experience of children with SEN and may have a poor understanding of their needs. In addition, LEAs face considerable financial constraints. The combination of these two factors influences LEAs' handling of the process with the consequence that they perhaps do not give enough consideration to children's best interests, and as a result the process sometimes descends into a "battle" with parents. For example, we are aware of cases where the LEA first refuses to carry out a statutory assessment, then issues a note in lieu instead of a statement, forcing the parents to go to SENDIST twice before their child's needs are finally met. In such situations it is hard to avoid the conclusion that LEAs are dragging the process out, in order to avoid funding the specialist provision the child needs. The fact that a number of Tribunal cases are settled by the LEA withdrawing on the day of the hearing suggests that many LEAs "play the system" to limit their expenditure. Of course, they are also aware that for every parent that is willing to go to SENDIST, many do not have the emotional, financial or intellectual resources to do so. What the outcomes are for their children is not known. All of this means that it is not surprising that many parents become antagonistic towards their LEA. Few start off feeling that way. Most assume initially that the LEA will want to help their child. As one desperate mother said on our helpline "I thought if my child needed help it would be provided". Sadly, it seems that the needs of the child often becomes the last consideration.

33. Most children with significant speech and language impairments need a statement if their needs are to be met. Few mainstream schools are currently able to give them the support they need. Yet, LEAs are increasingly reluctant to assess children with speech and language impairments, or give them statements. This often leads to a situation where schools say they cannot offer any more support to a child without a statement, and the LEA insists the school can meet his or her needs, with the child and the parents caught in the gap in the middle. LEAs are supposed to publish information on their websites making it clear what support is available in schools and in what circumstances the LEA expects to issue a statement. Many LEAs still do not do this. The publication of *Raising Barriers to Achievement* in 2004 has exacerbated the trend

away from statements. The Government's strategy for SEN depicts a future vision where mainstream schools are able to meet the needs of all children with SEN except those with the most complex needs and provide an inclusive education for them. It will then be unnecessary to issue statements for all but a very small minority of children. Unfortunately, many LEAs have interpreted it to mean they should reduce their use of statements, but are not first making sure that their mainstream schools are able to provide appropriate support without them.

34. A further complication for many children with speech and language impairments is the vexed issue of speech and language therapy. Children with all but the mildest speech and language difficulties need speech and language therapy, and some require a high level of provision, at least once a week. However, as I have already said, there is a national shortage of speech and language therapists, and many services struggle to provide therapy to all children needing their support. As a result, many services do not provide speech and language therapy to school-age children unless they have a statement, or will only provide occasional consultations. Where LEAs then tell parents they "no longer issue statements" as some do (at least verbally), it can look to parents as though health and education authorities are colluding to deny their child the support he or she needs. Afasic welcomes the introduction of children's trusts and other recent initiatives and hopes that they will bring about positive changes to the situation. It is of course early days, but Afasic has seen no improvements so far.

35. Where statutory assessment is carried out, the same body, the LEA, is responsible both for carrying out the assessment and for providing the support specified on the statement. This represents a clear conflict of interests, especially given the financial pressures on LEAs. It is surely not a coincidence that LEAs' own employees (such as educational psychologists) are tending to couch their recommendations in rather unspecific terms. Often other local professionals, such as speech and language therapists, are doing the same. Parents may be told that this is the "local policy". In some cases it seems that the local PCT has an arrangement with the LEA not to recommend more speech and language therapy than it will be able to provide. In other cases, the speech and language therapy service itself has a policy of not doing so. This is in direct contravention of the Regulations referred to in paragraph 7:79 of the Code of Practice. Parents seeking an honest opinion about their child's needs may be forced to seek an assessment privately or at a specialist assessment centre run by the Health Service.

36. Paragraph 8:36 of the Code of Practice makes it clear that part 3 of the statement should specify clearly and in detail the provision that the LEA will make to meet the child's needs. In practice, the content of part 3 of many statements is so vague as to be in effect meaningless. Of course, this is because the recommendations in the advices often are not clear and specific enough. Although case law and the Code of Practice (in paragraph 8:49) make it clear that speech and language therapy should, in the case of children with speech and language impairments, be specified in part 3 of the statement, many LEAs are still putting it into part 6. Parents who are aware of the importance of these issues can appeal to SENDIST to secure a statement that is written in accordance with the law. Many parents, however, do not understand the importance of ensuring that the statement is written in accordance with the law and then wonder why their child isn't getting the help they thought he or she would receive once the statement is issued. The motivation for LEAs is, of course, much clearer. They would rather fund cheaper, or more readily available, support than anything that might be more problematical for them. Sadly, they do not seem to feel enough of a duty to provide the right support for the child to ensure that they do this.

37. One possible solution to the conflict of interests discussed in the last two paragraphs is to separate the duties of carrying out the assessment and providing the support. Assessments could be carried out in regional centres staffed by experienced staff with appropriate expertise. There should then be a legal duty on the LEA to provide the support they recommend.

38. The way to address the other flaws in the way that the "statementing process" is currently implemented is by policing it effectively. At the moment this is hardly done at all, other than by parents themselves, through their use of SENDIST, complaints to the local government ombudsman or DfES, or involvement of local MP or press. Relying on parents to police the system is unacceptable. Parents of children with SEN have enough to deal with, as it is. Theoretically, Ofsted has a role to play here, but does not always seem to have understood the implications for parents and children. We are not confident that the new inspection regime will improve the situation.

39. It must also be acknowledged that the "statementing process" has a number of advantages for parents. It does at least give them the right to request statutory assessment and a right of appeal if this is refused, or if the LEA does not issue a statement, or they wish to challenge the content of a statement. If the "statementing process" were abolished and LEAs and schools just had a vague duty to meet children's needs, there would be no guarantee that this would happen.

THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

40. The role of parents is crucial. They know their child better than anyone, and how he or she responds to a range of situations, so have a lot of useful information to impart, though they may not be able to do this using the terminology favoured by professionals. They are possibly also the only people involved in the process who have the best interests of the child at heart. Professionals may have their own political agendas.

It should also be remembered that for professionals, it is only a job, which they can put aside when they return home. For parents, the decisions that are made could affect their child's and their own entire lives. They are of central importance.

41. Having said that, some parents are better able to articulate their views than others. Some parents are not even used to being asked for their opinion, having grown used to not being offered choices in their lives. Some parents may have a degree of special needs themselves. Many parents may need support to understand the implications of their child's SEN and help to come to terms with what might be a difficult situation for them.

42. Support for the emotional impact of having a child with SEN and with understanding their child's needs and its implications may be provided by professionals, charities or voluntary groups, other parents or the Parent Partnership service. It is important that parents are assisted to access this support if they need it, but that is not the focus of this document.

43. Parents should be encouraged and, if necessary, assisted to play a full role in the decision-making process. Their views should be taken seriously. They should never be told, or led to feel, that they are being "humoured", while the important decisions are taken by professionals. A "we-know-best" attitude on the part of professionals or officials is unacceptable. The parental report submitted for statutory assessment should be given as much weight as professional advice. LEA officials and the Tribunal should take seriously parents' views. They should not necessarily have to be backed up by professional reports which have often had to be obtained at considerable expense. Unfortunately, relationships between parents and professionals are often very poor, with both sides having low opinions of the other. Afasic is very keen to promote good relationships and is keen to be involved in initiatives that do this.

44. LEAs all provide parent-partnership services to help parents play their full part in the decision-making process involved in SEN. Most do their best to achieve this within their remit as they see it. Many services, though, have very little funding and are practically a "one-man band", which places some constraints on what they are able to do. Some services are more independent from the LEA than others. While some make every effort to support parents to convey their perspective to the LEA, and to challenge the LEA if they have fallen short in some way, others do not. In some cases, parent-partnership services even seem to be used by LEAs to "bring parents round" to their own way of thinking in what appears to be a variation of the "good cop/bad cop" routine. This is unacceptable. Parent-partnership services must be independent of LEAs, and this should be properly policed.

HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

45. There is considerable variation in what professionals understand by the various "labels" that are used for different types of SEN. Some professionals will make distinctions between, say, "speech and language impairment" and "communication impairment", while others will use them to mean the same thing. Professionals working in education and health may also use the same term to mean slightly different things, causing further confusion. For example, some paediatricians use the term "developmental delay" to mean behind in one or more aspects of development, whereas educational psychologists might interpret it to mean "functioning within the MLD range". The label given to a child can also affect the support that is offered. For example, a child with a mild autistic spectrum disorder might be given a place in an ASD unit with non-verbal children when he or she might be more suited to a unit with children with Asperger syndrome. It might be helpful if more consensus could be reached over the use of terminology in SEN. This would also make it easier to collect statistics and make comparisons about eg the attainment levels of children with different types of SEN.

PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EBSD

46. Provision for children with speech and language impairments has already been covered. It is estimated that at least half of children described as EBSD also have speech and language difficulties, in many cases hitherto unidentified. In some cases providing support for the children's speech and language impairments will lead to an improvement in their behaviour in itself. In other cases, it will help them to derive maximum benefit from the behaviour programmes they are given. Many of these programmes assume a good command of language, and, if they are used with children who do not have this they are unlikely to be very effective.

47. Afasic recommends that all children whose behaviour is a cause for concern should be formally assessed to determine whether they have a speech and language impairment or other form of SEN. We also recommend that special schools or units for children with EBSD should have an appropriate allocation of speech and language therapy.

THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001

48. I have already discussed the legislative framework for SEN at some length. Afasic hopes that the Disability Act will in due course have beneficial effects for children with speech and language impairments. There is no sign that it has had much impact so far. Indeed, most disability planning done by schools addresses the issue of physical access but does not consider curriculum access, or broadening the curriculum to help facilitate full access to adult life when children leave school. Afasic would like to see all schools obliged to have and implement a communications policy.

49. Very few claims of disability discrimination involving children with speech and language impairments have been brought before SENDIST so far. This is not because discrimination is not happening. We know that many children with speech and language impairments are struggling to cope with the curriculum at school. Proving a failure to make the curriculum accessible is, however, extremely difficult in a quasi-legal setting. Disability discrimination in schools is another area which requires effective policing.

CONCLUSIONS

50. Most children with speech and language impairments, if they receive appropriate support from an early age can benefit and achieve at school and go on to obtain and retain employment and lead independent lives. The consequences for those who do not receive adequate support can be bleak. Without sufficient communication, literacy and numeracy skills many leave school effectively unemployable. They face a life on benefits and are at high risk of mental illness and becoming involved in crime. Governments must take a long-term view and understand that investing properly in SEN, while costly in the short-term, will make all the difference in the future.

Language Units Under Threat?—Summary of Responses up to March 2004

Within the space of a few months during spring/early summer 2003 Afasic received several reports of suspected threats to the continued existence of language units. As a result, we decided to appeal to our members and other contacts to let us know what was happening in their area, to enable us to build up a fuller picture of developments around the country. We are very grateful for the large number of responses we received, and would continue to welcome further feedback. This is a summary of the information supplied to us so far.

DEFINITE CLOSURES

We received news of the following confirmed closures:

- The only language unit in a shire county in the midlands. We received two reports about this unit, one from a professional, and one from a parent. The unit had eight places for children in key stage one, and there was a waiting list. However, the LEA decided that no new admissions would be allowed from the school year 2003–04 onwards, and the unit would close when the children already placed there had left. It was not clear why the LEA had made this decision or how they intended to support children with severe speech and language impairments in the future.
- A secondary school unit in southern England will not be admitting any more children from September 2004, and is expected to close when the children currently placed there complete year 11. The parent of a child at the unit supplied documentation to us which indicated that the reason for this closure is the difficulty in recruiting suitably qualified speech and language therapists.
- An authority in north-west England is planning to close two of its three existing language units for children aged four to seven years. The intention, apparently, is only to offer a unit placement to children with “complex difficulties” and develop an alternative service to support other children in their local mainstream schools.
- A diagnostic nursery unit in a unitary authority in the Midlands. This was not specifically a language unit, but did take a number of children with language and communication impairments. The parent who reported this closure to us claimed that the school governors decided to close the unit, for reasons that were not known, despite the fact that it was in a purpose-designed building. The LEA were apparently unable to intervene.
- A school with an attached language unit in a unitary authority in north-west England will shortly be closing. This will mean the closure of the unit in its current location. No firm decision about its future has been made, but it may be re-located elsewhere in the authority.
- A resource base at a nursery in a London borough will shortly be closing. The parent who reported this did not indicate whether any alternative provision for pre-school children would be made available.

NEW UNITS OPENING

There was some good news, about new units opening or other forms of provision being set up:

- A London borough has just opened its third primary school unit. The teacher who contacted us explained that all three units are more like specialist resourced provision and are much more involved with their host mainstream school than was typical in the past. In this borough, the education and speech and language therapy services together are starting up a Joint Communication Support Team to support children in primary schools and especially to improve support in secondary schools.
- A parent contacted us from a unitary authority in the West Midlands to report that a new unit for KS2 children had just opened in his area. This was in addition to the existing unit for nursery/ KS1 children.
- An Educational Psychologist working in a city in Scotland reported that her authority was setting up a new part-time provision in a primary school, in addition to the existing units, and had begun to provide an enhanced outreach service to a number of children in mainstream primary schools.
- A parent from a county in south-east England reported that a unit for pre-school children had recently been set up in her area.
- A parent from another county in south-east England reported that her authority was planning to set up shortly a 30-place secondary language unit and two primary units and one secondary unit for children with communication disorders, in addition to the existing units for specific speech and language impairments.

NO SIGNIFICANT CHANGE

Many replies simply outlined the range of provision available in the area where the writer lived or worked. This information illustrates how much variation there is between local authorities. Some LEAs have a full range of language units, covering all ages from pre-school through to secondary school. Some offer primary or infants' school units only, and some still have no units or specially resourced provision at all. Some LEAs offer some support services for children in mainstream schools, but again, there is huge variation in what exactly these provide from area to area.

CONCERNS ABOUT THE FUTURE OF LANGUAGE UNITS

The largest proportion of responses came from people who could not cite specific plans to close language units, but nevertheless expressed real concerns about perceived threats to the units in their area. The comments received have been grouped into a number of common themes:

Threatened closure of language unit "fought off":

- Two parents living in a county in southern England wrote about the threat to close the only language unit in their authority, which did not in fact materialise. The exact sequence of events is not entirely clear. One parent (who did not have a child at the unit) reported that the parents had "fought off" the threatened closure. The other response, from a parent of a child at the unit, reported that the head-teacher of the school informed parents that the unit was under threat of closure. This was subsequently denied by the LEA, but the parent had little confidence that the threat had been lifted from the unit, given that there had been no speech and language therapist there for nine months, and no therapy assistant for six months.

The need for language units: Several responses from parents and professionals stressed the need for language units for children with severe speech and language impairments.

- One parent living in a county in eastern England wrote to say that because there were no language units in his area, he had had to fight two Tribunal cases to secure a placement for his son at a special school for children with speech and language impairments.
- A parent in Wales who was struggling to secure a language unit placement for her son wrote to say that in her view more units were needed. Her local unit was full, so the LEA had offered an MLD unit which was not suitable, and even the MLD unit admitted they were often sent children with primarily speech and language needs because the language unit was full.
- Two parents from different parts of England contacted us to say that they were hoping to persuade their LEAs to open secondary school language units. One of these parents said the response so far from the LEA had been to suggest that language problems have resolved by 11, and children will generally just be left with some residual literacy difficulties.
- The head of a unit in north-east England wrote to say that she was concerned about the long waiting lists for places at her unit, which catered for a large geographical area. This meant that very few children below statutory school age secured places there, which had led to the loss of a

discrete nursery group and was not in the spirit of “early intervention”. There did not seem to be funding available, from eg government grants, to expand units, but the LEA had recently identified new and larger premises for the unit, which was good news.

- Many other people writing from various parts of the country reported long waiting-lists for local language units.
- A teacher in a unit in a county in south-east England explained why she felt that units were essential, especially for children with severe receptive difficulties. She wrote “I understand that children with physical difficulties could be included in mainstream provided the environment had been adapted. Unfortunately no-one suggests providing language -restricted environments in mainstream schools so that those with receptive language difficulties will cope. No-one suggests making the lessons less “pacey” so that those with slow processing can keep up. I don’t think our children can be fully included. They will always be consigned to a separate table with the TA, doing activities which may be well below their intellectual capability, simply because they can’t “keep up”. Many of our children are very able but will be regarded by many non-specialists as “average” when, in fact, they are often extremely able children. My big worry is that they will underachieve all their lives simply because the school environment had not been adapted to accommodate their disabilities.”

Language Units becoming too “mainstreamed”

Several people wrote to express reservations about attempts to create “inclusive” language units. Parents and professionals were doubtful about the ability of such “units” to meet the needs of children with severe speech and language impairments.

- A parent and a professional wrote from the same local authority in southern England to express their concerns about a unit (one of two in their area) that had become “fully inclusive”. According to the parent, this was because the school had been unable to recruit a new teacher to run the unit when the previous teacher left. This parent felt that the “inclusive model” did not provide adequate support for the children in the unit, and that they had all suffered as a result. She explained that there was only one LSA per year group, so the children were not supported full-time. As a result she had since moved her son to the other unit in the area. The professional who wrote to us shared the parent’s concerns and commented that she had “grave reservations” about the inclusive model, especially for “pupils with receptive disorders, and particularly when those pupils enter KS2”. She went on to add though that “I am old enough and cynical enough to believe that rigid “inclusion” is just a phase, and one day someone will suggest grouping those with similar difficulties so that they can be taught at a linguistic level that is appropriate to them.”
- A number of parents expressed concerns about a particular secondary school unit in a county in south-east England. This unit was opened for children with particularly complex communication needs and was intended for children who would otherwise have been placed in special schools. It offered highly specialised support. The unit as such has now been discontinued, and the children placed there are supported by staff in up to three specially-resourced bases. Several of the parents who contacted us felt that this could not meet the needs of the children for whom the unit was originally designed. At least one parent who would have opted for this unit in the past decided to appeal to SENDIST for a special school placement.
- A parent wrote to say that many parents in her area (in the west midlands) were concerned about how much time the children in their local secondary school unit were spending in mainstream classes.

Language units and speech and language therapy

Not surprisingly, this topic generated a number of responses.

- The head of a unit in north-east England expressed serious concern about the level of speech and language therapy at her unit which she felt was quite inadequate for children who had been identified as the most needy.
- A parent in a London borough wrote to say that the unit her child attended was not under threat, but had not had a speech and language therapist for six months.
- A teacher in a unit in a county in south-east England pointed out that in her area as in many others the Speech and Language Therapy service was already stretched and would not be able to provide the intensive input children with severe speech and language impairments needed unless they were all grouped together in units.

Language units becoming ASD units

Three responses from different parts of the country reported that local policy seemed to be increasingly to place children with speech and language impairments in mainstream schools (sometimes without statements) and to use language units for children with “complex difficulties”.

- In one case this subtle “change of use” had meant that one unit (in a county in south-east England) had been reprieved from a planned closure.
- One of the responses came from a speech and language therapist (in another county in south-east England) who said that her local unit was now under explicit pressure to accept children whose primary difficulty was an autistic spectrum disorder. She reported that she had been in contact with other speech and language therapists across the UK who said that similar things were happening in their area. She thought that her unit would either become in practice an autistic spectrum disorder unit or the LEA would argue there were not enough children with speech and language impairments to justify a unit and would close it down. She asserted that her LEA were no longer statementing children with speech and language impairment, an assertion supported by calls to the Afasic helpline from parents living in this county.
- A parent expressed concerns about a secondary school language unit in the west midlands which was now admitting children with a very wide range of needs, beyond a narrow definition of SLCN.

Language units and transport issues

- A speech and language therapist in a London borough wrote to say that the three resource bases in the area were under threat because of the LEA’s new policy of not offering transport to enable children to get to school, though some of these decisions had been successfully challenged. (Afasic played some part in achieving this).

This raises the concern that some LEAs might withdraw transport in order to hasten the end of special units. If children cannot get to school, their parents will not want to accept places there and the LEA can then argue the units are empty and so should be closed.

The work of language units not being sufficiently well understood or valued by Ofsted inspectors, school governors or non-specialist teachers

A number of teachers in units expressed concerns about this.

- One wrote at length (from a county in Eastern England) to express her frustration, saying: “We’ve not been threatened with closure as such but . . . little things heads and governors say . . . leave you wondering. It usually runs on the theme of “well you are the highest paid teacher we have and you only teach eight pupils and none of them from this school” . . . Despite achieving excellent results (frequently up to three years improvement in 18 months), being regarded by parents as the best thing that ever happened to their children, and by the schools we support as providing good service the last Ofsted resulted in changes that make our work almost impossible. I’m convinced they didn’t grasp what the set-up was and the head left us to take the flak. My team and I are very worried that the changes will in effect make what we do so much less effective that parents or schools will say “well, what’s the point sending children”. The provision will then phase itself out which I suppose would save face at county level. However, we know the need is there and just because it is expensive it shouldn’t be thrown away.”
- A teacher in a unit in a county in south-east England told us: “We were recently inspected by an excellent Ofsted inspector who had been a headteacher in a Special School. He was totally on our side but said that the other members of the Ofsted team were querying why the children weren’t part of “normal” classes. We argued successfully that the children needed a language-restricted environment and that if they were given the right sort of help at an early age, they could return to a mainstream environment (usually with literacy difficulties but good strategies). The Special Needs Inspector agreed fully that there was a need for specialist environments.”

LEAs’ “determination to mainstream children with speech and language impairments”

This topic generated a large number of responses. Several people wrote from various parts of southern England to report that their local language units had vacancies, largely because LEAs appeared to be pursuing a policy of placing children with severe speech and language impairments in mainstream.

- A teacher in a unit in an inner London borough with a number of vacancies reported that “It is very hard to get children statemented when they are in their first year of school because they have not “failed” yet, and if they are older there is often reluctance to move them from their current provision even when they do get statemented.”

- A parent wrote from a county in south-east England to tell us that her local language unit had a disproportionate number of KS2 children compared to KS1, apparently because the LEA was reluctant to statement younger children. This unit was now also providing support to children in the host mainstream school. This level of support was not available to children in other mainstream schools and so did not seem a very fair arrangement.

It is hard to see how this can be described as effective “early intervention”. Of particular concern was a range of evidence from two particular counties, one in western England and one in south-east England:

- A teacher claimed that her LEA had decided that the needs of children with even the most severe speech and language impairments could be met in mainstream. She reported that all the existing units now had lots of vacancies because children were no longer being placed there. She felt that her LEA did not understand that severe speech and language impairment is “very disabling and cannot always be dealt with appropriately within a fulltime mainstream placement” and regarded any such view as parents fussing. The over-riding concern seemed to be with the cost of maintaining language units, and she was convinced that the eventual plan was to close them all. She said that, when asked, LEA staff always insisted that parents were given “fully informed choice and were CHOOSING mainstream in almost every case.” This claim is not however borne out by the evidence of calls to the Afasic helpline from parents of children in this county. Several of them have been told the county “has no language units”. Some parents of course hear about language units from other parents or from speech and language therapists. One parent, of a child with language scores on the first centile, who asked about a language unit placement for her son, was told that he was “not severe enough” and his needs “could be met in mainstream”.
- A parent from the second county sent a press cutting featuring an interview with the head teacher of a school with a language unit which had vacancies because, according to the head, “parents are being told their children’s needs can be met in mainstream”. The Head went on to point out that “the level of therapy these children need is only available in specialist units”. A specialist teacher working for an LEA-run service in this county wrote to say that, although the authority had several units, parents were often choosing mainstream placements. However, calls to the Afasic helpline from this county bear out the head’s claims that parents are being pushed towards mainstream. Many parents are unaware of the existence of language units. Those who do ask about them are told their child “will not qualify” or often that the unit is “full” or “has very long waiting-lists”. Most parents in this county are apparently being told that mainstream is the “right placement” for their child.
- A parent, who is very active in an Afasic local group, told us that his county’s policy of placing children in mainstream was being achieved because many parents of younger children do not understand the impact of their child’s difficulties on their ability to learn in a mainstream setting, and are happy to think that their child can go to the local school, at least until it all goes horribly wrong.
- A teacher working in a language unit pointed out that many of the parents of children with speech and language impairments appear to have difficulties themselves and are easily convinced when they are told their child will be “OK” in mainstream and that support will be given to ensure success. She went on to say that “some of these children then come to us in year 2, with really low self-esteem and entrenched poor strategies.”

This suggests that there is some work to be done, for Afasic among others, to raise awareness among parents, professionals and officials of the impact of speech and language impairments, and to explain the importance of the right help for children with these difficulties.

OTHER CONCERNS

Inevitably, although we asked specifically about units, we did receive a number of comments about other issues, especially speech and language therapy and the difficulty of obtaining this for a child in a mainstream school.

This was becoming increasingly difficult now that many LEAs were trying to reduce the number of statements they issued. In some cases, they were now devolving most funding for SEN to schools. The problem was that schools rarely used this money to purchase speech and language therapy, and many health trusts only provided speech and language therapy to children with statements. To some people who contacted us, it rather looked as though LEAs and health Trusts were colluding to deny children the speech and language therapy they needed.

UPDATE: APRIL 2005

Since this report was written, we have continued to receive news about language units across the country, as follows:

- Protests about the decision to close the secondary school unit mentioned above led to a temporary reprieve. The LEA and host school still intend to close the unit in due course, but a vocal parents group has been formed to fight the proposal.
- Two parents contacted us in some distress regarding plans to close the unit attended by their children, in a rural part of northern England. The unit was not full and there were suggestions that the LEA had been trying to “run it down” for some time. There were also concerns about whether the proper consultation procedures had been followed. Partly as a result of this, perhaps, the plan to close the unit was postponed. We do not know what has happened since.
- We heard of another unit apparently under threat of closure, in a county in Eastern England. The parents of the children in the unit protested strongly, and the LEA agreed to move it to another school.
- A parent from another county in Eastern England contacted us to express his concerns about the situation at the unit his son attends. Afasic has heard many allegations that this county seems very unsupportive of its language units. In this particular case the unit teacher has left, whether willingly or unwillingly is a matter of some dispute. Although there do not appear to be any plans to close the provision entirely, and the intention is to recruit a replacement teacher, the unit will no longer be a full-time facility, but instead a resource base offering support on a part-time basis.
- There has been some good news. Several people contacted us to say that their authority is planning to open a secondary school unit. We believe that this will be the first such provision in NW England.

September 2005

Memorandum submitted by the Clapham Park Project

INTRODUCTION

The Clapham Park Project (CPP) is a New Deal for Communities Initiative. It was identified by the Borough-wide Strategic Partnership in February 1999, and began its 10-year programme to regenerate the Clapham Park area in April 2000.

An Education and Youth Theme Group was established in December 2002. The Group's first focus was supporting the raising of educational achievement against the national floor targets for education in Neighbourhood Renewal areas. Further focuses have been added as the work of the Project progresses, including increasing parental involvement and increasing satisfaction with services within the Youth Programme and the Community Education Action Zone.

During 2004, the Theme Group began to acknowledge that Special Educational Needs (SEN) was an issue that to date had received little attention, and was of growing concern. The KSA Partnership was contracted to support the Clapham Park Project in developing a strategy and forward plan that would help target improvements in meeting the special needs of children and young people in the Clapham Park area.

Work began in late 2004 with an information trawl, discussions with a wide range of interested stakeholders, and a consultative workshop in late January 2005. A first draft of this strategy was presented to a larger consultative workshop/conference in early May 2005. The views and ideas expressed by stakeholders at that event informed the final draft strategy outlined in this document—the Clapham Park Project Strategy for Inclusion—the basis for formal consultation with a full range of interested parties. The strategy is intended to act as the agenda for agreed key priorities for action and support by the Clapham Park Project and its partners, and guide the design of funded interventions and projects over the second half of the Project's 10-year mission.

Consideration was initially confined to developing a community-based strategy focussed on special educational needs (SEN). However the drive to develop an inclusion strategy in Clapham Park is more in tune with current national policies and strategies including those for SEN all of which are aimed at ensuring that the needs of all children are addressed within their local community. There are three major national drivers that affect our thinking:

1. The DfES Five Year Strategy (DfES 2004a) is focussed on ensuring that every child gets the best possible start in life with integrated services targeted on the needs of parents and children.
2. Every Child Matters (DfES 2003), the White Paper that led to the Children Act of 2004, on the future delivery of Children's Services details the Government's desire that within their local communities all children and young people will:
 - Be Healthy

- Stay Safe
- Enjoy and Achieve
- Make a Positive Contribution
- Achieve Economic Well-Being

The Children Act requires each Local Authority to prepare a Children and Young People's Plan (CYPP) by April 2006.

3. Removing Barriers to Achievement (DfES 2004b) the Government's strategy for SEN states that inclusive services and support should be in place that facilitates:

- Early Intervention
- Removing Barriers to Learning
- Raising Expectations and Achievements
- Delivering improvements in Partnership

The decision to develop a Clapham Park "Inclusion" Strategy is the obvious way to proceed in the contemporary climate. It is also much more in tune with what stakeholders in the Clapham Park area were saying during the rounds of discussions—almost everyone we spoke to placed SEN as one part of the wider challenge of Inclusion.

The strategy proposed in this document is therefore designed to support the development of inclusive services and practices for all children and young people in Clapham Park particularly those with additional and special educational needs (SEN).

Clapham Park is a diverse community facing many challenges. It faces local challenges of deprivation many of which are more severe than the rest of the country. These conditions are felt by a higher proportion of children and young people than in many other localities, both inside and beyond Lambeth.

There is widespread and passionate commitment to doing all that is possible to ensure that the difficulties faced by children and young people, and their families, are overcome or minimised by those in a position to remove barriers and improve the quality of life and services. If passion were enough, every problem in the area would be solved tomorrow, but the challenges have many facets and inclusion is a complex concept. This means that clarity over what we strive for is an important first step in arriving at what priorities we should address and how we should tackle them for the best chances of success.

The discussions and the two consultative workshops made it clear that we want an "Inclusion Strategy" to mean that:

"the needs of all our children and young people are able to be met in or through our locality, so that they all feel valued and cared for, and helped to achieve in education and in life".

Succeeding in reaching this goal will depend on making choices based on a clear and shared picture of the current reality. In making those tough choices, we need to recognise that:

- Some children and young people have greater needs than others
- It is harder to meet some needs than others
- Some needs are long lasting, some are short-term only
- Some start at birth, others develop or become known at other times
- Many categories of need are on the increase
- Some can be prevented or avoided
- Some can be fully met, others can't
- Some are common and solutions are relatively low cost
- Some are low-incidence and relatively high cost
- Some needs are already being met well by existing provision
- Some needs can only be met outside Clapham Park or beyond
- the Clapham Park Project can only add value to some areas of need, and not others.

The Inclusion "territory" covers many categories. The current DfES classification for Special Educational Needs identifies the following, although for some children no one individual category can suffice:

MLD—moderate learning difficulties

SLD—severe learning difficulties

PMLD—profound and multiple learning difficulties

PD—physical disability

HI—hearing impaired

VI—visually impaired

BESD—behaviour, emotional and social difficulties

Sp. LD—specific learning disorders
 Sp + La—speech and language disorders
 MSD—multi-sensory disorders
 CD—communication disorders
 ASD—autistic spectrum disorders

The education system deals with these classifications through a progressive “ladder” of interventions located in special needs registers—school action, school action plus, and statements of SEN.

However, other inclusion needs cover a wider range of difficulties and circumstances faced by children and young people, some of which have no “system label”, although Social Services maintain an “At risk” register:

- Bereavement
- Marital break-up
- Poor or irregular attendance at school
- Exclusion from school
- Not in Education, Employment or Training (NEET)
- Drug-taking
- Prostitution
- Suffering or at risk of physical or sexual abuse
- Young people in the Youth Justice System (Young offenders, At Risk of Offending)
- Trauma + disorientation
- Homelessness, or fragmented home life
- Worklessness
- Child carers
- Teenage mothers
- English as an additional language needs
- Poor physical, emotional and sexual health.

In many cases, children and young people with Special Educational Needs have other needs from the list above too. On the other hand, some have one or more of the inclusion needs above but no “formal” Special Educational Needs. It is this conundrum that the Inclusion Strategy has to address.

The first of many challenges for the Strategy then is to use the available information and intelligence to help decide where the most appropriate priorities lie for the Project to address or help to address, given its role and resources. That evidence base is presented in the next section.

BUILDING A BASELINE

Assembling the data and information required to build a rich picture of current realities

There is a wide range of relevant local and national documentation, which when combined with personal and professional views and experience help to produce a fuller picture of how things are now. Interviews with schools, parents and key local agencies were validated by what stakeholders said at the January and May consultative workshops. There exists a high degree of consensus on what the issues are, and a good level of agreement on what the priorities should be and how they should be addressed. The real problem identified by many stakeholders was that there were too many priorities, and more focus is needed. This section of the strategy brings together the information and intelligence gathered as a basis for identifying what matters most.

The Clapham Park Context

Statistical indicators show that the educational and social outcomes for the children and young people of the neighbourhood are such that the risk of exclusion is ever present.

Clapham Park’s challenges include poor job prospects, high levels of crime, educational underachievement, poor health, including children’s mental health, and problems with housing and the physical environment.

According to the 2001 Census the population of the Clapham Park NDC area is approximately 7,100, made up of about 3,060 households.

Clapham Park’s socio economic structure is broadly similar to Lambeth and the rest of London, except for higher numbers of people from BME communities, people aged 0–nine, lone parent households, households with dependent children and households with young children.

The scale of the challenge

There are just under 2,000 children under 16 in Clapham Park at any one time, and a further 375 aged 16–19.

Of these, about 750 have some kind of special need identified by their schools or by Health services. It is likely that there are a further 150 of 16–19-year-olds with a similar range of needs.

There are a number of dimensions of the cohort that include traditional categories of statemented SEN (see previous section for categories) and there is a high level of children with formal statements of SEN in Lambeth; non-statemented children (School Action Plus and School Action); in addition there are Young Offenders, Young People At Risk of Offending, Not in Education, Employment or Training (NEET), Excluded children, At Risk of Exclusion, Truants, At Risk of Truanting, Teenage Mothers, Underachieving children, At Risk of Underachieving, Unemployed Young People, Homeless Young People, and some whose situation or whereabouts is unknown.

Educational achievement of the children and young people who live in Clapham Park presents a difficult data challenge. There is considerable dispersal—for example, in 2003, the 780 pupils of primary age who were resident in the CPP area attended 37 different schools and those of secondary age attended 12 different secondary schools. Taken together, primary and secondary school pupils from the CPP residential area attended 49 schools in 13 Local Education Authorities. The dispersal does include some very small numbers, and at primary stage some 90% are catered for in only eight schools. As there is currently no secondary school within the CPP boundaries, all attend schools elsewhere.

Educational achievement in recent years (detailed 2004 data not available at the time of writing) shows that CPP pupils achieve the Lambeth average at GCSE, slightly below Lambeth averages at Key Stage 3 (age 14) and Key Stage 2 (age 11). Lambeth averages are below the national averages on all measures, but 2004 saw significant improvements and “catch-up” on national averages at all Key Stages.

What do Young People think?

From previous research in the Clapham Park area we know that young peoples’ top concerns are:

- Feeling unsafe
- Lack of transport
- Racism
- Exploitation of estate by outsiders
- Crack houses
- Unhealthy environment
- Drugs
- Prostitution
- Stigma of living on the estate
- The lack of resources and facilities

WHAT IS WORKING WELL?*Lots of project activity*

The Clapham Park Project has more than 30 projects up and running. Project activity is set out in a three-year business plan (2003–06) supported by plans for its six theme groups. There are five broad theme areas delivered through six theme groups in Clapham Park:

- Rebuilding our Community Networks
- A learning and Enterprising Community
- A healthy and caring community
- A safe and confident community
- Our landmark place

Lots of commitment from many people

The people we have talked to feel that the CPP is ideally placed to create a focussed effort on the target groups with the greatest needs, and many of those interviewed were excited by this opportunity to develop a broad, cross-cutting and radical approach to those children and young people with the greatest need for support.

Lots of data and information

The project has completed a wide range of feasibility and mapping studies in its first 3 years (Sure Start, Health Impact, Credit Unions etc.) to build its understanding of the estate and its needs.

Some inclusion needs being met well and some very good practice

There is some very good practice in the area, often at a small scale, and there are some very committed and capable people working and supporting children, young people and their families. For example, Livity Special School offers specialist provision for a range of needs within Lambeth, and has well-developed links with Health professionals. Support work for children with Autistic Spectrum Disorder at May Tree Nursery, the Youth Inclusion Project and the work of the Voluntary Sector—Contact-a-Family and Parents for Inclusion—are just some of the examples of leading edge work in the locality. In general, the needs of most of the younger children (Early Years, Nursery and Primary) are being met within the Project area, as are most of the high profile designated Special Educational Needs.

Annual funding pot

Clapham Park is a New Deal for Communities area, giving it access to resources to tackle its problems in a coordinated way. The Project receives £56 million over 10 years to 2010, and a new focus on Inclusion-related interventions and projects will be able to add value beyond the “normal” remit of other agencies and individual organisations.

BARRIERS AND RISKS—WHAT PEOPLE THINK MIGHT STOP US ACHIEVING OUR VISION*There are a lot of fingers in our pie*

The number of agencies, organisations, institutions, groups and individuals with a legitimate interest and who are involved in activities related to Inclusion that operate within or including Clapham Park makes a coherent approach difficult before direct work on the ground is reached. Many boundaries and territories of operation and responsibility are long-standing and the geographical delineation of the Project area itself hinders easy data assembly, continuity of contacts and collaboration. Many families have to deal with lots of different professionals and procedures at a time when their own needs and circumstances are immediate and pressing.

Lots of activity but limited impact on resistant problems

A Clapham Park Inclusion Strategy needs to cover a wide spectrum of young people who have needs greater than most—“Inclusion” is seen as encompassing SEN, and is the desirable focus for further work. A strategic approach would be welcomed to help bind together the many initiatives that are under way.

Fragmented leadership

There is a desire for better joint working within and beyond the Project, and most have identified linkages that work well and those that don't.

There is a perceived tension between the drive to impact on education floor targets and the individualised needs of some of the most at risk young people. There is confusion over who or what agency is, or should be, providing the leadership to drive forward improvements.

Usability and reliability of data

There is a lack of reliable contemporary data and data sharing about young people's needs, and the tightly defined boundary of the Project makes this extremely difficult to solve.

Poor transport

People who live on the estate feel isolated due to their limited access to public transport, leaving them isolated from surrounding services and opportunities. This is most marked for those with physical disabilities.

Lack of local continuity

There are issues of continuity of identification and support for children and young people as they move through the system. The pattern of school admissions, particularly at secondary transfer, works against easy collaboration on a child-centred and family-centred basis.

Increase in some inclusion needs—some under-supported aspects

There are small but growing numbers of children identified with Autistic Spectrum Disorder, and a reported increase in Behaviour and Emotional Difficulties. There are too few flexible options available for children who are not in full time education.

“At risk” young people are especially vulnerable from 16 onwards, and there are issues of homelessness and respite accommodation that are not being addressed

SUSTAINABILITY

There is widespread recognition that early intervention and family support is the “right” long-term emphasis, but quick and immediate impact solutions are also needed.

There are aspects of contrasting organisational cultures that adversely affect some young people—how they are spoken too, dealt with, listened to varies too widely.

Some potential partners are only marginally engaged—training providers and employers for example.

A number of interviewees felt that more work was needed to build capability and capacity in professional and volunteer workers, young people and families.

Clear and consistent messages emerged from the round of interviews and workshops.

Stakeholders want to support the development of an inclusion strategy that has the capability to encompass the needs of all children and young people.

We want our inclusion strategy to be based on three key components:

- Forcing different agencies working together cooperatively and constructively
- Based on a commitment to addressing the priorities of families
- Emphasising capacity building to ensure the needs of all children and young people and their parents and carers can be met by or through local facilities

Stakeholders want this increasing capacity to focus on early identification, assessment and support so that difficulties can be recognised and dealt with as soon as possible. Stakeholders considered that this would reduce long term needs and the necessity for specialised and exclusive provisions.

For those with recognised additional needs already resident in Clapham Park, stakeholders believed that any strategic developments should focus on improving outcomes at transition points such as from Early Years provision to primary, from primary to secondary education and secondary to further education.

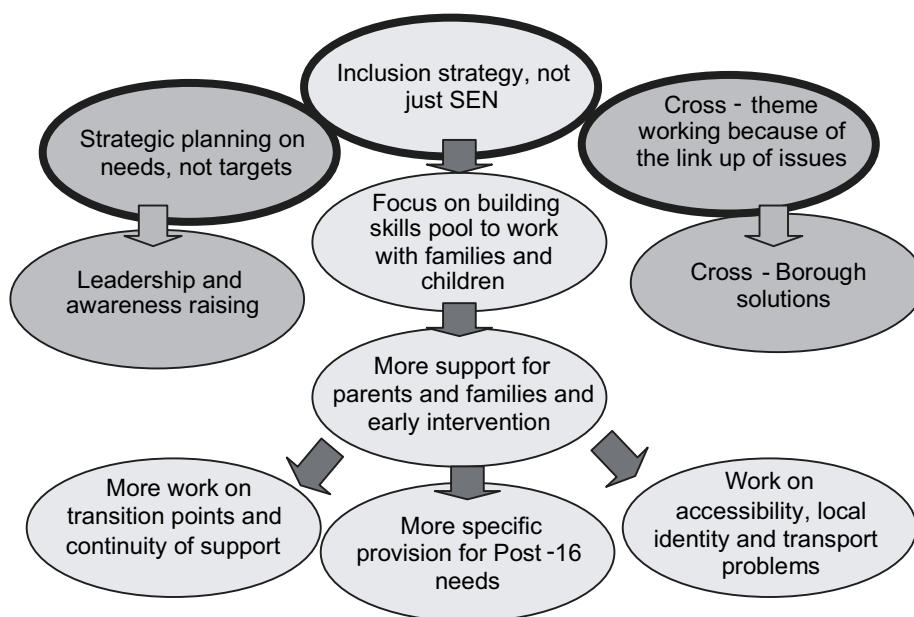
Many opinions concluded that an inclusion strategy should also address issues beyond the school day, such as the leisure and transport requirements of children and young people with additional needs.

Stakeholders want the inclusion strategy to be:

- Sustainable—leaving a legacy beyond the lifetime of the Clapham Park Project
- Needs-led, not target driven
- In tune with:
 - all statutory requirements and national policy drivers
 - local authority practice
- Implemented by Clapham Park and steered by representatives of stakeholder organisations

The following diagram summarises the emerging priority areas for action arising from the first phase of the consultation process.

WHAT STAKEHOLDERS SAY IS NEEDED AND HOW IT SHOULD BE DONE



There are many strategies, and this could simply be another of them. The test of its value lies in whether it makes any real and lasting impact on those for whom it seeks to help. Effective strategies are often different—they try to approach long-standing or complex social problems in different ways, and this usually means being bold and radical. Another key to effective strategy is as much about deciding what NOT to do as about selecting priorities. A third feature is that the strategy is clear about the impact it wishes to make, not just the activities it wants to carry out.

The strategic process we have followed in arriving at this Inclusion Strategy has been to build a clear understanding of how things are and what people want, and use this to develop a set of priorities, each of which has a clear link back to the picture of reality we have assembled.

The initial priority was seen as simply producing an Inclusion Strategy **BECAUSE** that's the real challenge we want to tackle and it recognises the many and connected facets of children and young people's lives **AND** it is more in tune with the contemporary legislative scene

Within the Inclusion Strategy, the proposed priorities and their justifications (arising from the research and early phases of consultation) are:

THE PRIORITIES

The first five priorities are what the focuses should be:

1. Focus on building and enlarging the skills pool to work with families and children **BECAUSE** many existing organisations do not have the capacity to extend their core work or to be more flexible in how they do it **AND** it is an excellent way to provide opportunities for people resident in the area to develop new skills and careers at the same time as helping others **AND** it is simply more effective to use local people to engage the community.

2. Target more support for parents, carers and families, especially for early intervention and to strengthen their skills and confidence **BECAUSE** this is where a real difference can be made on the ground, on families' own territories **AND** it is only by empowering the adults who care for our children by enabling them to be effective and confident that we can break cycles of low self-esteem **AND** we know from some of the good work going on that this works well and is much appreciated by those who are supported.

3. Make more specific provision for post-16 year-olds **BECAUSE** there are vulnerable young people in this age group for whom no single agency seems able to cope **AND** there are not enough appropriate facilities for young people, including short-term residential respite options and positive places to go.

4. Do more focussed work on the key transition points **BECAUSE** some of the neediest children and young people experience real discontinuity when they move schools **AND** even where good close support (health, educational or social) has been present in one phase of education it does not necessarily follow through across the transition stages.

5. Work on accessibility, local identity and transport problems BECAUSE these are closely linked to isolation of families and their children AND there are specific groups for whom transport and access are particularly acute, contributing to their effective exclusion from the life of the community.

The following four priorities are more concerned with how the Project and its partners should work:

6. Strategic planning should focus on needs, not targets and numbers only BECAUSE some of what we are trying to do is about longer-term change AND is not always amenable to short-term target hitting.

7. There needs to be some clarity about where the leadership and awareness-raising for this Inclusion Strategy should come from BECAUSE it needs to be kept high profile in people's minds AND in the work and thinking of the partner organisations.

8. Move to more Cross-theme working inside the Project BECAUSE the issues are so obviously interdependent AND it will help reduce the fragmentation that can accompany too many separate projects.

9. Seek to influence Cross-Borough solutions BECAUSE the boundaries of the project bear no relation to those used by key agencies AND children resident in Clapham Park do not necessarily draw on services and contacts from within the Project area AND the requirement for Lambeth to produce a Children and Young People's Plan as well as other current macro-level planning in Education, health and Regeneration makes it vital that CPP developments fit well to gain maximum benefit.

BALANCING THE PRIORITIES

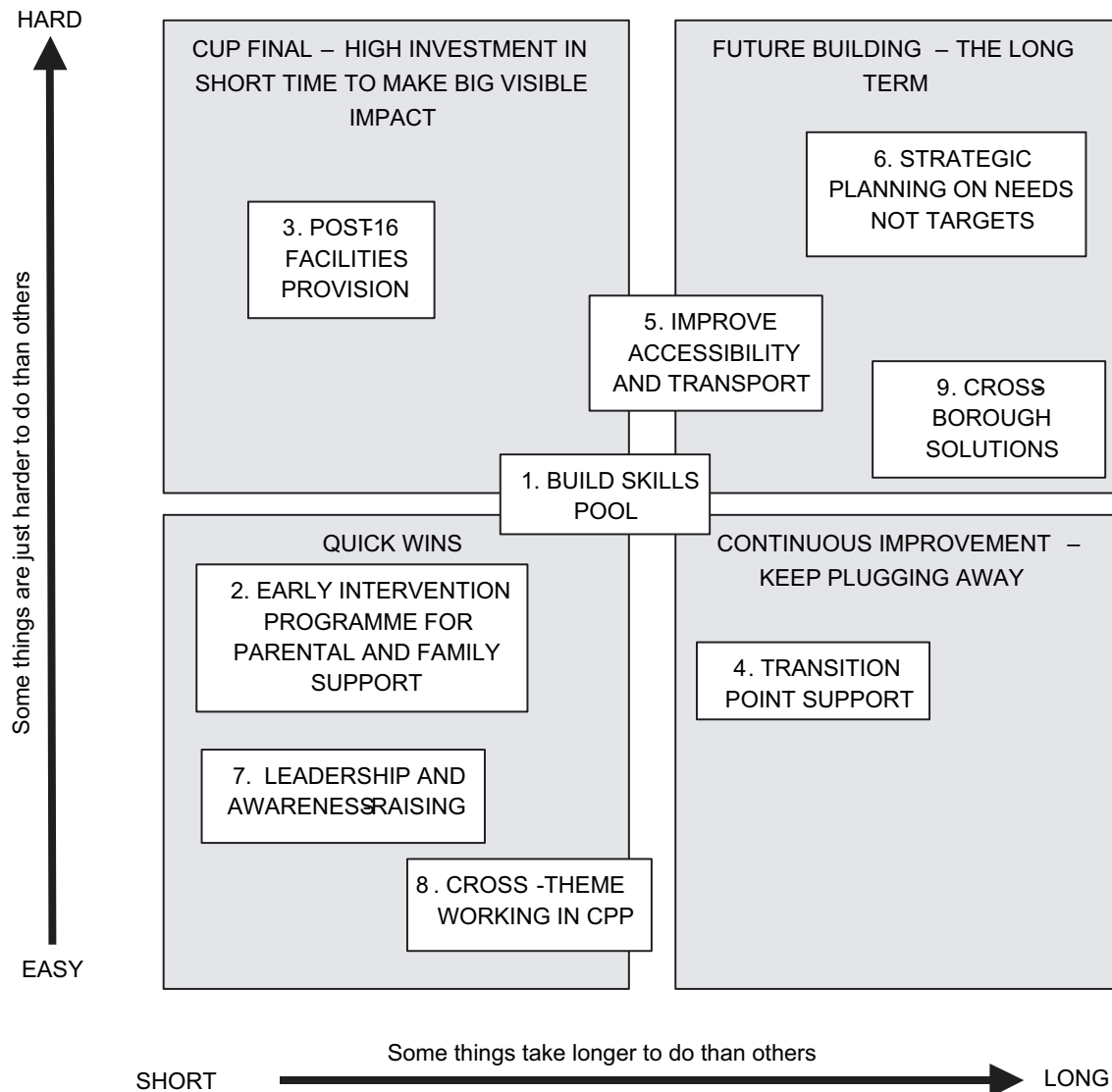
The greatest threat to a strategy is to have too many priorities. We currently have 9 priorities, and this may be too many. Making the hard choices of what matters most among them can be helped by the following framework

A Balanced Strategy Framework:

Some things are simply more difficult to achieve than others, and some things take longer than others. A balanced strategy makes choices from its priorities that will address a mix of these, as each has benefits, yet together they can make more impact over a range of timescales that is greater than the sum of the parts.

The framework simply has two dimensions—increasing difficulty to achieve, and increasing time scale to achieve.

When the nine priorities are mapped on to such a frame, the result is shown below:



Even if a priority is viewed as a longer-term challenge, there will be “quick win” steps that begin the journey.

When mapped in this way, the priorities begin to shape up as a coherent set, and it is possible to think about what specific actions are needed, and the next phase of detailed planning will address the tactical challenges of “In what ways will we take this forward?”, “When will it happen?” and “Who is going to do it and makes sure it’s done?”

A proposed high level action plan follows. Priorities have been clustered into the following four groupings to help make the forward plan more manageable:

Cluster A. Promoting the Inclusion Agenda (Priority 7)

Cluster B. Intervening in targeted aspects of the Inclusion agenda (Priorities 1, 2, 3, and 4)

Cluster C. Improving connectivity (Priorities 5 and 9)

Cluster D. Increasing the value-added potential of the Clapham Park Project (Priorities 6 and 8)

GOAL

To meet the inclusion needs of all our children and young people in or through our locality, so that they all feel valued and cared for, and helped to achieve in education and in life.

<i>Priority (Objective)</i>	<i>Success Criteria</i>	<i>Key Actions</i>	<i>Critical Success Factors</i>
A. Promoting the Inclusion Agenda			
<p>A1. Achieving consensus and sign up to the strategy SO THAT it is driven by all to make a difference</p> <p>A2. Launching and disseminating the strategy to involve all stakeholders SO THAT it achieves maximum exposure and translation into benefits to children and young people that all can identify with</p>	<p>A1 and A2: High levels of awareness in partner organisations and the CPP public, and full sign up by key partners to an agreed set of roles, agreed actions and responsibilities</p>	<p>A1. Complete formal consultation of Inclusion Strategy and secure signed commitment of partners</p> <p>A2. Design high profile launch and publicity campaign using children, young people and their families as the front line voices, with the possible addition of a public personality to endorse and capture interest. Support the strategy with a Children and Young People's Entitlement</p>	<p>One person takes on the leadership mantle and assembles an active and committed support group that includes front line workers, children and young people and their families to keep the Inclusion thrust grounded and accountable</p> <p>RESOURCE AVAILABILITY</p>
B. Targeted Interventions			
<p>B1. Build skills pool by increasing the numbers of family and child support workers from within the CPP area SO THAT more inclusion needs are addressed in practical ways</p> <p>B2. Increase and improve family early intervention services SO THAT needs are picked up and addressed early</p> <p>B3. Improve continuity of support and information at 4 key transition points (3, 5, 11, 16) SO THAT children are not set back due to institutional processes</p> <p>B4. Create new provision for young people aged 16 and over, including arrangements for respite accommodation SO THAT knowledge and support of vulnerable YP does not stop or falter</p>	<p>B1. More workers reaching more families and children B1 and B2. Increased satisfaction of children, young people and families, reductions in key indicators such as attendance, developmental delay</p> <p>B1 and B2. Increased confidence reported by parents and carers as a result of increased skill levels in key areas of support for children and young people such as listening, counselling, managing behaviour, accessing help and information</p> <p>B3. Fewer changes of support professionals involved with children or families.</p> <p>B4. Fewer YP in Youth Justice System, reduction in substance abuse, alcoholism and prostitution, greater level of re-engagement in training, education and work</p>	<p>B1. Develop training programme and support materials based on findings from B2. Identify and train small group of "Learning Champions" from within the resident population and allocate their work to individuals and families in greatest need as learning coaches.</p> <p>B2. Audit existing family worker workforce availability and deployment across all partner organisations working in the CPP area. Agree highest priority target areas for new targeted project</p> <p>B3. Consult, design and initiate CPP Joint Agency Transition Project</p> <p>B4. Carry out feasibility study with key partners and develop proposal for funding support to establish a CPP centre for supporting young adults, and providing links into training and work</p>	<p>Training programme is attractive enough to sell itself to participants Enough people are encouraged and enabled to come forward to work in support roles</p> <p>That it is done quickly and that the resultant project concept is inspiring and seen as plausible in the community</p> <p>The willing engagement of key partners, particularly schools and pre-school providers, the LEA and Health Authorities</p> <p>Joined up planning with Social Services, Youth Justice, Youth workers, voluntary and community groups, training providers and employers</p> <p>RESOURCE AVAILABILITY</p>

<i>Priority (Objective)</i>	<i>Success Criteria</i>	<i>Key Actions</i>	<i>Critical Success Factors</i>
C. Improving Connectivity			
C1. Build an understanding of, and seek levers to improve priority transport issues and their effect on children and young people in the CPP area	C1. Better understanding of the role of transport and accessibility in inclusion for specific groups in the community	C1. Seek partners to help in reviewing existing information about transport and accessibility patterns and problems, and if needed, design and carry out survey of current perceptions to identify highest priority target groups. Develop accessibility improvement action plan with partners based on the results.	The problem is widespread enough to be worth of this much attention in the face of competing priorities
C2. Improve the “fit” and connectivity between CPP-confined activity and Lambeth-wide initiatives in key areas affecting children and young people—early intervention, family support, continuity at transition and post-16 as the first priorities	C2. Reduction in barriers to inclusion caused by accessibility and transport for specific target groups	C2. Mount series of four focussed working sessions with Lambeth-wide organisations to update a map of interlocking initiatives and procedures that affect children and young people in each of the four specified thematic areas	A “logical” lead person or organisation can be readily identified and deployedKey agencies willing to participate
	C3. Greater impact on all four aspects due less duplication and more economic use of resources and expertise		RESOURCE AVAILABILITY
D. Increasing the value-added potential of the CPP Project			
D1. Evaluate the mutuality of agendas across theme groups and reconfigure to reduce the number but increase the “reach” of key projects, and translate these into needs-based planning approaches	Increased focus and effectiveness of theme group activity	D1. Carry out urgent review of theme group structure and activity and reshape theme groups around smaller number of integrated projects	CPP management agreement RESOURCE AVAILABILITY

September 2005

Memorandum submitted by Autism-in-Mind (AIM)

- Provision for SEN pupils in “mainstream” schools: availability of resources and expertise; different models of provision.
- Provision for SEN pupils in Special Schools.
- Raising standards of achievement for SEN pupils.
- The system of statements of need for SEN pupils (“the statementing process”).
- The role of parents in decisions about their children’s education.
- How special educational needs are defined.
- Provision for different types and levels of SEN, including emotional, behavioural and social difficulties (EBSD).
- The legislative framework for SEN provision and the effects of the Disability Act 2001, which extended the Disability Discrimination Act to education.

Autism-in-Mind can only address the issues being looked at by this Committee from the perspective of a National Group who supports parents and carers who have children with Autistic Spectrum Disorders.

Provision for SEN pupils in “mainstream” schools: availability of resources and expertise; different models of provision.

The provision for pupils with an ASD in “mainstream” is very much a postcode lottery. The service provision and resources differ greatly depending on where you live.

“What autism provision? There are continuing difficulties in mainstream provision, but that’s not autism provision!”

This is what many of our parents have told us.

The biggest problem continues to be lack of awareness of ASD and how it affects the child because there is still nowhere near enough ASD specific training delivered by professionals who do have the awareness and understanding of this very complex disorder.

Parents are still not being believed that their children have an ASD. Far too many schools “Nationwide” see the child’s problem as being something that the parent has perpetrated and in some way contributed to.

All Mainstream Schools need accredited and continuous training to address this problem and in our opinion it must be made mandatory. The Government must also make sure that all training teachers have ASD modules included in their training. This was recommended in the National Autism Plan for Children (NAP) but is still a very long way from being a reality. The reality is that the NAP provides a comprehensive map for the way forward for children with ASD. There is no need to reinvent the wheel it has already been invented.

Devolved Funding into schools is not providing the support for children with ASD. There are LEA’s who are now operating policies, many of which IPSEA consider to be illegal, where a Statement will not be issued to a child with Aspergers syndrome. It appears that a child not only has to be failing, but has to be at least 4 to 5 years behind it’s peer group before a Statement will be issued! Rita Jordan has been saying for years that support structures must be in place for a child with ASD before it fails. We have very serious concerns about children who have a diagnosis of Aspergers Syndrome.

Most Authorities see these children as only ever being placed into a mainstream setting with no hope of their parents ever being able to obtain a statement.

LEA’s lie to parents who are vulnerable and expect to be told the truth by professional bodies of people. They are told that their children do not fulfil the criteria need to be issued with a Statement. They are told that School Action Plus will meet the needs of their children. How can the needs of any child be met when there has not been an assessment of needs? It simply does not make sense.

PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

Sadly many of our children have suffered dreadfully when placed within a Special School. This is because children with ASD require “specialist provision” rather than Special Schools. Autism is a unique disability which we believe does not pigeon hole with any other disability for educational purposes. We therefore feel that some Special Schools are as inappropriate for our children as Mainstream Schools.

RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

Start by accepting that our children are different and therefore require specialist teaching. As well as the core subjects our children require specialist teaching to assist their communication and their socialisation skills. Being taken out of school one day each week for 12 weeks, as often happens is not the answer. Many of the Social Skills groups and Emotional Literacy Groups that our children are sent to were never designed for children with an ASD. Once again they are being made to “fit in” to an inappropriate setting. Effective Communication and Socialisation skills should be core subjects for our children and very much on going. If the barriers of communication and socialisation were being worked at then the standards would rise.

Make sure that the needs of these children are met within the classroom. Many of our children are now being taught in a corridor. Is this really inclusion? There is still far too much emphasis being placed on our children having to “fit in”. The educational provision should ALWAYS wrap around the child and not the child wrap around the provision.

How can a child who is being expected to maintain coping strategies for 13 years ever going to achieve anything? The Literacy and Numeracy Hour is a disaster for our children. It highlights their differences and inadequacies and leaves them feeling frustrated and useless. Is this really how we want disabled children to feel?

If the teachers teaching our children had been given the correct training then they would have a greater understanding of them. This in itself would help raise standards in achievement.

Far too many of our children are actually being taught by Non Teaching Assistants and Learning Support Assistants, simply because it is the easiest option for the school. What about the child?

Because many children with Aspergers Syndrome are unable to obtain a Statement they are failing in mainstream classrooms. Their needs are not being assessed because we now have a generalised attitude that children with AS and High Functioning Autism (HFA) do not need support. Please go back and revise this way of thinking. More and more children with AS and HFA are being referred to Child and Adolescence Mental Health for their input for very serious mental health issues which are being seen as a direct result of mismanagement of the child in school.

Children with AS and HFA are seriously socially disabled. When you do not even understand yourself how on earth are you supposed to make sense and make friends with the child sitting next to you? Who is teaching our children about themselves? Children with ASD cannot multi-task placing them in a classroom with 30 other children will not teach them effective communication and social skills. It merely highlights their differences. It also makes our children easy prey for bullies.

THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (“THE STATEMENTING PROCESS”)

One of the biggest challenges for parents is:

Obtaining a statement of SEN and then “policing” their LEA to ensure provision happens.

Parents are often placed under pressure by the LEAs and other Authorities not to pursue a Statement for their child. LEA’s make their criteria for obtaining a Statement very difficult to achieve.

With the LEAs, cost always comes before need. School Action/School Action Plus is cheaper and not legally-binding.

How can one meet the needs of a child with complex and specific needs without a full and formal assessment of that child’s needs?

SOLUTION: MEET THE NEEDS OF THE INDIVIDUAL CHILD AND NOT THE SYSTEM

Many of our parents have fought for years to obtain a Statement for their child and are still fighting. You can only enforce the legal responsibilities of any LEA once the child actually has a written Statement. Far too many parents never actually reach this point.

- Form a governing, national body (similar IPSEA).
- Ensure that every LEA has an independent body that can monitor and “police” the LEA when they are not complying with their duties under the current legislation.
- Ensure that this independent body has legal powers to ensure the LEA carries out these duties.
- Simplify the process. (Most parents don’t understand the legal implications and procedures).
- Speed up the process.

Parents would trust an independent body more than an agenda-run LEA. In addition to that, we believe that if an independent body were policing LEAs there would be less parents appealing to SENDIST. Many parents go to SENDIST to ensure that the LEA complies with its legal duties (writing a statement as it should, carrying out an assessment, making a statement etc.) This was never the reason for SENDIST being set up. LEAs are very aware that appealing to SENDIST is a lengthy and stressful process and many parents do not appeal for this reason. We have had parents who have appealed to SENDIST, obtained provision in their child’s statement and yet the LEA do not arrange the provision. The parent has then to go through the process of complaining to the Ombudsman. Bare in mind, this is the action of an informed parent. Not all parents are as informed. It is difficult enough raising a disabled child without the added stress of having to “police” the LEA and fight for their child’s legal right to obtain the provision to which they are entitled.

THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN’S EDUCATION

“Try Listening to them!”

That is the one thing that parents would like most. If we are ever to right the terrible wrongs that are being visited onto our children by the current system of education, then parents must be given the respect and the hearing that they deserve.

“WE” are the experts—we know where it has gone wrong and why—we know how to sort out this mess. We would actually give you the information free of charge.

Payment would be never having to see our children self-harm or retreat into their protective ASD shell again.

Most Authorities have parent support groups up and running—why not use the knowledge held by these parents?

Parents need to believe that they are being listened to, and that their knowledge and understanding of their child and is respected. Their input should be welcomed and valued and they should not be made to feel like intruders when asking questions about their child within a school setting.

Get parents on board at grass root level. Although there are Strategic Partnership Groups and their counterparts up and running all over the UK there are few who actually pay more than lip service to any parents involved in their groups. There is a place for parents within these groups and they need to be on an equal partnership footing?

All over the UK we are gearing up for unified service provision with the appointments of Directors for Children's Services. This is a brilliant opportunity to involve parents. BUT instead we find groups working on "integrated care pathways"—which would certainly benefit from the input of parents—alone.

Parents are still viewed as people who interfere with the professional's view of the ASD Big Picture. Could parents be included into the Big Picture?

ASD Educational outreach teams need the parents of ASD children to be a useful resource for the team. Consult parents and ask for their opinions. If there are parent groups up and running in an Authority the Authority could and should be using these groups as a sounding board.

If parents feel that they are being listened to and that their views and opinions are being taken seriously and valued—then they will remain on board any partnership groups.

Not every Authority has access to Tony Attwood, Simon Barron Cohen or Rita Jordan—but they will all have access to parents, many of whom can provide them with a comprehensive broad base of information and knowledge. Many parents know a great deal about their subject as they ALL live with it.

HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

Sadly a physical disability or an IQ usually defines them. This method of defining SEN is leaving thousands of our children and young people unsupported in schools. Autism-in-Mind seek to see Autistic Spectrum Disorder removed from within the umbrella of SEN simply because the needs of our children are so complex and specific. It is not our intention to neither compete with other SEN's nor yet minimise the impact that other SEN's have on children. But we believe that unless the uniqueness of this condition is recognised and accepted our children will be left failing into the next millennium.

A high IQ is of little relevance when a child is so chronically socially disabled by a condition that it finds just sitting next to another child impossible. Sitting next to another child can actually disable a child learning abilities. This needs to be recognised and accepted. A high IQ does NOT reduce the level of autism and is entirely separate from the ASD.

There are things that EVERY child with a diagnosis of ASD needs to be taught that would enable them to live as independent a life as possible, thus saving the State millions of pounds each year. At the moment these things are not even recognised as being part of the disability, simply because the child has a high IQ. What is the point of being able to crack the theory of relativity if you do not have the skills to purchase a bottle of milk from a shop? Many of our children learn things, which they do not understand. This may sound rather stupid but it is a fact. We have children who can sit and read a book from cover to cover in Hebrew but have not understood a word of what they have read. So is there any point in acquiring a skill that you are not able to use effectively?

We acknowledge that for many children with an ASD they have no shared meanings and understandings of things that the rest of us take for granted. This in itself is seriously disabling for our children and yet it is continually dismissed.

We therefore need to see a huge turnaround in the way an SEN is defined.

Autism-in-Mind would welcome the opportunity to discuss this very important issue with the Committee in more detail

PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES (EBSD).

This question is not relevant to children with Autism, although sadly they are often included with children who have including emotional, behavioural and social difficulties. Again we feel that this is because professionals fail to understand that although these problems may occur with an ASD they are present because the child is being taught in an inappropriate setting.

THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001, WHICH EXTENDED THE DISABILITY DISCRIMINATION ACT TO EDUCATION

Although LEA's should all have a clear understanding of what is required of them by law they all continue to flout their responsibilities and drag their heels on timescales, which are clearly defined in the 1996 Education Act and 2001 regulations.

This leaves parents with no choice but to "police" their individual LEA's, which is a quite shocking state of affairs. The very people who are supposed to be providing for their children's needs are punishing parents who have children with SEN. Although many parents do in fact "police" their LEA's there are many who, because of the disability of their child and the restrictions this places upon them as a family, are unable to do so.

Another serious issue is Statements that are issued without being specified and quantified. Unless a parent is very well versed they will again believe that a Statement is the answer to any problems that their child is facing in school. Sadly some Statements are so vague that it has been of little point obtaining one in the first place.

We believe that there is widespread abuse of the current legislative position and it must either be stopped at once or changed so that there is no room for abuse.

September 2006

Memorandum submitted by SEN Leadership Group, Raising Achievement Division, Children's Services Directorate, Somerset

In Somerset, the SEN Group works in very close partnership with Social Inclusion colleagues and School Improvement advisers, under one Head of Service, focussing on Raising Achievement. The SEN support services focus on both individual achievement and whole school improvement.

We greatly welcomed "Removing Barriers to Achievement" as well as the links to "Every Child Matters" and "The National Service Framework". Our strategy is illustrated in Anne Pinney's appendix to "Removing Barriers . . ." on the DfES website.

The subsequent guidance/toolkits have also proved helpful. In Somerset, government intent is expressed in our Inclusion policy "Access and Achievement for All", our SEN Strategy and our SEN Framework for interpreting the SEN Code of Practice.

Our submission follows the list of issues which the Committee will be looking at and we have attached key guidance on the SEN framework we use and SEN funding mechanism for individual pupils with the most complex SEN.

We also recommend that the reports of the DfES regional SEN advisers be consulted. We have two of those to date and would be please to submit them if required.

In our submission, we have followed the headings given, to cover the full range of SEN, including behavioural, emotional and social difficulties. However, given the national focus on this area, we have also included a more detailed response for this area, as an additional section.

PROVISION FOR SEN PUPILS IN MAINSTREAM SCHOOLS; AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

In Somerset SEN funding (£14.7 million/7.5% of the mainstream schools budget) is delegated to schools:

- SEN Support Services intervene early at School Action to build capacity and also carry out individual work with pupils;
- School Action Plus Funding brings additional resource for pupils with severe and complex needs;
- SEN Support Services are "core" funded from the Schools budget;
- Statements do not attract additional resources;
- SEN Support Services work from multi-professional area bases, with significant multi-agency working; and
- The SEN Group has developed Wave 3 Strategies to support the work of the Primary National Strategy and delivers them in partnership with consultants.

PROVISION FOR SEN IN SPECIAL SCHOOLS

Somerset recognises the importance of its specialist provision.

It has seven schools for learning difficulties and one for BESD. Intensive work has been carried out on:

- collaboration working with all community provisions, from early years to post 16;
- on developing out-reach;
- on enhancing specialisms; and
- on an interactive protocol for partnership working with mainstream schools and SEN support services.

THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS

- Clear criteria for when Somerset write Statements set out in attached SEN Framework;
- Statements do not attract additional funding;

- Statements continue to be important when the Local Authority decides it needs to set out explicitly the individual needs of a pupil with severe and complex special educational needs, and how a school should meet those needs;
- recognises that for nearly all children and young people, our mainstream schools have the expertise available (including Somerset Support Services) to make a Statement unnecessary;
- Statements written just to attract additional funding for a pupil “uses up” valuable Educational Psychology support service time, which would be better spent in “front-line” work schools and pupils;
- Annual Reviews introduced for all pupils with additional School Action Plus funding; and
- As funding is delegated, schools define models of provision to suit local circumstances.

This model is set out in the Somerset SEN Framework (attached).

- It is recommended that the Committee considers whether school should retain responsibility for provision for a pupil with SEN, even if they are considering permanent exclusion. (Otherwise pupil responsibility returns to LEA, leading to breaks in provision for vulnerable pupils).

RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

- P Scales widely used in Somerset mainstream and special schools to measure achievement and to track progress for pupils achieving well below age related expectations;
- Local Authority supports schools in introducing and using P Scales through comprehensive guidance and a seconded Teaching Assistant;
- Local Authority carries out analysis of the value added scores of the lowest 20% of pupils in end of Key Stage assessments; and
- SEN Support Services work on Wave 3 in partnership with advisers.

THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN’S EDUCATION

- Parents (and pupils) are important partners in the decision making process;
- parental views are always actively sought as part of the assessment process;
- Somerset IMPACT, an umbrella group of voluntary agencies is funded by Health, Social Care and Education to seek parents views through project work, audits and conferences;
- Somerset IMPACT and Parent Partnership are commissioned by the Local Authority to seek parents views about provision. We have consulted on SEN funding, dyslexia and behaviour difficulties last year;
- Parents have been fully involved in consultation about charges in roles of specialist provision; and
- We have a highly valued and active Parent Partnership Scheme, with representation on our SEN Strategy Groups to inform decision making.

HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

- The DfES codes provide sufficient detail to enable us to classify pupil needs consistently, when combined with our own School Action Plus Guidance Framework.
- The OTHER category is not helpful and we would welcome its removal.

PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EBSD

- See earlier not re schools retaining responsibility for a pupil’s education, even if they are permanently excluded;
- Recognition of the need for a variety of models of alternative provision to support schools in constructing worthwhile learning programmes;
- Somerset has developed an Emotional Health and Well-being/BESD graduated response strategy document, similar to the SEN Framework—about to be published;
- There is a strategic working group of head teachers (mainstreams and special; all phases), Members and Children’s Services colleagues, developing a Somerset continuum of strategies and provision for this area and based on partnership principles; and
- Our special school for BESD is involved in developing creative models within the school and as satellite provision, including for girls and children in public care. The school works in partnership with other schools, other providers and the Local Authority to develop strategy.

THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001 WHICH EXTENDED THE DDA TO EDUCATION

- The Government intent as expressed in “Removing Barriers to Achievement” is to “reduce reliance on Statements, however, tribunals continue to interpret the law as stated in various Education Acts. This causes tensions in Local Authorities with reducing statementing rates as a strategic intent;
- Tribunals as lay bodies in terms of Health Trust provision issues should be reviewed in terms of their ability to make clinical decisions in the debate between private and NHS therapists;
- We recommend that Tribunals should not be in a position where they give equal weight to private therapists who do not know the child and often have not seen the child in school (where the need is said to be “educational”);
- The Local Authority being responsible for provision of Health Services (therapies) in Statements because they are seen as “educational” needs is a recommended area for review;
- In issuing proposed Statements, the penalisation of LEAs for the failures of other agencies such as Health to submit advice in on time should be examined. The fewer the Statements, the greater the focus will be on severity and complexity, which is more difficult for Health colleagues to collate as more branches of Health are involved. Also, increasingly, the failure to keep to timeliness of a few, impacts greatly on the Local Authority’s ability to issue Statements within 18 weeks;
- DDA and the Disability Act 2001 are having beneficial effects on the accessibility of mainstream schools; further guidance on the anticipating duties, and using DFCG funds to meet these duties would support Local Authorities in making the most effective, strategic use of School Access Initiative funding; and
- SAI funding made available to special schools could reduce the number of independent/non-maintained special schools in the medium/long term.

Documents referred to in the text above are:

SEN Framework http://www.six.somerset.gov.uk/sixv3/content_view.asp?did=12461

and

SAP Guidance http://www.six.somerset.gov.uk/sixv3/content_view.asp?did=12459

ADDITIONAL COMMENTS ON EMOTIONAL HEALTH AND WELL-BEING

- The following are additional comments relating to BESD, to add to the above, given the national focus currently. We perceive BESD to be an area which is yet to be fully recognised as SEN and which requires more attention.

IDENTIFICATION

- Many pupils with BESD are not perceived as having SEN. Early identification is too frequently misinterpreted. In early stages/at lower levels of need, pupils with BESD can be perceived as naughty, disaffected, uncooperative, truants, etc Only when persistent and significant concerns are experienced, do some professionals consider there may be a special need.
- Pupils in mainstream schools experienced as having “behaviour problems’ are also those with learning “difficulties’/needs, which schools can experience difficulty in identifying/providing for (understanding) eg social and communication difficulties, specific learning difficulties, general learning delay, especially when not matched by social ability (eg being “streetwise”).
- Pupils with Kinaesthetic learning styles (and visual to a lesser extent) are challenging to teach within mainstream environments which are significantly auditory in delivery, particularly at key stages 3 and 4.
- The challenge of providing more flexible curricula can provoke increased stress for children and young people, hence emotional distress can evolve into school specific anxieties.

RESOURCE AND EXPERTISE

All of the above indicates the complexity of early identification, and indicates the level of expertise required for effective identification of needs.

We feel that EXPERTISE needs significant development:

- For earlier and effective identification of needs;
- For development of skill in describing social needs and emotional needs using language now provided in various documents: Promoting Emotional Health and Well being; PHSE end of Key Stage Statements; Foundation Stage Profile; Boxall Profile (these all describe emotional and social abilities/capacities—not simply behaviours)—the Primary National Strategy teaching and

learning materials also have descriptors of the five competencies in the Learning to Learn/ Profession (DK purple) books—some integration of these emerging descriptors is required (perhaps locally) and school staff then need training/CPD to grasp these; and

- When description of need is more effective it will empower school staff to understand development/ progression and how provision in school can promote progression.

CURRENT MODELS OF PROVISION

Generally, in schools, there is a grasp of the key role of relationships which promote emotional and social stability—calming down, and enabling more effective differentiation, increasing knowledge of a child such that their strengths and interests can be identified (behind the mask of behaviour) and worked with. However:

- Models of provision are still dominated by the goal of having a calm enough child who can then engage in learning;
- We need to increase staff understanding (including head teachers) of the whole person—integrating our image of key skills/social and emotional and thinking skills into an interdependent image ie achieving, having strengths valued/recognised increasing emotional development;
- Current models of provision are beginning to provide an appropriate framework for a continuum of provision to be available; and
- Work on assessment for learning/target setting for pupils with BESD needs more guidance. Adult directed solutions can disempower children and young people and undermine development/ learning.

PROVISION FOR SEN IN SPECIAL SCHOOLS

All of the above apply to CPD and models of provision in special schools.

The value of “supervision” and therapeutic approaches for BESD has yet to be given the emphasis and value that would ensure good practice and provision develops.

RAISING STANDARDS

This is dependent on a firm grasp of the significance of understanding emotional and social development and providing opportunities for progression in learning relationships in schools.

ROLE OF PARENTS

Although there is some skill in mainstream schools in working with parents, we sense there may be fear about a need for CPD opportunities on working with challenging parents.

And finally, there is a real issue about the time teachers/mainstream staff have to ensure constructive and productive review and target setting, as well as problem/solution solving.

September 2005

Memorandum submitted by SOS!SEN

As a helpline for parents of children with Special Educational Needs, we have over the past three years gathered a wealth of information on the problems associated obtaining adequate provision for children with SEN.

We have a small team of experts mainly from education; one of them was an LEA officer and is an Ofsted inspector for SEN. We have helped parents, from all over the country, at all levels of their path to improving the provision for their children. From interpreting letters from the LEA to representing them at tribunal (with an almost 100% success rate).

We have a wealth of experience on SEN, and would be happy to give oral evidence.

I have attached the two reports that we have published and a leaflet outlining our work.²³

²³ Not printed.

WHAT DO WE DO?

We offer a free, friendly, independent, confidential and local telephone helpline for parents and others looking for information and advice on Special Educational Needs (SEN). We concentrate on helping people to find their way through the legal and procedural maze which is so daunting to so many who try to obtain satisfactory provision for a child's special needs.

Our aim is to encourage parents and carers eventually to become empowered and confident to tackle for themselves the obstacles and difficulties, which arise, and in turn to use their knowledge and experience to help others

WHO ARE WE?

We are a small team of volunteers who have spent much of our lives in education or related services.

WHAT HELP CAN WE OFFER?

- interpreting official letters;
- interpreting the SEN Code of Practice and other related documents;
- checking proposed and revised Statements of special educational needs;
- helping prepare letters of request, comment and complaint;
- finding independent professional advice—eg independent educational psychologists, lawyers etc.;
- giving guidance on the next available procedures which may be suitable;
- acting as a “friend” to accompany parents on visits to the offices of officials in the education, health and social services and to meetings in schools;
- advising on preparation of case statements for SENDIST (Special Educational Needs and Disability Tribunal);
- presenting cases at the Tribunal;
- helping with complaints to the Local Government Ombudsman; and
- organising training workshops and other opportunities for parents and carers to come together.

WHERE ARE WE BASED?

We work from Hampton upon Thames. This location makes it easy for people from surrounding authorities to come to see us if they have a particularly complex problem, but our activities are not confined to local problems, and we have helped parents/carers from as far as Sheffield.

HOW DO WE WORK?

We can be called on the Helpline and one of our co-ordinators will listen carefully and either provide an immediate answer to questions or, more likely, take a few details and ask the most suitable member of the team to call back. The line is open seven days a week at all reasonable hours. On those occasions when we are not available a message and phone number can be left.

WHY DO WE DO IT?

We started the Helpline in October 2002 because we recognised that there are many parents and carers who are not fully aware of their children's rights to special education and of the complexities of the procedures to obtain these rights. Many did not have the financial resources to obtain the help of the legal profession but felt that they could not get anywhere without it. Whilst the role of lawyers and expert professionals is very important much can be done to help even if finances are very limited.

HOW SUCCESSFUL ARE WE?

Between October 2002 and February 2005, we were contacted by over 300 callers. We are growing fast. We have evident success from Tribunal results where almost all of the requests by parents for better provision have been upheld and, amongst other successes, in helping parents negotiate and obtain from their LEAs:

- agreement to carry out Statutory Assessments;
- improved Statements of Special Educational Need;
- increased educational support for their children in mainstream school or by placement in specialist schools;

- therapy for children with speech and language, sensory, and motor skill difficulties; and
- rights to school transport.

As a result of our workshops parents are becoming more sure about the types of questions to ask at Annual Reviews or when involved in the drawing up of Individual Education Plans (IEPs) for their children. Above all we have evidence that more and more parents are increasing their knowledge and confidence and that they are passing their knowledge on to other parents.

HOW ARE WE FUNDED?

To ensure our total independence we will not accept any offers of finance from Local Education Authorities. We do not believe that any fee for our help should be charged to parents. Our funds, therefore come from the usual range of events—social evenings, jumble sales and coffee mornings. We do not have a separate office and volunteers work from home. Basic costs are, therefore, not too difficult to cover. Other costs are!

Where we can, we help parents with limited means and who are trying to obtain the detailed advice of independent educational psychologists or therapists and, on occasion, paying for legal advice.

October 2005

Memorandum submitted by ISCG

The ISCG works to support school governors. Our aim is to provide governors with practical advice, up to date information and relevant services. We have no other agenda. As a group we have a wide range of skills and experience in all aspects of school governance. The ISCG works with the DfES, LEAs governing bodies, voluntary organisations and large companies who want to support their governor employees. Our publications are at the forefront of producing relevant information for governors and their clerks in a simple and accessible format.

School governors have a legal duty to see that their school identifies and does its best to cater for all pupils who have special educational needs. This duty also extends to pupils with a disability many of whom have special educational needs, so in most schools governors are likely to allocate oversight and responsibility to the same people.

The ISCG supports the recent strengthening of the rights of children with SEN or a disability to be educated in mainstream schools. We are however, concerned that the large-scale closure of special schools has meant that some mainstream schools have to try and cater for pupils with severe learning, behavioural and disability needs with insufficient expertise and resourcing. This does at times lead to health and safety concerns and is having a detrimental effect on the achievement of other pupils in the classrooms where there are pupils with complex needs.

PROVISION FOR PUPILS IN MAINSTREAM SCHOOLS

There has been a general improvement in the training and support of SENCOs which has lead to a significant improvement in early identification of SEN, and in the steps taken to meet those needs. However, the recent moves to increase delegation of SEN funding to schools including statemented funds, has meant that most primary schools have insufficient pockets of funding or the expertise to cater adequately for their SEN pupils.

Primary schools can cater for pupils with quite severe learning needs including those on school action plus and with statements, though the struggle to obtain adequate funding can be demoralising. It is where the learning difficulty is coupled with severe behavioural difficulties that schools are struggling, whether these spring from the child's socio-economic background or whether due to disabling conditions such as dyspraxia or autism. Very often their LEA, particularly the Unitary Authorities, also cannot provide schools with access to specialist help and advice on complex needs. The Learning Support Assistants (LSA) who are recruited to support these children are poorly paid, and on short-term contracts. They, therefore, have relatively little training, certainly not to the level of specialist knowledge often needed. Consequently, governors are forced into the unenviable position of having to agree the permanent exclusion of such pupils due to the school being unable to contain their dangerous behaviour.

The *New Children's Workforce* proposals for a properly trained and qualified workforce would meet some of the above problems no doubt. But it is hard to see how schools, on their present budgets with delegated SEN funding, would be able to afford this new specialist workforce.

Delegation of SEN funding in most secondary schools is less of a problem, though it has led to a reduction of centralized expertise in many Authorities. Links with special schools does not appear to have bridged this gap. It has left mainstream schools to build their expertise "as the need arises" and as best they can. The present climate of league tables and performance data does not encourage schools to take on SEN pupils, as it might affect overall standards of behaviour and achievement. It takes a very committed head and

governors to invest in quality support of SEN pupils, when a significant number may not achieve basic NVQ levels, and some pupils' progress is so minimal that it does not even register on the Key Stage Test levels. Furthermore, where these SEN pupils have complex needs, their volatility and inability to concentrate disrupts school life, takes up inordinate amount of staff time and often puts them and other students at risk. Governors dislike intensely having to permanently exclude deeply damaged SEN pupils, especially if the school was "their last chance", but there is no alternative.

DfES statistics show the high percentage of SEN pupils excluded. We are not doing them or other pupils a service by allowing this to continue. The DfES proposal on collaboration between schools on the handling of pupils with behavioural difficulties, many of which are SEN pupils, seems rather like "moving the deckchairs round on the Titanic". It does not tackle the roots of the problem, which is early identification and on-going multi-disciplinary support for these children and their families as proposed in Every Child Matters (ECM).

PROVISION IN SPECIAL SCHOOLS

Special Schools and Special Units still have a significant role to play both as centres of expertise and also to allow more pupils the respite of full or part-time education where they can mix with peers with similar problems and receive expert help. Any further closure of Special Schools should be halted until completion of area audits of specialist provision to ensure that parents, pupils and schools have access to appropriate provision and support and know where to find it.

The National Curriculum is not always the most appropriate framework for raising standards of pupils with severe learning or emotional and behavioural difficulties. For many even learning simple numeracy and literacy is really beyond their ability and their curriculum should be much more life-skills orientated. We need to help them to be as independent as possible for the sake of themselves and their parents. Special schools should be allowed to review and revise their curriculum provision in the light of the needs of their pupils.

STATEMENTS OF NEED FOR SEN PUPILS

The ISCG is deeply concerned about moves to remove statementing of SEN children. This is parents' one legal safeguard against inadequate provision. Even when ECM is introduced fully parents will still need that legal "Statement of Need" that protects a child's right to specific provision throughout their education. Sadly, obtaining a statement is very dependent on parents' ability and willingness to fight for their children's rights. The process itself is still very slow and bureaucratic and too many LEAs are still using bureaucracy to delay the process further, eg returning all the paperwork because one piece is missing, even when the rest demonstrates the child's need, and requiring the school re-submit often weeks or months later.

Memorandum submitted by Education Walsall

This submission is made by Education Walsall through the Strategic SEN Steering Group which comprises representative from education, health, social care, voluntary agencies and parents.

1. PROVISION FOR SEN PUPILS IN "MAINSTREAM" SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

1.1 We subscribe to the Inclusion Statement which identifies mainstream education as the right of all children & young people. In order to make sure that the needs of all children are met, there should be clear identification of the budget for SEN in mainstream schools.

1.2 Mainstream schools should have access to a package of support from special schools, additionally resources mainstream schools and LEA support services to appropriately differentiate provision within the mainstream context.

2. PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

2.1 Special schools continue to provide appropriate educational provision for children and young people with the most severe, complex and long-term needs. All special schools should have clear links with mainstream schools which enables both partners to participate effectively in teaching and learning.

2.2 All children and young people in special schools should have opportunities to experience teaching and learning with their mainstream peers as part of their curriculum entitlement. Mainstream children and young people should have opportunities to visit, access curriculum and join in activities in special schools where appropriate.

3. RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

3.1 There should be movement away from focusing on IEPs to measure progress and an emphasis on attainment for all children and young people with SEN. Inclusive schools are achieving schools however; in some cases schools promoting inclusive practice feel penalised by league table performance data which measures achievement but not necessarily wider attainment. This needs to be clarified to support inclusion.

4. THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS ("THE STATEMENTING PROCESS")

4.1 The statutory process of statementing is bureaucratic and focuses largely on the failure of children and young people in order to secure resources.

4.2 For the large majority of these children and young people and their parents, it is a cumbersome process which leads to relatively limited additional resource and unclear learning outcomes. Further, though children make progress, it is often difficult to cease to maintain a statement because it is seen as removing an entitlement.

4.3 The process and culture of multi-disciplinary assessment is more immediately relevant for those children and young people with the most severe, complex and long-term needs.

4.4 Early intervention and prevention is often inhibited by the bureaucratic process associated with statements and the related political questions of resource allocation. Early intervention, with the right processes in place (multi-disciplinary working) can clearly identify those children and young people requiring additional support without undergoing a statutory assessment.

4.5 In Walsall we have introduced an additional arrangement beyond school action plus which delivers support quickly and efficiently for children who would have previously undergone lengthy and costly statutory assessments. "School Action Intensive" seeks to reduce bureaucratic costs and recycle funding from statementing into early intervention.

5. THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

5.1 The SEN Code of Practice clearly outlines the expectation of parent involvement in decisions about their children's education. This remains appropriate, should be adhered to and promoted.

5.2 Walsall has established a Parent Forum, which is now beginning to self-manage and provides representation on strategic groups. We have implemented programmes of training and awareness raising for parent groups as well as fora for seeking their views.

6. HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

6.1 Special educational needs represents a broader "continuum" than a medical diagnosis. There is an increasing focus on "categories" of need which can detract from attention to effective responses through intervention in schools, eg a diagnosis of autism is not required to plan an appropriate programme that meets a range of observed communication needs.

6.2 The SEN Code of Practice clearly describes a conceptual model of "needs" and relates this to a framework for intervention through a graduated response, engaging all appropriate stake holders. In Walsall we seek to promote this social model of need in order to support confidence in developing the capacity of schools, teachers and other professionals to respond to diversity.

7. PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES (ESBD)

7.1 We subscribe to the Inclusion Statement which identifies mainstream education as the right of all children & young people. Special schools continue to provide appropriate educational provision for children and young people with the most severe, complex and long-term needs.

7.2 Children and young people with ESBD present the most significant challenge to inclusion. ESBD as an identified special educational need can be met across the continuum of provision described. ESBD is complex in that challenging behaviour is not only related to the individual but also to the educational and wider social context, often a product of multiple causes. Effective responses are most frequently found in well structured multi-agency liaison and shared responsibility as intervention frequently needs to take place in a number of areas of a young person's life. Positive outcomes have been observed in the context of BEST teams and Consultation models of support service delivery as identified by Ofsted and HMI.

8. THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001, WHICH EXTENDED THE DISABILITY DISCRIMINATION ACT TO EDUCATION

8.1 Walsall supports the extension of the Disability Discrimination Act to education and promotes this extension of equal opportunity for children and young people and their parents.

8.2 In Walsall we have organised disability awareness training for parents and in our modular SEN Involvement Programme with schools have devoted one module to disability.

October 2005

Memorandum submitted by CASE

SUBMISSION ON SPECIAL EDUCATIONAL NEEDS

CASE (Campaign for State Education) is a national campaigning organisation committed to high quality and well resourced education for all children and young people. It is a voluntary organisation funded by members' subscriptions and donations and has no political affiliations.

CASE would like the Select Committee to consider the following:

- the extent to which the revised Code of Practice is being followed; and
- the funding of SEN and its impact on the progress of children.

In particular:

1. Resources

- how local authorities and schools allocate the funding for SEN and whether the costs for schools are fully met. This is particularly in schools where there is a high level of unstatemented special need, especially emotional, behavioural and social difficulties;
- the role and sufficiency of educational psychologists and other specialist staff eg speech therapists, behaviour support teams. In particular, the support they are able to provide to children in school and to teaching staff;
- the role of Governing Bodies in monitoring and evaluating the way schools support children with SEN and identify the progress they have made;
- clarity about the amount of time provided for SENCOs to fulfil their duties—ideally it should be a full time post at senior management level; and
- the amount and quality of the training offered to teachers and support staff—initially and ongoing—on how to diagnose and support children with SEN.

2. Statements

- whether there has been an increase or decrease in statements in the last 10 years, the level of detail they provide and how effective they have been; and
- the time between diagnosis and support/funding being provided.

3. Parents and Children

- the level of information and support being offered to parents by schools and how many provide support groups for parents of children with SEN;
- the average number of reviews in a year—ideally three, once a term—and whether parents and children are fully involved;
- the effectiveness of Parent Partnership schemes—both independent and local authority based;
- how children's views are accessed and used to set targets and determine progress;
- the effectiveness of SEN policies and the extent to which they are shared with parents; and
- the satisfaction of parents with the provision their children are receiving.

4. Achievement and Selection

- where schools set children according to ability in some or all subjects the proportion of children with SEN who are in the higher and lower sets;
- numbers of children with SEN achieving Level 4 or above at KS2 and 5 GCSEs at KS4;
- the success of disabled children who are educated in mainstream schools; and

- the number/proportion of children with SEN admitted to selective schools as compared to non selective schools.

5. *Inclusion*

- the number of children with SEN who are excluded;
- the extent to which schools have become more accessible;
- whether children with SEN have access to the full curriculum and whether this is the case for all children ie to what extent are children still being withdrawn from curriculum areas to be taught separately and how this impacts on the quality of their education;
- the level of support and continuity of provision at times of transition—eg from early years to primary, primary to secondary and secondary to post-16; and
- the increase in inclusion—numbers of special schools which have closed because the children are in mainstream schools and any evaluation of the different outcomes.

6. *16–19 Provision*

- the support provided for post-16 students and their progress/success—evidence from the Learning Skills Council.

CASE POLICY

Special Educational Needs

1. Schools should be resourced to respond to the true level of need and diversity of their pupils.
2. Children with emotional and behavioural difficulties are children with special educational needs. Schools should be given the resources and expertise to support them rather than be forced to exclude them.
3. Where possible SEN co-ordinators should be full time posts with proper training to enable schools to fulfil their obligations within the Code of Practice. Disability Equality Training should be part of teacher training and INSET provision.
4. Parents and pupils, where appropriate, must be involved in decision making and at all stages of assessment.
5. The LEA should ensure that independent advice and advocacy are available to all parents.
6. LEA support services are a vital link in any schemes for integration and their function and status should be maintained.
7. Statements should be sufficiently detailed to enable parents to check that the support promised is being provided. There should be time limits set within which the LEA has to provide the necessary services set out by a statement. Appeal and complaint procedures should be operated in such a way that parents are able to make complaints about inadequate provision for their child's special needs.
7. The Office for Standards in Education (Ofsted) and the Qualifications and Curriculum Authority (QCA) should play their part in ensuring that a broad and balanced curriculum including the full National Curriculum is available to all children with special educational needs.
8. CASE is a signatory of the Centre for Studies on Integration in Education (CSIE) charter. CASE believes that all children regardless of the nature and degree of disability or learning difficulty should ideally be educated in mainstream education. The assessment of a child's special needs should be used to determine the support and changes necessary within a mainstream school. Should a child's education ever have to take place in a separate setting the aim should be to return to mainstream education. The reason for the placement and the review arrangements must be clear. LEAs should not place children in segregated provision on the grounds of "efficient use of resources". Parents should not have to hear that their child is too expensive, dependent or different to be placed in their local school.

October 2005

Memorandum submitted by Nuffield Hearing and Speech Centre, Free Royal Free Hospital NHS Trust

INTRODUCTION

Observations from Mrs Pam Williams, Principal Speech and Language Therapist and Dr Breege Mac Ardle, Consultant in Audiological Medicine at the Nuffield Hearing and Speech Centre, RNTNE Hospital, Royal Free Hospital NHS Trust. This is a National Centre of Excellence for second opinions on the assessment, diagnosis and management of children with severe speech and language disorders. Our Trust also provides a unique Speech and Language Unit for children aged four to seven years with very severe

speech and language disorders. All children who attend the Unit have a statement of SEN and are paid for by their local LEAs or a combination of LEA & PCT. The speech and language therapy department has produced and published an internationally recognised treatment resource for children with severe speech disorders, entitled “The Nuffield Centre Dyspraxia Programme” (1985; 1992; 2004). Our department receives up to 40 requests per week by telephone, e-mail and letter from parents and professionals for advice about how to meet children’s speech and language therapy needs.

EVIDENCE

Despite clear evidence based research that provision of direct ongoing speech and language therapy is effective for children with severe speech disorders, most local speech and language therapy services do not provide this direct therapy, which can be required over many years. If children’s needs are not met they can have difficulties throughout their school years and this may have long-term consequences for their future employability and ability to participate in society.

CHILDREN IN MAINSTREAM SCHOOLS

Most children with primary speech and language disorders are placed in mainstream school.

Without a statement of SEN, children are placed on School Action or School Action Plus and only receive a speech and language therapy programme, set by a qualified speech and language therapist, but delivered by an untrained teaching assistant/LSA.

Many schools have difficulty in delivering IEPs effectively, due to frequent changes of speech and language therapists or vacant posts. Only a very small number of LEAs/individual schools employ speech and language therapists directly and so are dependent on local PCTs to provide a service.

Families struggle currently to obtain a statement of SEN, because the children are identified as only having one area of need. However, not only can these children not communicate, they struggle to access the curriculum, cope emotionally, academically and socially. Research has shown that as a group they are very much at risk of having literacy acquisition difficulties.

Even when children acquire a Statement of SEN (often after a long struggle by parents), direct speech and language therapy is frequently not identified in Section 3. This is despite case law, which has confirmed that speech and language disorders should be regarded as an educational need.

PARENTS

We see many parents in a high state of distress as they cannot get their child’s needs recognised or met. Many parents are not aware of the current legislation or their child’s rights. Local services frequently do not inform them of supportive national or local voluntary organisations. Most have no idea that they may be entitled to claim Disability Living Allowance.

We often see parents who are paying for expensive private speech and language therapy for their child to compensate for lack of appropriate local provision. In many cases this is causing great financial hardship or is only possible through the support of extended family.

When parents become aware of the current legislation, they often have to fight very hard and pay considerable sums of money (eg up to £10,000) to bring the LEA to Tribunal in order to have their child’s needs recognised and obtain appropriate speech and language provision and placement.

SPECIALIST PROVISIONS

For the children with the severest difficulties, mainstream school is not appropriate. They need to be placed in specialist Units/Schools across the educational age range.

Many primary level Speech and Language Therapy Units have limited speech and language therapy cover (despite their name) and there are all too few secondary level Units. We are very concerned that a number of special schools, which cater for children with severe speech and language problems have already shut or are under threat of closure, including our own Unit, because of the current inclusion policy.

SUGGESTED SOLUTIONS

- Increased recognition by LEAs of the nature and the emotional, social and academic consequences of speech and language disorders.
- Increased acknowledgement that children with severe speech and language disorders require regular, direct and long-term speech and language therapy.
- Speech and language therapy services need to be reviewed and must be considered as an educational provision for school aged children.

- More commitment by education, health and social services to inform parents about choices, the current legislation and local and national support organisations.

October 2005

Memorandum submitted by the National Governors' Council

1. BACKGROUND TO THE NATIONAL GOVERNORS' COUNCIL

1.1 The National Governors' Council (NGC) is the main representative body for school governors in England. The members of NGC are independent Associations of governing bodies in two thirds of the LEA areas in the country. NGC seeks to represent the interests of all school governors and governing bodies in all phases and types of school.

1.2 NGC sent a questionnaire to our member associations and asked for their views on SEN provision in their areas. This memorandum is generated from the responses to the questionnaire as well as existing policy work NGC has carried out in relation to SEN.

1.3 We hope that this memorandum will be a helpful contribution to the Committee's deliberations on SEN.

2. GOVERNING BODY RESPONSIBILITIES FOR SEN

2.1 The governing body is responsible for the strategic leadership within the school. It is the governing body's responsibility to formulate policies for the school and to monitor and evaluate their effectiveness. It is not the governing body's role to engage in the implementation of policy or day to day management of the school.

2.2 Governing bodies have specific responsibilities under the Special Needs Code of Practice. Governing bodies are required to set a SEN policy and monitor and evaluate its effectiveness. Although it is not a statutory requirement it is considered good practice for governing bodies to nominate a member to be the SEN governor. There are very few governing bodies which do not have such a governor.

3. SUMMARY OF FINDINGS

3.1 Governors believe that the most important factor in determining the provision for a particular child is the educational need of that child. To this end it is important that a range of educational provision is available and each pupil is educated in the most appropriate setting for their needs. Governors are concerned that schools are not always adequately resourced to meet the needs of SEN pupils.

4. HAVE GOVERNING BODIES SUFFICIENT KNOWLEDGE AND EXPERIENCE TO CARRY OUT THEIR ROLE?

4.1 The NGC has asked its members whether they feel that they have sufficient knowledge/experience to meet their statutory responsibilities for SEN. The majority of our respondents said that on a personal level they felt they did have sufficient knowledge/experience to carry out the role. However, a number of our respondents felt that while they as an individual had sufficient knowledge/experience they were not convinced that this was true of the whole governing body. It should be noted that members in special schools were less convinced that mainstream governors fully understood their role, or indeed were totally familiar with the SEN Code of Practice.

4.2 The importance of appropriate training was acknowledged by all those who responded. In particular it was felt to be vital for those taking on the role of SEN governor. The majority of governors felt that the efforts of the staff in the school and in particular the SEN Co-ordinator (SENCO) were invaluable in providing them with information and knowledge on SEN issues.

5. PROVISION FOR SEN PUPILS IN "MAINSTREAM" SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

5.1 Most governors felt that the needs of pupils with SEN were being met. However, they felt that this did require more resources than were allocated to the school for the pupils. A number felt that the introduction of personalised learning by their schools had made a difference because it was clearly tailored to the needs of the individual child.

5.2 The biggest issue in relation to meeting the needs of SEN pupils, stated or not, related to the amount of resources devoted to them. The general view was that the funding allocated for SEN was not sufficient to meet the needs of the pupils. Governors do not profess to have the professional background/

knowledge to comment on the detailed methodology by which the numbers of SEN pupils in the school are calculated, however, most take the view that that using free school meal entitlement as a proxy indicator is too crude a measure.

5.3 Many felt that their schools in an effort to provide the best possible education for pupils with SEN had no choice but to allocate more resources to these pupils than had been delegated by the authority. This was particularly true in those areas where it was felt there was reluctance to statement pupils. Other members report that the funding they receive is sufficient.

5.4 Some members expressed concern about where “gifted and talented” pupils fitted into this agenda.

6. THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (“THE STATEMENTING PROCESS”)

6.1 The statementing process falls within the day to day management of the school and, therefore, outside the scope of the direct responsibilities of the governing body. However, many SEN governors have knowledge of the process. The majority of these report that the process took too long, involved too many resources and was too bureaucratic. Many governors feel that the resources needed to get a pupil statemented were disproportionate to the amount subsequently allocated to meet the needs of the pupil.

6.2 There was also a view that in some authorities the approach to statementing and SEN in general was finance rather than needs lead. In some instances it was felt that pupils who really should have statements were not statemented until the situation became critical largely due to financial considerations. Shortages of sufficiently experienced and expert staff in local authorities were also thought to be contributory factors to problems in the statementing process. Others thought that the views of teaching professionals were not always given sufficient weight during the process.

6.3 Delays in statementing were felt to be detrimental to pupils’ long-term educational outcomes. On the plus side, the fact that the process gave parents the opportunity to have an input was felt to be a positive factor in the system.

7. SPECIAL SCHOOLS

7.1 Governors from special schools generally reported that pupils were well-catered for, but experiences varied in different local authority areas. Some reported a high-level of local authority support for special schools, whereas others felt that the local authority was totally unsupportive, to the extent in one case of not informing parents that special schools existed and were an option. Most governors believe that special schools have a vital and important role to play in education provision, both as the main educational setting for some pupils and also as a valuable resource which “mainstream” schools can use for advice and “outreach” services.

8. PROVISION FOR DIFFERENT TYPES OF SEN, INCLUDING EMOTIONAL BEHAVIOURAL AND SOCIAL DIFFICULTIES

8.1 Governors believe that the needs of the individual child should be at the forefront of any decision about the appropriate educational setting for that child. They believe that a range of provision must be available to enable all pupils to achieve their potential. There is concern in some areas that special schools have been closed or are under threat of closure and the alternative provision will not be adequate to meet the needs of the pupils involved. One special school governor reported that her school for pupils with Moderate Learning Difficulties (MLD) was being told by the local authority that there were no pupils with MLD—which they do not believe—and were being put under pressure to accept pupils with EBD.

8.2 A number of governors reported the difficulty their schools faced in balancing the needs of one child against all the others in the classroom. It was felt that even with designated one to one support some pupils unfortunately had a negative impact upon the education of their classmates.

CONCLUSION

8.3 Governors support the inclusion agenda, but not at the expense of the needs of the individual child. Both “mainstream” and special schools have an important role to play and children should be educated in the situation which is best for them.

October 2005

Memorandum submitted by St Margaret's School, The Children's Trust, Tadworth, Surrey

INTRODUCTION

St Margaret's School is a non-maintained special school based in Tadworth in Surrey. As part of The Children's Trust, a registered national charity, the school provides residential and day education to 40 children with profound and multiple learning difficulties and complex health needs.

The school takes pupils from across the UK with a range of severe physical disabilities and profound learning difficulties. All pupils function at a cognitive level similar to that of a six to 12 month old baby. The pupils at St Margaret's have complex medical needs, degenerative conditions and additional sensory impairments.

In addition to the education provided by St Margaret's School, The Children's Trust also provides a range of other service to children with multiple disabilities and complex health needs from across the UK including:

- Residential nursing care for short breaks, medium term transitional care and continuing care for children unable to return home;
- Residential intensive rehabilitation for children with an acquired brain injury;
- Short break care delivered in the family home;
- Palliative care; and
- Support for children returning to school after an acquired brain injury.

In submitting our written evidence, we have responded to issues one to seven in turn (as per numbered paragraphs below). We have not responded to section eight.

1. PROVISION FOR SEN PUPILS IN "MAINSTREAM" SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

1.1 At St Margaret's School we provide education which is tailored to the needs of the child, as part of a specialist curriculum. Pupils are opted out of the National Curriculum which is meaningless for this group of students, for whom the core curriculum areas and national levels of exams and attainment would have no benefits.

1.2 The pupils at St Margaret's function cognitively at the same level as a six to 12 month old baby and have associated complex medical needs. They require adult enablers to facilitate access to the curriculum. Full integration within a "mainstream" curriculum in a class of mixed ability would not enhance the learning experience of our pupils and would fail to allow them to develop their potential.

1.3 The current debate (particularly within the media) has focused heavily on the needs of children within the autistic spectrum. Whilst not wishing to detract at all from the attention that important group deserves, we wish to ensure that education policy takes proper account of the exceptional needs of children with profound disabilities and complex medical problems. This small but significant group appears to have been somewhat lost in this debate. We hope that the Education and Skills Committee will not forget this important group of pupils in its report.

1.4 We would stress that inclusion in mainstream schools is not wrong for all pupils with SEN just as it is not necessarily the right approach for all SEN pupils. This issue cannot be approached with the attitude that "one size fits all" and the needs of each pupil must be considered. "Inclusion" should be seen more as a question of opportunity than one of location.

2. PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

2.1 It seems clear that for many pupils with low incidence SEN or PMLD there is an obvious need to retain special schools as the only arena in which their very special needs can be catered for in a service which is high in expertise. The skills set and inter-professional working between groups of staff from different disciplines (from physiotherapy to nursing to education) would be extremely difficult to replicate in a "mainstream" school where the needs of pupils differ so widely.

2.2 As with many other children who have PMLD/complex needs, many of the pupils have been out of the education system before starting at St Margaret's School. This is due to the nature of their needs and the complexity of managing the needs of such children. For example P started at St Margaret's School as a residential pupil in 2001. Prior to joining St Margaret's she had been at home 24 hours a day for four years due to her local authority being unable to find a suitable educational placement for her. She did not receive any occupational therapy, physiotherapy or any education until she started at the school aged nine. It is our view that if "Every Child Matters" no child should be out of the system because the systems can not cope with the complexity of their needs.

2.3 Many pupils with degenerative conditions also suffer when their schools are no longer able to cope with their increasing needs. For example Y has Rett Syndrome, and started at St Margaret's School in July 2003. Prior to starting at St Margaret's she attended her local primary school, but her parents were left with

no choice but to withdraw her from the school after it became apparent they could no longer cope with her increasing needs. She remained at home for 18 months, whilst the authority argued about funding to place her out of authority. Specialist schools have the expertise and staff to deal with children who have deteriorating conditions and the tailored curricula, such as that at St Margaret's will work to help the child to stabilise in their achievements—not just to “move forward”.

2.4 St Margaret's School operates on a 48 week educational year, rather than the 39 week year in most mainstream schools. The longer educational year ensures that long holidays do not interrupt the pupil's programmes as they are unable to maintain progress over long breaks

2.5 Many pupils with PMLD are unable to self-engage and require an adult facilitator to help them to participate in their education. Special schools have the staff resources and skills to enable them to do this whereas mainstream schools do not.

3. RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

3.1 If the Committee is looking for evidence of achievement for SEN pupils, particularly for those with PMLD, the NASS website gives an example of how “achievement and value added” can be demonstrated with these pupils (www.nasschools.org.uk)

3.2 Clearly the raising of standards is an important aim, but we are concerned that due consideration must also be given to the fact that pupils with PMLD cannot be measured against national norms. For example a child cognitively functioning at six months with a visual and hearing impairment and cerebral palsy will not even reach National Curriculum “P” levels.

3.3 In order to address this, at St Margaret's School we have our own developmental curriculum written by staff and pupils are measured against this. The curriculum is tailored to each pupil and through it we are able to demonstrate improvement in those pupils that do not have degenerative or deteriorative conditions, and stability in others.

3.4 Examples of attainment vary widely amongst pupils but include such achievements as a pupil demonstrating understanding of up to five familiar words in context; a pupil maintaining his or her ability to stand in his/her standing frame and holding his/her head up for five seconds at a time; or a pupil closing his/her eyes in anticipation of his/her hair being washed, in response to the touch of a flannel.

4. THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS

4.1 Whilst the present system is not servicing the overall SEN population well, we are clear that it is vital for pupils with PMLD. This group benefit enormously from having every service needed spelt out in their Statements. It gives clarity to both families and local authorities over what will be provided and therefore we would be loathe to see this disappear.

4.2 We are, however, concerned that the statementing process does not always cover all aspects of a child's needs, particularly for those children who are residential pupils out of authority. We recently had to deal with the case of a young girl with Rett Syndrome whose feet had grown and therefore needed a new pair of orthopaedic boots to enable her to continue to walk. The LEA refused to provide funding, citing that this was not an “educational” need and advised the family to contact the PCT. On contacting the PCT the child's family were told that health would not fund the new boots as the child was (as a residential pupil) now living outside of the authority. Without the proper boots, the child would have been forced to remain in her wheelchair rather than being able to walk around the classroom and her residential home. What is particularly tragic about this story is that Rett Syndrome is a degenerative condition, with most children only remaining ambulant for a few years after onset. Therefore every day counts. It was only when the school pointed out to the authority that this would become a child protection issue that funding (a sum of only £200) was forthcoming.

4.3 We are also keen to ensure that any changes in the statementing process will not have an impact on important services such as physiotherapy. Early intervention by key services such as occupational and physiotherapy will often not only improve the quality of life for children with PMLD but, further more, save the public purse in the long run by identifying problems early.

5. THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

5.1 In order to be able to become fully involved in their child's education it is vital that parents are given enough information to be able to make an informed choice. However, particularly with parents of PMLD pupils (for whom parents have been sole carers for many years often with very little support from the system), they may not always be best placed to make objective decisions about what is best for their child in educational terms. We believe that there should be a much more developed advocacy service on behalf of the child.

6. HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

6.1 It is our view that the categories of special needs must be redefined as they are too broad at the present time. For example, as the system currently stands there is no defined category for pupils with PMLD. We believe that this should be addressed as a matter of urgency.

7. PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES (EBSD)

7.1 As previously mentioned we are concerned that PMLD pupils are often forgotten in the debate about SEN provision. We would urge the Committee to give serious consideration to the needs of this group of children and not just to concentrate on the provision for low level SEN.

7.2 Special schools need to be seen as educational establishments that offer highly specialised teaching and support to pupils. They offer an educational experience which cannot be replicated in a mainstream setting.

7.3 In order to be able to cope with the growing population of PMLD pupils, teacher training and Continual Professional Development must be further developed to empower staff to be able to deal with the needs of this group of pupils.

October 2005

Memorandum submitted by the Early Childhood Forum

The Early Childhood Forum welcomes this opportunity to respond to the Select Committee. We believe that all children should have access to high quality inclusive early years services and settings. To inform this process, ECF urges the Committee to focus on early years as a key element of its inquiry and not restrict its investigations to school based provision.

BACKGROUND

1. The Early Childhood Forum (ECF) is a coalition of professional associations, voluntary organisations and interest groups united in their concern to develop the care and education of young children from birth to eight. ECF is unique. It is the only body that brings together nearly 50 member organisations, covering the full spectrum of early years providers (see end for list of membership).

2. ECF includes a number of organisations that represent the rights of disabled children. Our policy agenda includes a section on Addressing Inequalities and Valuing Diversity and we maintain an active debate on inclusion. We have agreed a definition which features on the Sure Start web site:

ECF believes that inclusion is a process of identifying, understanding and breaking down barriers to participation and belonging (ECF, 2003).

3. As part of the dissemination process of the ECF inclusion definition, the National Children's Bureau, which facilitates ECF, will be hosting a series of conferences on the theme of Participation and Belonging: ensuring equality for every child. The aim is to support change in settings by working with practitioners across children's services in the early years sector.

CONTEXTUAL INFORMATION

4. The population of children with SEN and disability is diverse and includes a growing number of children with significant continuing additional needs: these children and their families often require a high level of long term support. For instance, the report of the British Childhood Visual Impairment Study Group (Rahi et al, 2003) found that visually impaired children are now more likely:

- to have been premature;
- to be of South Asian origin;
- to have associated neurological problems;
- to have a condition which is not treatable;
- to have had their condition from very early life;
- to have similarly affected siblings; and
- to be from areas of disadvantage.

5. The population of disabled children is also much larger than previously thought with 7% and not 3% of all children having a disability or long term health need. For the early years this means that we need to be planning for 250,000 disabled children under 5 needing to access high quality early years services.

6. Other factors such as unemployment and poverty are more prevalent in families with a disabled child and there is evidence of difficulties for these families in accessing services (Daycare Trust, 2001). Other research has shown that the combination of disadvantaged circumstances and difficulties in securing access to appropriate services, which are found for the majority of families with a disabled child, are particularly acute for families from minority ethnic groups (Fazil et al, 2002).

7. Consequently, support services require a high degree of specialist knowledge and flexibility in structure to meet the diverse needs of individual children and families within their cultural community.

SPECIAL EDUCATIONAL NEEDS: A NEW LOOK

8. We would like to take this opportunity of using some of the comments from Mary Warnock's pamphlet to present the case for your inquiry to fully include the early years sector.

9. Warnock gives two positive views on early years provision:

- the benefits of early education for long term outcomes for children
- the benefits of the concentration of resources on early years

10. Some of her other statements provide an opportunity to consider the inclusive nature of early years provision.

“the concept of inclusion must embrace a feeling of belonging”

(page 15):

this is at the heart of the ECF definition and at the heart of our policy agenda.

“the failure to distinguish various kinds of needs has been disastrous for many children”

(page 21):

early childhood principles focus on the individual child and the way that each child learns best in the context of a sound knowledge of child development—true personalized learning.

“the greater the pressure to raise academic standards, the worse the fate of those who could never shine according to such standards”

(page 24):

early childhood principles focus on assessment for learning based on informed observations of individual children; these are set in the context of the core documents, Birth to Three Matters and the Curriculum Guidance for the Foundation Stage which provide a framework of learning opportunities for children, not an abstract set of standards.

“inclusion should mean being involved in the common enterprise of learning”

(page 39):

early childhood principles recognise the community of learning which involves parents, practitioners, supporting professionals, and the child; the concept of “reflective practitioner” is embedded in early years quality assurance schemes to ensure that quality is at the heart of evolving practice.

a redefinition of inclusion which “allows children to pursue the common goals of education in the environment within which they can best be taught and learn”

(page 54):

while for Warnock this may mean the recreation of specialist schools, in early childhood the focus of supporting and extending children's learning is by creating effective learning environments indoors and out in local community settings.

11. Warnock suggests that one of the good outcomes of her work has been a focus on training and whole setting responsibility for SEN. In this we cannot be complacent. The Audit Commission report (2003) found a “lottery of provision” in early years. Early Support has been developed to counter this by providing a family-focussed programme designed to deliver better co-ordinated services through effective multiagency working. Emerging findings are positive and may provide a model of specialist and targeted services which support inclusion in universal services, across the age range.

RECOMMENDATIONS

12. ECF would recommend the Education and Skills Committee to consider the opportunities and omissions in early childhood provision for children with SEN and disabilities in the context of

- the challenge of a changing population of children (paragraph 4)
- the role of support services (paragraph 6)
- the emerging findings of the Early Support Programme (paragraph 11).

13. The Early Childhood Forum would recommend to the Committee that it may find that “the principles which inform early education can be seen to provide for the whole of education a model of genuine inclusion” (Lloyd, 1997, p 172).

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- October 2005*

Memorandum submitted by Autism Bedfordshire

Autism Bedfordshire covers Bedfordshire and Luton. Luton has reduced the number of placements in special schools so that children on the Autistic Spectrum with an associated learning difficulty are in mainstream. Bedfordshire are developing their inclusion strategy and have reduced numbers of children with Autistic Spectrum Disorder being accepted into special provision.

We receive a considerable number of helpline calls from parents of these children.

In all the questions below we are considering children with Autistic Spectrum Disorders.

1. PROVISION FOR SEN PUPILS IN “MAINSTREAM” SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

Helpline calls highlight a deficit in the lack of support and training within the mainstream schools to support children with Autistic Spectrum Disorders. This leads to disenfranchising the young people and high figures of exclusion in mainstream schools for children on the autistic spectrum.

There are some cases where mainstream school is never going to be appropriate because the school environment can never be altered to accommodate the sensory overload that children with ASD suffer in mainstream environments. Visual, auditory, sensory and olfactory overload is greatly mis-understood and overlooked when placing children in mainstream.

There are also some cases where mainstream school is never going to be appropriate because of the severe social understanding difficulties that some children with ASD encounter.

Both sensory overload and social understanding difficulties are an unmet need that often leads to high anxiety and challenging behaviour.

It is therefore imperative that there is specialist provision available to accommodate the needs of these children with ASD.

It is advantageous for children with ASD to be in their local community school, but with the provision of a specialist classroom to support their needs. This would allow each child to participate in their local community and for parents to live within easy reach of the school, thus enabling the school parent partnership.

There is a major funding issue for all of the above. ASD specific advisory teachers have extensive case loads in Bedfordshire and Luton and are unable to offer the support to schools as required.

2. PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

There are not enough specialist places for children on the Autistic Spectrum in special schools. The Autistic Spectrum includes children who are high academically but cannot cope with their ASD related difficulties. These children have been at greatest risk with the inclusion policy. They suffer terrible anxiety through being unable to cope at school and this puts unacceptable stress on the children and their families. These children under achieve and are often excluded.

3. RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

Helpline calls highlight a deficit in the lack of support and training within the mainstream schools to support children with Autistic Spectrum Disorders. Increased funding for training and support services is essential if these children are going to achieve. Academic achievement must be side by side with social achievement, and ensuring that the high anxiety levels of these students is addressed.

4. THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS ("THE STATEMENTING PROCESS")

All SEN pupils should have a right to an individual child centred planning process actioned by a multidisciplinary team. Support services such as Speech and Language Therapy, and Occupational Therapy from Health services are lacking and this has a negative impact on the child's education.

Any change to the Statementing process would need to include the following:

- A system whereby parent's legal rights to specialist educational and health care help for their children is upheld.
- Full multi disciplinary assessment and ongoing Independent Education Planning.
- A system that ensures that additional funding needs are linked to each child to enable them to have the input they require. This funding may have to extend to support services from health.

5. THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

It is absolutely imperative that the parents are involved at every stage with equal input to the multidisciplinary team decisions. In some cases the children too should be involved.

Education, Health and Social Services must have a responsibility to provide parents with training and resources to be able to contribute equally to their child's development outside school.

6. HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

Care must be taken not to exclude children who are academically able on the Autistic Spectrum. These children still have social, communication and processing difficulties that have a profound impact on the children's ability to cope in mainstream settings.

Their needs are too often overlooked and the child is perceived as being wilfully naughty or challenging. Schools need an individual strategy to support each child that helps them to learn and understand what social behaviour is expected at school and home. Some children may not be able to learn these social behaviours. All staff at school must be trained to understand these children's needs.

7. PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES (EBSD)

Children with ASD are the highest figures for disability and yet they seem to have the least recognition. As there has recently been an increase in support for children with EBSD, there must be an equal increase in support for children with ASD. The impact on the child in later life is enormous. Research and through our helpline we know that this group of children can follow two pathways, either to become well known to the Police and/or mental health services. This is the harsh reality that not only impacts on the child and his/her family, but has an impact on society in general.

8. THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001, WHICH EXTENDED THE DISABILITY DISCRIMINATION ACT TO EDUCATION

Through our helpline we hear of children who are still being excluded from activities, even within special schools because they are on the Autistic Spectrum.

October 2005

Memorandum submitted by Parents for Inclusion

1. INFORMATION ABOUT PARENTS FOR INCLUSION

Parents for Inclusion is a charity run by parents for parents of disabled children. It was set up to promote the full participation of disabled children in mainstream education and in their local community. We are a registered charity, set up in 1984, (charity number 1070675) and a company limited by guarantee.

OUR KEY AIMS ARE

- Helping disabled children be included in their schools and local communities.
- Giving parents the hope, confidence and the tools to plan a positive future together with their disabled children.
- Bringing about a change of attitudes so there is less discrimination towards young disabled people.
- Providing effective advice, information and training to parents so they can help disabled children take control of their own lives.
- Encouraging closer working between parents and professionals to benefit as many children as possible.

We offer a freephone helpline, train parents to be advocates for their disabled child, train professionals in inclusive practice, run inclusion groups in schools, and provide a whole range of accessible information.

2. GENERAL STATEMENT

2.1. We want a society where all children are loved, feel secure, flourish, make friends and are happy at school. We believe that it is physical and social barriers which prevent disabled children being included, rather than the disabled children themselves.

Disabled children are all those children who experience discrimination as a result of their differences, whether that be a physical or sensory impairment, learning difficulties, special educational needs, emotional or behavioural difficulties, or as a result of experiencing distress.

We are parents who have chosen to send our disabled children to mainstream schools, and to work within a framework which often lets down a substantial number of young people who attend them. We have chosen not to over protect or limit our children's life chances because the system is in need of progressive change to welcome all young people. We are parents who believe that it is our children who are bringing about substantial changes, and creative opportunities, which not only support disabled children, but all children. Thanks to Warnock, and the 1981 Education Act our children were given the opportunity to belong. They have been the pioneers, and the instruments of change in many schools. Many of them are having well supported and exciting school experiences, and the older ones have gone on to lead interesting creative lives. See "Where are they now" booklet enclosed

Parents and professionals have a great influence over these children's futures. So we work with them to help them see the children as individual people first, with human rights and preferences and a right to an optimistic and self determined future. They then go on to make sure these children are included, in all kinds of ways, in the world. All our work is aimed at improving life chances and the quality of life for these children.

"We believed in her right from the beginning. We believed in her from the moment she was born—that she was going to reach her potential and have a full inclusive life because we have included her from the word go." Parent.

We have found that when both professionals and parents understand that segregation discriminates against the disabled child, they become open to finding solutions, to see inclusion as a human rights issue, and find solutions to change the barriers of exclusion.

"For many non-disabled course participants, both professionals and parents, meeting a disabled professional is still an unfamiliar experience, and meeting a disabled adult who shares their insight and perception on what it was like growing up as a disabled person is even less usual. For people who mostly work with children and for parents whose children have yet to grow up, this meeting opens up the door to images of positive and possible futures for young people."—Pi Trainer.

Parental Choice

Our parents believe that this debate is not about parental choice, but about the rights of young disabled people to be respected, valued, and to live in inclusive communities. Parental choice has become such a branded concept, and yet in Italy where there is not a choice because children are included right from the start, it does not seem to be an issue. (Children in Scotland delegation to study inclusion in Italy)

We have worked closely with parents at the grass roots, and have published various reports: “Dreaming the Dream: inclusion a human rights issue”, with full recommendations from parents and professionals, “All Our Children Belong”, a report from our black and minority ethnic parents. In both reports you will see that the rights of the disabled child is the key agenda. Please find attached.

2. OUR EVIDENCE

Throughout our training and inclusion work in schools we have individual evidence which shows how when attitudinal barriers are broken down and young people are provided with the right support they and the school flourish. We have evidence to prove that this considerable societal change takes time to achieve, as the barriers are linked to discrimination, rejection and prejudice. Time and attitudinal changes, which can and do take place through Disability Equality Training, are paramount issues which must be considered by this Committee.

Example. A young person with the label autism had great difficulties in settling into their primary school. With support from Pi the parents were able to get the right number of teaching and learning support hours through a number of special educational needs tribunals. This young person continued to have a very fulfilling primary school education, with this school which has inclusive policies, and an accessible site. He was barred at secondary level. Through an appeal the young person obtained a place at a London City Academy, and within the first year he had been given a prize for very good achievement. He is settled and doing well, within his own school community.

Example. A delightful young disabled child eventually found a nursery that gave her the opportunity to join, recognising that she had considerable medical needs, physical disabilities, and leaning needs. Two other nurseries had shunned her. Through their commitment, and close collaboration with the parents this nursery offered a stimulating and enhancing environment, where she flourished, made great progress, and made friends within her community. She has gone on to primary school, having been rejected by another less progressive school, and she is doing very well. She had a birthday party before she left, where 18 young children attended. Parents for inclusion ran an Inclusion Group for parents in the school, and this is what her parent said:

“The Inclusion Group was a life line because as a parent you pick your way through the maze of wanting your child to be happy. It can be really be hard as a parent to watch your child be placed on the outside and not feel responsible for that in someway, or to want better. Meeting with other parents makes you realise that you are just ordinary, picking your way through an extraordinary complicated system, Our children are not complicated, they are just kids who want to make friends at school and to do stuff. Without the group, everything can get lost. The inclusion groups are vital to break the isolation and to help you know that everybody is a bit scared, a bit overwhelmed and that they are parents who just love their kids. Most importantly to know that everybody is coping in the same way.” Disabled parent.

Cleves school in Newham is another example where very young disabled children are welcomed and included into their primary school.

Lambeth Education has had a policy to support inclusive education across the borough. They now have four special schools from 14 ILEA schools.

They have three accessible schools, one is Jubilee school that includes many children who are deaf or partially deaf. They are teaching the whole school to sign, which is having a substantial effect on the community. Kings Avenue Primary School has young people with visual impairments, and a visual impairment outreach service into mainstream schools.

We also have evidence from our helpline calls which show that Local Education Authorities and schools will direct families to special schools right from the start, or during a young person’s time at school. This will always be the case when the going gets tough, and there is another option as to where to place a child. Rather than finding solutions within their school environment, or LEA resources, young people find themselves often removed from their community schools and placed in special schools which are completely inappropriate for their needs, or emotional health.

The evidence which supported the Government’s own strategy to move towards increasing inclusion in mainstream schools, to encompass recommendations from Disabled people, and to include Education in the Disability Discrimination Act, must be reconsidered by this Committee. They were all progressive and clear steps towards recognising the rights of disabled people in this country, and simply cannot be disregarded by this enquiry.

We have many other such examples, which we would like to have the opportunity to bring to the Committee.

Barriers to inclusion

We have statistics that show the considerable concerns and difficulties which parents have to tackle in the quest for inclusion. Getting support for a young person who needs support and extra resources can be an enormous challenge, and the systems set up often prevent parents from getting the right support; ie the Special Needs Tribunal is very time consuming, and causes considerable stress and breakdowns for some parents.

Is it any wonder that some parents who have not heard of the social model, or the tools for inclusion, or the concept of planning positive futures, become exhausted and fearful? It is so easy at this point to forget the intrinsic right for disabled young people to be part of local schools and communities, and opt for what they feel is a safer option.

In schools where there are good inclusive policies, and an inclusive ethos, parents are happy to keep their children there, and to contribute to further developing the schools' inclusive agenda.

Mary Warnock herself stated at her launch that if she had known more about the whole situation, she may not have written the report in the same way. This is essential evidence for the Committee to hold on to when making this enquiry.

Recommendations

- That there is an agenda to celebrate disabled people and young disabled people in this country, and that disabled people are fully represented on any committees considering agenda which affect them or young disabled people. We hope very much that your committee will have a disabled representative on board so that the inquiry has full access to this unique perspective. We would be very happy to recommend someone.
- That the Government celebrates and acknowledges the enormous strides they have made in supporting the inclusion agenda, and research the positive advances that have been made.
- To research what actually happens to these young people once they leave full time education from both Special and Mainstream schools, and build in an outcome agenda for all further research.
- That Disability Equality Training is given the same status as Race equality and strongly recommended to all professionals working with disabled young people.
- That there is an urgent inquiry into the funding of special schools and an analysis made of their effectiveness in relation to their long term value and outcomes. That evidence submitted by the Audit Commission on SEN/Disability is considered.
- That no more special schools are built, and a 15–20 year plan is put into place to develop well resourced mainstream schools building on the already established good practice across the UK.
- That the system of Statements is removed, and resources are placed into mainstream schools.
- More funding is placed into the voluntary sector committed to creating inclusive communities.
- That the parental choice is fully debated alongside inclusion a human rights issue.
- Final comment. Representative from Parents for Inclusion would welcome an opportunity to give evidence orally. We have further evidence to offer, but unfortunately due to the deadline, and work commitments we were unable to do this paper justice.

SUPPORTING APPENDICES

1. *"Where are they Now?"*

the voices of 15 young adults who were among the first disabled children to go to mainstream schools. Published by The Alliance for Inclusive Education 2004—(Booklet).

2. *"All our Children Belong"*

exploring the experiences of black and minority ethnic parents of disabled children. Published by Parents for Inclusion 2004—(Report).

3. *"Dreaming the Dream, Inclusion, an issue of social justice"*

report of a three year community project involving young disabled people, parents, disabled people, and professionals, brought together by Parents for Inclusion. Published 2001 (following the Special Educational Needs and Disability Act)—(Report).

September 2005

Memorandum submitted by the Dyspraxia Foundation

My name is Frances Shawcross and I was a Volunteer Local Co-ordinator for the Dyspraxia foundation for about 10 years and now I am on their Education Panel as a parent support volunteer. I am also a volunteer for the Rathbone Special Education Advice Line. The views below are my own and not necessarily those of the above organisations.

1. PROVISION FOR SEN PUPILS IN “MAINSTREAM” SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE: DIFFERENT MODEL OF PROVISION

A result of more money being delegated/devolved to mainstream schools is that LSA's are being employed, especially in secondary schools, with interest/experience/training in a particular subject and not in special needs. I think this is unfortunate because:

- (a) it removes the focus of the needs of SEN children and dilutes the opportunities for training for specific SEN difficulties.
- (b) children with SEN do not have the continuity of help, including moving from one class to another when bullying can take place.

2. Many children with SEN require input from therapists or specialist teachers which is not easy to fit into a mainstream school day, either the children are removed from class, someone does something different within the classroom or they are expected to get the help out of school hours.

Resources units in mainstream schools sometimes provide the right balance.

3. Some children cannot cope with large classes/schools however much help is in place.

4. PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

Raising standards of achievement for SEN pupils

More specialist training for teachers and a greater provision of therapists, eg occupational therapists, speech and language therapists, physiotherapists is needed. Although there must be co-operation with the Health Services, provision should not solely be left to them.

5. THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (THE STATEMENTING PROCESS)

I think a full assessment of the child's difficulties is vital. Otherwise, to use a medical analogy, it is a question of taking a temperature, not finding out why the temperature is not normal, checking outcomes, not causes. Especially with Dyspraxia, teachers see children failing in everyday tasks such as sitting still and put it down to their being lazy and/or unco-operative when they are actually making great efforts to conform, but they simply cannot do it.

6. In general I think the SEN Code of Practice, when followed, is very good. However, many (most?) statements have not been prepared fully taking into account 8:32 of the Code of Practice, especially regarding conflicting opinions. Part 3 is often written in general terms, not specified and quantified, or “bandings” or similar are stated without saying what the provision must be. The word “should” is sometimes used instead of “will” or “must” and then if the provision is not met then parents are told that it should be provided but there are problems eg staffing or funding, and it a statement of intent, not what must happen.

7. There are problems with getting therapy assessments under the statementing process.

Reading C of P 7:16 (viii), 7:28, 7:74–77 it seems that parents can ask for, say, SALT and OT assessments. This is most important for children with Dyspraxia because in many regions there is an age limit for assessments under the NHS—as low as age eight and in most places 11. In practice parents are told that an assessment is not possible or that “every effort to respond promptly” 7:77 will delay the process too long.

8. Parents have great difficulty knowing which school is appropriate for their children. They have only 15 days to respond to a proposed statement. This is further compounded by the fact that some schools will not let parents visit the school except “through the LEA” or “until funding is in place”.

9. THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

Parents do not automatically become experts in their children's SEN or the Code of Practice etc However they do know their children and know when they are unhappy. Schools tend to see this as children manipulating their parents or parents are being over anxious or over protective.

10. 2:23 of the SEN Code of Practice: Parents may wish to access the local disagreement resolution procedures at any time during the SEN process, including where there is a disagreement with the school about any aspect of their child's special educational provision.

However, the SEN toolkit states that this is voluntary for all parties, including schools and LEA's which gives them a reason not to take part.

11. Would it be possible for foster carers to have some rights if they want to? This could include discussing and agreeing IEP's, requesting statutory assessments and appealing to the Tribunal.

At present these decisions are by divisions of the local authority which could (must?) be a conflict of interest.

12. HOW SPECIAL NEEDS ARE DEFINED

The four areas of need as stated in the Code of Practice seem a good basis either individually or across two or more areas.

If I am asked to consider a statement I try to imagine how that particular child will cope in the setting with the provision suggested. I realise that it is difficult for an LEA to do this yet appear even handed, following policies, but C of P 7:52 does require them to do this.

13. THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001

Not enough weight is given to the amended Section 316 of the Education Act 1996 which states that children with a statement should be educated in a mainstream school, unless that is against the wishes of the parent (and other reasons). In practice if the local special schools are not appropriate or the child does not meet the criteria, children are placed in mainstream schools against the wishes of the parents often to the detriment of the child's education and well-being. There does not seem to be any onus on the LEA to find a suitable school either in another authority or a non-maintained special school. (See also paragraph 8 above)

14. There is no time limit for LEA's to make a decision after receiving review meeting minutes and the parents have no right of appeal if the LEA decides not to amend/increase provision.

15. I do not think that the Disability Act of 2001 has changed the attitudes of teachers very much. Children are still being punished for things they cannot help, eg not sitting still, not doing enough work in the time allowed, being excluded from trips. Discrimination is often excused stating "justification".

16. Does the fact that the "responsible body" in respect of Disability Discrimination does not consist of those working in schools on a day-to-day basis put the responsibility in the wrong place?

Footnote: in my experience LEA's too often make decisions solely on financial considerations—not on the SEN of the child.

3 October 2005

Memorandum submitted by The Five Minute Box

THE IMPORTANCE OF EARLY INTERVENTION

Children need to be engaged in a teaching system for early literacy skills as soon as they enter school. While most children will acquire the phonic skills, sight vocabulary and handwriting skills they need from regular class lessons, there are always a few children who just need more time. These children really do need a few minutes a day to ensure mastery and retention of skills.

The main reasons for early intervention through a system such as The Five Minute Box are:

- screening all children on entering school at age five ensures that none "slip through the net", and provides baseline data for school records;
- children's precious natural self-esteem is not lost;
- sessions giving a few minutes daily practice of skills are far more effective than once weekly withdrawal sessions when children have fallen behind;
- providing an easy to manage teaching system for any child who needs extra time to learn or to consolidate basic skills, means that the Teaching Assistants can manage it and can take ownership of the children's progress;
- it ensures that any child who may turn out to be dyslexic has had multi-sensory teaching for two years, rather than having to wait to be diagnosed at the age of seven, and then having to start a multi-sensory programme which requires a specialist teacher;
- to allow a progressive system to be in place as part of class management without the need for planning, photocopying and paperwork;
- to provide support for the skills being taught in any other phonic scheme already in place in a school;
- to enable small steps progress to be shared with parents—with learned skills taken home to share, rather than unknown tasks being taken home to learn with parents; and

- most importantly, to give children access to a system that they can engage in with enthusiasm, taking ownership of their learning and progress.

Normal learners should go straight through and out of the Box in a matter of weeks. Those children who find it more difficult to acquire the skills can remain on the programme for as long as necessary, working daily with a support assistant. This is typically five or six children out of 30 at the end of Reception—age four to five, two or three children out of 30 at the end of Year 1—age five to six, and then on-going one or two per class who are dyslexic or MLD, and who will continue to be supported with specialist teaching.

If there is a successful early intervention programme in place in school, it means that any child who enters the school as a transfer, or as a second language child, can quickly be screened and supported if necessary by a Teaching Assistant.

HOW DID THE FIVE MINUTE BOX ORIGINATE?

The Box was originally designed to be used by teaching assistants for a few minutes a day to give children daily practice with the multi sensory skills that were being taught by a visiting special needs support teacher. Children were not retaining skills that were taught once a week, but made more progress when they had daily practice.

It was originally designed for junior age children as a second start programme, but then was introduced lower and lower down the school in order to catch children before they had time to “fail”. The Head Teacher of the infant school agreed to “five minutes a day” of SENCO directed teaching assistant time daily—hence the name!

It is important that the children have 1 : 1 time with an assistant, because if there are two children, one will always be working more slowly than the other and seeing themselves as failing. The reason the Box works is that the children make progress at their own rate, seeing progress towards their own targets, and so their self esteem remains high.

Ideally, all children should go through the programme as they start school to ensure that they have the basic skills established for phonics, irregular keyword reading, and the ability to write in response to sounds and high frequency words.

Most children will work through the programme in a matter of weeks, but those who need longer to acquire the skills simply remain on the programme for as long as it takes. Generally there are around five or six children at the end of Reception, and one or two at the end of Year 1 who need on going support. Those children may be dyslexic, or slower learners. Some children have remained on the programme for up to two years, but they still come happily to work on the Box a few times a week. They see themselves as the lucky ones who still get to work 1 : 1 with a Teaching Assistant.

The programme has three elements—phonics, keywords, and personal and sequential knowledge.

It has also been very successful with second language children. It can be picked up and used from the minute they arrive in school to give them a start on learning English.

Ideally you need one Box per Reception and Year 1 class, then access to a Box for Year 2 onwards for those few children who continue to need it.

Recently it has been used in the Nursery for the brighter children who are ready for it in the term before they begin school.

It is entirely multi sensory—hear it, see it, say it, write it for sounds, irregular keywords and generalised spelling. Most children need regular opportunities to learn and remember their personal information and days of the week, so this is built into the programme and is recorded in the child’s Record of Achievement.

Teaching assistants can be very quickly trained to use the Box—there is a 20 minute video which explains the philosophy behind the activities and the way to use the Box. This can be referred back to at a later date to refresh their memories!

Everything is included in the Box—there is no need to photocopy, prepare worksheets etc Every child is responsible for managing the materials—they take responsibility for materials. Giving children ownership of the programme is one of the reasons it is so successful. They are never having to wait for someone else to get organised. Children will open The Box and make a start with the routine even if their assistant has been temporarily delayed.

THE NUMBER BOX

The Number Box works in much the same way as the five minute box. It gives children a chance to practise and consolidate number skills for as long as they need, until they are able to work at an abstract level of understanding. The resources included cover all the areas of maths that need support up to junior age.

The instruction book gives the small steps activities needed to ensure that children have a complete understanding of basic maths skills.

It also has a Record of Achievement/Recording booklet which gives IEP targets on the front, and space for the teaching assistant to make brief notes during each session.

The children need to work gradually through the number activities daily continuing until they are entirely confident with the processes and concepts, plus one of the other activities from the second half of the book which will support the class topics from the Numeracy Strategy.

The Box can be used on a 1 : 1 basis for a few minutes a day from Reception onwards, or it can be used by a teaching assistant who is supporting children in the daily maths lessons. It means that no-one has to go off looking for resources during a lesson.

WHAT IS THE FIVE MINUTE BOX?

The idea of the Five Minute Box, as an early intervention and screening tool, grew out of years of experience with primary age children who had failed to master the art of reading and spelling, and who had become disenchanted with the process of learning. By Junior School age, these children needed regular extra teaching and often needed to use expensive resources to motivate them to acquire the skills. Withdrawing children from lessons to teach them basic skills meant that they were missing subjects that they enjoyed.

Early detection of Dyslexia or general learning difficulties means that support and meaningful teaching can be put in place before a child begins to miss out on the teaching that is going on in the Early Years stage of his education.

For any child to succeed they must have good self-esteem, and be taught self-help strategies that will carry them through the years of learning ahead of them.

Dyslexia, as a term to describe reading difficulties, is most commonly associated with reading words the wrong way round. In fact, as any parent of a dyslexic child knows, there are far more implications to the term. These children may have difficulties with sequencing. They may have poor short-term or long-term auditory memory problems. They may have poor visual perception or visual memory. They may have poor organisational skills. Any one of these alone is enough to cause a child to fail in his early life in school, and a combination of these factors can cause loss of self-esteem and poor learning. Late recognition of any difficulties can lead to stressful family life when a parent knows something is not right, but is unable to have it recognised by the school because of the high demand on advisory services.

The need for simple steps learning, linked to a regular, consistent, multi-sensory style of teaching is behind the development of the Five Minute Box.

Used from the age of school entry, the programme of teaching has been designed to cover the basics skills for the acquisition of literacy. It is designed for use by learning support assistants on a daily basis and requires nothing more than time.

Although the basic skills needed by a child to learn to read and write are covered in all Reception classes, there are always a group of children who struggle with the pace of learning. This may be due to dyslexic type difficulties, or to a slower rate of learning. It may be due to a child having had absences from school for illness. The Five Minute Box is designed to supplement the teaching of these skills by giving as much time as each child needs to acquire them. The skills are separated into different areas, so that a child can make progress in one area, while still being allowed time to completely master another area at a slower pace.

Motivation, organisation and self-help strategies are built in to the programme. The recording of progress is shared each session with the child, and progress is divided into small “milestones”. These stages can readily be shared with parents and are easily monitored by the SENCO and class teacher.

BENEFITS OF THE FIVE MINUTE BOX

The Five Minute Box was designed within school settings to fulfil several purposes:

- to screen all children on entering school at age five to ensure that none “slipped through the net” and to provide baseline data for school records
- to provide an easy to manage teaching system for any child who needed extra time to learn or to consolidate basic skills, managed by an LSA for a few minutes a day
- to ensure that any child who may turn out to be dyslexic has had multi-sensory teaching for two years rather than waiting to be diagnosed and then having to start from the beginning again
- to work alongside any phonic reading and spelling scheme already in place in school
- most importantly, it is a system that children engage in with the utmost enthusiasm, taking ownership of their learning and progressing from the very first time they open the Box

Head Teachers

- Structured “Wave 3” support for Literacy Difficulties from Reception onwards
- System works alongside Literacy Hour

- Support that can be provided by LSAs and monitored by SENCO
- Easily accessed record keeping
- Knowledge that all children have complete early phonic knowledge and numbers reading
- ELS & ALS can be reduced
- No time needed for photocopying resources

Class Teachers

- “Box” time is flexible—can be either arranged to fit in with the daily timetable as a regular slot, or used to fit in with any extra time available
- All children go through the Box on school entry—the more able do so rapidly, others remain and continue support as long as is necessary
- LSA time with Box is structured and does not need daily planning by teacher
- Equally useful for EAL children entering late Infant or Junior classes

Learning Support Assistants

- Minimal training is required—an instructional video is included or training sessions can be arranged
- Ownership of provision and progress—providing a valued role for them
- Children giving cause for concern can be easily referred to SENCO

Parents

- Parents can be involved at an early stage using easy to follow tasks
- Additional routine practice is beneficial to children
- Progress through Box is easy to report to and share with parents
- Support from home is important for children plus shared knowledge of success

Children

- Benefit from 1:1 time on a regular basis/ensures against children failing
- Routine is rapidly learned so children always work with confidence
- All-important self-esteem is maintained as children see progress on recording chart and are aware of progress through small steps targets
- Self-organisation skills developed. Suitable for Autistic Spectrum Children
- Allows children to gain secure phonic knowledge and literacy skills at their own pace

Educational Psychologists

- Good tool to recommend for early intervention before the need for an assessment
- Gives accurate record of progress over time, rate of progress, amount of progress, identifies areas of relative strengths and weaknesses
- Decreased referrals at School Action Plus

FURTHER BENEFITS OF THE FIVE MINUTE BOX

- Harnesses the time of LSAs to be more productive
- Since introduction four years ago, not one referral for external intervention for literacy at Key Stage 1
- A resource that lasts for years, all components available as individual items
- TAs take responsibility for learning
- Children manage their own materials
- The system designs out “learned helplessness”
- The system sets children up for success, not failure
- Avoids “Death by worksheet”
- No photocopying or preparation time needed. All LSA time is directed to the child
- Success criteria clear and achievable

- Feelings of self-worth generated in children
- Makes for independent learners
- The system costs less than an Educational Psychologist visit for one child for one hour yet helps hundreds of children
- Permanent resource for the class/school
- Created by experienced SENCO with RSA Diploma in Dyslexic Strategies
- Affords the luxury of consolidating the “known” for children
- The whole system is underpinned by the psychology of learning
- Fear triggers “fight or flight” reaction. The system removes fear of the unknown by working from the predictable which is particularly useful for Aspergers and Autistic children.

October 2005

Memorandum submitted by the Association of Colleges (AoC)

INTRODUCTION

AoC (the Association of Colleges) is the representative body for colleges of further education, including general FE colleges, sixth form colleges and specialist colleges in England, Wales (through our association with fforum) and Northern Ireland (through our association with ANIC). AoC was established in 1996 by the colleges themselves to provide a voice for further education at national and regional levels. Some 98% of the 450-plus general FE colleges, sixth form colleges and specialist colleges in the three countries are in membership. These colleges are the largest providers of post-16 general and vocational education and training in the UK. They serve over 4 million of the 6 million learners participating in post-statutory education and training, offering lifelong learning opportunities for school leavers and adults over a vast range of academic and vocational qualifications. Levels of study range from the basic skills needed to remedy disadvantage, through to professional qualifications and higher education degrees. NATSPEC colleges are associate members of AoC.

SUMMARY

- Many further education colleges have hundreds of students with a very wide variety of learning difficulty and/or disability (LDD)
- These students are catered for in mainstream provision with appropriate support and benefit from the wide range of provision and facilities available
- The main difficulty faced by colleges is in attracting suitably qualified staff when the pay levels are considerably less than those of schools
- Increasing provision for 14–16 learners will place additional demands on colleges to cater for the specialist needs of those with LDD
- The 2005 Disability Discrimination (DDA) Act amends existing legislation, placing a duty on public sector authorities to promote disability equality
- the wider scope of the new Act raises questions as to whether LSC can fulfil its new statutory duties within extreme financial constraints, predicted as becoming more challenging over the next few years
- LSC currently funds support costs for residential students that should be funded by other government departments
- DfES and LSC needs to clarify arrangements to enable a single planning process for providers delivering post-16 learners
- There are questions about the means by which assessment of young people’s needs will take place in future with the publication of Youth Matters, which effectively disbands Connexions as a national service
- There are questions as to whether the common funding approach, proposed in the LSC “An Agenda for Inclusive Learning” will be implemented to ensure regional fairness as well as being implemented for schools as well as colleges
- There are questions about the level of skills in LSCs, to secure appropriate provision for learners, and the communications that need to be developed and enhanced between agencies and the development needs of practitioners
- To combat the variable quality in existing provision, providers should use a system of peer review to bring about improvements.

1. While the main focus of this enquiry may be provision in schools, this cannot be treated in isolation. Colleges currently cater for a very wide range of learning difficulty and/or disability and the diversity of the college post-16 sector is a great potential source of strength in meeting individual needs. This includes severe to moderate learning difficulties, sensory impairment, physical disability, specific learning disability (eg dyslexia), mental health problems and emotional and behavioural difficulties.

2. More people than ever with self-declared learning difficulties and/or disabilities are now engaged in LSC-funded education and training—around 579,000 learners across the post-16 sector in 2003–04, with a total cost of the programmes for these learners of over £1,000,000,000.

3. For the purposes of this submission we feel that the most appropriate definition to adopt is that taken from section 13 of the Learning and Skills Act 2000. A person has a learning difficulty if:

“(a) he has a significantly greater difficulty in learning than the majority of persons of his age, or:

(b) he has a disability which either prevents or hinders him from making use of facilities of a kind generally provided by institutions providing post-16 education or training.”

4. Students with learning difficulties and/or disabilities are catered for in mainstream college provision with appropriate support and benefit greatly from the wide range of provision and facilities available. This ensures they can be placed on the most appropriate provision to meet their individual needs and that specialist support and teaching is available. Colleges have access to additional learning support funds which they can deploy as needed to ensure appropriate support is provided.

5. Colleges which cater for this level of need are happy to increase their intake and are often under considerable pressure to do so. However, one limiting factor is the considerable difficulty they experience in attracting appropriately qualified specialist staff. This is chiefly because the pay in schools is significantly higher than in colleges and in addition school staff are paid an extra allowance in recognition of their specialist qualification. Colleges often have to recruit and train staff, often sponsoring them to obtain relevant qualifications. This is costly.

6. We recognise that there are some learners with needs that are so complex that they cannot be catered for in a general college and will need the resources only available in a specialist college.

7. Colleges are heavily involved in the provision of learning to students from the age of 14 onwards. Questions remain as to how successfully colleges can respond to the increased demand on specialist resources for those with learning difficulties and/or disabilities in the current climate.

8. The 2005 Disability Discrimination (DDA) Act amends existing legislation, placing a duty on public sector authorities to promote disability equality. The wider scope of the new Act raises questions as to whether LSC can fulfil its new statutory duties within extreme financial constraints, predicted as becoming more challenging over the next few years. The LSC's main duties are to secure proper facilities for education and training, which are suitable to the needs of persons, aged 16–19 and to secure reasonable facilities for education and training, which are suitable to the needs of persons of persons over the age of 19 including learners with learning difficulties and/or disabilities.

9. The general duty placed upon the LSC is that it should eliminate discrimination and harassment, promote equality of opportunity between disabled and non-disabled people, and take into account people's disabilities, even if this means treating them more favourably than non-disabled people. This will have funding implications for the LSC when considering its funding priorities. LSC cannot decide not to make provision for any individual learner simply because the budget is overspent.

10. It is also the case in residential institutions that LSC is funding the residential costs in addition to educational costs. We strongly recommend that conversations take place between government departments to ensure each allocates resources appropriately. Currently we understand that 46% of residential costs relate to living and support costs that should be allocated elsewhere.

11. All this is set within a context of increased demand and static supply. Proposals in ‘Every Child Matters’ encourage multi-agency working and the development of Children's Trusts which will be critical to draw funding from various streams to support the learning needs of these groups. There is a need to plan at an early stage for the transition both into, and out of FE.

12. College principals urge for the use of greater prescriptive planning, to help institutions/LEAs/LSCs plan for demand and incorporate sufficient places/resources in their 3 and 5 year plans. Whilst the recommendation to move to regional LSC directors holding ‘placement budgets’, the issue remains about how fairness is to be measured, and how appeals against decisions might be heard.

13. Streamlining development plans will be essential—currently these are particularly complex for specialist schools. DfES and LSC needs to clarify arrangements to enable a single planning process for providers delivering post-16 learners.

14. It will be essential for the LSC to develop its shared approach to planning and funding with partners, as envisaged in its Annual Statement of Priorities', published in December 2004. Central Government's approach to collaborative packages of provision, better able to meet individual needs, will also require proactive involvement by the Department for Education and Skills (DfES) in supporting and developing the essential cross-departmental approach, implicit in the ‘Valuing People’ initiative working with people with learning disabilities, and in the development of Children's Trusts.

15. There are questions as to whether the common funding approach, proposed in the LSC “An Agenda for Inclusive Learning” will be implemented with sufficient checks and balances to ensure regional fairness. Arrangements should be set up to review the capacity of the system, to meet the needs of learners with learning difficulties and/or disabilities within a region and ensure that capacity is developed in order to meet current and future demand.

16. There are also questions as to how a common funding approach can be implemented for schools as well as colleges, to promote further collaboration with colleges (3.23). Review is needed of the methods of claiming funding which are currently complex and inefficient.

17. There are questions about the means by which assessment of young people’s needs will take place in future with the publication of Youth Matters, which effectively disbands Connexions as a national service. The assessment of individuals’ needs is key to the development of learner-centred packages. In light of the proposals set out in the Green Paper, it is likely that the Secretary of State will give the responsibility for carrying out assessments to another organisation.

18. There are questions about the level of skills in LSCs, to secure appropriate provision for learners, and the communications that need to be developed and enhanced between agencies and the development needs of practitioners. There will be a need for building LSC staff capacity to understand the complexity of the issues involved and to make far greater progress with mainstreaming disability and learning difficulty than has been the case to date.

19. It is recognised that provision for LLDD is variable in quality. AoC recommends, in line with LSC LLDD Review Steering group, that providers should increasingly network and use peer review to develop and improve the quality of provision. This should be set up within the wider context of self regulation for the FE sector, currently under discussion with the Department, LSC and other agencies.

October 2005

Memorandum submitted by The Bridge for Social Communication

1. INTRODUCTION

Current figures estimate that 1:100 of the population have Autistic Spectrum Difficulties. For children—and others whose social difficulties may arise from ADHD, ADD, Dyspraxia—there is a high risk of bullying, exclusion and isolation.

Their relationships often suffer from the pressure this puts on them and can even lead to family breakdown. Yet despite the high risk, to date, no child accessing—the bridge—has been excluded from school.

—the bridge—, is a Richmond-based charity, set up in 2002 to help children and families with social communication difficulties by providing a range of services. The majority of the children are from mainstream schools and attached units, although some of the older children now attend specialist secondary provision. Through careful use of therapists’ advice, the children have fun while participating in activities aimed at helping them to integrate more fully into society. While the children have fun, parents meet in support groups. Our activities include:

- Talking Group—five to seven year olds develop social skills through games and play.
- Talking Group Drama—social interaction and fun for children from seven to 13.
- Sport—introducing social skills through team games, six to 13-year-olds.
- Activate—Occupational and Speech and Language therapy for pairs of children socialising together, for five to 13-year-olds.
- Inform—Parent/Professional discussion evenings.
- Liase—Work with local and national bodies to find innovative solutions to shortages in service provision and increase best practice. This includes providing multi-disciplinary teacher training for teaching staff where—the bridge—acts as the co-ordinator on behalf of schools and health professionals.

Synopsis of Findings

- (a) That SEN funding relates to education and health yet services are funded separately with no apparent relationship to individual statemented need in terms of incidence, setting or outcomes for children in the longer term. This causes serious problems for effective service delivery to promote good outcomes for ASD children. Even the latest National Service Framework guidelines may not be sufficiently clear in terms of how education commissions health services to overcome current problems.
- (b) That ASD is a newly emerging area of need without the benefit of longer term planning for service delivery in comparison to that for the visual or hearing impaired. There is a case for special status

to put services in place. This might be done through the establishment of local, multi-professional/ NGO groups with commissioning and planning responsibilities as outlined in the National Autism Plan for Children

- (c) That parents should be recognised as the fixed point for the child's care and provided with training and support to enable them to work alongside professionals. Equally all professionals need to have clear guidelines for multi-disciplinary working and service delivery to make the most of health and education budgets focussed around the child.

The information contained in this paper is the result of consultation with members and users of services provided by—the bridge—and NAS Richmond. It does not necessarily reflect the opinions of the trustees of—the bridge—for social communication.

2. PROVISION FOR SEN PUPILS IN “MAINSTREAM” SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

* A mixed, flexible provision of SEN placements, as envisaged by the Government, to encompass inclusion, specialist units and special schools is also supported by parents canvassed who need to see that individual need is considered and choice is available to them. However when it comes to practice parents in Richmond report the following:

- (a) A perceived overarching indifference to service users and lack of rigour/strategic planning in the way decisions are made relating to SEN provision for the ASD community.
- (b) That councillors have expressed publicly their inability to accurately appraise SEN matters put in front of them by officers and that there is a need for overview and scrutiny of this area of public service. This request, backed by parent groups, has been taken off the agenda for the education and leisure committee.
- (c) Poor communication with parent groups in terms of planning, feeding back and problem solving on SEN matters is leading to a reliance on SEN tribunal to negotiate between parents and the LEA on many occasions.
- (d) There is concern that the current allocation of SEN resources, such as EP services, are made according to the numbers of children claiming free school meals at a school. This does not reflect the reality of SEN children in settings or delivery of the statement.
- (e) Furthermore discussions about devolving SEN budgets on similar lines to school heads is causing concern about how effective this would be in solving problems as buying power would be diluted. Some consider this to be a method of the LEA trying to step aside from dealing with issues relating to SEN inclusion.
- (f) Currently special units in Richmond have no allocation of Educational Psychology services made available to them.
- (g) That the sixth form college in Richmond appears to have no training budget for ASD pupils or a clear, college wide strategy on ASD inclusion despite having a number of children on its roll.
- (h) That children with above average intelligence and an ASD diagnosis on school action plus are not given priority at transition and hence their secondary placements could fail causing mental anguish.
- (i) That home-educated ASD children are not able to access support services to help parents with curriculum differentiation and delivery.
- (j) That parents are not always treated as partners in education.
- (k) There are on-going problems relating to the provision of therapy within schools at primary, secondary levels and tertiary levels caused by the health/education divide and current service commissioning priorities.
- (l) That specialist, peripatetic ASD teachers are not available in Richmond although there are teachers for hearing and sight impaired children. This service is available in other London boroughs. Richmond schools report benefits when visiting professionals help with curriculum differentiation.
- (m) That methods for multi-disciplinary working and responsibility for delivering teaching programmes are not always clearly outlined between the teaching staff, support staff and health professionals. Consequently valuable information given to a learning support assistant may not be followed through in terms of programme delivery. Parents are often left out of this planning and so unable to follow through work at home.
- (n) That the primary concern of the LEA and council appears to be budgetary control and not educational outcome.

3. RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

Concern is reported about the following:

- (a) The role of the SENCO as an administrator and as an expert to help differentiate the curriculum for ASD children is unrealistic in practice. Time and skills for this role are often not available and so in reality the work is left to Learning Support Assistants who are not sufficiently trained to take on the responsibility, which should in fact be that of the teacher.
- (b) The division of responsibility between the teacher and LSA. LSAs are reported as being used to do a range of jobs around the class-room which are not related to the child's needs and in other cases teaching-staff devolve responsibility for the child to the LSA.
- (c) The need for specialist, visiting teaching staff who can provide differentiated programmes of work for ASD children and problem solving experience. This role is established in other London boroughs.
- (d) Teachers need to be able to look beyond the National Curriculum and read between the lines of the statement to differentiate work, with the help of specialist advisors, and deliver work to children that is 95% attainable and 5% stretch.
- (e) Training as piloted by—the bridge—, which provides input from speech and language, occupational therapy and educational psychology on an annual basis to mainstream teaching staff is providing a starting point for addressing these issues.

4. THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS ("THE STATEMENTING PROCESS")

- (a) It is difficult for parents to police the LEA's decisions against the rights of their child and to monitor the preparation of a statement without legal advice. There is a belief that this difficulty is being used to 'dupe' parents and save the LEA money. For example, despite case law and good practice guidance, there appears to be an ongoing habit of putting speech and language therapy into the health rather than educational part of the statement. Even when this is changed after a request from parents the provision is documented as broadly as possible by the LEA, making it difficult for parents to have a document that will enable them to access funds for the service when these health professionals fail to meet the statemented needs of the child because of staff shortages.
- (b) The process takes too long and in the meantime the child's education, social relationships and self-esteem can be severely compromised.

5. THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

- (a) That parents should be acknowledged as the central point of continuing care for their children and be offered access to training and support services so that they can work alongside professionals to deliver the best outcome for their child. However, parents would find key-workers very helpful.

October 2005

Memorandum submitted by Scope

Scope the national disability organisation welcomes the opportunity to provide written evidence to the Select Committee Enquiry into Special Educational Needs.

Scope's current 'Time to Get Equal' campaign aims to raise awareness of the problems and barriers disabled people face in their everyday lives and this includes barriers in education. As well as campaigning and policy work, Scope also provides direct services to disabled people. These services include special schools which we are in the process of developing and re-provisioning, in order to provide mainstream opportunities. Our ultimate goal is that disabled children, regardless of impairment, will be taught in mainstream schools. This will include co-location of our schools (as a medium term goal) and increased outreach work to mainstream schools. Scope believes that if inclusion begins at school (and in early years) and children learn and socialise together, this will lead to a more tolerant and inclusive society, where all people are valued.

At present, we recognise that there are many barriers to inclusive schooling but we believe that these barriers can be overcome. At present, disabled people are still only half as likely as non disabled people to be qualified to degree level and are twice as likely as non disabled people to have no qualification at all. This pattern of inequality has not changed since 1998.²⁴

²⁴ DRC (December 2004) Disability Briefing.

Scope has particular concerns, which are detailed below and pertain particularly to two of the areas that the Select Committee wish to investigate; 1, Raising standards of achievement for pupils with special educational needs and 2, Provision for pupils with special educational needs in 'mainstream' schools: availability of resources and expertise; different models of provision.

1. RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

Information on schools: league tables

Despite recent moves to include contextual value added (CVA) (and other information available for parents made available through the school profiles), league tables remain a crude indicator of how a school is achieving and schools can be exposed to unnecessary distortion in the media where generally, only GCSE and A-level grades are reported. Scope would like to see the variability of rates at which all pupils progress reflected in value added measures as current measures do not take into account those working below the national curriculum levels. Although we acknowledge that including those working below the usual attainment range for their key stage from threshold indicators could skew the results of inclusive schools, not including these pupils work against the very philosophy of inclusion. However, we remain concerned about the extent to which performance tables can actually reflect the complexity of school communities.

In our response to the Consultation on Performance Tables and Pupils with Special educational Needs (2004), Scope wanted to ensure that any Ofsted reported judgements on a schools' 'inclusivity' would incorporate a number of elements (not just those with statements and those on School Action and School Action Plus) but an indicator of inclusion should incorporate the range of lessons that children are included in with their non-disabled peers; the availability of specialist staff and support; involvement in their local community and, crucially, the views of the child about the schools effectiveness on including them.

The curriculum

Recently, tools such as P scales and Pivots have been developed to assess those working below the National Curriculum Level 1. These assessment tools are used in Scope's schools to measure progress of children with special educational needs. Teachers in mainstream schools will need training around adaptations to the curriculum and in the use of such tools. P scales do not fully reflect the progression of those with the most severe and complex needs who may find it difficult to move up even one P scale over a long period of time. For those working on P levels 1–3, some pupils may never move up from P level 3 in their whole school career. There is a need to develop ways of valuing what these pupils are doing, and for these 'smaller steps' to be reflected in value added measures. Many schools have already developed ways to record children's progress within a P level, PIVATS for example, break the P levels down even lower (5 sub levels for each P level). Scope feels it should be compulsory for schools to provide P scales data in the future, but provision needs to be made for within level development and there needs to be adequate support and material to ensure consistency. P scales and pivots are open to teachers' interpretations, so moderation will be essential however. Teachers in mainstream schools will need training to ensure that they are confident in using P scales and Pivots.

Exams

Scope welcomed the announcement that examining bodies would be covered under the Disability Discrimination Act from 2006. However we are apprehensive that taking away indicated certificates before exams have adopted the principles of 'inclusive design' could mean that disabled students are discriminated against in certain exams; there have been reported concerns to Scope about modern languages in particular. Although currently pupils can opt out of elements of the exam, we are concerned about pupils having to demonstrate that they can meet assessments and exams, that haven't been designed with their needs in mind. This is crucial at a time when school standards are of such high priority. Scope wants all assessment procedures to adopt the principles of 'inclusive design' before regulations and access arrangements are changed. Withdrawing indicated certificates before assessments are inclusive to disabled students is unacceptable.

2. PROVISION OF SEN PUPILS IN MAINSTREAM SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

Admissions

We need schools to reflect the communities that they seek to represent. Scope believes that the capacity for schools to select pupils on grounds of academic ability is wrong and academies shouldn't be able to adopt their own admission procedures. The concept of 'choice' can exacerbate segregation because real choice is often only exercised by those that have the capacity to make choices and this is often determined by economic and social factors. Scope recommends that schools are subject to common admission procedures to prevent 'hierarchies' developing between neighbouring schools.

In terms of legislative changes, Scope would like to see a statutory right to educational inclusion so that any pupil (or their parent on their behalf) can ask for inclusion in a mainstream school. If the school refused, the school (and not the parent) would have to go to SENDIST to seek sanction to refuse that placement.

Resourcing mainstream schools

Schools should now be accessible to disabled pupils. The Schools Access Initiative, triggered by the NUT and Scope's 'Within Reach' campaign have enabled many mainstream schools to become physically accessible. However, Scope have some concerns about the extent to which schools are accessible to disabled pupils and that the SAI is no-longer ring-fenced but delivered through the single capital pot. Progress on the accessibility plans (required by SENDA) has been slow and a recent Ofsted report²⁵ showed that over half of schools visited had no accessibility plans. We have recently written a letter to the Secretary of State for Education outlining our concerns and to ask in particular for the continuation of funding after 2008.

Teacher training

Developing teachers' skills and confidence in mainstream schools is fundamental to making inclusion work. This was recognised in the recent Government strategy.²⁶ However, at present there are separate teaching standards for those wanting to specialise in 'special' educational needs and very little disability equality training or consideration of disability issues at initial teacher training. If inclusion is to become a reality, teachers need to have a sense of responsibility for all children and teaching children with 'special' educational needs shouldn't be seen as a separate and individual 'expertise' within the teacher training programme. Initial teacher training also needs to be accompanied by a sustained in-house teacher training programme for teachers.

Specialist support

The ability of schools and their staff to collaborate with those who have specialist knowledge and with other professionals, such as social workers, health visitors, and speech and language therapists is vital to successful inclusion.

Scope are exploring a pilot project for an 'inclusion team'. This team would comprise of those key professionals that individual pupils require for a supported mainstream placement. Scope would like to see each LEA providing an 'inclusion team'. The statement of SEN would then be the right for the school to draw upon the local inclusion team to 'enable inclusion', and this would make the statement work for the provider of inclusion, rather than segregated provision.

Children with special educational needs need consistency through co-ordinated support within schools and co-location of services through extended schools and children's centres. Children's centres in each local authority should be inclusive and this would help to alter parental expectations from the outset; which would increase demand for inclusion later in the child's education.

October 2005

Memorandum submitted by the Northern Council of Education Authorities

1. PROVISION FOR SEN PUPILS IN "MAINSTREAM SCHOOLS": AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

(a) Models need to be as inclusive as possible. For example, separate units in mainstream schools can be as isolating as separate special schools.

(b) There is still a need to provide whole school training to reinforce the message to teachers that 'good teaching is good teaching'; there is no separate 'magic' pedagogy for SEN.

(c) Resourcing should start from the standpoint of resourcing schools so that they can meet a diverse range of needs and are accountable for how they use resources. For example: there can be difficulties in pupils accessing laptop computers or in having computers repaired, unwillingness to change nappies in an educational setting can be a barrier to inclusion and could contravene DDA requirements.

(d) There needs to be a 'joining up' with other issues—workforce remodelling, BIP, BEST, extended schools and children's centres—so that the principles of inclusion are embedded in all aspects of school life, reducing the need for separate provision.

(e) There needs to be clarity on the responsibility for and resourcing of specialist equipment for pupils requiring medical support

²⁵ Ofsted (2004) Special educational needs and disability: towards inclusive schools.

²⁶ DfES (2004) Removing Barriers to Achievement.

2. PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

(a) There is some expertise and some good practice in special schools but many staff have no special qualifications or training and some schools receive poor Ofsted reports. A culture shift is required to reduce reliance on special schools (amongst both parents and school staff) and develop the new role of special schools in relation to in-reach/out-reach in partnership with other local authority SEN services.

(b) Other agencies may prefer the convenience of delivering their services to pupils in special schools but inclusion requires the delivery of services in the child's mainstream locality. The timescale and organisational issues to facilitate this are key factors for success.

(c) Pupils in special schools could be dually registered at their local mainstream school to support their inclusion and the Government would need to take the funding implications of this into account.

(d) Special schools need to be adequately resourced to provide support/training to mainstream schools

(e) LSC funding is inadequate and places pressure on the local authority to provide, at the cost of mainstream services, provision and transport for post 16 pupils.

3. RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

(a) Evidence demonstrates that inclusion is effective in raising the achievement of pupils with SEN.

(b) There is also evidence that the placement of pupils with SEN in mainstream does not hinder the progress of mainstream pupils (see 'The Impact of Population Inclusivity in Schools on Student Outcomes' EPPI-Centre, Social Science Research Unit, Institute of Education, University of London <http://eppi.ioe.ac.uk>)

(c) Further attention should be given by school improvement partners and local authority SEN and School Improvement Officers to ensure that the progress of pupils with SEN is monitored alongside that of their peers. Individualised pupil planning should be supplemented by P levels (eg PIVATS) where appropriate.

(d) A national agreement on the measurement of value added progress, web sites of good examples and a more accountable monitoring system by the DfES would reinforce the importance of measuring pupil progress

4. THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (THE STATEMENTING PROCESSES)

Although in depth assessments to understand the learning style and potential of pupils continue to be required, the current system requires radical change as Statementing is:

(a) Lengthy, arduous, costly and excessively bureaucratic.

(b) An inhibitor to change, 'locking' local authorities into what they are already providing.

(c) Potentially unfair, as parents with skills and resources can pursue a legal process to get what they want regardless of an individual local authority's policy for SEN. SENDIST is inherently conservative and an inhibitor to change.

(d) A process which labels individuals rather than focusing on addressing the needs of all.

(e) Prevents local authorities from offering an immediate response to pupil needs. Funding for pupils with SEN should not be dependent on having a Statement.

5. THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

(a) Parents should be involved and informed from the earliest stages of planning and not be faced with stark choices/deadlines.

(b) Parental preference needs to be in the context of the outcome of a thorough assessment of need and within the context of local authority policy.

(c) Parents of pupils with SEN should have the same 'rights' as all parents, neither more nor less.

(d) Parents of pupils with SEN are not always made aware of the pupil's entitlement to special examination arrangements.

(e) All school staff need basic information about procedures for identifying and providing resources for pupils with SEN in order to ensure parents are given the right information from the start.

6. HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

- (a) This should be in the context of personalised learning for all pupils, with the emphasis on individual need, not fitting children into categories using labels.
- (b) A label may give a general picture but children don't fit neatly into categories and usually there are a range of factors which are barriers to learning for a particular child.
- (c) Labels are not consistently applied across agencies.

7. PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES (EBSD)

- (a) The above points apply to EBSD, although this is potentially the most challenging issue for inclusion, in the context of a political stance to 'get tough on' behaviour and also a continuing divide in some schools between SEN and pastoral systems. Out of authority provision for EBSD can be extremely costly. There can be long waiting lists to access CAMHS.
- (b) Provision of therapies—either resources should be made available to local authorities or a health facility to make therapeutic support for pupils with SEN a priority.

8. THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001, WHICH EXTENDED THE DISABILITY DISCRIMINATION ACT TO EDUCATION

- (a) This needs to be reformed (see comments on statementing above) and seems outdated in the light of, for example, provision mapping as a means of monitoring and evaluation for SEN.
- (b) The implementation of DDA (requirement to make reasonable adjustments in all areas of school life) could be effective in itself to ensure that special needs are met and pupils with SEN have access to all aspects of school life. For example, reasonable adjustments following a risk assessment must be explored before a pupil with ADHD could be excluded from a school outing

9. ADDITIONAL POINTS

- (a) The Government's voice on inclusion can be inconsistent. There are still barriers to inclusion regarding the tensions between inclusion and league tables and between inclusion and zero tolerance of behavioural difficulties.
- (b) There is a need for real joined up thinking in relation to the standards and inclusion agendas
- (c) Changes in the role of local authorities and their relationship with schools have had an impact on inclusion and strategic planning for SEN. Schools have ever increasing autonomy and control over the SEN budget in order to allow greater flexibility in response to needs and to facilitate early intervention. The role of the local authority in monitoring provision and appropriate use of resources and in responding to parental concern requires development and clarity.
- (d) Micro-management of education by government has a negative impact.
- (e) Transitions of pupils with SEN at 16+ to access further education, training or adult services remains problematic, with particular concerns around LSC funding levels, access to therapeutic services and criteria for additional years in FE.
- (f) There is a need to ensure that pupils with SEN are given more of a voice in decision making.
- (g) One local authority has three City Academies out of a total of eight secondary schools. This presents a danger of limiting the choice for parents of pupils with SEN.

October 2005

Memorandum submitted by the Society for Mucopolysaccharide Diseases

1. The Society for Mucopolysaccharide Diseases is patient representation service advocating for the needs of those with Mucopolysaccharide (MPS) or Related diseases. We are a charitable organisation supporting a group of diseases which are extremely rare and multi faceted resulting in a range of complex physical and learning difficulties which present in varying degrees depending on the disease. The majority of these diseases are life limiting resulting in death in childhood and are progressive, degenerative conditions. As an organisation that commits itself to working alongside these families to represent their needs on a daily basis, we believe that we are well placed to submit information which will be of benefit to this inquiry. We work with families all over the UK and therefore are in constant contact with Local Education Authorities and schools. We undertake numerous visits to these schools and are afforded the opportunity in most cases to assess, and contribute to Statements of Special Educational Needs to ensure that the school provision reflects the individual child's needs in relation to their disease.

2. Overall, we face a number of difficulties when supporting families to ensure their child's Special Educational Needs are met. We find continually that educational establishments are not designed to provide for those with multi-organ progressive conditions with associated learning difficulties and usually not in a mainstream environment. Some children can deteriorate very rapidly, even overnight, which means flexibility of approach to the child's condition to ensure they can maximise their educational potential, is of paramount importance. A number of our diseases, namely MPS 1, II, III and ML II encompass a neurodegenerative element, which means that skills learnt are gradually lost as the disease progresses. This means that again, the child's curriculum needs to focus on what the children are most receptive too as they will be unable to meet educational targets as their condition deteriorates. The school day has to fit around their needs, with caring and nursing needs becoming paramount as the disease progresses. A majority of schools are not set up to deal with this need to balance care with education and will often reject the children on the grounds that they do not 'fit' within their current educational system. Often, this group of children's behaviour is perceived as 'deliberate' and 'attention seeking' rather than acknowledgement that due to the neurological nature of the disease this group of children display unpredictable aggressive behaviour, which they cannot be held accountable for.

3. As highlighted above, these diseases are extremely rare and therefore there are very few people who will have ever heard of them, even doctors and paediatricians at the height of their profession. It is often the parents, not the professionals who become the experts on their child's condition and it is vitally important that they have a full and active part in the statementing process and beyond. Yearly annual reviews are not sufficient for these children, neither is the absence of the Local Educational Authority, which is often our experience. As the condition can change so rapidly, funding often becomes an issue, with parents having to defend their right for one to one support for their child. There is no doubt that in order for every child with an MPS or Related Disease to exercise their full educational potential, they need one to one, or sometimes two to one support to ensure their safety and others in an educational environment. Without this it is highly likely that they will not reach their potential or have a flexible, creative curriculum, which fully meets their complex, needs.

CASE STUDY: CHILD A

The situation concerning Child A, who has Sanfilippo disease (MPS III), relates to ongoing issues with school from 2001. This case highlights the difficulties that can amount from schools not understanding the disease or its manifestations.

The school did not understand the issues around Child A's disease particularly concerning his behaviour and were not providing a flexible programme to accommodate this. Child A was isolated from his classmates at a time when he should be constantly supported within the classroom setting to interact as much as possible. He was forced to eat in the dining hall at lunchtimes even though he liked to eat in isolation as he does not like large crowds of people and high levels of noise. This was further impacting on his behaviour, which he could not be held accountable for. Child A was excluded two to three times due to behaviour and violent outbursts which could have been avoided with better understanding and management.

Child A was refused a place in the school's 6th Form as a consequence of these behaviour issues, there was no attempt to work through the concerns and the reasons they were occurring, Child A was excluded from the educational setting because his school were not willing to accommodate his diverse and complex needs.

His last exclusion was a fixed term exclusion for eight days (plus two weeks for the Christmas break) due to violence and issues were raised over the length of time Child A was to be excluded. The exclusion was extended and Child A was only offered a return on a part-time basis. An official meeting was set up to meet with the school and the school governors.

Issues were raised with future school needs. No suitable educational placement was available. The family were told that if this was pursued, Child A's 6th Form statement would be removed. At this point, legal advice was sought, as well as support from the MP.

Legal action was instigated, investigations taken forward to look at educational placements and the lack of support and services for individuals with severe learning difficulties. A meeting was set up with the Education Department to discuss new provisions being developed for Child A and others in the area with severe learning difficulties.

The MPS Society worked with the education department in setting up a specialist provision for Child A. 2:1 support was agreed as part of this provision. A new Statement of Special Educational Needs was set up, stating clearly Child A's needs and how they should be met, along with a new ethos of working. Training was given by the MPS Society and continues to be given when new members of staff join. A meeting was co-ordinated with the school and the family and an introductory meeting was set up for Child A and his parents to visit the school and the teachers.

This case highlights the consequences of not understanding the manifestations of the disease and also the positive outcome of the local education authority working closely with the MPS Society to devise provision which adequately meets Child A's current and future needs in relation to the progression of the disease.

CASE STUDY: CHILD B

In this situation, concerns were raised by Child B's (who also has Sanfilippo Disease, MPS III) parents regarding her current school which was to close down in the near future due to government initiatives to have more inclusive education in mainstream schools. The family were not opposed to this for those individuals it would benefit, but for Child B they felt she would not be adequately supported in this environment. This was due to the high level of support she requires both educationally and physically, and accommodation of her changing medical needs which would leave her extremely vulnerable if moved into a mainstream setting.

The only other school available to the family refused to take on students as classes were too large and they did not have the nurses available to meet needs. Due to staff cutbacks the level of support and care for Child B had declined. Child B was supposed to have 1:1 support but this was not happening. This was placing Child B at considerable risk.

The family have had meetings with the school and education authority, involving other families and the MP but felt they were not making progress, and their needs and concerns for Child B were being ignored.

The MPS Society put the family in touch with legal services who took up the family's case. They addressed issues concerning the educational provision that will be made for Child B after the summer holiday.

The MPS Society continues to provide support with amendments to the SEN Statement. A report and supporting information has been provided to the local education authority. The SEN Statement did not address Child B's needs and how they should be met resulting in Child B being put at risk in an educational environment.

The family refused to send Child B to her existing school in September due to lack of support and concerns for her safety. The school agreed to meet to look at the needs and write a care plan to address the supports Child B needs. This did not happen and no care plan was drawn up by the school. The family sent Child B to school on the proviso that a parent would accompany her until they felt comfortable with leaving her. The statement was reviewed, however there are still outstanding issues with the proposed statement. The family are awaiting a meeting, and a letter of complaint has been sent by their Solicitor. The family have considered moving Child B to a school out of the area as they feel this is the only way her needs will be met.

4. SUMMARY

These two case studies above are only a small part of the educational support parents are requesting from the MPS Society due to the lack of understanding and provision to meet their child's needs. In these cases the extreme circumstances led to legal action being taken to address serious concerns which would have arisen if these children had continued to attend an inappropriate educational setting to ensure the children receive the education which they are entitled to.

Below is a list of frequent concerns we face when supporting these families, which have to be addressed in any educational placement for this group of children.

- adequate facilities to assist with the frequent changing of nappies;
- lack of medical management in relation to specific aspects of the disease, particularly feeding can result in a high risk of choking which raises concerns around the health and safety of the child while at school;
- minimal concentration span which results in children requiring constant 1:1 support in order to be kept on task;
- extreme tiredness from sleep disturbance which means these children can often be awake for much of the night is not acknowledged or accommodated as it does not "fit" with the school day;
- lack of accommodation of the child's medical condition which is associated with their behaviour and other needs which means they are often left at risk of injury which, at worst, can result in paralysis if not managed appropriately;
- no facilities available for the children who require gastrostomy feeding as their condition deteriorates; and
- targets and expectations placed on this group of children are unrealistic knowing that these children are not going to progress. Accommodation of their educational needs specific to their condition is often ignored as they do not meet the targets set out in Individual Education Plans

Unless this group of children's needs are addressed within an educational environment, they face at best poor educational provision and at worst the risk of their safety being compromised by a lack of understanding and commitment to meeting these complex medical and progressive conditions.

Memorandum submitted by TreeHouse

1. TreeHouse is the national charity for autism education and runs a special school for children with autism. It was established in 1997 by the parents of newly diagnosed children with autism in response to the huge unmet national need for specialist autism education. TreeHouse is in contact with thousands of parents who have children with autism across the UK, the majority of whom have struggled to access education. TreeHouse runs a pioneering and innovative pro-inclusion special school which currently educates 43 children with autism. In doing so, we deliver the education that LEAs are legally required to make available for our children—meaning we are filling a basic gap in provision.

2. TreeHouse is delighted to have the opportunity to give evidence to this inquiry on Special Educational Needs (SEN). We commend the Committee for choosing to investigate this area; there is an urgent need to improve SEN provision and this will require political prioritisation. TreeHouse is a member of the Steering Group of the Special Educational Consortium (SEC) and we fully support the SEC submission. As a supplement, this submission is intended to highlight key autism-specific issues. TreeHouse has taken note of the areas that the Committee intends to investigate, and our submission is intended to highlight the key issues for autism in these areas. If the Committee would be assisted by a more detailed explanation, TreeHouse would be delighted to put forward a senior member of staff to give oral evidence.

3. Autism is unique because there is no other condition of such complexity, affecting so many children in the UK, about which so little is known and for which society's response is currently so inadequate. Virtually 1% of school-age children are on the autism spectrum and 27% of them have been excluded from school, the majority more than once (ONS, 2005). Unlike for other special educational needs, society still does not know how to educate children with autism. Yet the absence of appropriate education can mean that children with autism never acquire even the most basic skills—speech, functional communication or self care.

4. One of the greatest barriers to progress for children with autism is low expectations. Too many children, particularly those who are 'passive' and do not disrupt the education of other children, are merely kept safe in schools rather than educated to their full potential. TreeHouse has shown that children in our school can make real progress when their needs are accurately assessed and appropriate interventions are put in place.

5. This inquiry is taking place in the context of the Government's strategy for SEN, 'Removing Barriers to Achievement'. TreeHouse was involved in the development of this strategy and we support its contents, particularly the focus on a future role for special schools within a spectrum of provision and the need to improve SEN training. We hope the Committee will recognise the value of 'Removing Barriers to Achievement' and will urge Government to progress its implementation.

6. In summary, TreeHouse's primary concerns are:

- (a) the quality and quantity of training on autism available to education professionals
- (b) the need to develop a spectrum of autism provision in each local area.

7. We also wish to highlight the impact of delegation on the resourcing of specialist SEN services and the legal bias against 'independent' schools (ie voluntary sector schools set up to address underprovision), which can prevent parents from accessing the most appropriate provision for their children.

8. SUBMISSION 1—THE NEED TO INVEST IN TRAINING AND AUTISM AWARENESS

9. All children with autism need to be taught by teachers, practitioners and support staff who have skills and expertise in autism education. Autism requires provision every bit as specialist as that for children with visual and hearing impairments. For example, teachers require:

- (a) Practical skills as well as a theoretical understanding communication systems such as signing (Makaton) and PECS (Picture Exchange Communication System)
- (b) The ability to use highly technical behaviour management skills
- (c) The ability to significantly differentiate the curriculum to address the unique and idiosyncratic learning styles of each child.

10. Yet there is no equivalent of 'teachers of the deaf' or 'teachers of the blind' for autism, and no requirement that professionals demonstrate any level of expertise before teaching children on the autistic spectrum. It is deplorable that only 22% of teachers who teach children with autism have had any training at all, and this is usually for less than half a day.²⁷

²⁷ Barnard, J. et al (2002), *Autism in Schools: Crisis or Challenge?*, London: NAS.

11. TreeHouse would urge the Committee to recommend:

- (a) that all educational professionals should receive a basic level of training in autism, and that every school should ensure that at least one member of staff has a recognised autism qualification to act as a central resource of expertise. This parallels the ‘training and professional development pyramid’ outlined in ‘Removing Barriers to Achievement’ (paragraph 3.9, p. 56) for all SEN. TreeHouse submits that the complexity of autism as a condition and increased rates of prevalence justify specific autism training modules within this framework.
- (b) that DfES should convene a working party to determine core standards for autism training. Such standards would cover the full spectrum of autism education and would also need to address problematic areas such as medication and physical restraint. Ensuring that all staff possess a basic understanding of autism will increase the likelihood that support from specialists will be welcomed rather than viewed with suspicion.

12. SUBMISSION 2—THE NEED FOR A SPECTRUM OF AUTISM PROVISION

13. TreeHouse believes in sustainable inclusion—that people with autism should be able to access a full and inclusive life within their own community. Education must work towards this goal. ‘Inclusion’ for children with autism will not always result from a placement in a mainstream school. Specialist education, meaning access to skilled teachers and an appropriate environment, is often an essential component of social inclusion for children with autism. Yet the most recent survey suggested that there are only 7,500 specialist places for an estimated 90,000 children with autism across the country (Jones, 2002). Even assuming that 75% of children with autism could be successfully placed in mainstream schools, which is an extremely ambitious target, this would leave thousands of children with autism without an appropriate school place.

14. Autism is a broad spectrum condition, and there needs to be a spectrum of educational provision to meet the spectrum of need. Mainstream and specialist provision must not be seen as “either/or” solutions, as there is a need for a range of approaches and placements. A one-size-fits-all approach—be this a blanket policy in favour of special schools or a blanket policy in favour of mainstreaming—is potentially disastrous for large numbers of children with autism, each of whom will have unique needs, strengths and potential.

15. The need for a flexible and sensitive approach to each child’s needs is in danger of being lost in a polarised debate in which individual children’s stories are generalised as what is ‘right’ for all children with SEN. ‘Special’ does not necessarily equal ‘specialist’: Generic special schools which cater for a wide range of special educational needs may not always be better equipped to meet the particular challenge posed by autism than many mainstream schools.

16. TreeHouse submits that the spectrum of provision that should be available for all children with autism is set out in the APPGA (All Party Parliamentary Group on Autism) Manifesto (APPGA: 2003):

- (a) an autism-specific educational provision, including a unit attached to a mainstream school or
- (b) a mainstream school where autism-specific support is provided, tailored to the individual or
- (c) a special school with experience and expertise in autism or
- (d) a recognised home-based educational programme or
- (e) a combination of the above, tailored to the child’s educational needs

17. Establishing a spectrum of provision in every local area will require significant initial capital expenditure and ongoing revenue costs. Yet this needs to be viewed in an ‘invest to save’ context; the best available estimate is that only 7% of the current lifetime cost of a person with autism to the state is spent on education (Knapp and Jarbrink, 2001). Increased expenditure on educational provision, and also on staff training, may result in significantly reduced long term costs—as well as better outcomes for people with autism and their families.

18. SUBMISSION 3—MAINSTREAM VS SPECIAL SCHOOLS—A FALSE DISTINCTION

19. ‘Removing Barriers to Achievement’ states that “special schools have an important role to play within the overall spectrum of provision for children with SEN—educating some children directly and sharing their expertise with mainstream schools to support greater inclusion” (paragraph 2.12, p 34). TreeHouse is fully behind this agenda.

20. Until very recently, children with SEN had severe limitations placed on their entitlement to a mainstream school place. TreeHouse welcomes the changes that occurred in September 2002 when the Special Educational Needs and Disability Act came into operation.

21. Positive inclusion most often occurs in schools with higher staff:pupil ratios. But it is not just the numbers of staff that matters—the quality of their training, autism awareness, access to external professional expertise, and practical skills are crucial factors in understanding and meeting the needs of all children with autism.

22. However, the aim of sending children to mainstream school should not entail ignoring difference and ‘treating all pupils the same’. Schools must be responsive to the needs of the individual child and commit appropriate resources for the entire duration of the school day. Sadly, TreeHouse hears from parents that their child’s ‘inclusion’ in mainstream school is merely cosmetic or tokenistic, with children left on their own in complete isolation from the curriculum and their peers. By contrast, TreeHouse’s school provides an example of the potential for specialist educational provision to work with mainstream settings, with the result that a quarter of our children are currently on dual placements with TreeHouse and local mainstream schools.²⁸

23. SUBMISSION 4—LOCAL RESOURCING OF EXTERNAL PROFESSIONAL EXPERTISE: THE DANGERS OF DELEGATION

24. ‘Removing Barriers to Achievement’ cites research commissioned by the then-DfEE and the National Association for Special Educational Needs (NASEN) in 2000 which concluded that “increased delegation of SEN resources has eroded the availability of support in some areas, and that learning and behavioural support were most affected” (paragraph 2.35, p.48). A more recent report by Ofsted highlights the negative impact of delegation on an LEA’s ability to provide targeted support to schools that are struggling to raise standards for children with SEN.²⁹ Nevertheless, ‘Removing Barriers to Achievement’ states that the Government ‘want[s] to see further delegation’ of funding from LEAs to schools (ibid.).

25. Children with autism frequently require external expertise to assist them in their educational and social environment (from educational psychologists, speech and language therapists, etc). These essential services have traditionally been housed within central LEA teams, enabling all schools to draw on a pool of professionals and benefit from economies of scale and more experienced staff. Yet TreeHouse has witnessed a decline in the availability of behaviour support and language support at LEA level.

26. The advantages of delegating the commissioning of these services to Head Teachers and Governors are not yet clear. Accountability and an over-reliance on parental scrutiny are key problems. In TreeHouse’s experience, it is usually only Heads and Governors with direct, often family, experiences of SEN who have sufficient awareness to invest in important expert services.

27. The development of local communities of schools, federations and specialist school networks is a welcome development in principle. TreeHouse has established strong relationships with several neighbouring schools. However, in specific relation to the commissioning of expensive professional services, there is little evidence that children are benefiting from delegation. Too much is being left to chance.

28. TreeHouse submits that the Committee should recommend that:

- (a) an evaluation of the impact of delegation on SEN support services should be prioritised by DfES;
- (b) while that evaluation is awaited, LEAs should receive guidance to retain sufficient funds to deliver central SEN support to schools; and
- (c) DfES should consider the potential for specialist schools such as TreeHouse, whether in the maintained or voluntary sector, to become SEN support services for our local community of schools, operating as centres of enhanced provision. To fulfil this role, funding needs to be made available to release our staff for outreach work, following the model increasingly adopted for maintained special schools.

29. SUBMISSION 5—IMPROVING THE STATEMENTING PROCESS

30. Too often, the statementing process consists of a series of battles that pit parents against LEAs. However, when applied—and implemented—properly, statementing offers one of the clearest and most certain means of ensuring children with SEN obtain the provision they require.

31. The statementing process is inherently adversarial in nature. Parents and professionals are entitled to request an assessment of SEN, which the LEA are entitled to decline. This often triggers the first of what may be many stressful visits to SEN Tribunals, and is reflected in the rising number of ‘Refusal to Assess’ cases at SENDIST (Special Educational Needs and Disability Tribunal). Autism represents the single largest category of cases at SENDIST (see SENDIST Annual Reports).

32. In TreeHouse’s experience, the adversarial nature of the statementing process derives from the fact that a growing need chases increasingly finite resources. Only a root-and-branch reconfiguring of the funding system could alter this equation. As one LEA Head of SEN said to a parent: “you’ve got to look after your child—I’ve got to look after my budget”. In the absence of a radical reappraisal of SEN funding, upward pressure on budgets will either mean that children with autism are educated at the expense of others, or that children with autism will be in danger of not accessing any education at all.

²⁸ This proportion is far higher than the overall national proportion of children with SEN who are dual registered. ‘Removing Barriers to Achievement’ reports that of the approx. 94,000 children who attend special schools, only 2,000 spend part of their time in a mainstream school. See “Key facts on special schools/PLASC, p 34”.

²⁹ Ofsted (2005), *Inclusion: The Impact of LEA Support and Outreach Services*, London: Ofsted.

33. Making a proper separation between assessment and provision would go some way in mitigating the conflict. However, only when the scarcity of resources earmarked for provision (and not allocated to legal proceedings) is tackled will the situation improve. Cross-authority or regional pooling may go some way to alleviate the resource gap.

34. In addition, LEA commissioners must recognise the changing nature of the population of children with SEN and expand the breadth and depth of provision available for particular groups of children, such as children with autism. The APPGA Manifesto (APPGA, 2003), endorsed by over 300 politicians from all main parties, calls for each LEA to establish a spectrum of provision for autism, from home programmes through resourced units and special schools to mainstream schools where the staff have the training and expertise to teach these children. If sufficient provision is available, the conflicts between parents and LEAs over statementing will naturally reduce.

35. SUBMISSION 6—INCREASING PARENTAL TRUST IN THE SEN LEGAL FRAMEWORK

Parental trust in the SEN legal framework has been corroded because SENDIST is powerless to enforce statement provisions. Parents are then faced with the prospect of a Judicial Review in the High Court and all the time, expense and anxiety this entails. A simple legal mechanism to ensure that statements, once agreed, will be implemented would significantly improve trust in statementing. SENDIST itself would appear to be the ideal vehicle to deliver this.

36. The lack of such a legal mechanism shocks many parents, who understandably assume that provision will follow an agreed statement. If the Government wishes to reduce the number of statements issued, the approach needs to be one focussed on reducing parental demand for statements by increasing confidence in school-based provision. There needs to be a consequential recognition that some pupils, such as many children with autism, will always require provision that costs more than any individual school can be expected to fund from its budget.

37. SUBMISSION 7—RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

38. TreeHouse welcomes the Government's commitment to increasing expectations for all children (paragraph. 3.1, p 52) and to the aims of 'personalised learning'.

39. The freedom to focus specifically on the needs of the children with autism is of high importance, especially where these contrast significantly from the needs of typically developing children. 'Removing Barriers to Achievement' promises to 'put children with SEN at the heart of personalised learning, helping schools to vary the pace and approach to learning to meet individual children's needs' (p 50).

40. The best provision is most likely where schools give greater curriculum differentiation. This needs to reflect the fact that many children with SEN are operating below National Curriculum Level 1, and require significant support to develop basic skills which typically-developing children learn as a matter of course. Yet schools across the country are struggling to know how to teach children with autism. TreeHouse is already playing its part, offering our children "challenging and relevant curriculums" (paragraph. 2.16, p 38).

41. New models for assessing achievement on a daily and termly basis need to be innovated in order to assist mainstream schools and ensure compliance with the national curriculum. Factors to consider are the need for precision in data collection, attention to detail in curriculum differentiation and greater personalization of teaching approaches as well as curriculum materials. This is still an area of ongoing discovery and exploration in relation to children with autism. DfES must ensure firstly that more research in this area is commissioned and secondly that research findings are translated into practice.

42. SUBMISSION 8—THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

43. Recent developments and the broad sweep of legislation in the education field have placed greater emphasis on the roles of parents. TreeHouse gives qualified support to these changes. Parents generally know their children's needs better than anyone else.

44. However, recent remarks by the Prime Minister and the Secretary of State for Education have raised our concern that the balance has swung too far. Commenting on another aspect of the Government's education policy, the Prime Minister said: "It is not government edict that is determining the fate of city academies, but parent power. Parents are choosing city academies, and that is enough for me".³⁰

45. TreeHouse has some reservations about placing the onus on parents as the guarantor of the quality of education their children receive. Even though TreeHouse blazed the trail for a wave of parent-founded autism schools, this was a desperate response to underprovision, not a sustainable answer to system failures. Parents of children with autism have a hard enough job to do themselves without having to ensure schools

³⁰ Tony Blair quoted by Reuters (2005) "Blair to announce schools shake-up", Monday 12 September. Available online <http://uk.news.yahoo.com/12092005/325/blair-announce-schools-shake.html>

and LEAs are doing their jobs properly, too. Parents who fight for provision for their child risk being labelled as ‘pushy’, while children whose parents are less equipped to engage with their school and LEA may miss out on much-needed support.

46. A regime in which the role of parents is prioritised will inherently favour those parents ready-equipped with the skills and information to scrutinise and campaign for better services. This, of course, contains inherent dilemmas in public policy where educational outcomes are already subject to socio-economic and educational inequalities. Once children are placed in schools such as TreeHouse, some LEAs abdicate their legal duties to the child, refusing to attend annual reviews and leaving parents to monitor the quality of their child’s education.

47. Finally, it should be remembered that many children (and a disproportionate number of them with SEN) do not live their daily lives with the love and support of their parents. Government should be careful not to build such assumptions into their provision for children without substantial safeguards.

48. SUBMISSION 9—ADDRESSING THE LEGAL BIAS AGAINST INDEPENDENT SCHOOLS

49. Aside from SEN, independent schools are linked to the idea of privilege. In SEN, it is a very different story—charities have set up schools outside the maintained sector to provide appropriate education for disabled children whose needs were being ignored. The legal framework in recent years has provided parents with, in theory, greater choice in deciding where their child is educated. However, the law remains imperfect and is still subject to the judgement of LEAs who continue to over-rule parents on grounds of cost.

50. The Special Educational Needs and Disability Act 2001 (SENDA) created a greater right to a mainstream school place for parents of children with SEN. This was a welcome development, forcing mainstream schools to become more inclusive for children with a wide range of needs. At the same time, the Act preserved parents’ rights to request a maintained special school—s316 Education Act 1996 (as amended by SENDA) states that a child with a statement must be educated in a mainstream school unless that is incompatible with the wishes of his parents (inter alia).

51. There are two different sets of legal provisions in this area, one for maintained schools, the other for independent and non-maintained schools. If a parent is looking for a maintained school place, any additional expense of the place can be balanced against the benefit to the child—enabling parents to access a more expensive place if this is what their child really needs. This right does not apply for independent and non-maintained schools. These schools are generally more expensive than maintained schools as they have to provide an infrastructure that would otherwise be provided by the LEA, and may well have higher staffing levels so that children’s needs can be met appropriately. To get a place in these schools, parents are forced to prove that no maintained school can meet their child’s needs—rather than simply establishing that the independent or non-maintained school in question is what the child really needs.

52. The system does not fully promote parental choice even in relation to maintained schools. If a parent expresses a preference for any maintained school, whether special or mainstream, the LEA is obliged to name this school in the statement unless it is unsuitable for the child, or to send the child to the school would be incompatible with the efficient education of other children or the efficient use of resources (schedule 27, paragraph 3(3) Education Act 1996). It is arguable that this aspect of the law should also be changed to oblige an LEA to send a child to any maintained school requested by the parents.

53. CONCLUSION, SOLUTIONS AND RECOMMENDATIONS

54. Whilst LEAs are forced to meet an infinite need with finite budgets, the postcode lottery of provision will remain. TreeHouse supports the distinct separation of assessment and resource provision within LEAs—scrutinised by closer DfES monitoring. However, of more fundamental importance is recognition from central Government that more resources—human and financial—need to be directed towards the SEN framework if all children are to receive the support that they need.

55. Children with autism are regularly being failed by the current SEN system. TreeHouse proposes:

- (a) Measures to promote innovation in pedagogy, such as that undertaken by TreeHouse’s school.
- (b) An initiative to develop national standards and competencies required to be effective teacher of children with autism.
- (c) A consequential requirement that teachers and other professionals will undertake the necessary training to meet these standards.
- (d) A strategic focus on the need for a spectrum of autism provision in every local area, supported by local outreach services and regional specialist centres.

Memorandum submitted by the Trade Union Disability Alliance (TUDA)

The Trade Union Disability Alliance (TUDA) brings together disabled trade unionists with affiliated branches and trade unions from across the trade union movement to move forward on issues affecting all disabled trade unionists. Trade unionists may also be parents or teachers of disabled children, or former pupils with Special Educational Needs.

TUDA's work is defined by the social model of disability. We define disabled people as people who have a mobility and/or sensory impairment, and/or a chronic illness or condition, and/or learning difficulties, and/or are users/survivors of the mental health system.

MAINSTREAM AND "SPECIAL" SCHOOL PROVISION, AVAILABILITY OF RESOURCES AND EXPERTISE, DIFFERENT MODELS OF PROVISION, RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

TUDA does not wish to make a detailed submission to the inquiry. We do, though, wish to make it clear that we believe all children are best able to fulfil their educational and social potential when provision is made within a mainstream setting. However, this provision needs to be appropriate and adequate, and a variety of types of provision needs to be available. All too often inclusion is now seen as an excuse for cost-cutting, with specialist teachers being replaced by learning support assistants: this is NOT inclusive education. It is also vital to retain the expertise and excellence that does exist within the segregated system when moving to inclusive education.

We are particularly concerned that bullying is now being used as a reason to halt the move towards inclusive education when inclusion is regarded as being more expensive than segregation. The current debate around bullying seems to betray a number of erroneous and offensive beliefs:

- Disabled children are 'natural victims'.
- Unlike non-disabled children, disabled children are incapable of dealing with bullying and overcoming it.
- School anti-bullying strategies do not work, and bullying will always exist.
- There is no bullying in segregated schools.

We are particularly concerned because, when disabled children are segregated from their peers, they are inevitably much more vulnerable to bullying outside of school hours because they are socially isolated. This is particularly acute when the school is boarding or outside of their local area. Social isolation impacts on educational as well as social development. Segregation during school years also makes it much harder for disabled children to integrate into the community once they become adults, and can have a life-long detrimental effect.

We believe that it is much better for disabled children, as with all children, to learn how to deal with bullying and abuse within the framework of a school-wide anti-bullying strategy. This makes it much more likely that disabled children will be able to deal with the abuse and bullying they encounter once they become adults, as well as maximising their educational and social potential.

THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

Parents are best placed to make informed decisions about their children's education, but they require adequate and appropriate information in order to do this. We do not believe that they receive this at present. In addition, many parents of disabled children receive very inaccurate information about their child's life chances from medical professionals from birth onwards, and make educational decisions based on this. It is also entirely inappropriate to expect parents to support inclusive education if their child is being offered mainstream education that is not really inclusive at all.

However, many more parents report being unable to get a place for their child within the mainstream when they are clear that this is what they want for their child and best suits their needs. Teachers are understandably reluctant to accept disabled pupils unless and until they are given adequate resources to meet their educational and other needs. It is clear that these resources are very often not being provided at present, and that children are being segregated against their parents' wishes.

HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

We believe that both language and definitions need to be radically rethought in the context of the 21st century, and in particular the new public sector duty to promote disability equality. The choice of the term 'special' may or may not have been appropriate in its historical context, but many disabled people now find it deeply offensive. Equally, what is 'special' about disabled children's need to be educated? The reality is

that all children's educational needs differ. Perpetuating the myth that disabled children have one set of needs and non-disabled children another continues the current lack of flexibility within the education system. Only when it is recognised that all children may have very different educational needs however they are defined can we start providing education that really does meet the needs of every pupil.

October 2005

Memorandum submitted by Valuing People Support Team, Department of Health

1. INTRODUCTION

1.1 I am the London regional adviser for the Valuing People Support Team. Valuing People is the Government's national learning disability strategy. My main task is to support London local authorities to implement Valuing People's objectives. Each local authority has a Learning Disability Partnership Board which brings together local authority and mainstream community services (including health) and has representatives of people with learning disabilities and family carers.

1.2 In addition, I am the team's national lead on education for adults and children. This includes "transition" from school to adulthood. Objective 2 of Valuing People is to improve the experience of young people in transition. The importance of transition is also recognised in the National Service Framework, which is concurrently impacting on local work with Health, Social Services and Education.

1.3 One of the key strands of Valuing People is "person-centred planning". This is a move away from simply slotting people into existing service structures, and towards supporting them to plan for themselves. The aim is that resources can then be used to help people to lead the lives they choose.

2. WORK IN PROGRESS

2.1 I am currently leading a national programme to introduce person-centred planning into the Year 9 (age 13–14) transition review for young people with SEN statements. Simply by bringing what we have learned through planning with people in adult services to the school-based SEN reviews, it has been possible to create meetings which concentrate on what is really important to and for the young person and their family, rather than what has often been a process determined by bureaucratic priorities.

2.2 This work, based on a pilot which took place in four London boroughs in 2004–05, is now taking place in half of English local authorities. In the first year, the Valuing People Support Team funded the programme. It is now joint-funded with the DfES. The remaining local authorities will become involved in 2006–07, and the programme will be complete in 2008 (funds permitting).

3. OUTCOMES

3.1 At these reviews, young people and their parents are involved in the planning, in ways that were previously impossible. The transition reviews have been led by their own issues, interests and concerns. The evaluation by parents, young people and professionals, so far, is that this is a far more effective and productive way of working, and people particularly like the problem-solving approach. In fact the approach is so popular that we are having to restrict the pace of development somewhat so that we can guarantee its quality.

3.2 What we have learned is that this way of working is applicable to children of all ages in mainstream and special schools, and with the whole range of SEN. It would be a very positive way of involving families in planning as soon as children are identified or diagnosed. We can see the potential for it to become a tool for self-assessment, as outlined in the Social Care Green Paper. It also links closely to the ideas contained in "Life-Chances for Disabled People", "Every Child Matters" and the Green Paper "Youth Matters".

4. RECOMMENDATION

4.1 That what we have learned and continue to learn from this programme is used to establish ways of working that will reduce the conflict inherent in the current SEN processes, by the introduction of person-centred approaches which are more meaningful to young people and their families.

October 2005

Memorandum submitted by John McKeown Associates

My background in relation to this inquiry is that I am a practising Chartered Educational Psychologist with some 30 years experience of working in local education authorities and as part of my own independent consultancy. I have been an active observer of the legislative background and administration of special educational needs policy and legislation over the course of my professional career. I would add that I have been a participant in around 50 special educational needs tribunals since 1994 involving disputes between parents and local education authorities with regard to the appropriate provision for their children. I would make the following points in relations to the issues to be considered by Parliamentary Committee as follows:

PROVISION FOR SEN PUPILS IN MAINSTREAM SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

There is no doubt that the initiative towards greater inclusion of children with special educational needs in mainstream schools has increased the expertise of teachers and other professionals to cope with more children with SEN within the mainstream context. In many cases this has been successful from the point of view of the children concerned. However, I would want to draw a distinction between appropriate and inappropriate inclusion policy and to draw the Committee's attention to children who clearly struggle and fail with the context of the mainstream despite the efforts of teachers and support staff.

Government policy has driven hard the concept of being able to meet the needs of children with SEN in mainstream schools. Local education authorities in complying with policy initiatives have adopted models of inclusion by which a large number of children are supported in mainstream schools with the use of teaching and learning support assistants. Often this has been combined with other support facilities in the form of small group and individual help within special-needs departments. This model contrasts with that of the special school where differentiated support is more readily available within small classes.

The 'support within the classroom model' can work perfectly well providing the special educational needs of the children concerned are not too severe. What has happened over the recent period is the local authorities in conforming to inclusion policies have increasingly been expected to 'mainstream' an increasingly high proportion of children with profound special educational needs who cannot cope with the varying attentional requirements of the mainstream class because of their learning and behavioural difficulties. In the case of these children and young people failure can become more rather than less conspicuous and the demands of trying to keep up with the pace of the class is incompatible with their learning potential and learning needs.

Some professionals within the system, charged and employed on the basis of their commitment to inclusion, do not in my view scrutinise the potential damage which can be done to children as a result of inappropriate inclusion policies.

PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

It is essential to retain and develop the quality and distinctive contribution that can be made by special schools to meeting the needs of those children with severe needs. Undoubtedly there is a role for greater liaison between special schools in mainstream schools and much has been done over recent years to promote this initiative. It is my view that any further initiatives to close special schools as a matter of policy should now cease.

RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

Raising the standards of achievement for SEN pupils involves a realistic evaluation of learning potential and the conditions under which the potential can be realised. Discussions about inappropriate and appropriate inclusion policies are central to this process together with the maintenance and development of expertise of staff.

The quality of those professionally promoting learning in schools either as teachers or teaching assistants needs to be considerably improved in some sectors of special education. One area of particular concern is that for children with severe learning difficulties with the continuity of competent support is often unacceptably variable for individual children on a year by year basis.

THE SYSTEM OF STATEMENTS OF NEEDS FOR SEN PUPILS

Over 30 years in the profession I have seen the development from simple informal schemes of identification and provision to the highly bureaucratic and complex systems that we now have currently in place. One of the main reasons for this has been the emergence of overbearing management systems whereby important decisions about individual children's needs are made by committees of individuals who are

unreasonably distant from the children themselves. Clearly it is important that managerial systems should be efficient and well-run but the balance between managerial control and professional opinion has gone too far in the direction professional decisions being too readily influenced by managers and policy initiatives.

I would support the retention of the system of statements—but means have to be put in place to reduce the time taken to produce statements and deal with appeals.

THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

The continued and expanding involvement of parents continues to be a priority. Much has been done over recent years through the SEN legislation to provide parents with advice and support. Access to legal aid in relation to representation at tribunal is needed for certain cases for the reasonable administration of justice . . .

HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

I am satisfied with the way special educational needs are defined. However there are difficulties in the interface between aspects of medical diagnosis and special educational needs, which requires clarification and training for both educational and medical professionals.

PROVISION OF A DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES

My comments in the first section about inclusion policy are highly relevant to this issue. Those individuals with significant emotional behavioural and social difficulties experience considerable problems of learning due to their poor executive functioning and personal organisation. Their difficulties affect other students in their learning as well. Realistic evaluations need to be made more actively in planning for the needs of the EBS group of pupils and students. The assumption should not be made that all children with these kinds of difficulties can be integrated in mainstream schools.

THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION

I have no suggestions for change here apart from the need if possible to speed up the process.

October 2005

Memorandum submitted by Rathbone

1. RATHBONE—WHO WE ARE AND WHAT WE DO

- Rathbone is a charity working in Scotland, England and Wales. We operate from 70 centres and projects. We support over 13,500 young people and adults every year and we employ 1,200 staff. Rathbone is dedicated to working with young people who very often have not been successful in their secondary education. Many such young people require access to education and training opportunities that are tailored specifically to their learning and social support needs.
- The charity works in the main with young people who at 16 leave school without having attained a level 2 or equivalent qualification. The range of Rathbone provision encompasses learners working at or below level 2 basic and key skills as well as young people who have progressed to apprenticeship learning at level 3. The majority of the Rathbone learner group will have prior attainment levels well below the level 2 benchmark threshold. The charity works also with young people who are NEET at 16.
- At Rathbone, we make every attempt to personalise the support that we provide in order to enable each of our clients to get the most out of their time with us. We are also committed to supporting young people who are excluded from school. Rathbone works also with young people who are subject to the provisions of the youth justice system. Rathbone staff have been at the forefront of innovative initiatives to encourage young people who are not in education, employment or training to recommit to positive activities. Seven out of 10 of those with whom we work in this way progress into positive further training or education outcomes.
- Eighteen of the Rathbone centres currently make provision for young people who are 14+ are either partially or wholly excluded from school. In these centres Rathbone works with LEAs and schools to provide alternatives to school whilst enabling the young people concerned to follow elements of the Key Stage 4 curriculum along with other activities that are work and PSD related.

- Some of the Rathbone learner group have learning difficulties. Most however have learning support needs that arise from other behavioural and social factors. For these reasons virtually all of the learner cohort are endorsed by Connexions and therefore attract additional learning and social support needs funding from the LSC and its equivalents in Wales and Scotland.

2. PROVISION FOR SEN PUPILS IN MAINSTREAM SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

- Rathbone is acutely aware of the wide range of responses applied to meeting the needs of pupils with SEN through our work with 18 LEAs for 14–16 young people at risk of or excluded from formal education and through the large number of young people placed on LSC funded vocational and pre-vocational courses from across 14 LSCs.
- Much of the information that we receive regarding these learners, who often have been both educationally and socially excluded, is limited in most cases and vague in others. What is always clear is that the young person has had consistent issues with the formal system for some considerable time. It would seem that despite the best efforts of the main-stream staff the offer is not appropriate for a considerable proportion of young people.
- The increased flexibility at KS4 is now adding to the administrative burden of the staff in relation to these learners and it is often only through liaison and partnership with other agencies that provision can be found to meet learner need.
- Resources for teaching and learning are very costly in terms of expertise and assessment across the wide and diverse umbrella of the SEN population. Despite all the TTA investment in standards for SEN we still have too few qualified practitioners. The 14–19 increased flexibility offer is posing challenges with many FE and work based staff not having equivalent qualification, remuneration and opportunity for CPD to those of staff in schools. LLUK is addressing this issue but in the mean time the learners suffer from a lack of specialist intervention.

3. PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

- Rathbone responds to a small proportion of learners who primarily are designated as EDSD and have gone through the special school route. Many join us without any real experience of work related learning and the vast majority have significant and often profound needs in relation to language, communication, literacy and numeracy.
- The developments of specialist teachers offering support in CPD and good practice is welcome but does not extend to the work based learning sector. Further liaison in the local partnership/business/voluntary communities would be welcome.
- This is an expensive resource which we believe should be reserved for the most profound disabilities and only where appropriate. Resources could be re focussed into provision that is alternative and more appropriately meets need.

4. RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

- We believe the levels of achievement are too low for this group of learners. There has been little progression for most learners over time. We acknowledge that the learning process will be slower for these learners; however currently too many fail and many do not make enough progress to function effectively in society. It is not that they cannot. It is that which is on offer is not appropriate.
- We believe that achievement is ad hoc and partial unless professional assessment and the planning of personalised programmes of learning are provided by trained specialists. This does not happen often enough in the current system.

5. THE SYSTEMS OF STATEMENTS OF NEED FOR SEN PUPILS ('THE STATEMENTING PROCESS')

- Our view is that the current system is too costly, over-bureaucratic and is a barrier to progression for the majority of young people who are subject to it. It meets the needs of a limited number of profoundly affected young people.
- Rathbone believes that all young people with an identified need should have access to funds to support their learning, wherever it is located. Innovative new ideas about allocating such funds should be developed on a regional basis to ensure equity and impartiality.

6. THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

- We believe that parents play a key role in the education of their children, at all stages of the learning journey. Involvement in the foundation, primary stage is vital and should be integral to the personalised programme. From KS4 onwards the involvement is important but should be proportionate to need and on a reducing scale.
- The provision of independent advice lines and advocacy services in LEAs is good practice and should, we believe be continued into work based learning in the form of IAG, which also protects through its advocacy role and independent status.

7. HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

- The definition of SEN is complex and confused across the services working with young people. Current legislation does not help. The move to 14–19 provision also adds complexity to an already confused situation. Having two sets of terminology is absurd. We believe that all learners within the criteria defined by the Common Inspection Framework (CIF) for schools and learning and skills should be the same. We suggest that it should be learners with difficulties and or disabilities and that they all are entitled to a personalised learning plan to meet their individual need.

8. PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES (EBSD)

- The Rathbone client group often fall into this category, whether they have been statemented or not. They are mostly defined as NEET.
- We are clear that when they reach us effective learning has not taken place for the majority of this group. Our facilitation of learning is more effective for this hard to reach group because we put the learner at the heart of our response. We do not succeed with all, but those we work with have enhanced life chances.
- We believe that a personalised learning framework is essential offering clear boundaries, expectations and entitlements for learning. We are continuing to develop models to deliver to this diverse and disparate client group.

9. THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001, WHICH EXTENDED THE DISABILITY DISCRIMINATION ACT TO EDUCATION

- We welcome the latest legislation bringing educational provision within the remit of prejudicial and discriminatory practice. This development has highlighted the costs of such responsibilities.
- We believe that rationalisation of the SEN/statementing process will maximise the use of funding and resources and more effectively fulfil the aspirations of the legislation, moving us closer to a more equitable offer for all learners.

October 2005

Memorandum submitted by SCOPE and the National Union of Teachers (NUT)

SCOPE AND THE NUT'S JOINT SUBMISSION ON THE SCHOOLS ACCESS INITIATIVE

Scope and the NUT believe that in order for disabled pupils to be able to attend their local community schools, it is vital that there are significant resources to make schools accessible. Scope and the NUT have jointly commissioned two reports (and the DfES commissioned a further report) to successfully lobby for more resources to make schools accessible.

In 1995 the then Conservative Government announced the Schools Access Initiative (SAI) which continues today and with funding until 2008. However, we are unsure about the continuation after 2008 and we have concerns that the SAI is no longer ring-fenced.

We attach a letter recently sent to the Secretary of State for Education and Skills. Both Scope and the NUT feel that the continuation of funding is fundamental in enabling schools to meet their duties under SENDA 2001 and in light of the forthcoming new duties to promote disability equality which will flow from the Disability Discrimination Act 2005.

Brief history of the Within Reach Campaign

In 1992, Scope and the NUT commissioned Coopers and Lybrand to carry out research into the costs of ensuring access to mainstream schools for disabled pupils. One of the three high-cost areas identified in the report was the conversion of existing premises.

A second report commissioned in 1993 assessed the readiness of schools to act as “resourced mainstream schools”. This report, which was called Within Reach—the School Survey, worryingly found that disabled pupils only had access to all the teaching space in 26% of primary schools and 10% of secondary schools. The researchers estimated that the cost of significantly improving access to the school premises in 75% of primary schools and 50% of secondary schools would be a total of £310 million.

These findings were presented by Scope and the NUT to the Government and this led to the inception of the Schools Access Initiative; £10 million was ring fenced in a fund and schools were invited to bid through their local education authority. Between 1997 and the present day, the Labour Government has significantly boosted the SAI year on year, to support the accessibility of schools and to enable schools to meet their duties under the accompanying legislation (SENDA 2001).

A third report, commissioned in 2000 (in partnership with the DfES), evaluated the impact of the SAI. The researchers found that through the direct experiences of including disabled children, attitudes had become markedly more inclusive and understanding and knowledge of accessibility had significantly improved.

Both Scope and the NUT believe that making physical adjustments is a vital starting point for the process of inclusion of disabled children in mainstream schools. This is why we are calling for the continuation of dedicated grant funding after 2007–08. It is essential that the Government gives a renewed commitment to dedicated ring fenced funding in order to achieve accessibility in all schools.

October 2005

Memorandum submitted by The Children’s Society

1. INTRODUCTION

1.1 As a national voluntary children’s organisation, The Children’s Society welcomes the opportunity to submit evidence to this inquiry on Special Educational Needs. The Children’s Society is concerned with the welfare of all children and young people, but especially those who are at risk of social exclusion and discrimination. We have a particular interest in disabled children, looked after children, children in trouble with the law, young refugees, and children and young people at risk on the streets.

1.2 Our organisation works across England and has a well developed practice base working directly with children and young people in a range of school, community based and specialist projects. We have a wealth of experience working with disabled children and young people and many other groups of children who have special educational needs. Our particular concern is to ensure that the views of disabled children and young people are heard and taken seriously in decisions that affect their lives and in the development of policies, practices and services.

1.3 The Children’s Society is a member of the Special Educational Consortium and fully supports their submission to the Inquiry. This submission focuses on a number of additional points that have emerged from our practice and issues raised specifically by disabled children and young people that we work with.

2. PROVISION FOR PUPILS IN MAINSTREAM SCHOOLS

2.1 Despite the Government’s commitment to embed inclusion in every school and early years setting lack of training, funding and discriminatory attitudes in many mainstream schools still prevail. The inclusion agenda has had little impact on the proportion of children with special educational needs in mainstream schools or on the range of special educational needs catered for. Ofsted³¹ reports that there has been little change in the overall numbers of mainstream pupils educated in mainstream schools in the last four to five years and points to a 10% increase in the number of pupils placed at independent special schools since 2001. They noted that over half the schools they inspected were unaware of the reasonable adjustments duty from Part 4 of the Disability Discrimination Act and that accessibility plans that had been produced were predominantly “paper exercises to fulfil a statutory responsibility”.

2.2 However, we know that there are examples of well-resourced schools which have a climate of acceptance of all pupils, including those who have complex needs. These schools have fully embraced the accommodations and adaptations required for disabled children in their locality. Most importantly these schools do not ignore difference, they do not treat all pupils the same. They concentrate on being responsive to the needs of the individual child. They are schools that recognise that positive inclusion requires realistic

³¹ Ofsted [2004] Special Educational Needs and Disability : Towards Inclusive Schools.

staff pupil ratios; quality training for all staff, pupils and governors on disability awareness; access to expert professional advice; a whole range of appropriate forms of support for pupils and their teachers; a culture of high expectations and a commitment to ensuring all pupils can access the whole life of the school.

2.3 In schools which embrace inclusion much attention is given to raising awareness about disability throughout the whole school community including pupils, teaching staff, governors, lunchtime supervisors, caretakers and parents. The Children's Society would like to see disability awareness becoming a core component of the curriculum at both primary and secondary levels as well as being incorporated into the underlying ethos of extended schools. This will be of benefit to the whole community and must lead eventually to a shift in the general perception of impairment and disability within society as young people grow up together, learning about one another. .

2.3 Developing schools in a way that all children can flourish gives disabled children the opportunity to belong and participate in community life. Disabled children and young people emphasised this point in The Children's Society's award winning Ask Us Initiative³²

“We want to do what other children do

We want to go where other children go

We want to part of our community not apart from it”

Inclusion promotes familiarity and tolerance and reduces fear and rejection and research³³ has shown that effective inclusion improves achievement for all pupils.

2.4 The Children's Society 's supports an inclusive education for all children, in schools which have the resources, support and trained staff to ensure that children's experience of school is positive and that they develop to their full potential. We welcome the positive proposals to promote inclusion in the Government's 10 year strategy for SEN³⁴ and urge more priority be given to the implementation of the strategy.

2.5 We are concerned that increased delegation to individual schools of the resourcing of specialist SEN services will in the short term at least limit the availability of support services which can play a key role in the development of inclusive practice. Initiatives such as that developed in York “Go on then . . . Make Inclusion Work”³⁵ have demonstrated how the Local Education Authority can play an important role working in partnership with the voluntary sector and disabled children and young people in the provision of resources to promote inclusion in large numbers of local schools.

3. THE PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

3.1 We urge the inquiry to consider the particular vulnerability of children with SEN and disabled children placed in residential special schools. As the DfES good practice guidance on commissioning placements³⁶ notes, “far too often placements are made which may be unnecessarily expensive , remote from home, and/or which are not in the child's best interests and which do not contribute to good outcomes”. The report points out that outcomes for looked after children and children with SEN and disabilities placed out of authority are worse than for children placed within their home authority. In reality placements are too often made on the basis of availability rather than choice. It is The Children's Society's view that out of authority placements in residential schools should be restricted to situations where they are clearly in the child's best interest and children's views as well as that of their parents should be taken into account in decisions about placements.

3.2 We know that disabled children are extremely vulnerable to abuse of all kinds and are more likely to suffer abuse than other children living away from home.³⁷ As well as being a long way from home some children can be at school for up to 52 weeks a year. The distance, cost of travel and time involved make it difficult for parents and social workers to keep in touch with disabled children placed a long way from home. Their isolation from their placing authority means that changes in behaviour and other indicators of abuse may not be noticed and questioned. A recent Safeguarding Report noted that some councils fail to adequately monitor individual placements of children placed outside their home area.³⁸ Research by Abbott, Morris and Ward³⁹ concluded that, in practice, the current legislative framework is not adequately protecting and promoting the interests of disabled children at residential schools. We urge the inquiry to take steps to ensure that all children placed out of authority in residential special schools have access to an independent advocate.

³² Ask Us The Children's Society 2001.

³³ Inclusion and Pupil Achievement DFES RR578 2004.

³⁴ Removing Barriers to Achievement: The Government's Strategy for SEN.

³⁵ Go on then Make Inclusion Work; Institute for Citizenship City of York Council.

³⁶ Commissioning placements and services for looked after children and children with special educational needs and disabilities in residential placements. DfES June 2005.

³⁷ “It doesn't happen to disabled children” Child Protection and Disabled Children Report of the National Working Group on Child Protection and Disability.NSPCC 2003.

³⁸ Safeguarding children: the second joint chief inspectors report on arrangements to safeguard children. July 2005.

³⁹ The Best Place to Be? policy, practice and the experiences of residential school placements for disabled children. Joseph Rowntree Foundation, 2001.

3.3 It is imperative that robust arrangements are always in place to ensure children are safe when they are placed in residential special schools. We are also concerned about the confusion that still exists regarding statutory notification duties which assist placing authorities retain protective oversight of all the children they are responsible for . . . There is an urgent need for the DfES to take action to ensure that local education authorities notify the responsible local authority when a child is resident in an educational setting for three months or more as required by Section 85 of the Children Act 1989.

4. THE ROLE OF CHILDREN IN DECISIONS ABOUT THEIR EDUCATION

4.1 We support the fact that the inquiry will be looking at the role of parents in decisions about their child's education. In addition we urge the inquiry to consider the role of children and young people in decisions about their education.

4.2 The importance of taking the views, wishes and feelings of children and young people into account in relation to decisions about their care and education is clearly reflected in a range of legislation, regulation and guidance including the SEN Code of Practice; Removing Barriers to Achievement; The National Service Framework for Children and Young People [Standard 3]; The Children Act 1989 and 2004 and Every Child Matters. Despite this plethora of good intentions the experience of many disabled children and young people is that they are rarely consulted and involved in decisions about their education. In our experience many children and young people with communication impairments are not involved in the development of their personal educational plan, not invited to their transition planning meeting and often not consulted about school placements including a decision to place a child many miles away from home in a residential special school. The Progress on Safeguards for Children Living Away from Home Report⁴⁰ found that in schools children are not systematically consulted on matters which affect them and many authorities are failing to meet their duties particularly in relation to young people with communication impairments or complex needs.

4.3 Children and young people also have an essential role to play in determining to what extent schools are genuinely inclusive. Any assessment about inclusion must gauge the extent to which children and young people feel valued and included. The voice of children and young people should be at the heart of any evaluation of inclusive policy and practice.

5. THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND IN PARTICULAR THE DISABILITY DISCRIMINATION ACT 2005

5.1 Schools are at very different stages of meeting their current obligations towards disabled children. A 2004 Ofsted report⁴¹ highlighted that over half the schools visited had no accessibility plans and that only a minority of mainstream schools meet special needs very well. More recent research involving interviews with LEA officers shows that progress is slow and limited for disabled children in schools and that pupils with special educational needs are still losing out on admissions policies and practices⁴².

5.2 The Children's Society particularly welcomes the new duties in the Disability Discrimination Act 2005 which place on schools an active requirement to produce disability equality schemes. We feel this has the potential to encourage the promotion of positive attitudes within the school community through ensuring that educational programmes, anti-bullying strategies, and citizenship activities have an explicit focus on disability equality. Bullying is identified by children and young people that we work with as one of the singular most important issues to tackle in schools and as an inhibitor to their happiness and educational success. In an ERSC funded study by the University of Edinburgh on the views and experiences of over 300 disabled children, bullying is identified as the main reason why disabled children move from inclusive schooling to special schools⁴³. We believe it is a matter of urgency that schools develop a greater awareness of both the existing and new DDA duties, operate in the light of their duties and that Ofsted incorporate the new disability equality scheme duties into their inspection framework .

October 2005

⁴⁰ Progress on Safeguards for children Living Away from Home: a review of action since People Like Us. Stuart and Baines Joseph Rowntree Foundation 2004.

⁴¹ Special educational needs and disability: towards inclusive schools. Ofsted October 2004.

⁴² Admissions & Exclusions of Pupils with Special Educational Needs, National Foundation for Educational Research, January 2005.

⁴³ The 'Lives of Disabled Children' Colin Barnes, Marian Corker, Sarah Cunningham-Burley, John Davis, Mark Priestley, Tom Shakespeare and Nick Watson. ESRC's Research Programme on Children 5-16: Growing into the 21st Century.

Memorandum submitted by the Royal College of Speech and Language Therapists

SUMMARY OF RECOMMENDATIONS: ROYAL COLLEGE OF SPEECH AND LANGUAGE THERAPISTS—RESPONSE TO SEN INQUIRY

PROVISION FOR SEN PUPILS IN ‘MAINSTREAM’ SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

RCSLT recommends that the Select Committee:

1. consider the recommendations in the attached RCSLT paper (see Annex 1).
2. consider evidence from the models of collaborative practice from projects funded by Standards Fund and Children’s Fund. (Roulstone et al, 2005).
3. audit the recommendations set out in the Law report (2000) and the report on the Provision of SLT services to children with SEN (DH/DfEE, 2000).
4. support the identification and use of mainstream levers to embed good practice and that these examples of best practice are disseminated eg by the use of ‘champions’.
5. consider the need to review the support to deaf children and children with communication aids in mainstream schools.
6. consider aspects of the attached joint bid (See Annex 2) which may help to inform their work.
7. consult with the TDA during the review of the teacher training curriculum regarding input about child development and SEN and communication development and impairment.

PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

8. RCSLT recommends that the Select Committee consider the need to assess the impact and outcomes of different models of service delivery for children with SEN in special schools.

RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

RCSLT recommends that the Select Committee:

9. supports the view that communication skills development is mainstreamed into all aspects of school life.
10. considers that parents and/or carers are seen as core to support raising levels of achievement and that they are effectively supported.

THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (“THE STATEMENTING PROCESS”)

11. RCSLT recommends that the Select Committee consider the need for (i) a full review of the statementing process; (ii) a review of the costs of the statementing process and, (iii) a review of costs of tribunals.

THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN’S EDUCATION

12. RCSLT recommends the development of good practice standards in the process of engaging both parents and children/young people in choices and decisions.

HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

13. RCSLT recommends the review of the use of the definitions for SEN.

PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES (EBSD)

14. RCSLT recommends that the Select Committee needs to consider a scope of best practice models of service delivery and identify learning to support dissemination.

THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001, WHICH EXTENDED THE DISABILITY DISCRIMINATION ACT TO EDUCATION

15. RCSLT recommends that the Select Committee consider the need to identify good practice in the use of the legislative framework to support children with SEN.

INQUIRY INTO SPECIAL EDUCATIONAL NEEDS

1. The Royal College of Speech and Language Therapists (RCSLT) is the professional body for speech and language therapists in the UK and has over 12,000 members. The RCSLT is responsible for setting, promoting and maintaining high standards in education, clinical practice and ethical conduct.

Our mission

To represent speech and language therapists and support workers, promote excellence in practice and influence health, education and social care policies.

To deliver our mission we aim to:

Represent

- the interests of speech and language therapists and support workers and provide a voice locally, nationally and internationally

Influence

- and lobby governments and others to shape policy so that issues concerning the profession are reflected in public policy and people with communication, eating, drinking or swallowing difficulties receive optimum care

Support and protect

- the value of a profession whose members deliver quality services to meet diverse needs
- the professional interests of speech and language therapists and support workers

Develop

- and educate speech and language therapists professionally and academically, building our resource of professional expertise and leadership
- speech and language therapy and its professional practice through the use of evidence-based practice
- speech and language therapy as an integral part of the modernised workforce across health, education and social care

Build

- a sustainable, member-focused, organisation with the capacity to deliver our mission effectively, efficiently and in accordance with our values
- the systems, attitudes and resources to offer the best possible support and development to our staff

2. The Royal College of Speech and Language Therapists (RCSLT) is submitting this written evidence having sought comments and feedback from specialist speech and language therapists working with children with special educational needs.

PROVISION FOR SEN PUPILS IN 'MAINSTREAM' SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

3. RCSLT recommends that the Select Committee consider the attached RCSLT position paper Supporting children with speech, language and communication needs within integrated children's services and the recommendations within the paper. The paper aims to summarise the role and approach by speech and language therapists (SLTs) providing support to children with speech, language, communication, eating, drinking or swallowing needs (See Annex 1).

4. RCSLT recommends that the Select Committee consider evidence from the models of collaborative practice from projects funded by Standards Fund and Children's Fund (Roulstone, Owen & French, 2005). This also highlights the importance of SLT interventions using a systems level approach.

5. RCSLT recommends that the Select Committee audit the recommendations set out in:

- (i) The Law report (2000) and

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- (ii) The Department of Health/DfEE report on the Provision of speech and language therapy services to children with SEN (England): Report of the working group (2000) which included a recommendation that, since communication is so fundamental to learning and progression, addressing speech and language impairment should normally be recorded as educational provision to evaluate the level of implementation.
6. RCSLT recommends that the Select Committee support the identification and use of mainstream levers to embed good practice. Examples provided by SLTs in Nottingham include:
- (i) Challenging the philosophy and value base of the school —should these children be here?
 - (ii) Resources—used flexibly and in a timely way
 - (iii) The development of competencies for all staff via mainstream CPD
 - (iv) Not only considering the additional hours of support time but also raising the baseline of staff skills to create a more appropriate ‘communication environment’
 - (v) The use of the learning and teaching rewards to incentivise and ensure that responsibility is taken for children with SEN in mainstream schools by all staff
 - (vi) Encouraging the use of planning, preparation and assessment time to support children with SEN.
7. RCSLT recommends that the Select Committee considers how these examples of best practice are disseminated eg by the use of ‘champions’.
8. RCSLT recommends that the Select Committee consider the need to review the support to:
- deaf children in mainstream schools. There is concern about how many severely deaf children are “included” inappropriately in mainstream education with insufficient resources available
 - children with communication aids in mainstream schools.
9. RCSLT recommends that the Select Committee consider aspects of the attached joint bid (See Annex 2) that may help to inform their work, particularly with respect to developing an inclusive communicative environment.
10. RCSLT recommends that the Select Committee consult with the TDA during the review of teacher training curriculum regarding input about child development and special needs generally, and communication development and impairment in particular. RCSLT welcomes Communicating Matters (DfES September 2005) as a new initiative, which is in the process of being implemented, but we would wish to express our concern at the lack of consultation with RCSLT and SLTs in the roll out. RCSLT would wish to bring to the attention of the Select Committee that this work is a good start as it is aimed at giving Foundation Stage teacher’s skills regarding better use of communication in the classroom. However, it has a minimal focus on special educational needs and covers only a narrow age range.
11. Some schools have been funding SLT from their school budget (eg in Withywood, Bristol), but are expressing the concern that this is not sustainable without long-term commitment of funds for SLT services from more centralised sources.
12. Where speech and language therapy provision is too sparse, the biggest problem is that support for children is not timely enough, and becomes biased towards long-term needs. Impairments that can be resolved in the short term, left untreated, may become more severe and pervasive, and less responsive to therapy, resulting in spiralling unmet needs and potentially having a negative impact on the child’s psychosocial development and stability.
13. In 1997, the Government Green Paper Excellence for all children: Meeting Special Educational Needs included the following statement:
- “By 2002, speech and language therapy will be provided more effectively for those children who need it.”
14. Though the statement in the Green Paper is vague enough for some to argue that speech and language therapy is indeed being provided more effectively for children who need it, consideration of the recommendations from the working group would suggest that many have yet to be implemented.
15. As inclusion policies have taken effect, children who previously would have been taught in a language unit are now in mainstream class. There is little included in the teacher training curriculum on how to teach children with communication impairments and teachers are therefore unable to help these children achieve their potential.
16. Access to speech and language therapy is also worse for many children who are now in mainstream as previously they would have had daily or at least weekly contact with a language unit SLT. Few mainstream schools have this level of contact.
17. Different Local Authorities have implemented inclusion at different rates and the models of service delivery vary significantly across England. There is a need to evaluate the outcomes of provision for children in mainstream schools. In developing effective mainstream services, there are examples where the approach taken (Nottingham SLT service) has been to identify the factors that can add to the success of provision in a mainstream setting (see Annex 3).

18. Vital specialist SLT input may not be available for deaf children in mainstream settings. Too often a non-specialist SLT is expected to treat deaf children in mainstream settings, without the support of a specialist. SLT managers often state they are unable to supply a service to deaf children in mainstream because they have no specialist. Either way the child loses out. A Teacher of the Deaf (ToD) may be involved, and his/her input needs to be balanced by appropriate experienced SLT input.

PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

19. RCSLT recommends that the Select Committee consider the need to assess the impact and outcomes of different models of service delivery for children with SEN in special schools.

20. This is as the range of special schools is considerable and results in a variation of models of provision according to the nature of the school. One of the impacts of placing children with SEN into mainstream schools is the shifting population within SEN school provision. Some special schools now have a population of children who are different from the original specification of the school. For example, schools designated for children with moderate learning difficulties often have a high number of children with emotional/behavioural, social difficulties, autistic spectrum disorders or more significant learning difficulties.

21. Deaf children in Special Schools are more likely to have access to the local SLT service, but there remains concern re: expertise (appropriate post-grad. training) and frequency of input (ie staff resource).

22. For children requiring communication aids, less individual equipment is available for pupils, particularly those with PMLD, which is where CAP (Communication Aids Project) has been a boon. Children who would never have had their own equipment now have it in some instances. The more able child who needs AAC will be funded through the education budget often—although not always. Fundraising and charities sometimes provide equipment but this is not an effective or efficient method of providing support.

RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

23. RCSLT recommends that the Select Committee supports the view that communication skills development is mainstreamed into all aspects of school life as children need to communicate with a range of people and to meet a range of needs in the different contexts in which they have to function for example:

- (i) The classroom—access to the curriculum and in conveying day- day needs and communicating with peers and adults
- (ii) The playground—socialising
- (iii) All activities outside the classroom—including meal times, games etc

24. RCSLT recommends that parents and/or carers are seen as core to support raising levels of achievement and that they are effectively supported. Children with speech, language and communication needs have different requirements to enable them to maximise their potential and quality of life at school and in their home and community environments.

25. Particular consideration needs to be given to children with SEN and for whom English is a second language and whose language, culture and religious needs have to be taken into account.

26. Some teacher's work on spoken language skills as an essential foundation for other aspects of school achievement, and value joint work with SLT. Others feel pressurised into working towards specific literacy and numeracy targets instead due to constraints of the National Curriculum and its interpretation by the head teacher. Such pressures make collaborative practice for SLTs more difficult.

27. Communication skills have a fundamental role on the learning process and on how children demonstrate that they truly understand something by reforming the information in their own words—repeating statements does not indicate understanding—children with communication impairments have great difficulty in doing this (Wells, G, 1979; 1984; 1985).

28. In order to raise standards in children with communication difficulties, there is a need for a strong evidence base to understand what works and why; a greater access to SLTs who can work with a child, his/her teacher and LSA and the child's parents on a frequent basis and an awareness of mainstream teaching staff on the importance of collaboration with SLTs and an openness to trying new approaches. The difficulty for teachers can often be the needs of the rest of the class: one child with a communication difficulty may need a different teaching approach to the rest of the class but the teacher is only one person and to use two teaching approaches in every activity in the school day would limit the amount that all children could achieve in the day. Where a child with a communication impairment (or indeed with any of the more marked special needs) is included in the mainstream class, a teacher is surely more likely to be able to attend to their needs as well as the rest of the class if the class size was limited, eg to only 20 other children rather than 29. This may be very costly, but in order for standards to be raised in children with SEN, the funding that previously supported them in special schools and units should stay with them in the included environment.

29. Providing children with access to the communication equipment they need, when they need it following careful interdisciplinary assessment will help to raise standards.

30. It is very important to set appropriate expectation of achievement for deaf children. Too often standards for both communication and general behaviour are set too low. Standards should be set individually for each child.

THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS ('THE STATEMENTING PROCESS')

31. RCSLT recommends that the Select Committee consider the need for:

- (i) A full review of the statementing process;
- (ii) A review of the costs of the statementing process; and
- (iii) A review of costs of tribunals.

32. The rationale for this includes:

- (i) The need to address inequities in the system. RCSLT has ongoing feedback from both parents and SLTs that the statementing process is flawed. There is no link between the statement and level of resource available. For children with communication impairment, the responsibility for provision lies within health whilst the ultimate responsibility for meeting needs rests with education. This creates ongoing tensions between health who have the requirement to identify the child's needs and yet not be finally responsible for meeting those needs and education who are responsible for delivering services. There are particular concerns from parents that statements are resource rather than needs—led which leads to mistrust and tribunals. This situation was the subject of extensive consideration by the DfEE working group in 2000 (paragraph 4). There was no political will at the time to change the legislature to place a clearer requirement on health. However, there are now precedents for such changes, eg the Additional Support for Learning (Scotland) Act 2004, which could be considered as part of the overall review of the statementing process.
- (ii) Some children with higher levels of need do not have statements
- (iii) Practice between LEAs varies considerably with some working collaboratively with health and only issuing statements for children who are required to attend a special school or where there may be specific issues
- (iv) Many children with specific language impairment (SLI) do not get a statement. There is variation between authorities as to how well SLI is recognised
- (v) Funding and resources to support children with SEN (with or without a statement) is not adequate. It would be helpful to assess the costs of children in a special school setting versus costs for supporting them in mainstream schools and where the funding comes from (how much is health versus education)
- (vi) Costs of both the statementing and tribunal process. It is important to identify the costs of both processes. Time and money could be better spent on providing quality services. Approximately £3,000 per child is spent on the statementing process with £6 million being spent on tribunals (ICAN, 2005)
- (vii) In some education areas, funding has been targeted early intervention in the school action stages of provision. This seems to result in the reduction in the need for issuing statements. It would be useful to review these approaches, particularly to discover if parents support these approaches. Parents are likely to be particularly resistant to any dilatation of the statementing process since this is their only protection for gaining resources for their child.
- (viii) A review of the training of tribunal members and their understanding of models of service provision for children with speech, language and communication needs.
- (ix) SLTs, teachers (and parents) usually work from a social rather than medical model of disability, where functional descriptions of need mean more than labels and percentile scores, yet the present system seems biased towards the latter.
- (x) The statementing process, requiring evidence of two terms of failure, is not preventative in nature.
- (xi) SLTs feel unable to state what communication aids or levels of SLT is required as the LEA would have to fund these and there may be resource constraints.
- (xii) The needs of children change (eg following a cochlear implant, or following introduction of good amplification). The process of setting up a review of the child's needs is not flexible. It is not always easy to access the Educational Psychologist (EP) to set review in motion.
- (xiii) There are frequent huge discrepancies between the detailed assessment of need made by a specialist SLT and a shorter assessment made by a generalist EP. The SLT may wonder why her time has been "wasted" when the EP's comments are heeded and the SLT's not heeded.

THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

33. RCSLT recommends the development of good practice standards in the process of engaging both parents and children/young people in choices and decisions.

34. Parents are saying that the process of getting their child's needs recognised and responded to is too slow. Parents also talk of the constant fight throughout the life of their special needs child to access resources. This is particularly problematic at transitional points. The Department of Health has recently established a working group to look at transitional arrangements (chaired by Professor Sir David Hall). They do have opinions and appreciate choices, but only in the context of access to information, in a format they understand, from sources they trust.

35. Parents prefer a transparent system of multi-agency working and single point of contact for information. Parents from many communities only collaborate willingly with individuals with whom they already have a trusting relationship. It is important to consider what systems are set up locally to allow for flexible approaches to meeting the needs of both parents and children in enabling them to make decisions.

36. Parents must take an important role in decisions about their children's education. However, parents' wishes may be contra to professional advice. For example, in the field of deafness, parents may insist on an oral educational setting for a child who clearly (in professional opinion) needs a signing setting in order to access the curriculum. The process for joint working in these scenarios needs to be strengthened. A parent comments: "They (SLTs) don't seem to have any continuity at all. I just feel as if I was pushed from pillar to post". There is a clear need to promote service support to children and families over the long-term as children's needs will vary along their care pathway. "I think as long as us parents know what's going on, I can accept that, it's the not knowing. Chasing people up all the time we have enough to do. You don't need to be chasing like we are it's very wearing, like I said, because you have to be on your toes all the time. I feel, I mean I'm not. I feel that (child's name) is my priority, if I don't fight for her rights then there's no-one else who will do it for me. I just want her to have the best. So that she can develop to the best of her potential. If that means fighting for a service that she's rightfully entitled to then that's the way it is going to be. I am willing to do that for her" (Roulstone, S, forthcoming).

HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

37. RCSLT recommends the review of the use of the definitions for SEN. Key questions to support this review include:

- (i) What is the purpose of creating these definitions?
- (ii) What will they be used for? eg service provision, resource allocation.
- (iii) How can problems with inconsistency in application of definitions be addressed within and across professional groups and the health and education sector?

38. Currently there is too much emphasis on medical diagnoses and long-term needs. We need to be more responsive to difficulties that are preventable through timely short-term intervention, and to be more open to functional definitions of problems and needs.

39. Labels are a two edged sword but nevertheless, in most cases, very important for parents. The crucial issue of definition however is that whether or not it enables a child to get the support he/she needs in order to achieve their potential. The reality is that we do not know what a child's potential is and we do not know whether or not a different environment would have enabled them to achieve a higher level. Again, there is a need for a strong evidence base to support our decisions regarding defining children in terms of the need.

PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES (EBSD)

40. RCSLT recommends that the Select Committee needs to consider a scope of best practice models of service delivery and identify learning to support dissemination.

41. In Nottingham, there are a number of projects underway to support children with behavioural problems eg 'Place to be', MAST project, Standards Fund Project (Jane Storer and Julie Larouche—Report November 2004) which highlighted the link between children with behavioural and social difficulties and children with communication difficulties.

42. Many types of SEN (eg ASD, EBSD) are managed best through multi agency working, which still needs to be better coordinated and better centred around the service user (as proposed in Every Child Matters).

43. In addressing this issue, the needs of the rest of the class must be considered as teachers are only human. With inclusion, a mainstream class may not just have one but several children with more specific needs than the average mainstream child. Providing extra support in the form of LSAs is one way but this means that the child with the most need gets support from the least qualified (though not necessarily the least able) member of staff. Each child's needs and abilities must be considered individually alongside that of the prospective schools ability to address his or her needs. Neither the child nor the school gain anything from a child being placed with them when the school has insufficient resources to manage already high levels of demand, which may occur.

44. Deaf children tend to show relatively high levels of EBSD due to their communication difficulties. Increased provision of specialist SLT input can help to combat this. There is concern about the poor amount of SLT training made available to Learning Support Assistants. This training is vital to ensure effective use of specialist SLT time, enabling specialist resources to reach deaf children in the classroom throughout the school week, whether in Mainstream, Hearing-Impaired departments or Special Schools.

THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001, WHICH EXTENDED THE DISABILITY DISCRIMINATION ACT TO EDUCATION

45. RCSLT recommends that the Select Committee consider the need to identify good practice in the use of the legislative framework to support children with SEN.

46. In Nottingham, the SLT service uses the DDA to encourage schools to include in the access plan how they intend to make reasonable adjustments in relation to:

- The environment
- The curriculum
- Information provision—including the use of signs and symbols

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October 2005

Memorandum submitted by The Young ME Sufferers Trust

ABOUT THE YOUNG ME SUFFERERS TRUST

The Young ME Sufferers Trust works with Nisai Education to provide a virtual classroom for Stage 3 pupils with ME/CFS and free over-16 virtual education for students with ME/CFS in conjunction with the Learning and Skills Council.

Full information about The Young ME Sufferers Trust including an endorsement by the Prime Minister is at www.tymestrust.org

The Trust's "Tymes Trustcard" is a pass card for children with ME in school, endorsed on its launch by Education Minister Baroness Ashton and by the Secondary Heads Association and supported by Lord Clement-Jones CBE and Earl Howe.

The Trust is the longest-running support organisation for children and young people with ME and specialises in education. It runs an Advice Line, a Professionals Referral Service for doctors, teachers and others, and produces VISION, an informative magazine in which children are encouraged to express their views. The Trust's publications are available free of charge on its website www.tymestrust.org

SUMMARY: THE TRUST CALLS FOR URGENT SPECIALIST TRAINING FOR TEACHERS OF CHILDREN WITH ME/CFS AND IS SUBMITTING THE FOLLOWING EXPLANATORY EVIDENCE

1. ME—also known as Chronic Fatigue Syndrome or ME/CFS—is the biggest cause of Long Term Sickness Absence from School, as first discovered by Dowsett and Colby (1997 Journal of Chronic Fatigue Syndrome). This is the largest study of ME ever undertaken. Dowsett and Colby studied a school roll of 333,024 children and 27,327 staff. They also found clusters of the illness.

2. There is now abundant research evidence that this is an organic illness and not a psychological disorder, yet many children with ME are still not being offered education suitable for their needs, and to enable them to perform to their ability in examinations. They suffer widespread discrimination against their disability.

3. Children with ME fall into two categories. They suffer from a chronic illness but they also have special educational needs because of its effects upon both the body and the brain. They often need part-time or home-based education, curriculum modifications, and special arrangements for examinations such as extra time, rest breaks and sitting the exam at home. These assist children with ME to perform to their ability when seeking qualifications and minimises the educational disadvantage caused by the effects of the illness on the brain. The authors of a paper revealing further objective evidence of cognitive dysfunction recently said that sufferers "appear to have to exert greater effort to process auditory information as effectively as demographically similar healthy adults. Our findings provide objective evidence for the subjective experience of cognitive difficulties in individuals with CFS."

4. Section 19 of the Education Act 1996 requires Local Education Authorities to make suitable provision for all children and young people who cannot attend school by reason of illness. But there is a significant overlap between medical and special educational needs in this illness and it is often virtually impossible to separate the two. Schools have a Duty of Care as well as a duty to provide suitable education for children with special educational needs. In ME these two overlap, since too much mental concentration can produce physical relapse and physical relapse means that the child can no longer study. School attendance or inappropriate educational demands are a key cause of relapse; this results in further educational disadvantage.

5. Two years ago, a study by The Young ME Sufferers Trust ("The Forgotten Children" 2003) found that 87% of 126 young people it consulted had struggled for recognition of their needs and 81% had had to change schools to gain such recognition. Sadly, the Trust is still receiving similar reports.

6. Such is the concern amongst young people and their families that this year, young members of the Trust, through its study "Our Needs Our Lives" (April 2005) have asked if new ME/CFS clinics being set up with NHS funding will support the Tymes Trustcard, which is a school pass card system set up and run by the Trust with the support of the Secondary Heads Association. The card protects the needs of young people with ME in school. However, we have no evidence as yet of this being done.

7. The Young ME Sufferers Trust has also set up a partnership with a private firm Nisai Education to provide a Virtual Classroom for secondary age children unable to attend school due to ME—a scheme which I was pleased to launch in 2004. They have secured 50 places for those over 16 to continue receiving free education. More government and LEA support for such virtual education schemes is needed, especially as it is not home-based education that isolates these children, it is the nature of their illness. The virtual classroom enables interaction with other pupils whom they may later meet, as well as increased educational achievement and support for recovery.

8. At the moment, evidence from families strongly suggests that both the special educational needs and the medical needs of children with ME are not being sufficiently addressed by schools and Local Education Authorities despite many government and professional publications.

8.1 In 2001, The Dept for Education and Skills stated in its statutory guidance "Access to Education for Children and Young People with Medical Needs" that "pupils who are unable to attend school because of medical needs should be able to access suitable and flexible education appropriate to their needs".

8.2 In 2002, Chapter 5 of The Chief Medical Officer's Working Group Report (Dept of Health) stated that: "nearly all children who are severely affected and many who are moderately affected will require the provision of home tuition and/or distance learning." Jane Colby was a member of the Working Group on Children.

8.3 In 2004, The Royal College of Paediatrics and Child Health stated that “as a general rule reintegration should be slow and cautious” and drew attention to the Dept for Education and Skills recommendation that a resumption of education in whatever form should be planned in a way which ensures that children and young people do not feel under pressure to study. It refers to the virtual classroom as a means of providing continuing education for children and young people with ME.

8.4 Unfortunately, parental reports suggest that these and other recommendations and statutory guidelines are too often disregarded. Denigratory remarks have been made, and continue to be made, together with suggestions that children with ME do not have genuine special educational needs.

9. It appears that LEAs are unwilling to make Statements of Special Educational Need for children with ME. Recommendations under the Code of Practice are often inadequate. The Trust has published the first ME/CFS guidelines for Educational Psychologists (September 2005) but believes that teacher training in the needs of pupils with ME is urgently needed. The Trust has run such courses, after which teachers have felt much better equipped for their task. A teacher who had attended one of the Trust’s courses won the first Thorntons Award for supporting her pupil.

10. Schools breach their Duty of Care if they insist on school attendance or fail to make suitable provision and thereby make the child worse. Discrimination issues arise when special educational needs are not provided for and special arrangements for examinations are not offered or the school refuses to apply to the Examinations Board. Ofsted is expected to identify a lack of suitable provision for these children but parents report to The Young ME Sufferers Trust that in their view these deficits are not being picked up in inspections.

10.1 The Trust holds on file a host of letters, emails and completed questionnaires from parents describing unkind and ignorant treatment at the hands of teachers and others in the education profession. To quote from a parent who recently contacted The Trust: “When I spoke to the head of the sixth form on Friday afternoon she said there wouldn’t be a problem if she went to school! It staggers me—I think that most people cope by pretending that it can’t really be a ‘proper’ illness.”

10.2 The entire paragraph from this parent’s letter reads: “We all have to put up with general disbelief in the condition. It has been made very clear to me in recent months from other parents behaviour round me that they think my daughter is unbalanced, school phobic, exam phobic, neurotic and suffers from panic attacks. The headmaster did admit to me recently that the school had never had a student who over the years had missed so much school. She was the only one in her year who did not attend the prom organised by her year on Saturday evening. They didn’t bother to invite her in the first place, and she probably was not well enough to be there, but it would have been good to have been included. I know that this is considered by the other children in her year as yet another example of her being odd and not fitting in. One parent told me that no-one at school believes that she is ill because sometimes she gets to go out and do interesting things. We didn’t receive the information from school about the sixth form, because she had been left off the list, and when I spoke to the head of the sixth form on Friday afternoon she said there wouldn’t be a problem if she went to school! It staggers me—I think that most people cope by pretending that it can’t really be a ‘proper’ illness.”

11. Lack of specialist knowledge, educational techniques, suitable courses, facilities and examination arrangements is still turning children who could potentially obtain qualifications into failures with few or no qualifications to their name. What is almost worse is that many believe it is their own fault.

12. The Trust is calling for urgent training programmes for teachers to give them the understanding and skills necessary to ensure that government statutory guidance is indeed followed for these children, whose condition is unique in its mixture of medical and special educational needs.

October 2005

Memorandum submitted by Autism Consultancy Services

INTRODUCTION

Autism Consultancy Services is a worldwide organisation that was set up in 1990 by Richard Exley, Richard set up his own company as he saw and witnessed firsthand a distinct lack of appropriate and specific services based around Autistic Spectrum Disorder. Throughout this paper there are several references to the approaches and interventions used within Autistic Spectrum Disorder range but that does not mean that either I as Richard Exley and/or Autism Consultancy Services endorses or supports the approaches mentioned. Over the years the remit for Autism Consultancy Services has changed considerably due to demand in the field and also continuing rising opportunities for Richard to be involved in both from a practical, legislative/advisory and supportive model. Primarily but not exclusively Autism Consultancy Services has four arms:

- I am a licensed trainer (City and Guilds 7407) and Richard has built and developed training packages that he hopes to get accredited in the future. Richard was one of the first people with Asperger’s syndrome in the UK and Europe to talk on and away from his personal experiences and has lectured all over the world including to the Australian parliament in 2002. My work takes

me all over the world as I lecturer at different places, schools, colleges, work places, parliaments etc Until 2003 Richard was also involved with the Distance Learning Courses on autism which are run through the University of Birmingham.

What made Richard's work unique being male is that across the Autistic Spectrum Disorder range it is felt by some colleagues that there are more males with a high functioning Autistic Spectrum Disorder hence 9:1 for people with a high functioning autistic disorder and 4:1 for more the classic cases of Autistic Spectrum Disorder and back in 1990 there were very few people with any form of an Autistic Spectrum Disorder on the international circuit namely Temple Grandin (USA), Donna Williams (Australia) and Jerry Newport (USA) and I was one of the first in the UK/Europe to set up a worldwide consultancy service solely for Autistic Spectrum Disorder.

- I am also a registered carer and currently support over one hundred people with Autistic Spectrum Disorder across the age and ability range including fifty on a regular basis through a befriending scheme and a worldwide supported employment project including using my contacts in the business world, I also run and manage two social groups both link in with other organisations like sexual health clinics, employment agencies/employers, sport clubs, youth clubs and amateur dramatic societies etc

I am also a Named Person for children with Special Educational Needs especially with an interest in those with an Autistic Spectrum Disorder this has now been extended to being an expert witness in tribunals and courts. I also run the world's only advocacy (self, group citizen etc,) service for people with Autistic Spectrum Disorder which is both online and in person as well as having an active role in ensuring that Autistic Spectrum Disorder is in the public eye of policymakers and legislators including with colleagues in the European Union, United Nations and the World Health Organisation.

- I am also a Trustee to four charities; I am helping other organisations become charities and companies which are limited by guarantee. For existing charities I act as an advisor on issues such as providing them with the latest research, good practice guidelines from the Charity Commission and Companies House etc as well as helping in key areas such as fundraising where I have helped organise events. I am also a governor for two schools near to where I live.

I also sit on a number of working groups representing the Autistic Spectrum Disorder angle either professionally and/or as an advocate/champion for those with Autistic Spectrum Disorder who may find attending/participating at meetings difficult. I am also a regular attendee of the All Party Parliamentary Group on Autism meetings and have been since the inception in February 2000.

- Finally I am a researcher into Autistic Spectrum Disorder, primarily I look at the day to day issues and how people with Autistic Spectrum Disorder can contribute and participate in a society that still does not recognise or understand the true complexities and extent of Autistic Spectrum Disorder. I am involved with a number of projects including conducting research into a number of things around an Autistic Spectrum Disorder and I have strong/ongoing links with students, universities/colleges, professionals, research scientists etc all over the world. That said I do not wish or have any personal involvement as a participant of any research despite being in regular contact with an increasing number of researchers/scientists well including those linked with the Medical Research Council, the Institute of Psychiatry and the Royal Colleges etc.

My current and latest research explored a small group of people with Autistic Spectrum Disorder through a year looking at the issues around "reasonable access" as defined by the Disability Discrimination Act (1995) and the possible places where people with Autistic Spectrum Disorder may go at different times of the year and was diarised each day by each person writing how they got on but looking at stress, triggers and how service providers (large and small) coped with the Autistic Spectrum Disorder and how service providers made reasonable adjustments and access for people with an Autistic Spectrum Disorder as well as exploring the training needs of different service providers.

When I contacted the Chief Executive of the Disability Rights Commission (Bob Niven), the Minister for the Disabled (Anne McGuire) and the All Party Parliamentary Group on Autism with an offer to present them my findings/outcomes I was told "my research is unnecessary, irrelevant and bias" I have written to Tony Blair and David Blunkett as Secretary of State for Work and Pensions and to date I have not had a reply or an acknowledgement, as for David Blunkett I even arranged for my letter to be typed in Braille and offered to send a cassette/CD with the letter dictated.

Before I start, Autism Consultancy Services believes we need to be more specific a) what a Special Educational Need is and b) what a disability is. Autism Consultancy Services believes that a Special Educational Need is a barrier to learning. The wide range of strategies employed by the skilled staff in a number of our schools is often insufficient to overcome such barriers. As for a disability Autism Consultancy Services believes this is "a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities" which is shared with the Disability Discrimination Act (1995).

That said we must recognise there are different types of disabilities including physical, sensory, developmental, cognitive, psychiatric, and health-related. However Autism Consultancy Services believes that we need to go the extra mile in looking at the a) social understanding which underpins the problems for many people with an Autistic Spectrum Disorder and b) exploring the sensory needs of the person with

an Autistic Spectrum Disorder, sensory being that they are either hypo and/or hyper to the five senses of smell, touch, taste, sight and hearing, but each sense must be seen as an individual sense for example as someone may have good visual skills may have poor auditory skills etc which are often neglected and ignored particularly when the definition of Autistic Spectrum Disorders and disability through the Disability Discrimination Act (1995). does not address this either.

Autism Consultancy Services is unique in that I have spent many years working with colleagues from a variety of disciplines and backgrounds including working with the Royal Institute of British Architects, interior designers and town planners etc looking at the individual and complex sensory needs of people with Autistic Spectrum Disorder when designing and building new schools and hospitals etc as well as helping improve existing buildings to cater for those with an Autistic Spectrum Disorder by addressing the issues of flooring, ceilings, lighting, colour schemes etc

The general description for an Autistic Spectrum Disorder are present from birth or very early in development and affect essential human behaviours such as social interaction, the ability to communicate ideas and feelings, imagination, and the development of relationships with others furthermore Autistic Spectrum Disorder is referred to as a spectrum disorder because there are a range of symptoms and characteristics that present themselves in different ways. Within the autistic spectrum there are different subgroups namely Asperger's syndrome, high functioning autism, Rett Syndrome, Childhood Disintegrative Disorder etc.

That said many people who either don't live and/or work with people with an Autistic Spectrum Disorder understand what social understanding means. Therefore to extend and reinforce my argument I have tried to summarise in that social understanding is, it is a knowledge of social aspects of the human condition, how they have evolved over time, the variations that occur in differing physical environments and cultural settings, and the emerging trends that appear likely to shape the future.

As Gray (1994) says "We must approach the "social impairment within an Autistic Spectrum Disorder" as a shared impairment by working to improve social understanding from both sides of the social equation." A way to address the social understanding deficit is through Social Stories (Gray 1993)—which is a social story is a story written according to specific guidelines to describe a situation in terms of relevant cues and common responses (Gray & Garand, 1993).

The underlying philosophy stresses the importance of "abandoning all assumptions"—to seek to understand the person's perspective, to ensure a student has the social information he/she needs, and to present information so it is accessible and easily understood. As a result, every social story has a reassuring, accepting quality—positively and matter of fact describing a specific event (Gray et al, 1993; Gray & Jonker et al, 1994). Experience indicates social stories are often effective with mid to higher functioning students from preschool to adult.

1. (a) *Are we properly identifying children with SEN?*

Following extensive interviews (phone, email, 1:1 etc) with people on the mailing list of Autism Consultancy Services the outcome showed a clear no. Children/young people with an Autistic Spectrum Disorder are not being recognised and/or identified correctly and accurately, where identification does take place it remains ad hoc. There has become a trend for one size fits all through a framework for diagnosis that is 25-years-old hence based on the Triad of Impairment (Gould and Wing 1979). Wing and Gould acknowledged that there were many children who did not exactly fit Kanner's description of 'early childhood autism but who nevertheless had significant social difficulties.

However, such framework is misleading in that what constitutes an Autistic Spectrum Disorder varies from person to person and furthermore the framework precludes the sensory differences in that their senses can be either hyper or hypo and each sense is unique and how information is processed is unique as well as being unique for every person, and if you read Kanner's original paper you would clearly be able to recognise the sensory difficulties for each person. Once again the example I used earlier comes back into play in that someone can have good visual/spatial skills/awareness but yet have very poor auditory skills and as a result their senses become distorted due to the inability of separation.

Another child may have fairly good auditory, verbal and visual skills but may have problems in smell and taste in that their food needs to be prepared and cooked a certain way and then eaten in a further way—my Norwegian colleagues Karl Reichelt and Ann Marie Knivsberg have been involved in researching this area for many years and have worked beyond the gluten/casein free diets that many children/young people with an Autistic Spectrum Disorder have undertaken. Another child may have problems differentiating between sweet and sour foods etc or a child may have problems with hard floors, certain lights, aftershaves/perfumes or unable to block out sunlight and when the clocks go forward/back can have no bearing too even with thick curtains across the window etc.

Some people with an Autistic Spectrum Disorder also have irrational fears/phobias like paraskevidekatriaphobia, (fear of Friday 13th) the number eight (including the past tense of the word eat), the washing machine etc—it could be perceived that people with an Autistic Spectrum Disorder are

perceived as being social phobic and/or agoraphobic and become so anxious that they experience panic attacks, which are intense and unexpected bursts of terror accompanied by physical symptoms including self harm and mutilation.

Remember that an Autistic Spectrum Disorder is often described as a “hidden or invisible disability” in that it isn’t always noticeable, recognisable or identifiable at first hand but that does not mean it or parts of it don’t exist. Some people with an Autistic Spectrum Disorder become obsessive and repetitive behaviour can intermingle with each other of course these can be separate but sometimes the repetitive behaviour can become an obsession. Obsessions can be things like watching the same video/DVD over and over and over again or collecting pieces of paper, stones, shoelaces, seashells, pictures of animals, logo’s, vehicles, specific characters, hand-flapping, spinning etc Yet some people with an Autistic Spectrum Disorder may seem unaware of physical pain, heat, or cold and unable to differentiate between boiled water from the kettle and hot water from the tap.

As regards pain things like bruises and grazes don’t always appear on the skin until a while later, as for things like scabs they may appear but a child with an Autistic Spectrum Disorder may tend to pick at them until they bleed or release pus and remain unaware of the risk of spreading of germs, infection and contamination and yet may have a fear of needles, furthermore most people with an Autistic Spectrum Disorder have very soft and supple skin. That said even when the subject of germs is being discussed in general or specific terms it has been noted that some children with Autistic Spectrum Disorder can inadvertently develop a form of Obsessive Compulsive Disorder (OCD) including excessive hand washing and can make their hands sore and bleed or develop eczema, dermatitis and other skin problems.

All in all there is no one test for Autistic Spectrum Disorder when a child is born (it is also undetectable in the womb) such as testing saliva, urine, blood etc The Triad of Impairments is based on an assessment of core behaviours, history taking and observation in several settings. Yet the issues that I have just mentioned are often explored after the diagnosis which can vary on where you live in who gives the diagnosis in terms if it is a multi disciplinary team as set out by the National Initiative for Assessment and Screening in Autism (NIASA) report through the National Autism Plan for Children (Baird et al 2003) as many people are using and interpreting the guidelines ad hoc and this is causing unnecessary confusion and anger for many parents etc

Parental information may be supplemented by standardised observational measures such as the Autism Diagnostic Observational Schedule (ADOS; Lord et al, 1999). Various checklists are also available, including:

- Childhood Autism Disorder Rating Scale (Schopler et al, 1986)
- Autism Disorder Behaviour Checklist (Krug et al, 1980)
- An Autism Screening Questionnaire, which is derived from the ADI-R (Berument et al, 1999).

Autistic Spectrum Disorder is firmly on the increase and it is not just here in the UK either, as to why this is debated and whether it is better assessment/diagnosis, greater awareness etc is unclear. The numbers are startling, and we need to devote more resources to determining what is going on. The latest estimated figures from the National Autistic Society for children are below:

People with learning disabilities (IQ under 70)

(Note 1: Almost all of these people will require a high level of support throughout their lives)

<i>Children</i>	<i>Kanner’s</i>	<i>Other Spectrum Disorders</i>
	6,700	20,000
Total	26700	

People with average or high ability (IQ 70 or above).

(Note 2: Many, perhaps most of these people, will become semi or fully independent as adults but need understanding and help as children)

<i>Children</i>	<i>Asperger’s syndrome</i>	<i>Other Spectrum Disorders</i>
	48, 100	46,700
Total	94,800	
Overall Total	121,500	

Below is a table that provides the prevalence rates for Autistic Spectrum Disorder:

<i>People with Learning Disabilities (IQ under 70)</i>	<i>Approximate Rates per 10,000</i>
Kanner's syndrome	5
Other spectrum disorders	15
Total	20
People with average or high ability (IQ 70 or above)	
Asperger's syndrome	36
Other spectrum disorders	35
Total	71
Possible total prevalence rate of all autistic spectrum disorders	91

— Remember children with Autistic Spectrum Disorder become adults with an Autistic Spectrum Disorder; Figures have been corrected to the nearest 100.

There are no sharp boundaries separating 'typical' autism from other autistic disorders, including Asperger's syndrome. therefore going upon the figures I have just quoted are based upon the 2001 census and could potentially mean about 1:86 has an Autistic Spectrum Disorder and that could mean more people than with a physical disability, learning disability, sensory (blindness, deafness etc) disability and Autistic Spectrum Disorder is found across all races, cultures, creeds and nationalities.

1. (b) and doing so early enough?

Autism Consultancy Services believes this is clearly not the case. Early intervention is imperative. Early intervention refers to offering an Autistic Spectrum Disorder specific intervention at the earliest age possible. It is about applying a structured approach to the education of children with an Autistic Spectrum Disorder. Children who receive educational intervention before the age of four years have shown to significantly improve their chances of learning new skills and adapting to their environment, when compared with children who begin intervention at a later age. However what makes the argument more problematic is that it still remains comparatively rare for a child to receive a diagnosis of Autistic Spectrum Disorder prior to their fourth birthday even though the signs may be there but undetected or recognised, which can cause a dilemma for parents/carers through early intervention as by the child reaches their fourth birthday a child will have already gained or developed a number of skills and competences.

Research indicates that intervention should commence as soon as possible after diagnosis (Clunies-Ross, 1988), that early intervention prevents declines in intellectual development (Guralnick, 1998) and that early intervention leads to improvements in most areas of deficit in autism (Smith, 1999; Birnbauer and Leach, 1993; Jocelyn, Casiro, et al, 1998). One-on-one intensive intervention is the ideal teaching setting for children with an Autistic Spectrum Disorder. The needs and skills of children vary considerably, and no one program/method/approach will fit every child and trying to place a proverbial square peg into a round hole is unadvisable and not recommended as of the long term and adverse damage in most areas of development including adulthood which can lead to problems with anti social behaviour, the prison service/criminal justice system etc.

This does not have or necessarily mean an approach such as Applied Behavioural Analysis (ABA) or the Earlybird (Shields, 1999) or Help programmes offered by the National Autistic Society.

There are many approaches for Autistic Spectrum Disorder and research shows no one program being more effective than the other as each child must and needs to be seen as an individual throughout their life especially during their education, education is for life for people with an Autistic Spectrum Disorder, as Segar (1997) believes that "Autistic people have to understand scientifically what non-autistic people already understand instinctively." or "the best key to overcoming autism is understanding it"

The difficulty and frequent dilemma is what to do and how long to do it as whilst Autistic Spectrum Disorder is not diagnosed prior to two years (except in rare circumstances) but often children are diagnosed anything from four years up. Additionally a lot is happening in or minds and bodies prior to that age and parents and educators could be causing inadvertent problems by going through a process that can be traumatic, emotional and distressing, guilt ridden for all the family problems such as long term mental health and self esteem problems could be impending and it is often a case of the chicken and the egg in which comes first.

However with the correct/appropriate help including accurate, ongoing training on Autistic Spectrum Disorder (and not just a one day awareness course either) for all professionals that the child will come into contact with, no matter how small is imperative including professions like secretaries, caretakers, auxiliary personnel etc Whilst the Children Act encompassed with Every Child Matters (2003) through the autism exemplar talks about multi agency working, a common assessment framework, a common core of skills and knowledge, a workplace reform and professional development.

Regrettably these key areas are still not happening in many local authorities due to a number of reasons including trying to agree responsibility of where autism is in whether it is a learning disability or mental health disorder despite people with an Autistic Spectrum Disorder can have one or the other or in some cases both or some authorities see the word guideline and therefore feel it is not applicable to them as an authority.

The nervous system of a person with an Autistic Spectrum Disorder does not work in a balanced way and is under stress as it is more sensitive to sight, sounds, movement and touch than the nervous system of a person without an Autistic Spectrum Disorder. The bombardment of sensory information throughout the day means a person with an Autistic Spectrum Disorder is easily overwhelmed and this can result in challenging behaviour at school or after school when the child gets home. Furthermore when people with an Autistic Spectrum Disorder feel stressed, very tired, ill or worried, minor changes can be upsetting to them and cause tearfulness, anger or distress. It can be like this all of time for a person with an Autistic Spectrum Disorder hence their needs for routine and predictability.

Challenging behaviours are exacerbated by crowds, heat, noise, fatigue, illness, sensory overload and medication. A person with an Autistic Spectrum Disorder finds other people unpredictable as they can not always understand what is meant or what others expect of them, daily events can be uncertain and unpredictable. Change is difficult as the pragmatic use of memory experiences are compromised which makes it difficult to be adaptable and to anticipate what will happen. Challenging behaviour is those children who display behaviour of such intensity or frequency or duration that the physical safety of the child or those nearby is put at risk. That said "difficult or challenging behaviour is not a part of an Autistic Spectrum Disorder, but it is a common reaction of pupils with these disorders, faced with a confusing world and with limited abilities to communicate their frustrations or control other people". (Jordan and Jones 1998).

In all the literature I have read, the words 'challenging behaviour' and 'communication' difficulties seem to run together (Clements and Zarkowska 2000, Cumine et al 2000, Howlin 1998, Jordan and Powell 1999, O'Brien 1998, Smith Myles and Simpson 1998, Waterhouse 2000,). Whether it is an inability to process the verbal and non-verbal information given or an inability on the individual's part with an Autistic Spectrum Disorder to verbalise their needs or frustrations, both play an important part in the resulting challenging behaviour displayed.

Before being able to address challenging behaviour there is a need to identify and observe behaviour patterns taking note of specific details and behaviours when they occur, how often they occur, what level of communication is adopted and the resulting outcome ie the challenging behaviour displayed and how it is dealt with. Different methods of recording observations include ABC—Antecedent, Behaviour Consequence (Cumine et al 2000) STAR—Settings, Triggers, Actions, Results (Zarkowska and Clements 1994) TOAD—Talking out of turn, Out of seat behaviour, Attention seeking, Disruptive behaviour (Wragg 1994, cited O'Brien 1998).

Observation encourages the observer to be analytical and reflective about everything they do, how they do it and note everything they say and how they say it, the manner of their voice, the words used (O'Brien 1998). Whichever method of recording is used, the outcome of the resulting analysis should lead to implementation of appropriate strategies to help with the individuals challenging behaviour.

There is a need to ensure carers and professionals are consistent in giving simple and concise instructions, in most cases using the child's name so they are aware the instructions include them. Metaphors, colloquialisms and slang are difficult for the child with an Autistic Spectrum Disorder to understand. In some displays of challenging behaviour the individual with Autistic Spectrum Disorder can resort to shouting, screaming, hitting, pinching or kicking. It is important that staff work together and is consistent with the language they use to address any outburst of challenging behaviour within the classroom, including normal verbal and non-verbal language.

Social stories, Social Scripts and SOCCSS—Situation, Options, Consequences, Choices, Strategies, Simulation (Smith Myles and Simpson 1998) have been proven to help with social interaction of children with an Autistic Spectrum Disorder. All of these depend on having adults structure their behaviour through stories, pictures or role play and using effective communication skills verbal or non-verbal to improve what was a difficult situation/concept for the child to understand.

The repetition of the stories and the sameness being of paramount importance to the child. Once a difficult situation has been identified, social stories can be developed to explain and show the child how to behave next time to attempt to alleviate the challenging behaviour displayed. It is important that the stories are not presented when the challenging behaviour is occurring. The child needs to be reminded of the situation at calm moments of the day (Attwood 1998, Clements and Zarkowska 2000, Gray 1995 cited Howlin 1998).

For the child with an Autistic Spectrum Disorder a failure to develop the in-built mechanism, apparent in most children, of communication in general and verbal language results in an inability to function as well as others. It may present itself as a complete failure to learn to speak or use gestures or alternatively as an acquisition of words or gestures/signs but not used in a communicative way. For some children this can lead to displays of what others may see as challenging behaviour (Clements and Zarkowska 2000). Although some children with Autistic Spectrum Disorder are non-verbal, this does not mean they are non-communicative. Communication for a child with autism may present itself in many different ways. Many attempts to communicate may be construed as behavioural problems and may not always be socially acceptable and what they are attempting to communicate may prove difficult to determine.

The introduction of the Picture Exchange Communication System or the Treatment and Education of Autistic and related Communication Handicapped Children programme for a non-verbal or verbal child with an Autistic Spectrum Disorder can assist communication and help alleviate some of the possible frustrations associated with challenging behaviour (Clements and Zarkowska 2000, Cumine et al 2000, Jordan and Jones 1999, Jordan and Powell 1998, Powell and Jordan 1997,).

The Picture Exchange Communication System provides a tool for early communication by offering an opportunity to quickly develop 'real spontaneous communication' (Cumine et al 2000, Jordan and Jones 1999) and the Treatment and Education of Autistic and related Communication Handicapped Children programme helps to introduce routine and stability to what can be, for many children with an Autistic Spectrum Disorder with hyper sense sensitivity, a very confusing and over stimulating classroom situation (Cumine et al 2000). It sets out to provide visual information, structure and predictability.

Children/young people with a high functioning Autistic Spectrum Disorder or Asperger's syndrome (which are not the same condition as felt by the members on the Autism Consultancy Services database) often have average or above average intelligence based on IQ and this is causing a whole range of problems across all areas of society from education, health, welfare support and financial support/assistance (through the Department for Work and Pensions and the Benefits Agency) often such people may have good intelligence but still lack, appreciate and understand their own and other people's usage of skills/concepts in that they are very literal, have little appreciation of abstract concepts etc.

For example children with an Autistic Spectrum Disorder can have little sense of danger, self help skills—cooking, cleaning, understanding the concept of money, differentiating between hot and cold, unable to feel/describe when in pain generalisation, problem solving, planning, executive functioning including skills, transferring from one situation to another (including theory into practice) and due to the impairment in imagination as described by Wing a child with an Autistic Spectrum Disorder may get confused when something like the school hall that can be used for PE and also for eating his lunch etc

Play for children with an Autistic Spectrum Disorder is also impaired as well as being a crucial area of development; play is a diverse and complex behaviour that is viewed as central to the normal development of children (Jordan and Libby, 1997). However, it is very difficult to come to a concise definition of what is meant by play. Dictionaries vary in the definitions they offer, most, however, seem to imply some kind of fun, a way of entertaining oneself. Garvey (1977) expands on this, listing play as having the following characteristics: Below are two short lists that lists some of the strengths and weaknesses and neither list is meant to be exhaustive.

- Play is pleasurable and enjoyable.
- Play has no goal imposed on it from the outside.
- Play is spontaneous and voluntary.
- Play involves some active engagement on the part of the player.
- Play has certain systematic relations to what is not play. It can be contrasted to non-play.

A child's play goes through a number of developmental stages (Boucher, 1999):

- Sensory motor play
- Exploratory and manipulative play
- Physical play including rough and tumble
- Social play
- Pretend (make-believe) play.

It is sometimes suggested that there are two types of pretend play. So, for example, Libby et al (1998) differentiates functional play (eg pushing a toy car along the carpet and making a brmmmm noise) from symbolic play, which involves treating an object or situation as if it is something else (eg pretending a banana is a telephone).

In Libby et al study, children with an Autistic Spectrum Disorder did not demonstrate significantly less functional play than children with Down syndrome or young children with typical development. Children with an Autistic Spectrum Disorder did however, have difficulties in the production of symbolic play although there was evidence of some capacity to engage in symbolic play, albeit mainly object substitution. Not all researchers make the distinction between symbolic and functional play.

A child with an Autistic Spectrum Disorder will rarely be perceived as the playing child (Beyer and Gammeltoft, 2000) and their play can be impaired at all developmental stages. Most research, however, has concentrated on pretence, especially symbolic play. Research has shown that for young children with an Autistic Spectrum Disorder, sensory motor play dominates beyond the verbal mental age, at which it normally declines in infants without an Autistic Spectrum Disorder (Jordan and Libby, 1997). Further, having missed out the early experiences of manipulation and combination enjoyed by children without an Autistic Spectrum Disorder, toys and objects are used in an inflexible way.

For example, a child with an Autistic Spectrum Disorder may be preoccupied with spinning the wheels on a toy car, rather than playing a racing or driving game. Roeyers and van Berckelaer-Onnes (1994) describe children with an Autistic Spectrum Disorder as missing the curiosity of typically developing

children. Roeyers and van Berckelaer-Onnes concluded that children with an Autistic Spectrum Disorder play behaviour is often limited to simple manipulation, the quality of their play is lower than that of non-autistic children of comparable mental age and (spontaneous) symbolic play is usually absent or impaired.

Some children with an Autistic Spectrum Disorder do not give any indication that they want to play with other children, preferring to play by themselves; other children would like to but they can have great difficulty in indicating this wish. All have difficulty in getting the other children to play with them. Jarrold, Boucher and Smith (1996) found that not only are children with an Autistic Spectrum Disorder impaired in their production of spontaneous pretend play, but that they also spend significantly less of their time compared with controls in functional play (eg making a doll walk). They argue that the finding that children with an Autistic Spectrum Disorder show impaired levels of functional play is a problem for Leslie's metarepresentational account (Leslie, 1987) because functional play does not require metarepresentational abilities, but is nevertheless impaired.

Similarly, Williams, Reddy and Costell (2001) found that in contrast to matched controls (children with Down Syndrome and typically developing children), children with an Autistic Spectrum Disorder did not normally engage in elaborate functional play (eg stirring a spoon in a pot). Instead their play consisted of simple functional play (eg placing a spoon in a pot but not stirring it). The control groups divided their time equally between these two types of play. Children with an Autistic Spectrum Disorder also produced fewer different acts and spent less of their play time in functional play that was new, when compared with the control groups.

In summary the play of children with an Autistic Spectrum Disorder can, therefore, be seen as impoverished. As Sherratt (1999) postulates, the difficulty that children with an Autistic Spectrum Disorder experience in pretend play arises from difficulties they have in both the fluid organisation of thought processes and in communicating these thoughts to others. Further, disturbance of play in a child with an Autistic Spectrum Disorder may lead directly to disturbance in all aspects of development (Jordan and Libby, 1997) although it could be that an inflexibility of thought processes causes an impairment in play and also an impaired development of other skills (Sherratt, 2001a). Sherratt and Peter (2002) suggest that teaching children with an Autistic Spectrum Disorder to play may increase a fluidity of thought and reduce conceptual fragmentation. In particular, if play is taught to young children it may assist them in reducing repetitive and rigid behavioural patterns and encourage communication development.

It is also a good idea to recognise in line with current educational psychological research that children with an Autistic Spectrum Disorder will benefit from formal training in "executive functional skills" ie specific skills like thinking and remembering effectively and basic skills such as sequencing events and understanding timetables. That said it has not been determined what exactly constitutes executive functions it could include:

- Working memory (holding information in mind while doing something else, and then being able to act upon that information)
- Organisation (categorisation, management of items in space and time)
- Planning (foresight)
- Prospective memory (remembering to remember)
- Follow-through (remembering to do)
- Arousal (control of mood, focus and energy)
- Activation (getting started)
- Sustaining alertness and effort
- Behavioural inhibition (stopping oneself before or during an activity)
- Prioritising
- Problem-solving
- Inhibiting verbal and non-verbal responding
- Cognitive flexibility (assessing options, dealing with ambiguity, shifting perspectives)
- Quickly retrieving and analyzing information
- Sequencing (thinking sequential steps through)
- Strategic thinking
- Self monitoring (being aware of one's thoughts, feelings and behaviour, and the impact of that behaviour on others)

Subsequently those who have problems in executive functioning likely have problems in important areas of life functioning includes:

- Getting started on boring and mundane tasks (procrastinating)
- Remember what one has to do (out of sight and mind)
- Underestimating time to complete tasks.
- Awareness of time, and passage of time

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- Handling frustrating situations
 - Offending others by being unaware of socially appropriate behaviour in given context
 - Frustrating others by interrupting, taking over, completing sentences, and being impatient
 - Handling negative emotions (acting on emotions like anger, when calming down is more beneficial)
 - Being attentive in boring or slow moving situations)
 - Thinking through the potential consequences of actions before acting
 - Remembering
 - Completing long-term projects
 - Finishing the last parts of a project, which are tedious and relatively unrewarding
 - Jumping into new exciting, creative activities which are not well thought out
 - Variable motivation

For a number of people with an Autistic Spectrum Disorder and their families/carers the lists above will be identifiable as people with an Autistic Spectrum Disorder have significant problems and differences within executive functioning. The frontal and prefrontal regions of the brain are most involved in behavioural inhibition other executive functions. It is the outer surface of the front of the brain, behind the forehead and eyes. There is typically lower metabolic activity and regional cerebral blood flow in this area when someone is showing problems with executive functioning.

Strengths often seen in Autistic Spectrum Disorder

- Construction tasks eg puzzles
- Rote memory—good at remembering things that other people have forgotten
- Adherence to activity routines
- Ability to process visual displays
- Splinter skills eg artistic or musical talent.
- Honest
- Determined
- Aware of sounds that others cannot hear
- Kind
- Forthright
- A loner (and happy to be so)
- A perfectionist
- A reliable friend
- Observant of details that others might not see
- Humorous in a unique way
- Liked by adults

Weaknesses seen in Autistic Spectrum Disorder:

- Understanding intention of others.
- Knowledge of social convention and interpersonal interactions.
- Ability to express emotions in conventional manner.
- Overwhelmed by sensory stimulation.
- Difficulty with change.
- Making mistakes
- Making friends
- Taking advice
- Managing their anger
- Handwriting
- Avoiding being teased
- Tolerating specific sounds
- Explaining thoughts through speech
- Coping with surprises

All in all Autism Consultancy Services is not against inclusion and integration—but we believe it needs to be done correctly over time, reviewed and methodically as one size does not fit all, children and young people with an Autistic Spectrum Disorder have very specific/individual, profound, complex and varied needs and when doing your washing you wouldn't place your colours within your whites and therefore children/young people with an Autistic Spectrum Disorder need specialist environments that are unique to the individual.

Furthermore as a result of the lack of joined up thinking and planning and the continued ignorance and arrogance towards Autistic Spectrum Disorder including false perceptions that an Autistic Spectrum Disorder is a psychiatric, mental health or personality disorder, it can only affect children, children who may withdraw into a world of their own and all people with an Autistic Spectrum Disorder are extraordinarily talented/gifted in music, science, arts, maths etc Parents are using the legal system more and more through the courts, tribunals and other hearings against professionals and the local authorities and being scrutinised unnecessarily for conditions such as Munchausen's Syndrome by Proxy.

Munchausen's Syndrome by Proxy "is a condition manifest by persons feigning or inducing illness in themselves for no other apparent gain than adopting the sick role and thus exposing themselves to painful and sometimes damaging and disfiguring medical procedure. The perpetrator is often a parent and typically the mother. However, there have been cases where the father acts as perpetrator. Perpetrators show an avid interest for hospital care and usually have experience in the medical field; Munchausen's syndrome is present in 10% of such perpetrators.

Munchausen's Syndrome by Proxy is a sort of enigma—which brings me to my original purpose; a quest for the truth about Munchausen's Syndrome by Proxy. The most important question for me being: what causes Munchausen's Syndrome by Proxy? It is a disturbing disorder, which is closely tied to behaviour and, on the surface, loosely connected to the brain. No concrete psychological or neurological data exists on the causes of child abuse.

Most theories on the causes of child abuse point to past abuse, family dysfunction and depression—the same symptoms existing in Munchausen's Syndrome by Proxy perpetrators. However, it seems far too simple to write off Munchausen's Syndrome by Proxy as child abuse and ignore the psychological components of the syndrome, such as the perpetrator assuming the role of a sick individual by proxy.

Information on Munchausen's Syndrome by Proxy is unanimous on several basic points: the identification, symptoms of the perpetrator and consensus (more or less) that is at least, a form of child abuse. The vast black hole of diagnosis, treatment for the perpetrator and victim and concrete warning signs poses a great risk to the victims. The perpetrators are not overtly inadequate caretakers, but in fact the very opposite. Furthermore, coupled with their ability to deceive and lie to obtain their desired ends creates difficulty in diagnosing Munchausen's Syndrome by Proxy for doctors. The perpetrator is most likely deeply caught in their psychological, internal experience, while the child suffers through physical, external experience.

1. (c) *Do we need categorisation of disability?*

The fact is yes we do the sooner the better. A person with an Autistic Spectrum Disorder can have normal or above normal intelligence, but have serious deficits in the areas of communication and social interaction. Testing of cognitive abilities is difficult in light of the communication and social impairments. There can be tremendous differences among people with an Autistic Spectrum Disorder. Furthermore once again when we do our washing we don't put our colours in with our whites and vice versa as we have little or no idea on how things might come out and we can't afford to take a chance in case the damage is irreversible or irreparable.

The measured intelligence of individuals with this disorder ranges from "IQs" of less than 70 to more than 130. Those who carry a diagnosis of an Autistic Spectrum Disorder, but not mental retardation, can still experience significant learning problems and will benefit from accommodations in the classroom or in testing situations. Neurological research is just beginning to document the exact nature of an Autistic Spectrum Disorder. Certain cell groups in the brains of children and young people with an Autistic Spectrum Disorder are abnormal in size or proportion, causing problems in sensory perception and linking information from the various parts of the nervous system.

Children and young people with an Autistic Spectrum Disorder may not see the "big picture," or recognise all of the cues in their environment. Some studies have shown that children with an Autistic Spectrum Disorder process auditory information and respond to visual stimulation at different rates. For such learners, their environment appears like a motion picture with the sound track running at the wrong speed. The most difficult problems deal with the child's inability to recognise and respond to the behaviour and communication of others.

There are several educational model programs designed for children with an Autistic Spectrum Disorder, eg Picture Exchange Communication System), Higashi, Applied Behavioural Analysis), SPELL, (Structure, Positive, Empathetic, Low Links), Auditory Integration Training and Sensory Integration Therapy etc each of which may be tailored to the needs of the child. One example is the Treatment and Education of Autistic and Related Communication Handicapped Children. The Treatment and Education of Autistic and Related

Communication Handicapped Children program which offers structured teaching in a centre-based and community-based setting. The Treatment and Education of Autistic and Related Communication Handicapped Children Model, like many other programs designed for students with an Autistic Spectrum Disorder, utilizes clearly defined work areas, visual schedules to provide organisation, and visual prompts to sequence steps in a task.

There are other treatment options and programs available to individuals with an Autistic Spectrum Disorder, medical and dietary interventions are discussed elsewhere. It is important to remember that no one option or program will fully educate children with an Autistic Spectrum Disorder. Intervention must be based on the strengths and challenges of each individual and it should combine selected components from a variety of intervention models.

What makes understanding an Autistic Spectrum Disorder so difficult, and consequently and Autistic Spectrum Disorder research and practice so compelling, is the wide-ranging complexity of the disorder. Autistic Spectrum Disorder practices will need to be considered under a holistic approach. Everyone with Autistic Spectrum Disorder is different and unique and will undoubtedly change as one ages and is exposed to ever-changing biological and environmental influences.

In addition, the classical psychological diagnosis of an Autistic Spectrum Disorder is a description of associated behaviours, which though quite useful may hide the fact that several different causes could have an outwardly similar manifestation of symptoms. An Autistic Spectrum Disorder is also unique in that the related research also exists on spectrum, from “basic” (medical and biological) science to “applied” (behavioural, communication, educational, etc.) science and everything in between.

It could be argued that the educational needs of children with Statements of Special Educational Needs are laid out in Section two of the Statement of Special Educational Needs and are therefore known to the Local Education Authorities and Autism Consultancy Services argues that the Statement of Special Educational Needs is drawn up by the Local Educational Authorities from evidence submitted and is selective. This view is borne out of the fact the bulk of the ongoing work that Autism Consultancy Services provides is trying to get the Statement of Special Educational Needs correct from the child’s point of view via the parental submission to the statements and the parent’s unique and invaluable knowledge of their own child.

This localised position is backed up by the increasing numbers of parents nationwide who are compelled to take their Local Educational Authority to the Special Educational Needs Tribunal (which back in 2000 was around 18% of the 2100 or so cases per annum are being brought by parents of children/young people with an Autistic Spectrum Disorder). Furthermore it is also evident there are issues around inclusion which do not seem to find a place on statements, for example there is a reluctance on the Local Education Authorities part to address in detail problems around transport, the detailed specification of speech and language therapy or occupational therapy in section 3b of the statement (on the basis they are health matters) and such matters for the child at unstructured times.

Many children/young people with a diagnosis of high functioning Autistic Spectrum Disorder and/or Asperger’s syndrome miss out significantly due to their intelligence being average or above average and when their prognosis is presumed better and will achieve. Whilst this is true it is imperative to recognise that just because someone appears more articulate doesn’t necessarily mean they are in that some children with a high functioning diagnosis will become like Jekyll and Hyde in that they will hide and conceal their problems at school but at home will become distressed which often has a bearing on the whole family including the child’s siblings and even extended family.

People with a high functioning Autistic Spectrum Disorder usually have fewer problems with language than those with a classic Autistic Spectrum Disorder, often speaking fluently, though their words can sometimes sound formal or stilted. Once again problems such as planning, transferring skills from one situation to another (including theory into practice) appreciating another’s needs and views, have stereotyped behaviour, unable to separate fact from fiction and vice versa, a co-morbid diagnosis such as Attention Deficit (Hyperactivity) Disorder or that they have macrocephalus (a larger than normal head size), or epilepsy etc.

Additionally many children/young people with a high functioning Autistic Spectrum Disorder will be left out in team games both through the National Curriculum and break time and left out once more when they reach adolescence when peers start to take an interest in sexual/relationship related matters and as some people with a high functioning Autistic Spectrum Disorder are aware of their difficulties it has been noted that some contemplate suicide or self harm.

It needs to be noted that approximately 20%–30% of children/ young people with an Autistic Spectrum Disorder have epilepsy which is particularly prone around adolescence and puberty.

Furthermore it is unknown how many people with Autistic Spectrum Disorder also have AD(H)D as a dual diagnosis including diagnoses like Down syndrome or Scotopic Sensitivity Syndrome, Landau Kleffner Syndrome, irritable bowel syndrome, Prader-Willi Syndrome. People with an Autistic Spectrum Disorder do not have a personality disorder such as manic depression, schizophrenia and linking the two together is unnecessary and a dangerous combination in terms of assessment and management. Regarding adolescence this is a crucial area for all those with an Autistic Spectrum Disorder as within everyone else in society it is a time that shapes and makes us who we are in our adult years.

Whilst people with an Autistic Spectrum Disorder go through the physical signs of puberty at a normal age the difficulties become most apparent in from my own research some children have shaved off their pubic hair due to the fear of change, also get obsessed about germs and self cleansing and if they see a bit of dirt on them or something else such as food they panic including under things like finger/toe nails etc The subject of Personal Social Health Education needs to be taught in a careful, sensitive and diplomatic way including when addressing the issue of sex as in my experience most people with an Autistic Spectrum Disorder will either be more familiar with slang terms or the correct names for parts of the body etc but very rarely understand both and this in itself can cause confusion.

To the same token some people with an Autistic Spectrum Disorder may refuse to have a shower with their peers after a games lesson, the issues around relationships also are a problem and discovering sexual organs and their sex drive can all pose a problem as many people with a high functioning Autistic Spectrum Disorder and Asperger's syndrome want a relationship but have very little clue how to go about it, how to sustain and maintain it especially the social side from the school disco, to going out and as a result can be open to victimisation and abuse (including sexual), this period of uncertainty within our minds and bodies can carry on and in my research carries on at least until the person reaches their early—mid twenties.

Since the introduction of the Internet many people with an Autistic Spectrum Disorder may go into chat rooms and be unable to pick up, note and recognise innuendos and see people they talk to in chat rooms as their friends especially those they haven't met in person, when I have broached the subject of paedophilia etc with some of my young people I am often ignored as for example comments come out "it won't happen to me".

Going back to the social side a number of people with an Autistic Spectrum Disorder want friends but often on their terms and where they can talk about their thing which is OK after a while but may become tedious and too much for the listener and the child with an Autistic Spectrum Disorder might not pick up on the social cues even the obvious such as yawning and walking away.

The biggest problem for a number of people (including adults) with an Autistic Spectrum Disorder is that to the naked eye is that they look normal and may sound normal for a while and it is only when you engage the problems start to become apparent and noticeable. To some people this could be fascinating and intriguing when the young person could be seen as freaky or as a little professor or mildly eccentric but this could be problematic as much as it is complimentary when coming into contact with people like the police, the criminal justice system which is a very, very big issue and needs addressing properly—all in all what is cute at six might not be cute at 16.

1. (d) *Rise in the number of pupils with non-statemented Special Needs—Causes and potential cures.*

There is a number of reasons of why pupils with non statemented special needs is rising is because the criteria for obtaining a statement of Special Educational Needs has become ad hoc in terms of where you live as different Local Education Authorities have different criteria or may be bending the rule or if the LEA feels the child does not have specific needs. In my conversations with people on my mailing list it has also become apparent that the moment parents/carers mention a diagnosis along the autistic spectrum the Local Education Authorities clamps up and either refuses any additional help whatsoever or even questions the diagnosis.

The biggest factor for the causes is that money and resources (existing resources) can and should be made available—hence failing to look and appreciate the individual, putting all the eggs into one basket, or in some cases putting your colours in your whites and will have no real idea what you will get until you open the door of the washing machine. Whilst Autism Consultancy Services recognises and appreciates we are all governed by time, money and resources but placing square pegs into round holes is not an answer for short, medium or long term.

Due to most Local Education Authorities, schools and teaching staff and the lack of accurate, regular and consistent training they have little or no understanding of what Autistic Spectrum Disorder is all about. Over the last years and since schools have been given funds through devolution to schools each school has a different idea on how the funds can be spent.

Regrettably I have seen many schools that place the money aligned for Special Educational Needs has been mixed with other funds and a variety of things have been purchased for example sports facilities, a new member of staff that has no direct contact with the children with Special Educational Needs, a new computer system and so on.

The biggest problem is continuity and consistency within local authorities and I have noticed a difference since devolving of funds is that what a child may get in a primary school may not be carried through to secondary school particularly since the decision was made to reduce the numbers of Statements of Special Educational Needs. In the rare cases where Statements of Special Educational Needs are issued they are not maintained or updated with new information, advice, and evidence or through the Individual Education Plans either with the school or the Local Education Authority.

What makes Autistic Spectrum Disorder unique is that just because a child appears to have grasped/understood a concept does not necessarily mean they have, for example if someone asked a child if they wanted a drink of orange or pineapple juice the child may say either the first or last thing that they heard

unaware of what was being asked and may repeat through echolalia and this is not specific to choice and decision making it can also extend to when the child has an assignment on comprehension in that they may be able to read well but as to understand and then take things out other than what someone has written and quote them directly either in written and/or verbal contexts. It has also been noted that children with an Autistic Spectrum Disorder will impersonate characters from films, cartoons in every sense by saying things the character says and dressing up like the character and then in every setting.

A successful Individual Education Plan needs to ask the following questions:

- Reviews the plan
- Checks whether the things in it are happening
- Looks for ways to make sure that those that aren't happening do get done
- Agrees who will do what and by when
- Identifies how people will know if the plan is no longer working and needs a further review

Once the following has been answered we then need to look at the following model:

- Essentials (or non-negotiable)—Things that must happen if the person is to achieve their lifestyle and maintain their well-being.
- Important (or strong preferences)—Things that will make a significant difference and without which life may be tolerable but little more.
- Pleasures (or highly desirable)—Things that the person would like to have (or not have) in their life to make it more pleasurable and satisfying.

The answer to this is to restore Statements of Special Educational Needs and have an independent body that is responsible to Parliament but not just the Department for Education and Skills; it needs to encompass other departments such as the Department of Health. When it comes to parents and carers applying for benefits such as Disability Living Allowance, Incapacity Benefit, Mobility cars that when a decision must be based on the diagnosis and not on something like IQ or other tests that look at intelligence.

If we continue the downward spiral of removing and/or reducing the number of Statements of Special Educational Needs how are we going to assess the needs of the child and ensure that guidelines that have been drawn up are followed and adhered too. It is well documented that parents and carers of all children who have a disability have to fight and struggle for everything and just because their child turns 18 do not mean the problems go away or disappear including that Autistic Spectrum Disorder is a disorder that only affects children.

It is a problem that needs addressing that when a child becomes 18 parents have an additional struggle with local authorities in whether their son/daughter will come under the learning disability or mental health services as well as keeping and securing funding for the rest of that person's life including long after our parents have become unable to care or passed away.

When we become parents we have no handbook and when we have a child with a disability everything that we have been taught from our parents and done with other children with a disability we often learn as we go along and need support from friends, family and professionals and not to be put down, condemned, to be disbelieved or patronised.

Having a child with a disability such as an Autistic Spectrum Disorder is harder than most due to the complexities, variability and the child can show furthermore there are many contradictions within an Autistic Spectrum Disorder in that people with an Autistic Spectrum Disorder can do some things but not others. Once again there is a myth that all people with an Autistic Spectrum Disorder are talented in areas such as maths, art, music etc but the actual figure of people with an Autistic Spectrum Disorder who are exceptionally talented is 1% of all people with an Autistic Spectrum Disorder. Personally I believe a talent is only a talent if it is useful for the individual and whilst it can be used as a way to engage and communicate with the person with an Autistic Spectrum Disorder it can also be isolating, soul-destroying problems where people exploit and use the talent to the extreme which can lead to bullying etc.

There is no consistency within authorities and it has become common practice to place people with a high functioning Autistic Spectrum Disorder in the mental health services which causes no end of problems as psychiatrists often use medicinal drugs that often cause Tardive Dyskinesia and mental health problems including addiction to medicinal drugs and not just anti depressant drugs either which could cause damage to the gut, kidney and liver of the child/young person with an Autistic Spectrum Disorder, all in all Local Education Authorities, schools and the system needs to recognise the needs of the child, not the condition be driven as needs led to the individual as a person, and his or her Autistic Spectrum Disorder. It is regrettable that most General Practitioners don't understand Autistic Spectrum Disorders either and will either refer to a psychiatrist and/or prescribe drugs when all the person may need is someone like a counsellor.

2. (a) *what steps can be taken to make the Statementing process less adversarial?*

We need to ensure that good practice is based upon evidence and built upon, whilst this may sound bureaucratic there needs to be some reviews of statementing and to ensure that all LEAs are singing from the same hymn sheet.

Within each local authority and Local Education Authorities there needs to be a body set up which has representatives from the council including councillors as the gap between Westminster and local authorities continues to widen hence helping to increase the postcode lottery also within the independent body there needs to be people who have ongoing experience as well as those people who have worked hands on. Perhaps those who provide education and care for children with Autistic Spectrum Disorder need to be working towards a charter mark that shows good practice (but is reviewed every three years by an expert panel) and is recognised in society like the Kitemark.

The whole statementing process needs to be simplified and to help parents understand there needs to be an emphasis in understanding the process, what it means as they go through it and guidelines and support mechanisms where they can challenge the Local Education Authority without feeling threatened or intimidated. Furthermore there also needs to be a department within government that works with the Department for Education and Skills that links in with other educational organisations including those in the private/voluntary sector and not just the big organisations either as there is a lot of knowledge and expertise out there that can and needs to be tapped into and at the moment it is underused and disvalued.

There also needs to be a process that speeds up the process in that once a child has received a diagnosis there doesn't need to be further assessments if joined up thinking and planning is working correctly as why can't educationalists assess educational needs when making a case for diagnosis, in my experience 95% of children who are diagnosed with an Autistic Spectrum Disorder will invariably need a Statement of Special Educational Needs which should list and name all the needs and not just those that could include needs met by other agencies including the Department for Work and Pensions and the Department of Health.

2. (b) *How can we increase parental trust in Statementing whilst making it less bureaucratic?*

Parents would trust an independent body more than an agenda-run Local Education Authority which is based on funding and money more so than needs and how those needs can be met effectively and accurately. Furthermore Local Education Authorities need to recognise the individual, the needs of the person as they are to each person and not solely based upon a text book, website or journal etc

Whilst Autism Consultancy Services feels it is OK to use the above as reference and to check out facts and as a guide but not to see all people with an Autistic Spectrum Disorder as the same and with the same needs. Another area to make statementing less bureaucratic is to communicate on a regular basis and more importantly on a consistent and honest and equal platform. It may also need to be possible to use staff time more effectively if staff were encouraged to work different hours as many parents who work are unable to phone or make contact with Local Education Authority personnel during the day or get time off to attend meetings etc Statements of Special Educational Need need to be updated in conjunction with Individual Education Plans as they are not being maintained or amended particularly when the child is going through the transition stages including between primary and secondary schools and even changing basic information such as the address of where the child lives.

All in all communication needs to extend to all parties and agencies including the service that is providing the support, education and provision. Local Education Authority personnel also need to stop putting a kybosh or their own feelings to make parents feel guilty for their views or beliefs. Parents are experts of their children; they know their children better than anyone else and within their unique knowledge and expertise they know what works, doesn't work and how effective or ineffective things may be and whilst trial and error is how we all learn it is important to recognise that mistakes will occur but there must be a balance struck when the costs and risks are being learnt which can be extended to a risk assessment and the ultimate decision must be made by the parents without continual harassment and questioning of issues.

2. (c) *How can we ensure that the Statementing process is conducted even-handedly across the UK?*

We can ensure that we don't use the one size fits all model that has been used excessively over few the last years, this can be extended to disabilities/special educational needs too. All children/young people are individual and how their statement is drawn up must be individual. When taking advice on Statements and how provision can be met we need to take evidence from all quarters including external agencies across the voluntary, private and public sectors.

Statements need to be regulated and not seen as an expensive part of Local Education Authority budgets, for children with an Autistic Spectrum Disorder it is important to recognise they will become adults with an Autistic Spectrum Disorder, as there is too much suffering from discrimination in terms of education for ageing, linked to the failure to recognise their specific needs . . . There are many fine lines between personality and an Autistic Spectrum Disorder, it might not be possible to identify and separate the two at any time or within any one person but it is important to work with the whole person as to dealing with the two as separate identities as it is almost inevitable they will overlap. If a mapping exercise is to be conducted

to obtain a picture of what is going on, what is happening and what needs to be done it needs to be done accurately and impartially by listening to all views, and ensuring feedback is constructive and made available for those that want and need it.

Local authorities need to be able to share information and advice more easily and through regional forums. Finally if a child moves from one authority to another the Statement of Special Educational Need must go with the child and the needs set out must continue to be met based on the evidence, due to the problems with change—particularly short term and unannounced change for many children/young people with an Autistic Spectrum Disorder there may need to be additional support put in place for a while until stability is restored, as to how long to maintain this additional support it is similar to how long is a piece of string?

2. (d) *Is there an alternative to Statementing that will provide the same certainty and security of provision for children?*

No as long as Statements of Special Educational Needs identify real needs for the person, Statements also need to be specific and accurate as well as amended regularly by continual advice from all areas including the parents. Local Education Authorities and personnel need to be checked, reviewed and evaluated for such through an independent body which can work along side the Office for Standards in Education. Statements of Special Educational Needs need to be encouraged and used by colleges and universities for when young people are going through the further/higher education system as in my experience many colleges and universities are ill equipped to support and help people with an Autistic Spectrum Disorder.

As personnel in learning support centres and lecturers don't always understand the real issues and instead see the person as an adult and the ownership for all issues including those that are non-academic eg socialising during breaks, looking for somewhere to live after leaving halls, finding the local amenities in the community as well as ensuring they attend lectures, meet deadlines for assignments and due to many people with an Autistic Spectrum Disorder being unaware of their specific needs or how to explain them in a way in which they understand and can be understood which relates to the problems of abstract thinking etc,

Furthermore many people with an Autistic Spectrum Disorder have short term concentration and attention spans people with an Autistic Spectrum Disorder may forget to attend lectures or go for extra help/support or in some cases won't go at all particularly those with a high functioning Autistic Spectrum Disorder feel they are "sponging" or "scrounging" off the system when it needs to be encouraged that we all need help of some help may it be financial, practical or emotional or a combination.

In my experience university and college life mainly focuses the on academic and performance of children where many children with Special Educational Needs will not be able to reach or sustain academic qualifications as their peers. Furthermore the information on final Statements of Special Educational Needs if done properly, accurately and correctively is a good template that parents can refer too when clarifying and/or confirming the relevant sections in a chronological order—ie if it is not broken why fix it?

2. (e) *Should LEAs continue to have responsibility for drawing up Statements?*

A totally 'independent' national governing body is needed (perhaps having charity status)—its panel drawn from experienced Special Educational Need/disability organisations such as Independent Panel for Special Educational Advice, Children with Disabilities, Network 81 etc Also included should be representation from Special Educational Needs specific voluntary organisations, such as Autism Consultancy Services and/or Autism in Mind. The Government could review this on an annual basis in conjunction with local authorities.

It is well documented and researched that when parents have a child with additional needs or a disability there is a constant fight and struggle for most things eg education, respite, equipment etc Is it possible or feasible that when the child is going through the assessment and diagnostic process that professionals could work collaboratively and cohesively to help parents through a minefield of mazes, confusion and stress to help signpost and direct them to people in welfare support, social services, respite care, organisations that work in the disability field (not just national organisations either as most national organisations have local branches, affiliates etc) and organisations that provide equipment etc.

If Local Education Authorities are to continue being responsible for Statements of Special Educational Need, there still needs to be an organisation that can oversee the process and ensure the statements are accurate, maintained, not based on funding and services that are the cheaper option. Provision must be user led and services must accommodate all the needs of the person and not the person over their needs. Within Part two there needs to be detail and description of the Autistic Spectrum Disorder which are described clearly, thoroughly and in a way that can be understood by all parties. Additionally it should set out unambiguously the nature and severity of the needs in all settings and not just in the classroom and include play/break time particularly for those with an Autistic Spectrum Disorder with their problems around unstructured times.

Within the area of the Statement of Special Educational Needs where and when setting out the provision it must be made clear:

- The appropriate facilities, equipment and staffing arrangements.
- The appropriate (including sensory and non-sensory) modification to the curriculum.
- The appropriate exclusions from the curriculum.

Within the provision there is a need for clear, honest and regular Individual Education Plans Individual Education Plans with clear ongoing targets that show progress of short, medium and long targets. These targets need to be based on the child with his/her need and not needs and the child, in order to have a successful Individual Education Plan the Individual Education Plan is ongoing and ideally is ongoing and as mentioned earlier for the person with an Autistic Spectrum Disorder and their difficulty of transferring skills from one place to another can Individual Education Plan targets be developed for when the child is at home.

3. (a) *Is the Government right to allow the continuation of a programme of closures and integration?*

The terms mainstreaming and inclusion are often used interchangeably in education today. This inconsistency in usage has led to some confusion about what educators mean when they talk about inclusion or full inclusion. Mainstreaming is the practice of educating the disabled student in the general education classroom. Inclusion is a newer term used to describe the placement of students in regular classes for all or nearly all of the school day; mainstreaming is often associated with sending a student from a special education class to a regular class for specified periods. Although in some inclusion models students are mainstreamed only part of the day, students in full inclusion programs remain in the general classroom for the entire day.

Throughout my evidence I have talked about whether to use “delusion” or “illusion”. Delusion means “a mistaken idea or belief”. Illusion a ‘false appearance or deceptive impression of reality’. They are synonyms—but we have chosen “delusion” because it is stronger—below are the three Common Delusions:

- Inclusion means that everybody must love everybody else or “We must all be one big, happy family!” Sometimes this delusion pushes people into pretending, or wanting others to pretend, that real differences of opinion and personality don’t exist or don’t really matter.
- Inclusion means everyone must always be happy and satisfied or “Inclusion cures all ills. The delusion that Inclusion equals happiness leads to its opposite: a pseudo-community in which people who are disagreeable or suffering have no place unless the group has the magic to cure them. Groups trapped in this delusion hold up a false kind of status difference that values people who act happy more than people who suffer. This delusion creates disappointment that Inclusion is not the panacea.
- Inclusion is the same as friendship or “We are really all the same”.

Friendship grows mysteriously between people as a mutual gift. It shouldn’t be assumed and it can’t be legislated. But people can choose to work for inclusive schools and communities, and schools and agencies and associations can carefully build up norms and customs that communicate the expectation that people will work hard to recognise, honour, and find common cause for action in their differences.

Going upon that so what is integration, it is “To Make or Become Whole or Complete” or

“To Bring Parts Together into a Whole” all too often many people get the words inclusion and integration confused or mixed up when really they are very different. To put things into context I have defined the two words below:

- Inclusion means providing all the features and arrangements that allow everyone to access and participate in their environment in advance of any stated need. It is a proactive, anticipatory approach intended to facilitate as much independence as possible.
- Integration means providing certain features and arrangements that allow some people to access and participate in their environment in limited circumstances and in reaction to a stated need. It is a reactive, non-anticipatory approach, which provides for a limited degree of independence.

To answer the question about should the Government right to allow a continuation of closures and integration, Autism Consultancy Services believes this is a definite no, as requested already we need an urgent, neutral and impartial view on what we have already. Whilst the Government continue to go ahead the choice of the parents is continually being denied. Giving parents/carers choice comes in the following sections

- Happiness and renewal—Wanting to be happier? Wanting to feel good more often? Looking for quiet confidence and a sense of peace that never leaves?
- Empowerment—Wish you could really know what you want out of life and develop the confidence to pursue your dreams?
- Growth—Would you like to break through limitations, drop self-judgments and live with more clarity and comfort?

Earlier I mentioned that most children with an Autistic Spectrum Disorder can be like Jekyll and Hyde and recent research shows that children and young people with an Autistic Spectrum Disorder will invariably surmount their problems entirely, bring their problems home and potentially explode from the moment they walk through the door or try to work through their problems out themselves and explode sporadically and in turn makes it harder for parents/carers to establish the real problem or route of their problems which will exacerbate on to other family members.

Once again the issues of once a child/young person has left school and entered the next stage of his/her life comes to mind and they enter adult services or support (if any) if the correct and accurate provision is not made available when the child needs it most the likelihood that greater support will be needed later on in the child's life including counselling, psychotherapy, cognitive behavioural therapy etc.

Our life as children is a very small part of our lifespan children are not mini adults nor are they objects or products of us as adults. The history of childhood is a subject of controversy. Since serious historical investigation began into this area in the late 1960s, historians have increasingly divided into two contrasting camps of opinion, those advocating "continuity" in child rearing practices, and those emphasising "change".

If we as adults (including parents/carers/ policymakers and legislators) fail children and adolescents by not meeting their individual needs there is a risk for developing trauma-related problems. These problems include severe anxiety, depression, and substance abuse. Failure at school, susceptibility to victimisation and abuse, and criminality—it is unknown how many people with an Autistic Spectrum Disorder are in prison or one of the three special hospitals.

Many healthcare systems, teachers, and caregivers are only now beginning to recognise and address the problem. This programme presents an overview of the effects of childhood trauma on the individual and on society. On the other hand if we see children as children especially those up to six years of age and provide healthy, safe and nurturing environment that includes opportunities to support the emotional, social, physical, cognitive, and spiritual aspects of children within the context of their community that welcomes their participation and empowers them as a basis for their future.

Neuroscientists have succeeded in demonstrating that the first years of a child's life are critical for establishing the foundation for later development and learning that will ultimately see the child through to successful adulthood. More than three decades of brain research demonstrates that the brain is almost entirely developed by the time a child enters school. However if we get it wrong it can lead to stress which can affect the way people think, act, and feel. Response to stress is both learned and natural and may be appropriate and healthy, or it may be inappropriate and unhealthy. However, excessive stress can interfere with life, activities, and health.

3. (b) *Should guidance to LEAs about Inclusion be changed?*

Yes, greater consideration should be given to Mental Health issues. Children with an Autistic Spectrum Disorder are continually being abused and failed by the existing 'Inclusion' state system even within joined up thinking and planning. The Child and Adolescent Mental Health Services are failing to meet the mental health needs of children, young people and adults with an Autistic Spectrum Disorder. Commissioning and delivery of Child and Adolescent Mental Health Services present challenging workforce, resource and ethical problems.

Child and Adolescent Mental Health Services have drawn attention to the literature that I have referenced and other literature on some issues that impact on the decisions of policymakers (who set the imperatives for and the direction of services), strategists (who are responsible for designing services to meet identified objectives), commissioners (who are responsible for prioritising key aspects of service delivery and allocating new resources to service developments in pursuit of the strategists' objectives and designs) as well as practitioners (who face the task of delivering healthcare).

The epidemiology of children's mental health problems and disorders illustrates the enormous influence of social deprivation, exclusion, and poverty on the mental health of the population and the huge distances that civil societies still have to go, despite undoubtedly enormous progress, to achieve equitable and responsive services. The requirements on services are characterised by the complexity of both the problems faced by young people and their families and the complexity of the task of integrating, across teams and agencies, the responses they often require.

This has led Child and Adolescent Mental Health Services to re-examine the interface between scientific approaches to healthcare and the humanities, ie the kind and breadth of evidence that is admitted into evidence-based practice in understanding the dilemmas that their patients face, and, in particular, how evidence should be combined with values in developing responsive and sensitive child-centred decision-making. The growing complexity of clinical practice in this area requires, we argue, the skills equally.

What makes this increasingly problematic for people with an Autistic Spectrum Disorder is that an Autistic Spectrum Disorder is not a mental health diagnosis and nor is it a mental health based solution. It has become all too often for families and children/young people with an Autistic Spectrum Disorder to go down the psychiatric route which either involves medicinal drugs that I mentioned earlier and/or they are

sent home as very few psychiatrists truly understand Autistic Spectrum Disorder and the varying prognoses and even if parent/carers insist they are often sent with coping strategies or to help put things in place that clearly don't and won't work.

That said in a number of parts of the country social groups (a group is a collection of two or more individuals who have developed a common social identity relating to some object of activity) where people with Asperger's syndrome get together on a regular basis once a week/fortnight/month etc and whilst these are a start it is often the social which is looked at where users may go to the pub, pictures or meet at a venue to share experiences.

Many Social Groups meet monthly and some more frequent than other Social Groups activities are discussed and decided on by group members. Autism Consultancy Services works with a number of small groups UK-wide to help people gain and improve the skills they need to make successful contributions to meetings. The difficulty that Autism Consultancy Services faces is twofold a) the infrequency of meetings as it often takes time for meetings to get going and to be led by the users as to someone like me as a coordinator/facilitator and b) who pays and runs the groups as due to the complexities and issues surrounding funding it is commonplace in whether such a key area is an area for health as in speech and language therapists, educationalists as in teachers, senior teachers etc but yet many children/young people with an Autistic Spectrum Disorder don't get this additional support on their Statement of Special Educational Need either or social services as it is a social problem.

Whilst the statutory agencies argue and decide whose responsibility it is the issues and the need continues to grow and the apparent pettiness is proving unhelpful and the talk about cohesive working is still not working due to different criteria in funding and delivery of key services. The added dimension is where some users are more vocal and verbal than others and in my experience those who appear more vocal/verbal often have significant needs and problems including in social skills eg turn taking, when to raise their voice, intonation, assertiveness etc Social skills are a behavioural manifestation of social cognition (Minshew & Goldstein, 1998; Loveland, Pearson, Tunali-Kotoski, Ortegon & Gibbs; 2001; Travis, Sigman & Ruskin, 2001).

Social skills are those communication, problem-solving, decision making, self-management, and peer relations abilities that allow one to initiate and maintain positive social relationships with others. Deficits or excesses in social behaviour interfere with learning, teaching, and the classroom's orchestration and climate. Social competence is linked to peer acceptance, teacher acceptance, inclusion success and post school success. Displaying poor social skills is likely to get one rejected by others (other kids don't like them and won't associate with them).

For the child with an Autistic Spectrum Disorder or Asperger's syndrome social skills training is imperative and often broken down into the following four areas:

Manners & positive interaction with others

- approaching others in social acceptable ways
- how to asking for permission rather than acting impulsively
- how to make and keep friends
- sharing toys/materials

Appropriate classroom behaviour

- work habits/academic survival skills
- listening
- attending to task
- following directions
- seeking attention properly
- accepting the consequences of one's behaviour

Better ways to handle frustration/anger

- counting to 10 before reacting
- distracting oneself to a pleasurable task
- learning an internal dialog to cool oneself down and reflect upon the best course of action

Acceptable ways to resolve conflict with others

- what to do when you make mistakes
- handling teasing and taunting

There are two main terms and definitions with social skills:

- Socially skilled: the ability to respond to a given environment in a manner that produces, maintains, and enhances positive interpersonal (between people) effects
- Social competence: one's overall social functioning, a composite or multitude of generalized social skills. (Social competence can be improved by teaching social behaviours/social skills)

Children and young people with an Autistic Spectrum Disorder are frequently described as having “social cognitive deficits” (Schopler, Mesibov & Kuncie, 1998) which implies that the underlying cognition fails to support the presentation of “appropriate” social skills. This core cognitive deficit appears to be the result of syndrome of weaknesses that would support the development of social cognitive knowledge.

A number of theories have significance in understanding genesis of the behavioural outcomes, or social skills of persons with an Autistic Spectrum Disorder. Central Coherence Theory (Frith, 1989; Happé, 1994) speaks to the fact that most persons on the an Autistic Spectrum Disorder spectrum are weak in their ability to conceptualize whole chunks of information; they demonstrate a preference for attending to details and relying on their rote memories to make sense of the ever-changing world around them.

Children and young people with an Autistic Spectrum Disorder may also have difficulty with the organisation of written expression or independently planning to complete class assignments. Theory of Mind (ToM), (Baron-Cohen, 1995) establishes that persons with an Autistic Spectrum Disorder have difficulty considering the perspective of others, such as their emotions, motives and intents.

By failing to account for other's perspectives, people with an Autistic Spectrum Disorder tend to misinterpret their messages (Tager-Flusberg, 2000). People with an Autistic Spectrum Disorder also tend to talk at length about their own topic of interest because of their difficulty monitoring and responding to the social cues/social needs of their communicative partner. Twachtman-Cullen (2000) indicates many of the social skill deficits observed in persons with an Autistic Spectrum Disorder may have their genesis in these students lack of ability to decipher subtle meaning from their environment in part due to all of the above mentioned theories; in other words, these students have a global processing deficit.

The I LAUGH Framework (Winner, 2000) was developed to provide an overall model of social cognitive deficits. “I LAUGH” is an acronym that represents the following concepts:

- I = Initiation: The difficulty initiating language or action for interactions or tasks that are not routine.
- L = Listening with one's eyes and brain: the difficulty with auditory processing as well as visual processing of the subtle cues provided in social interactions that facilitate social knowledge.
- A = Abstract and inferential: the difficulty deciphering meaning from abstract language and non-verbal cues provided both through student's curriculum tasks as well as through social interaction.
- U = Understanding the perspective of others: difficulty interpreting the motives, emotions and intents of others, which is fundamental for successful social interpretation and social regulation.
- G = Getting the big picture or gestalt processing: difficulty recognising and comprehending underlying concepts.
- H = Humour: these students often demonstrate a lovely sense of humour but may fail to use humour appropriately given particular contexts.

The intent of the framework is to demonstrate how complex social skills, such as maintaining a conversation or personal problem solving, actually require a symphonic coordination of the I LAUGH Framework's cognitive components for a person to behaviourally demonstrate social the use of appropriate social skills. A critical component of any diagnostic assessment for students with possible social cognitive deficits is an interview with the parent and/or close caregiver. The Asperger's Syndrome Diagnostic Scale, (Myles, Bock & Simpson, 2001) and the Gilliam Asperger's Rating Scale, GADS, (Gilliam, 2001) have recently been published to explore the more typical language, social, sensory and organisational development we might expect to observe in students with Asperger's Syndrome.

Neither scale is designed to be the single instrument used to make a diagnosis, but each is useful for directing the evaluator to explore the more specific nature of developmental issues associated with persons with Asperger's Syndrome. The information they elicit is valuable and serves as an excellent supplement to social-pragmatic observations and deeper informal and formal assessments of language.

Appropriate social skills are a demonstration of subtle but complex social knowledge. To more fully understand the origin of social skill deficits it is important to gain further knowledge about a student's ability to process and react to different types of socially based information. The “I LAUGH Framework” describes different components to consider in the evaluation of students suspected as having social cognitive deficits. Meaningful interaction is the key to understanding and making sense of the world around us. What ever we do with our children we have to do with ‘their’ autism in ‘our’ minds. It does not work the other way around.

3. (c) *Should the law be changed to remove the current bias in favour of Inclusion?*

The law should be amended as with most things there are pros and cons and I have listed some of the pros and cons of inclusion for those with an Autistic Spectrum Disorder:

The Pros

- Access to “better” models of social and linguistic behaviour.
- Easier access to full curriculum resources and National Curriculum.
- Specialist subject teaching to develop person’s interests and strengths.
- Peers available as a resource for “buddies” and teaching aides but not to replace the work/role of teacher.
- Higher expectations to develop knowledge.
- Broader opportunities for curriculum development, qualifications and career choice.
- Locational opportunity for social integration within a community and for family involvement.
- Opportunities to spread awareness and tolerance of Autistic Spectrum Disorder in society.
- A better context for developing understanding of, and conformity to the cultural values and rules of society.

The Cons

- Many staff and pupils to be adjusted and adjusted to.
- The National Curriculum may not be designed to meet the special needs of the person.
- Less likelihood of staff having knowledge of Autistic Spectrum Disorder.
- Poorer staff: pupil ratio to identify and meet needs and develop skills except where extra support is allocated to the person on a 1:1 or small groups as most people with an Autistic Spectrum Disorder work better and concentrate more in this way.
- Fewer opportunities to learn in functional contexts and to address difficulties that interfere with chances.
- Poorer understanding of isolated affects of an Autistic Spectrum Disorder and fewer opportunities to work with and support families.
- Fewer opportunities for staff to share problems/experiences and successes with others and gain support.
- Assumptions of “normality” as a framework offer less understanding and tolerance of difference.
- Poorer staff: pupil ratio to identify and meet needs and develop skills.

Personally I feel that inclusion can work and be an effective system if done properly. I think the general education teacher should be trained in how to work with children that have disabilities. I also feel that there should be an abundance of resources available to the general education teacher (ie modified curriculum, special education teachers, resource teachers, aids, administrators, etc). With the adequate resources and training, inclusion could be an extremely successful program. Having an Autistic Spectrum Disorder is defined as “a severe disorder of thinking, communication, interpersonal relationships, and behavior” (Smith, 2001, p 506). People with this disability often cannot develop social relationships, have verbal communication problems, and need sameness in their environments (Smith, 2001).

Regular education classrooms are bigger and less structured and this can make it extremely difficult for a student with an Autistic Spectrum Disorder to perform up to his or her potential. In an entirely inclusive program students have little time in special education settings (Doelling, 1998). They depend on paraprofessionals that make them less involved in teacher instruction and independent work (Bang & Lamb, 1996). Many teachers feel inadequate to give what is necessary for a child to be prosperous in his or her classroom.

Kasari, Freeman, Bauminger, and Atkins (1999) studied parental perceptions of inclusion. Their research found that more often than not, parents of children with an Autistic Spectrum Disorder in their study preferred mainstreaming to full inclusion. Over half of the parents stated that their children’s needs could not be met in an inclusive setting (Kasari, 1999). Although integration is important, experts agree that specially trained teachers are necessary to put carefully designed instructional programs to work. Students need structured schedules, concrete examples, limited distractions, and controlled teacher verbal communication (Smith, 2001).

The debate over inclusion is on going and really depends on what is best for the individual student. Children with an Autistic Spectrum Disorder exhibit different characteristics and function at different levels (Smith, 2001). It is necessary to look at each case separately because what works for one person may not work for another. People with an Autistic Spectrum Disorder have a disability with thinking, communicating, socially interacting, and behaving appropriately (Smith, 2001). Parents of children with an

Autistic Spectrum Disorder are typically concerned with peer avoidance and a lack of specialized instructors in inclusive schools (Kasari, 1999). In certain cases inclusion can be successful. However, it all depends on the students and the accommodations available to them. It can lead to better behavior and social acceptance if implemented correctly (Bang & Lamb, 1996).

Students with this disability generally need a more structured environment with specialized teachers for academic achievement. I do believe that mainstreaming for times such as recess and lunch are vital. Whitaker, Barratt, Joy, Potter, and Thomas (1998), did a study on ‘circles of friends’. A group of students, including those in regular education and those with an Autistic Spectrum Disorder, would often get together to promote acceptance and friendship. Teachers I have spoken to have described inclusion for children/young people with an Autistic Spectrum Disorder a learning experience for everyone involved.

Inclusion generally is not going to provide children and young people with an Autistic Spectrum Disorder the resources they need to be successful academically. However, in order for them to function in society they need a balance of specialized education and socialization. Since most children and young people with an Autistic Spectrum Disorder are visual learners, visual cues can be a lifeline. They inform students of the rules, their schedule, and changes in their routine.

For example, the teacher can create a person locator system on a bulletin board, which shows students what they will do and with whom that day. Remember one size does not fit all and everyone must and needs to be seen and viewed as an individual equal but we have to be clear in that a child with an Autistic Spectrum Disorder may have several academic qualifications but still have huge problems in socialisation and therefore when modernising and adapting the National Curriculum there must be an emphasis on social skills that the child can use in the real world including in the workplace.

4. *What are the ramifications of these answers on provision of SEN in the UK?*

Whilst Autism Consultancy Services recognises and appreciates it takes time and skill to create/generate new legislation and policy and then to reach local authorities for Councillors, policy makers, legislators and implementers but the whole system needs a thorough and methodical review where people who have varying knowledge, experience and expertise can meet round a table to discuss key issues. There needs to be a greater emphasis and push on bridging the gap between central government and local government.

Unfortunately departments have often been positioned competitively, favoured and driven by different departments or factions and thereby encouraging people and organisations to ‘choose’ one of them, rather than using a bit of ‘joined-up-thinking’ and recognising that they are interrelated and each has some significant benefits to bring. Increasingly, world-class organisations are recognising that the smart approach isn’t to ‘pick one’ but to adopt all the latest thinking in an integrated, cohesive and yes even ‘joined-up’ way.

The upshot of joining-up thinking is all these approaches is this: If you can combine effective, capable processes with skilled, improvement-focused teams and individuals who are working together to deliver goals and targets that fit together with those of all the other teams to deliver the overall business goals—then you are really heading towards the future you want.

If we are to assist people with Autistic Spectrum Disorder to achieve their full potential then we must not only address their needs, we must also begin to think in terms of the strengths that individuals with Autistic Spectrum Disorder have. We need to work with the Social Model of Disability hence people with Autistic Spectrum Disorder are disabled by the barriers that exist in a society that does not take account of their needs but addresses the accomplishments (community presence, choice, developing competence, respect and participation as described by O’Brien (1981).

Finally “Stand up for what you believe in, even if it means standing alone.”

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October 2005

Memorandum submitted by South and West Association of Leaders in Special Schools (SWALSS)

PROVISION FOR SEN PUPILS IN MAINSTREAM SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE: DIFFERENT MODELS OF PROVISION

- Need for one single definition of 'INCLUSION'
- Effective inclusion comes at a cost
- There is patchy provision
- Resources are not easy to access
- Training for SEN should be an integral part of ITT (not a token few hours or days)
- Training for LSAs needs to be available as a rolling programme
- Special Schools as RESOURCE CENTRES should be developed and funded to support inclusive practice
- There is a gap between rhetoric and reality
- Co-location of mainstream and special schools gives the best of both worlds

PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

- Part of a continuum of provision
- Changing role to include dual-placement working
- Special school staff in need of training as trainers to support mainstream colleagues in dual placements etc.
- Economy of scale for visiting professionals/treatment/therapy
- National initiatives do not always take into account the needs of children in Special Schools leading to ad hoc modifications with no central steer/moderation
- Regional SEN Partnerships could play a bigger part in coordinating and facilitating initiatives (good links in the SW!)
- Quality of provision is more important than location
- More able students with ASD need more appropriate provision
- Networks need to be facilitated to ensure sharing of ideas, expertise and successful practice

RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

- Appropriate resourcing and training of support staff to support learning
- Skill up teachers to manage learning for SEN pupils

- Early intervention
- Interpretation of ‘achievement’ needs to be broader and not just attainment
- Re-introduce Initial Teacher Training (ITT) with SEN specialism/qualification and provide access to on-going training
- Encourage and support development of Special Schools as Training Schools
- Use Special Schools for valid Teaching Practices in ITT & PGCE

THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS

- Expensive and complex
- Distressing for parents
- Provision to meet needs should be an entitlement

THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN’S EDUCATION

- Early involvement
- Adequate information
- Relevant support

HOW SEN ARE DEFINED

- Individual nature of needs makes definitions complex and open to misinterpretation.
- Children do not always fit neatly into one category or have a primary area of need

PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN

- BESD difficult to include because of disruptive behaviour
- Disruption is likely to be a result of unmet social and/or learning needs
- FLEXIBILITY of attitudes and staff is essential

LEGISLATIVE FRAMEWORK AND EFFECTS OF DDA

- * Parents do not always get full information about provision and options.

October 2005

Memorandum submitted by Priory Educational Services

INTRODUCTION

Priory Educational Services is part of the Priory Group Ltd, who are the largest independent providers of mental health services in Europe. The wider range of services provided by the company include general adult psychiatry, including addiction treatment, adolescent psychiatry (Priory is the largest group providing specific treatment for young people with eating disorders), neuro-rehabilitation, semi-secure psychiatric care as well as 17 schools and colleges accommodating children and young people with:

- Autistic Spectrum Disorders
- Social, Emotional and Behavioural Difficulties
- Specific Learning difficulties associated with Dyslexia/dispraxia

Priory is predominantly a public service company with the majority of students in the schools and colleges being funded either by their local authorities (occasionally in conjunction with the Primary Care Trust) or the Learning and Skills Council. All young people prior to admission will have been assessed by the local education authority as having special educational needs (statements). All schools and colleges reflect the priorities described in ‘Every Child Matters’.

ISSUE ONE: PROVISION FOR SEN PUPILS IN 'MAINSTREAM' SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

We believe that the best place for most children to receive their care and education is in a secure and loving family, with education being provided locally alongside their own peer group. For many children, despite their special educational needs, this remains the best option, provided that resources to meet those needs is available in the school. For a small number of children remaining at home is not an option due to various circumstances (almost all the children and young people in the seven schools Priory provides for students deemed to have SEBD come from dysfunctional families). A lack of consistent parental/adult support is reflected in levels of attainment and behaviour in school, resulting in the children we care for having, on average, more than double the number of school placements prior to coming to one of our schools. A significant number have not been attending school, or have not been allocated a place in a local school, for over 12 months.

We believe that exclusive educational provision should only be provided where it can be shown that better attainment levels can be delivered in such an environment. Initially we find that by offering intensive, sometimes one to one educational experiences, we are able to move students on, so that they can attend colleges or school local to our own school, or to return to their home local authority area and to mainstream provision. We say that one of our aims is to return young people to mainstream education 'one page ahead of the rest of the class/group'. This same philosophy can be applied to special units in mainstream schools. However, often behaviour in school reflects home circumstances, and six out of the seven schools offer 52 week care since all too often many of the problems in the classroom are a reflection of the difficulties at home. Whilst we reflect the terminology used in the Statements of Special Educational Needs, many of the children seemed SEBD also reflect many of the characteristics of children with aspects of Autistic Spectrum Disorders.

ISSUE TWO: PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

We are aware of much good work done in local special schools. However, often this is undone because of a lack of consistency between the school and the home (including local authority children's homes). Only a minority of the day is spent in school, therefore what goes on outside the school day is hugely important. By ensuring that care staff and school staff work closely together with shared objectives, good communication, and a common understanding of the issues we can demonstrate the advantages, which can be achieved in a residential special school.

ISSUE THREE: RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

Throughout all our schools we concentrate on achieving measurable outcomes for our students, which will help them, achieve independence in adult life. It is not enough for us to describe ourselves as 'good' and excuse the lack of measurable outcomes because 'our students do not have the ability to pass exams or achieve other externally verified results'. We must live in the real world, where education standards do matter and will influence the young persons subsequent life and achievements.

All our schools offer the full national curriculum. Students can access a wide range of examinations, including:

- GCSE
- Asdan Awards
- GNVQ
- BTEC
- NVQ
- 'A' and 'A/S' level
- City and Guilds
- ECDL
- NCFE and OCR

This year all our schools offered GCSE examinations. In addition to regular Ofsted inspections we commission our own independent termly inspections of both our education and care facilities. Across all our schools and colleges we can report:

- One school obtained 100% passes in GCSE A to C, whilst two others achieved 87% and 75%.
- One of our 6th form colleges with 50 students has 13 former students now in higher education.

Qualifications achieved in other schools include:

- Merit GNVQ in ICT
- BTEC Diploma in Public Services
- BTEC Diploma in Design

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- National Diploma for IT Practitioners
 - Level 3 (University place offered)
 - BTEC First Diploma in Performing Arts
 - (University place offered)
 - ASDAN Lifeskills Award
 - NCFE Certificate in Multimedia Design
 - NVQ Level 2 in culinary Arts.

Demonstrating the breadth of the curriculum 14 students at an SEBD school passed the basic training in tractor driving. Students are measured using the Key Stage SATS, which results comparing favourably with mainstream educational settings.

We celebrate success with our students. From an initial start of perhaps ‘celebrating’ that they achieved 100% attendance at school we move on to them achieving ‘verifiable’ results which will allow them to compete for jobs and secure lifestyles in their adult lives.

ISSUE 4: THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (‘THE STATEMENTING PROCESS’)

On the one hand we do not want our students to feel that they are ‘labelled’. On the other hand the ‘statement’ is the passport to our specialist facilities. We have evidence of a good level of consistency across the country in respect of the statementing process. Where we are being asked for a 52 week placement by a local authority the availability of a good social enquiry report is very variable. In some local authorities statutory reviews are very inconsistent.

Our big concern about the process of statementing is not so much the statement but what happens next. All children and young people admitted to any of our schools will have a statement of educational needs. We are approached by the Education Officer, Educational Psychologist or Social Worker. We do not take students without a comprehensive assessment. We encourage the young person and his parents to visit the school before making a decision. Increasingly however another part of the LA/LEA refuses to fund the placement and parents have then to apply to a Tribunal. We are asked as part of that process to confirm the availability of a place. Local authorities often ask for a delay in the hearing, and this can go on for up to a year. We are declining requests for other students because we have made a commitment, and the child or young person often goes with no or minimal education. Even when the request for the placement does not go to an external Tribunal local authorities will delay decision making even though it is their staff who have asked for the place in the first instance.

ISSUE FIVE: THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN’S EDUCATION

For many parents, they have reached or passed the point of despair because of the behaviour of their child. In over 90% of the cases where a pre-admission visit is made parents are encouraging their son or daughter to accept the place offered. With schools for students assessed as having SEBD parental choice is often limited. For our other schools, and through organisations such as the National Autistic Society, it is parents who choose the school for their child. We encourage parents to attend all ‘reviews’ and give regular reports to both the student and the family.

ISSUE SIX: HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

We would like our schools and colleges to be defined not by the students they accommodate but by the educational and care services they provide.

If we think of our schools as Specialist Schools defined by the type of education offered we begin to fit in much more easily to the structures outline recently in the White Paper. Just as there are secondary schools specialising in Maths or English, we specialise in providing education for students who cannot survive or progress in mainstream education. Who provides the school or college is less important than what is provided. We offer like any other school the core curriculum, but we have additional skills to enable our students to succeed. The funding route for such schools should be the same as for any other school. We welcome our contact with Ofsted and CSCI and measurement of ‘best value’ or ‘value for money’ should apply as much to us, as a private provider as to a school independently managed by local governors but within the public sector. (Just as every student will have an individual education and care plan, our fee rates reflect the level of individual education and care needed. One size fits all is not appropriate. We have a fee banding system—with fee levels potentially reducing as student’s progress.)

ISSUE SEVEN: PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIORAL AND SOCIAL DIFFICULTIES (EBSO)

We acknowledge that we are at the most acute end of the spectrum. All our schools should only be admitting students whose needs have been carefully assessed, and for whom a neighbourhood solution is not possible. However, we believe that the current system is unfair on both our students and their families, because they have to pass additional 'tests' to receive the education and care they need. We are not critical of much of the assessment process in respect of educational need. There is a remarkable consistency in most parts of the country. We are concerned that parents have to revert to Tribunals to challenge decisions of local authorities, where financial policies are given greater priority than educational and care needs. The principles behind the 'choice' directive should apply to this area of education just as it does to mainstream education. Finally, we believe that the assessment should embrace 'the whole child'. We welcome the bringing together social services children and families services with education within Children's Services Departments in the hope that social and educational needs will be comprehensively assessed when considering a place in one of our specialist schools.

ISSUE EIGHT: THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001, WHICH EXTENDED THE DISABILITY DISCRIMINATION ACT TO EDUCATION

We acknowledge that the needs of the students, and those who teach or care for him or her should be paramount. Our schools should be accessible to those students who have physical as well educational and care needs. Currently only one school would fully meet the criteria demanded in the Disability Discrimination Act. One of the advantages of being a privately owned company is that we can access capital to make alterations more easily than a local authority can, and we can make decisions very quickly. As a responsible organisation we would never put profit before meeting need (if our shareholders did they should not be investing in this type of industry). Our values reflect all those deemed important by good local authorities and as such where there is a need, be it a student or an employee, our buildings and services should meet that need. However, to apply regulations regardless of any unmet need would be wasteful and would take away from the existing challenges.

CONCLUSION

We would like to be seen as a provider of specialist education, not special education. All students, regardless of need should be seen as special. Assessment of educational and care needs, and the necessary funding streams should be part of a total process. In this respect we commend the approach by the Learning and Skills Council. Because we share the same values and objectives, we believe that there should be far greater partnership working between local authorities and ourselves. The old purchaser/provider relationship is neither appropriate nor good enough. Increasingly as local authorities move away from direct provision the expertise in providing education and care for children and young people with social, educational and behavioural difficulties is to be found in providers such as Priory Educational Services. We want to share that knowledge and experience in order to improve services to those students, who without appropriate interventions are likely to be a drain on public services into their adult lives.

October 2005

Memorandum submitted by RADAR

1. RADAR is the UK's leading disability rights campaigning organisation and a network of pan-disability organisations and individuals run by and for disabled people. Our vision is of a society where human difference is routinely anticipated, expertly accommodated and positively celebrated.

2. The release of reviews of 'Special' Educational Needs (SEN) provision in schools and the recent statements by Baroness Warnock and the Conservative Party have renewed the debate on inclusive education. This RADAR position paper has been prepared to underpin further debate and ongoing discussion (including on RADAR Network) regarding the inclusion of students with 'Special' Educational Needs and disabilities in mainstream schools. It will also inform a response to the Conservative Committee on SEN and Statementing.

BACKGROUND

3. In 2004 the Government set out its agenda for inclusion of students with SEN as part of the "Every Child Matters" strategy—Removing Barriers to Achievement: The Government's Strategy for SEN. This document expresses a clear commitment to inclusion and sets out action to be taken in four key areas:

- (a) Early intervention
- (b) Removing barriers to learning

- (c) Raising expectations and achievement
- (d) Delivering improvements in partnership.

The Government has committed to a timetable of action to include the establishment of an Inclusion Development Programme, dissemination of good practice in transition planning, and the dissemination of effective teaching approaches for SEN across all ages.⁴⁴

4. The publication of statistics relating to statementing and the placement of students with ‘Special’ Educational Needs in England by the DfES in June, 2005, highlighted a great disparity across the country in the number of statemented pupils receiving an inclusive education. For example, in 2004 pupils with SEN statements in North Tyneside were 24 times more likely to receive a segregated education than those in Newham, London⁴⁵.

5. In June 2005 Baroness Warnock, who championed the policy of including pupils with learning difficulties in mainstream classrooms 24 years ago, called for a review of the inclusion policy, suggesting that more separate schools or units should be established. Her new book, “Special Educational Needs: A New Look”, argues that the policy of inclusion may have been carried too far.⁴⁶ It must be noted, however, that she does not condemn or reject the principles behind the policy of inclusion.

6. In July 2005 Ofsted published, “Inclusion: the impact of LEA support and outreach services”, a review of the quality of ‘Special’ Educational Needs provision by support agencies and external experts, outlining good practice for schools and LEAs in ensuring a successful inclusion policy. The report highlights some of the shortcomings of the current approach to inclusion, particularly with regard to the provision of funds for mainstream schools to buy services or use funds for the professional development of staff. However, the report also indicates that external services are being used successfully in many places to ensure the provision of a high quality education for all students in an inclusive environment and to assist in developing the skills of all teachers.

7. Following Baroness Warnock’s statements, the Conservative Shadow Spokesperson for Education, David Cameron, announced the establishment of a ‘Special Needs’ Committee to review special needs provision in schools. The Committee will be chaired by Sir Robert Balchin and call witnesses including Baroness Warnock, Heads of segregated education establishments and mainstream schools, and parents of children with SEN who have previously criticised the Government’s approach. RADAR has noted that the Committee does not, at this stage, seek to consult with students themselves, or organisations within the disability sector that may represent students with SEN or a disability.

COMMITMENT TO INCLUSION

8. RADAR remains committed to the principle of inclusive education. It is essential to ensure that, in addition to recognising the negative effects of segregation on students with disabilities and SEN, the significant benefits of inclusive education for all children are recognised. Research has shown that inclusive education is of benefit to all children in inclusive classrooms. These children demonstrate increased acceptance and appreciation of diversity; develop better communication and social skills; are more advanced in the development of ethical and moral principles; and demonstrate increased self esteem.

9. While RADAR does not support Baroness Warnock’s suggestion that inclusion has been pushed too far, we do concede the possibility that some of the children who most require special provision and additional help are not those with physical or learning disabilities, but those with social and behavioural difficulties. We do not, however, support the proposal for the creation of small separate schools or units that may well be isolated from mainstream partners. RADAR is concerned at the findings of a recent review by Ofsted⁴⁷ which found that very few mainstream schools had partnerships with local separate schools or units.

10. We believe the ‘where possible’ element of the inclusion policy is too often used as a ‘catch-all’ to avoid making the necessary adjustments and providing the resources required to enhance the capability of mainstream schools to educate students with specific needs. RADAR believes that the definition of ‘where possible’ should be in line with the definition of ‘reasonableness’ as set out in the Disability Discrimination Act, and that mainstream schools must make the necessary adjustments to create an inclusive environment.

⁴⁴ “Removing Barriers to Achievement: The Government’s Strategy for SEN” http://www.standards.dfes.gov.uk/literacy/publications/inclusion/883963/dfes011704_removebarrier.pdf

⁴⁵ Special Educational Needs in England, January 2005, DfES, [http://www.dfes.gov.uk/rsgateway/DB/SFR/—providing statistical information and analysis on the characteristics of pupils by their provision of SEN together with information on the incidence and placement of pupils with statements of SEN](http://www.dfes.gov.uk/rsgateway/DB/SFR/—providing%20statistical%20information%20and%20analysis%20on%20the%20characteristics%20of%20pupils%20by%20their%20provision%20of%20SEN%20together%20with%20information%20on%20the%20incidence%20and%20placement%20of%20pupils%20with%20statements%20of%20SEN).

⁴⁶ Baroness Warnock, June 2005, “Special Education Needs: A New Look” in Impact (No.11 in a series of policy discussions published by the Philosophy of Education Society of Great Britain).

⁴⁷ “Special Educational needs and disability: towards inclusive schools”, October 2004, Ofsted, <http://www.ofsted.gov.uk/publications/index.cfm?fuseaction=pubs.displayfile&id=3737&type=pdf>

11. A policy of 'inclusion where possible' should also extend beyond those students which either can or cannot be 100% educated in mainstream schools. The policy should allow for more flexibility for those students able to participate in some aspects of mainstream education, but not others. In addition to this, the co-location of separate units and mainstream educational facilities would enhance opportunities for the ongoing professional development of all staff in learning to teach students with SEN. (see Sections 15-19).

IDENTIFICATION OF CHILDREN WITH 'SPECIAL' EDUCATIONAL NEEDS

12. The Cameron Committee requests guidance on the identification of children with specific needs. RADAR supports the Government's proposals for early intervention to quickly identify those students with specific needs. We would also reiterate that SEN is not synonymous with disability. It is essential that these concepts are not confused in order to recognise that some students with disabilities require adjustments in order to make educational environments accessible, but do not have Special Educational Needs, just as some students without a disability may require SEN provision. RADAR believes that any bureaucracy surrounding a system of identifying and statementing students should avoid the use of automatic categories, and instead ensure a case-by-case approach is taken in order to identify students' particular needs. This would also ensure greater flexibility in adapting the additional provision required for students in line with their progression and development in overcoming challenges and managing their impairments.

13. RADAR believes that the current system of statementing can be too adversarial and often open to abuse. We are concerned that the evidence suggests that some schools and LEAs may be reluctant to provide students with a Statement of SEN due to the accompanying obligation to ensure adequate funds to support the needs of that student.⁴⁸ Adjustments to the bureaucracy surrounding SEN and the statementing system can and should occur, however a revised system must ensure that LEAs are obligated to provide adequate resources to support students with SEN in mainstream schools. We are also aware that the statementing system is potentially open to abuse whereby a disability is 'claimed' in order to gain additional resources to support students. For example, the distinction between dyslexia and poor reading skills could be blurred. RADAR warns against a knee-jerk reaction to cases of abuse, and we believe this should not be allowed to prevent students with genuine learning disabilities from gaining access to additional support.

14. Teachers need to be provided with additional training in SEN in order to assist in identifying students with specific needs. Many students within mainstream schools have hidden difficulties, for example Central Auditory Processing. Training teachers to recognise the signs, and enabling them to accommodate students with a range of specific needs in their classes, is crucial to supporting students who are dealing with a newly discovered difficulty, as well as those students with statements and established courses of action to provide for their needs.

TRAINING AND SUPPORT FOR TEACHERS

15. The Teacher Training Agency conducts a survey of Newly Qualified Teachers (NQTs) every year to gauge their opinions as to the effectiveness of their training. RADAR is concerned that NQTs have consistently indicated that they do not feel confident to teach children with SEN. In 2005 over 55% of NQTs indicated that their training was "poor to adequate" in preparing them to work with children with SEN.⁴⁹

16. The skills and techniques used to teach children with SEN are useful for responding to a number of different challenges in teaching. In particular RADAR does not believe the answer lies in establishing separate schools or units and concentrating knowledge and expertise within those units. A spread of skills across mainstream establishments would greatly enhance a school's capability to achieve a successful inclusive education environment.

17. RADAR would like to see SEN acknowledged as an important aspect of teacher training. A core module of teacher training should focus upon adjusting methods of teaching and finding ways to meet the needs of all individual pupils including students with statements of SEN, gifted and talented students and all those who learn in different ways.

18. Sufficient resources must also be provided to enable mainstream schools to provide for students with 'Special' Educational Needs. This includes making the necessary adjustments to ensure that schools are fully accessible for those with physical and sensory impairments. However, provision must also be made for the teaching of SEN skills within the ongoing professional development of all teachers. It must be recognised that the skills in teaching children with learning difficulties can also be good teaching practice for all the class.

⁴⁸ The National Association for Special Educational Needs has argued that LEAs may be unwilling to statement pupils because of the resulting legal and resource entitlements associated. www.nasen.org.uk

⁴⁹ This figure is in comparison to only 16% of NQTs rating the overall quality of their training as poor to adequate. The survey results can be found at: <http://www.tta.gov.uk/php/read.php?articleid=863§ionid=174>

19. The Teacher Training Agency, Ofsted and the DfES have identified cases of good practice in developing the skills of teachers with regard to students with specific needs. RADAR believes that models of good practice and pilot programmes should be developed to assist LEAs and schools in ensuring the overall spread of skills and expertise in SEN.⁵⁰

THE CLOSURE OF 'SPECIAL SCHOOLS'

20. Despite the recent media attention paid to the issue of closing 'special schools', recent figures indicate that the number of students in segregated education establishments has not actually fallen, rather there has been a minor increase in the number of students with statements attending them⁵¹. RADAR believes that there may be a case to suggest that, for children with specific educational needs as a result of impairment, supplementary expert services can be provided within mainstream schools. However, RADAR is committed to an agenda of inclusion. It is therefore essential that our focus remains on ensuring that mainstream schools are equipped to deliver a high quality education for the benefit of all children within an inclusive environment.

GUIDANCE TO LEAS

21. Currently, upon the closure of separate schools or units, LEAs are not required to commit funds to mainstream schools to directly support the students likely to be taken up by those schools. RADAR believes that more guidance should be given to LEAs regarding their obligation to students with SEN transferred to mainstream schools as a result of the closure of separate schools, in order to ensure that continued support and resource is maintained.

22. Further guidance should also be given to LEAs on their obligation to provide ongoing training for teachers and to adopt models of good practice. (see above Section 19).

CONCLUSIONS

23. RADAR remains strongly committed to an inclusive education policy. We believe that the answer lies in ensuring adequate resources are provided to underpin the policy, not with moving away from a policy which has seen positive outcomes for numerous children both with and without disabilities. A policy of inclusion should be implemented with enough flexibility to allow students with impairments and learning disabilities to participate in as many aspects of mainstream education as possible, but to retain access to and receive the resources required for specific expert help when required. Our priority must be to equip schools and teachers with the tools necessary to deliver a successful policy of inclusion.

24. RADAR is calling for:

- (a) A renewed commitment to a policy of inclusion, allowing for a flexible interpretation of 'where possible'.
- (b) A case-by-case approach in identifying and assessing students with 'Special' Educational Needs, and the avoidance of using restrictive categories.
- (c) An obligation for LEAs to provide adequate resources to support students with SEN in mainstream schools upon the closure of 'special' schools.
- (d) A core module to be included in teacher training to assist teachers in identifying and meeting the specific needs of ALL students, including those without statements.
- (e) Guidance to be given to LEAs to adopt models of good practice and allow for ongoing professional development of teachers within mainstream schools.
- (f) Recognition of the benefits of inclusive education for ALL students, not just those with statements of SEN.

October 2005

⁵⁰ "Inclusion: the impact of LEA support and outreach services" is a good starting place for good practice on inclusion—<http://www.ofsted.gov.uk/publications/index.cfm?fuseaction=pubs.displayfile&id=3958&type=pdf>

⁵¹ Special Educational Needs in England, January 2005, DfES, <http://www.dfes.gov.uk/rsgateway/DB/SFR/>

Memorandum submitted by the National Association of Paediatric Occupational Therapists (NAPOT)

INTRODUCTION

1.1 A majority of children's occupational therapists work in educational settings—mainstream and special schools and pre-schools. Services are also beginning to support the post-16 and higher education sectors.

1.2 NAPOT communicates regularly with its members throughout the UK, providing regular policy updates and inviting responses. Children's occupational therapists (OTs) are based largely in the NHS but also in local authorities and the independent sector.

1.3 NAPOT has a particular interest in multi-agency approaches and the provision of comprehensive support for children with special educational needs.

Occupational therapists work closely with children and young people, parents and teachers to improve access to both the learning and physical curricula.

1.4 NAPOT welcomes the chance to submit written evidence to the Committee and would appreciate the opportunity to submit oral evidence.

RESPONSE TO POINTS RAISED:

2. Provision for SEN pupils in mainstream schools : availability of resources and expertise; different models of provision

2.1 Over the past two decades, SEN legislation has resulted in a growing number of children with a wide range of special needs being included in mainstream schools and parents' expectations continue to increase. NAPOT welcomes greater choice and opportunities for children to be educated in their local communities and alongside their peers. However, mainstream schools have had to accommodate this change with very limited support and training from other agencies with regard to the specific needs of these children.

Occupational therapy referral rates have continued to rise in response to successive SEN legislation since the 1981 Education Act but with no specific increase in resources. Health authorities have been obliged to provide only 'within available resources' with the result that many children are 'included' in mainstream schools but are not fully able to reach their potential within such educational settings. The higher profile of special needs in mainstream schools has been matched with teachers' growing awareness of additional needs among existing pupils. This has led to steadily increasing referral rates with children waiting excessively long times for assessment and intervention—particularly those with developmental coordination disorder, including dyspraxia. (This condition can seriously affect many aspects of learning—from PE to handwriting, organisational skills and social interaction, with consequent effects on self-esteem). As Al Aynsley-Green, (now Children's Commissioner), has said 'to wait a year is an outrage for a child: it devastates the child and child's family and may seriously compromise the long-term outcome'. Yet children's occupational therapy waits across England are typically two years.⁵²

The importance of therapy services in supporting early intervention is stated in the SEN Strategy, (*Removing Barriers to Achievement*, DfES 2004). OT services have tended to focus scarce resources on preventive approaches in early years. Intervention for pupils at secondary school and in transition planning for moving on to further education and employment is rarely available.

Although some local examples of service level agreements exist, local education authorities have tended to overlook existing expertise where it resides in another agency and have failed to explore opportunities for joint funding to support pupils or negotiate effective partnership arrangements. Although further devolvement of budgets may encourage schools to take earlier action thus minimising later costs, this may make it even harder to negotiate funding to provide equitable multi-agency support.

2.2 Many OT services already offer a largely consultative approach following assessment—providing training to parents, carers and school staff (and also exploring workforce re-design to incorporate more junior and therapy assistant posts). However, therapists already operate within a broad skill-mix context—training and monitoring the work of many learning support assistants employed by schools. There is a danger of specialist expertise being spread too thinly to ensure effective outcomes for children. Nevertheless, OTs would wish to continue exploring the opportunities for extended schools to deliver more accessible and responsive local services.

2.3 A more efficient, cost-effective system to supply special equipment for school/home use (seating, self-care, IT access etc.) has been specified in Integrated Community Equipment Service (ICES) policies but progress across the country has been variable with schools, families and therapists still dealing with a complexity of funding and provision.

⁵² National Association of Paediatric Occupational Therapists, College of Occupational Therapists (2003) *Doubly Disadvantaged: Report of a Survey on Waiting Lists and Waiting Times for Occupational Therapy Services for Children with Developmental Coordination Disorder*.

2.4 School staff have taken on a big, new agenda in providing for special educational needs and NAPOT would like to commend the high levels of commitment and motivation which OTs working in schools often experience. However, teachers are under considerable pressure. Training in the needs of children with a wide range of developmental and medical conditions (including pre-registration teacher training) is minimal and little time is available to differentiate materials, attend review meetings or work with the child and visiting professionals. NAPOT recommends more involvement of health professionals in training and supporting teachers and other school staff. Such good practice does exist but it is patchy and inconsistent.

The learning support assistant may become the local 'expert' and while this may be appropriate with regard to the child's self-care and day to day management, it can be less so when devising programmes for accessing the academic curriculum. Visiting professionals also need to be able to work with the teacher.

Behavioural needs pose additional challenges in the classroom for which sufficient resources are often lacking and more consistent multi-agency support would help deliver better quality inclusion (a need recognised in the 2002 Ofsted report *Towards Inclusive Schools*).

The 2002 Audit Commission report 'Special Educational Needs—a mainstream issue' recommended that SEN should be given higher priority and clear expectations of inter-agency support established. This is reinforced in the National Service Framework for Children, Young People and Maternity Services, 2004 which states that local therapy services should be reviewed to ensure 'timely supply'.

2.5 The most effective school SEN systems are characterised by well-defined SENCo roles (with sufficient allocated time), close links with visiting professionals and transparent SEN budget arrangements which can be used flexibly to provide timely support. In some schools, workforce re-modelling has reduced allocation as SENCos have been re-deployed to manage classes.

2.6 A range of additional support services is required to meet children's needs. There would be value in a detailed review of levels of actual need and of the specific contribution of specialist services to meet those needs. Understandably, parents are particularly aware of and concerned, for example, about speech and communication. What may be less obvious is the need to develop underlying postural, sensory or perceptual abilities as the foundation on which cognitive skills can develop more efficiently. In such cases, joint therapy programmes can work effectively and a balance of therapy provision is therefore important but rarely planned from this perspective.

Protocols for joint working (therapy and schools) do exist (eg in Hampshire) and could form the basis for more widely available guidance.

2.6 Evidence of need is now available: the Audit Commission report (2002) noted OT as the second most common shortage area in health and social services provision for school support.

2.7 Special schools often provide good opportunities for developing 'life skills and independence'—a vital part of education for disabled pupils. Flexible ways of addressing these needs within the mainstream curriculum (adjusted timetable, after-school activities etc.) are required.

The current debate about mainstream and special schools risks overlooking the fact that fair comparisons can only be made where inclusion is properly resourced. Many children are 'included' in mainstream school but not able to fully participate in the curriculum due to lack of specialist support.

3. Provision for SEN pupils in special schools

Special schools are a valuable resource where high staff ratios, specialist expertise and small classes provide suitable environments for children with complex special needs.

Special schools are now encouraged to become an outreach resource; some retain high levels of expertise and access to such specialist support can be very helpful. However, current policy has contributed to a shift towards greater innovation sometimes taking place in mainstream settings.

Special schools require as much recognition, training and support as other settings. A range of provision (such as units within mainstream schools) can help maximise inclusion opportunities.

In the past, occupational therapists have often been attached to special schools; services now need to be spread across the full range of schools with the result that special schools sometimes receive less support and only more urgent needs (such as assessment for self-care and equipment) can be met.

4. Raising standards of achievement for SEN pupils

The emphasis on individualised approaches in current Government guidance (SEN Strategy; 'Higher Standards, Better Schools', 2005) is particularly helpful for children with SEN. The degree to which the curriculum sometimes needs to be differentiated while maintaining a child's sense of inclusion and self-esteem remains a considerable challenge in mainstream settings.

The recognition now given to 'P' scales reflects more positive, realistic assessment which can demonstrate different rates of progress and it would help to include them in statutory reporting. Ways of also recognising broader learning achievements (self-care, social skills and independence) are also required. Reviewing ways of incorporating therapy goals into IEPs would be helpful.

5. *The 'statementing process'*

Statementing has proved to be a fairly slow, centralised process which focuses some resources on administrative systems rather than direct support. Decisions on additional resource allocation are made by those with little direct experience of the child and there is rarely additional consultation with the team who knows the child well. It is therefore hard for informed, consistent and equitable decisions to be made.

There is a significant group of children with additional needs which may severely affect their learning but for whom it is difficult to obtain statements- and more importantly, the amount of help needed—they can be seriously disadvantaged.

One benefit of a statement is the statutory annual review; it is harder to sustain a regular multidisciplinary review system for children without statements.

For those children who do qualify, the current process does provide a ring-fenced resource. If there were to be further devolvement to individual schools, a guarantee of protection for the budget and some way of achieving better team consensus in allocating resources would be essential.

In particular, some mechanism is required whereby both health and local authorities are required to plan strategically and jointly provide resources needed to support children with special needs—essential to provide the 'timely' response specified in the NSF (Standard 8 Disabled Children and Young People and those with Complex Health Needs).

6. *The role of parents in decisions about their child's education*

NAPOT sees the active involvement of children and young people as well as their parents in decisions about their learning as essential.

Assumptions are easily made about particular types of school and it is important that parents and children are given every opportunity to make fully informed choices as to what may best suit their needs. This may require detailed discussion with the team of people who know the child well.

Therapists work with children at home as well as school and need to ensure therapy continues to be delivered in the most appropriate setting, helping parents support the child's 'full learning experience' (NSF). (This is particularly important for children who may not be accessing formal education because of eg school refusal or hospital stays).

7. *How special educational needs are defined*

As multi-agency working develops, a greater range of specialist terms are being used more widely. While jargon is to be avoided, specific terms do need to be used in order to ensure accuracy and an updated classification would be useful (together with translation of commonly used acronyms). This would be helpful to parents as well as professionals.

However, while definitions of SEN should be informed by factors such as medical diagnosis, they also need to more accurately reflect the impact on the child's abilities and learning. Such clarification could result in support being more available to children whose needs have been previously overlooked.

8. *Provision for different types and levels of SEN, including emotional, behavioural and social difficulties*

Children with disabilities are more vulnerable to emotional pressures and lower self-esteem.

LEAs and schools are often unaware of the full range of professional support on which they could draw. For example, at registration, OTs are trained to work equally with mental health and physical needs. While they could usefully join Behavioural Support Teams, OTs may already be working in a school and could support teachers (at Child and Adolescent Mental Health Service Tiers 1/2). OTs specialising in more complex psychological conditions could support teachers dealing with complex needs (but in spite of additional funding, most teams still lack the OTs specified in the NSF as part of a comprehensive CAMHS).

The needs of 'looked after' children who may have had disrupted social support systems are at particular risk and NAPOT welcomes efforts to provide specific teaching liaison and multi-agency support.

9. *The legislative framework for SEN provision and the effects of SENDA*

The Act has been welcome in extending rights to equal opportunities in educational settings; more clarity on how specific services in agencies such as health can help deliver better access to learning would be useful. This is particularly relevant to adapting the physical environment. (Unlike England, Scottish guidance specifically recommends the involvement of occupational therapists with this expertise). Good practice does exist—where OTs are funded by LEAs work alongside architects and access officers to adapt buildings, developing appropriate and cost-effective solutions to suit children with a range of disabilities—but this is

rare. As schools are able to employ architects and builders directly (who may not have extensive experience of children's needs), the requirement for access to the right specialist advice becomes even more crucial.

November 2005

Memorandum submitted by Cerebral Palsy Care

In 1991 the UK Government contributed £1.75 million towards the capital costs of the new International Peto Institute in Budapest.

The Peto Institute is the home of Conductive Education, a system of active learning/problem-solving for physically disabled children and adults, which has had life-changing results for tens of thousands of people in the United States, Europe, Israel and Australasia.

The Government obviously recognised the importance of Conductive Education, as it stressed the benefits that some UK residents would continue to gain by travelling to the Peto Institute—either as parents, journeying to Hungary for brief, intensive programmes of Conductive Education for their children, or as students training to become Conductors.

Ten years later Conductive Education survives in the UK, but only just—and with no official recognition as a valid form of education for children with motor disorders. It is left largely to voluntary groups to continue flying the flag for a system of learning that is highly valued by parents of physically disabled children. They have seen with their own eyes how this special education promotes independence as a state of mind, in their child, thereby facilitating a deeper and fuller integration into society.

“here is a copy of Laura’s Year One school report, which I am sure you are interested to see. We are very pleased and Tracy and I both feel that much of the achievement is due to the pre-school help that Laura was given at CPC. The physical development can quite easily be seen, but what you are building in at the same time is a mental confidence which helps greatly . . .”—Letter from a parent whose child attended Cerebral Palsy Care’s Learning Centre (written 14 July 2003).

However, few parents with physically disabled children have access to Conductive Education, and those that do find that it invariably comes to an end once the child reaches school age. Worse still, the lack of continued Conductive Education support within the school system usually leads to regression. It is severely demoralising for children to revert to such an extent that they are unable to take the active and integrated place in the community that they had begun to enjoy. This is especially sad when one considers the commitment the families have made, to ensure the giant steps taken by their children in the pre-school years.

Andrew Sutton, Founder-President of the Foundation for Conductive Education, writing in the June issue of *Whitehall & Westminster*, described the problem with special education in the following terms.

“... the system is characterised by a massive and debilitating shortage of practical skills and theoretical understanding. Official documents no longer refer to ‘special education’, just to ‘special educational needs’—that is to children’s difficulties but not to practical educational matters to do something about these. To put it bluntly, many parents find that children’s teachers—in mainstream or special schools—are not competent to advance or even maintain their disabled children’s development.”

We do not advocate the wholesale reorganisation of the education system, but rather wish to see it adopt Conductive Education’s central tenets of active learning and problem-solving. We favour a ‘transition into school’ plan that would enable trained Conductors and their teaching assistants to work in partnership with head-teachers, teachers and LSAs. This would ensure the continuity and consistency of approach to daily school life that a child familiar with Conductive Education requires, if their development is to advance.

The extra financial commitment at primary school level would be minimal, especially when compared with the long-term savings that would be made throughout the life of the child. If the Government genuinely wishes to see more disabled adults ‘off benefits’ and ‘into work’, then it must invest more in their education as it does currently with able-bodied children (50% of whom the Prime Minister wishes to see eventually enter University).

At a time when physical activity within the curriculum is a major priority, for all children, nowhere near enough is being done to promote physical activity for children who have to be taught how to move their bodies. This particular—and absolutely vital—‘special educational need’ is not being met.

However, the figure of 1 in 500 shows the relatively small number of children we are talking about, and that this ‘need’ can be met. There is a practical solution at hand for children with motor disorders, which can be taken forward into both special and mainstream schools.

All of this is possible, if you take this opportunity to ensure that Conductive Education becomes part of the political education agenda.

All of this is possible if *Every Child Matters*.

November 2005

Memorandum submitted by Belfairs High School, Southend, Essex

Belfairs High School is a fully non-selective Foundation school for students aged 11 to 18. It has a student population of approximately 1,250 of whom some 25% have been assessed as having special educational needs. The School's motto is "Success for All" (prior to its adoption by DfES!) reflecting an ethos of inclusion with extensive high quality specialist provision that has been identified by the Local Authority and the Excellence Cluster as exemplifying best practice. Belfairs is one of twelve secondary schools in the Authority; four are grammar schools, five others have partial selection linked to ability/aptitude/religious persuasion whilst the remaining two have been placed in special measures. Both of these schools have high SEN and deprivation indicators. Additionally there are five special schools that have undergone significant restructuring in recent times as the Authority seeks to move less 'needy' cases into mainstream allowing more extreme, and expensive, cases to be absorbed back from out of area provision.

PROVISION FOR SEN PUPILS IN 'MAINSTREAM' SCHOOLS; AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODES OF PROVISION

Experience of provision in Southend reveals that it is patchy with areas of highly concentrated demand in a few schools (partly as a consequence of selection) without the necessary staffing expertise to cater for such extensive needs in all cases. Where efforts are made to develop sufficient infrastructure such reputation then serves to attract further students with needs leading to unrealistic demands both on specialist staff but more significantly, teaching staff who are required to cope with a multitude of individualized demands often without sufficient knowledge or skills. The dual impact of this state of affairs is that those youngsters with special needs are not being adequately provided for, whilst others in the class are disturbed in their learning as a consequence of the adverse behaviour of the former group.

Often, statements of special educational needs specify that the student requires small groups as well as one to one input. Equally, a common problem relates to youngsters ability to cope with large and complex environments; this is of course exactly what confronts those youngsters when they attend most mainstream schools. Even if sufficient appropriate support can be offered within the classroom setting, there will invariably be issues arising with many of these vulnerable children as they move around the mainstream campus (which in the case of Belfairs is comprised of several well spaced buildings with numerous potential "hot spots" for covert behaviour).

RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

At Belfairs we can demonstrate good achievement for many of our SEN students. Nevertheless, as with all students, success depends upon the motivation of the youngsters, the support and reinforcement of parents and carers as well as the input offered by staff within the school. Students with low literacy levels or other skills deficiencies often respond most favorably to effective support, whilst the ever growing group diagnosed with emotional and behavioural issues (most notably ADHD) show little progress but sustained disruption. Whilst it is possible to cost the support provision needed to bring about the progress that SEN youngsters make (and demonstrate savings in comparison to special schools) it is difficult to assess the negative cost to the wider student population in terms of inadequate progress made as a result of distraction and disturbance.

THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (THE STATEMENTING PROCESS)

Experience suggests that the heavily bureaucratic process favours parents and their children who:

- Know the system
- Are articulate
- Have a reasonable standard of English
- Are well supported by the school or other professionals
- Can access information from other sources

The system militates against those students for whom parent/carers and other support is weak or ineffectual.

THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN'S EDUCATION

Parents need an awareness of exactly what constitutes “education”. Dictionary definition: Bring up from childhood so as to form habits, manners, intellectual aptitudes. Education starts at birth, not at Nursery or Infant school.

The nature of secondary schools (which have become increasingly complex organisations undergoing significant curriculum change) does not always best serve parents, especially those for whom school was not a successful or positive experience.

The mystique of education makes some parents wary therefore of approaching the school or staff.

The concept of education is too often seen as a narrow band of examinations, rather than a tool for living. This is particularly relevant to many children with SEN for whom living will always be different but successful provided it is judged by wider criteria.

Unfortunately, a growing number of parents either through ignorance or indifference are happy to absolve themselves of responsibility and “leave it to the professionals”.

There is a need for parenting skills to be developed and enhanced (particularly of the young single mothers who may be products of poor parenting). This is a delicate task that must not threaten self esteem or self belief but ensure that youngsters who are born into reduced circumstances have their opportunities maximized.

HOW SPECIAL NEEDS ARE DEFINED

This is undoubtedly a growth area with the inherent danger of wishing to label conditions in the hopes that this might in some way solve the difficulty. Dyslexia existed on the margins for many years before gaining a legitimacy (which is now threatened?) to be overtaken in more recent times by ADHD. The latter often prompting a response through medication rather than any form of therapeutic input.

With the advent of personalized learning there is a danger that every child will ultimately claim a special educational need somewhat akin to a fashion item!

THE LEGISLATIVE FRAMEWORK FOR SEN

Has become unwieldy and a minefield potentially for schools who operate in good faith to provide the best that they can but have no control over the resources or the organisation of the provision within an area.

Almost inevitably it is too complicated and therefore inaccessible to any but the well educated and articulate.

January 2006

Memorandum submitted by William Evans

THE LANGUAGE OF SPECIAL EDUCATIONAL NEEDS

PRELIMINARY

1. I am a practising solicitor. From 1969 to 1986 I worked for local authorities, including responsibility for the legal work of Education Committees. From 1986 I was secretary and in-house solicitor to other public bodies. Since retiring from full-time work in 1997 I have worked as part-time company secretary and in-house solicitor to some small local educational charities. I have chaired the governing body of an inner-city secondary school. From 1994 to early 2005 I was a part-time chairman of the Special Educational Needs Tribunal.

2. This memorandum is directed at bullet points 6 and 8 of the Education and Skills Committee's press release dated 21 July 2005:

- “How special educational needs are defined”, and
- “The legislative framework for SEN provision and the effects of the Disability Act 2001 which extends the Disability Discrimination Act to education.”

3. The gist of this memorandum is that the vocabulary of SEN, deriving from the legislation, has become outdated; that it is now out of kilter with the vocabulary of disability in both law and good practice; that that divergence creates particular difficulties for the implementing of much recommended good practice and some policies, particularly inclusion; and that a thorough review of SEN law is desirable, starting with redefining the concepts and updating the language used in SEN law and hence in SEN work.

4. What follows contains my personal views. In particular, nothing in this memorandum should be taken as representing the views of any of my past or present employers, or the Special Educational Needs Tribunal.

HOW THE PRESENT LAW CAME ABOUT

5. As Members will know, the current law of SEN is contained in the Education Act 1996, as amended by the SEN and Disability Act 2001. The 1996 Act largely repeated provisions in the Education Act 1993, which introduced a code of practice and a statutory tribunal to decide certain types of dispute between parents and local education authorities, but otherwise substantially re-enacted the Education Act 1981. The 1981 Act was based on recommendations of a committee chaired by Mary Warnock (Cmnd 7212), which reported in 1978 but had done much of its work from 1973. So the law we try to operate today is based on ideas formulated more than 30 years ago.

6. Before *Warnock*, what we now call SEN law was an irregular patchwork of uncoordinated provisions, many confined to pupils with particular descriptions of disability. Its vocabulary was inconsistent and disorderly. In place of the 10 descriptions of what were then called handicaps, listed in regulations made in 1959, Warnock proposed, and the 1981 Act introduced, generalised concepts of learning difficulty, special educational needs, and special educational provision. All were defined in terms of difference from the norm.

THE PRESENT STATE OF THE LAW

7. Apart from a code of practice, now in its second edition, a statutory tribunal to determine appeals, and a small extension of its jurisdiction over certain types of disability discrimination claim, SEN law remains much as it was in 1981, as do the concepts and the vocabulary used in the legislation. Those concepts and the vocabulary are adopted by people involved in SEN, whether in schools, the NHS, voluntary organisations, local and central government or the professions, or as parents.

8. As Members will know, the basic framework of SEN law is that schools must identify pupils with SEN and make special educational provision for them accordingly. If a pupil's needs are so severe or complex that the school is not likely to be able to meet them from the resources normally available to schools in the area, the local education authority must carry out a statutory assessment of the pupil's needs. If those needs call for provision beyond what local schools can normally be expected to deliver out of their delegated resources without external help, the authority may be required to issue a statement of special educational needs specifying what special educational provision the pupil should receive. That special educational provision is different from, or over and above, what most pupils receive. It may be delivered in a mainstream school (which may have a special unit) or a special school, maintained or independent. Regulations prescribe detailed requirements at various stages and in various circumstances.

9. The key word, repeated throughout the legislation, is "special". At every stage pupils with special educational needs are thus distinguished from "ordinary" or "normal" pupils. They are identified by whether they have a learning difficulty, which is defined in terms of the pupil having more difficulty in learning than most. Pupils' needs are assessed by methods which compare their cognitive abilities, capabilities and attainments with those of the majority of pupils. Delivery of educational provision for pupils so identified will be "special" and will often be "differentiated". Unlike other pupils, they will have individual education plans. Because the vocabulary permeates the whole system, and so influences the way people think, speak and behave, the whole system distinguishes pupils with SEN as "other".

HOW WE USE THE WORD "SPECIAL"

10. Since 1981 there have been changes in the way people at large in the UK use the word "special" outside the context of SEN. In some contexts the word has been evacuated of meaning by marketing hype, eg special offers, chef's specials. Sometimes "special" is a euphemism to disguise what we do not wish, for various reasons, to be specific about, eg special clinics, special forces, special operations. A school may be described diplomatically as being in special measures. Some people may use "special" as a term of abuse, a point noted by Mark Haddon in chapter 71 of *The curious incident of the dog in the night-time*. But mostly we use "special" to distinguish: to indicate difference from the norm, otherness.

HOW THAT CREATES PROBLEMS FOR INCLUSION

11. The Education Act 1976 required local education authorities to arrange for special education to be delivered in mainstream schools except where impracticable, incompatible with efficient education, or involving unreasonable expenditure. Since the late 1990s UK government policy has been that so far as possible pupils with SEN should be educated in mainstream schools. This memorandum is not about the politics of inclusion, or whether such a policy is justifiable or preferable, or what limits, if any, such a policy should have. This note accepts, as fact, that inclusion is government policy, and that government expects local education authorities and maintained schools to implement it. Inclusion has become indirectly almost a statutory duty, because it is advocated in the Secretary of State's code of practice, to which the 1996 Act requires everyone making decisions about a pupil with SEN to have regard. The only explicit statutory provision, however, is one in the 2001 Act (s.1, amending s.316 in the 1996 Act) reinforcing a parent's right in certain circumstances to choose a mainstream school, as distinct from a special one. The word "inclusion" does not appear in the legislation. It is not a legal technical term.

12. Schools and local education authorities find it hard to implement inclusion. Some difficulties are to do with whether they have enough resources for special education; some with how councils and schools fix their priorities and deploy the resources they have; some with how far local education authorities and schools should be free to exercise local discretion as distinct from doing what central government wishes; some with parents objecting to their children being educated with pupils with SEN, especially behavioural difficulties; some with how schools should manage behaviour, and the stances taken by teachers and those who represent them. But in addition to and underlying all these difficulties are conflicts and inconsistencies created by the vocabulary of SEN, which is not based on a concept, let alone a presumption, of including pupils with SEN in mainstream schools alongside their peers, but on rules which require that they be identified, distinguished, and treated differently.

THE LANGUAGE OF SEN AND THE LANGUAGE OF DISABILITY

13. The language of SEN law, and hence the language of SEN generally, is now out of joint, not only with policies to do with inclusion, but also with modern ideas about disability discrimination. When the 1981 Act came into force, the only UK statute relating to disability at large was the Chronically Sick and Disabled Persons Act 1970, a private member's bill passed without government support. The 1970 Act imposed a qualified duty on councils in their capacity as local social services authorities to make a limited range of services available to people with certain descriptions of disability. UK law then had no concept of disability discrimination.

14. While the concepts and vocabulary of SEN have remained static since 1981, the vocabulary of disability, like its politics, has moved on. In particular, much of the law relating to people with disabilities is now about discrimination, and about removing, avoiding or overcoming obstacles to social inclusion. We have developed, at any rate in the public and voluntary sectors, a language of disability that tries to be alert to how people with impairments feel about how they are described or referred to. That is reflected in current legislation, and in the guidance issued by public and voluntary bodies concerned with people with disabilities. It is under the head of disability discrimination that the law has developed, especially since the Disability Discrimination Act (DDA) 1995, and it is still developing.

15. That suggests one possible way forward. Not all pupils with SEN are disabled, as the DDA uses that term. Nor does every disabled pupil, as there defined, necessarily have SEN. The concepts overlap. It would be helpful if the law that applies to both sets were to be consistent, and to use consistent vocabulary. A new *Warnock* might usefully review the vocabulary of SEN in the light of current thinking and values about disability, and might helpfully update both the terms used in SEN law and the labels people who work in SEN are expected to apply to pupils.

16. Going further, a new Warnock might recommend complete restructuring of SEN law so as to remove from the whole sphere concepts and procedures, not just words, that create otherness.

17. Mainstream education having been largely excluded from the general implementation of the DDA 1995 as a special case, the 2001 Act introduced the concept of disability discrimination into maintained sector education. The 2001 Act was limited in its scope, and in the remedies it provided. Those limitations are reflected in how narrow the jurisdiction of the Special Educational Needs Tribunal is over disability discrimination claims and how limited the range of orders the Tribunal can make. That may be one explanation for the unexpectedly low numbers of claims made to the Tribunal. But the 2001 Act does suggest another way forward. A radical possibility might be to abolish SEN law altogether as a discrete area of public law, and instead to assimilate SEN into the general law of disability discrimination. The issues for parents, local education authorities, schools and tribunals would then be, not whether the pupil should be assessed or should have a statement, but whether the pupil is a disabled pupil and if so, whether the school or the local education authority (or, some would add, the local social services authority and the NHS) have made reasonable adjustments as required by the DDA. That would require primary legislation, not least to extend the definition of disability and cognate expressions. It would still be helpful to have a code of practice to give guidance on what is good practice, on what calls for an adjustment, and on what adjustments may or may not be reasonable; it would also still be helpful to have a tribunal to determine disputes. Problems to do with resources and their deployment would remain, but at least decisions about meeting pupils' needs would be made using concepts and vocabulary consistent with modern expectations and values surrounding impairment, and the focus would be on what the school should do rather than on what the pupil cannot.

Memorandum submitted by Allan Willis and Julie Maynard

PREFACE

The authors of this document are Allan Willis; an independent specialist educational psychologist in the field of social communication and language disorders and Julie Maynard who is a voluntary lay representative of parents at the SEN and Disability Tribunal. They met as part of their efforts to ensure children with special educational needs received an education that their learning needs called for and often work professionally together supporting parents at SENDIST Tribunal hearings. This document represents their substantial personal experiences of the special educational needs system in this Country both as professionals within the system and as “end users”.

INTRODUCTION

In the very early 1980s there was a very charismatic figure, Mary Warnock, leading from the front calling for major changes in the way we educate children with special educational needs. Her rallying cry was “Inclusion!” and we all fell behind her like a well-disciplined army chanting the mantra of the new dawn for our most vulnerable children. New legislation was put on the statute books and children with special needs suddenly had legal rights and protection. Even better, local education authorities (LAs) for the first time became accountable at last for providing an education that was appropriate to meet the educational needs of the child.

Today though Mary, Baroness Warnock has changed her mind and has in our view and professional experience, rightly raised the pressing serious concerns about the way inclusion is being implemented under current Government’s education policy for children with special needs. She feels the policy is seriously hindering many children and now, 25 years later, calls for major reforms in the statutory process and in the role of specialist schools and provision. We share her serious concerns about the policy of inclusion, particularly on its impact upon children who are on the autistic continuum or who experience speech language and communication impairment.

Over the last three years we have seen a dramatic increase in the number of referrals of children with autistic spectrum and language disorders who are in mainstream that are failing dismally. When things go wrong for a child with ASD, they can go spectacularly wrong. Children with ASD find mainstream the most challenging environment imaginable. They struggle with language, social interaction and often have behaviours that are extreme and bizarre. Yet, LA’s refuse to accept proven research that children with ASD do not learn from other children naturally because of the nature of their condition, which robs them of an interest in people and the motivation to interact with them. These children find noise, movement and general stimulation of the everyday world so overwhelming and terrifying that they try to shut it out. Placing them in a class of 30 noisy, lively children exacerbate their difficulties.

Of course we accept that there are some children who are able to learn in a mainstream setting and it is absolutely right that they be placed there, but we must consider the fact that a significant proportion of the autistic population, for example, find mainstream impossible to deal with and their needs require a much more specialist environment and teaching approach.

Another big concern for us is that under the current policy of inclusion, many children with complex special educational needs are being inappropriately placed in mainstream schools in an environment that is not led by the individual needs of the child but driven by a policy that is based upon ideology and dogma. Furthermore, local education authorities are deliberately failing in their statutory duties to identify and meet the special needs of the child.

In many respects, the 2001 Special Educational Needs and Disability Act (SENDA) has served only to further aggravate the matter, especially as it states that there is a duty to educate children with special needs in mainstream unless it is against the wishes of the parents or it is incompatible with the education of the other children. However, when we attend meetings with local education officers we are told that it has a statutory duty to educate the child in mainstream school in accordance with Government policy. No mention is ever made of parental choice or the individual needs of the child. However, the Government, it seems, now actively denies that it has any such policy.

Let’s take the first exemption, that relating to parents’ wishes. Sadly, it is the case that when parents actually do express a desire for their child to be educated in specialist provision this is usually now refused by the LA. We have represented substantial numbers of cases where parents express a desire for a specific specialist provision in contrast to the LA naming mainstream and these cases have eventually ended up at SENDIST. In the vast majority of cases we have witnessed and represented, the parents are successful in their appeals. It seems, therefore, that parental preference only works when the parent wants mainstream.

The second exemption relates to the effect upon other children in the class/school. The problem is one of how this can realistically be tested other than to have the child in mainstream and wait for them to fail or disrupt others education.

There is also, through the policy of inclusion, an erosion of the individual needs of the child and this is very much damaging a lot of the good work that we have as a society achieved in special educational needs over the last 30 years. Sadly, LAs are deliberately attempting to undermine much of the excellent legislation found in the 1981, 1993 and 1996 Education Acts, which promotes the individual needs of the child and provision that must meet those needs. This in our view as much to do with cost as it is dogma.

Baroness Warnock has also made comments about the statementing process by which a child receives a legal document called a “statement” at the end of a statutory assessment. She feels that this process should be abolished because there are now too many children with statements and she feels that this has all got out of hand. Although we are great are also incorrect. One of the great defining moments in special education history was the 1981 Education Act, which gave children with special needs the right to have their needs protected by the law through a statement. It is only through the statement that vulnerable children can have their educational provision defined, specified and quantified and it is only through the statement that local educational authorities can be held accountable for what they are providing. Moreover, the number of children who have a statement has dropped considerably over the years as noted by recent statistics published by the DfES and they are at a five-year low. Only around 2% of children benefit from a statement despite more children being identified with special needs.

It is saddening to note that we have seen a dramatic rise in the number of children who have been refused a statutory assessment by LAs resulting often in appeals to the Special Educational Needs and Disability Tribunal. Indeed the majority of appeals to the Tribunal, according to their Annual Report 2003–04, relates to the failure of LAs to undertake a statutory assessment. So far, in all of the appeals for refusal to assess that we have attended both as an expert witness and lay representative, it gives us no great pleasure to state that the parents have won every time. This means that an independent body, SENDIST, has looked at all of the evidence submitted pertaining to the needs of the child in these cases and has concluded that the LA should carry out an assessment.

Without a statement of special educational needs, a parent is unable to express a preference for specialist provision or secure appropriate help, so inclusion is imposed on our most vulnerable children through unlawful backdoor policies, which the Government is fully aware of, but refuses to act upon.

We are passionate believers in the principle of providing for our most vulnerable children through the protection of the law. We also, believe it or not, passionately believe in inclusion if it is the parental wish and right for the child. But inclusion at any cost should not be at the expense of the individual child’s needs because that ceases to be inclusion and becomes political dogma, which results in enabling LAs to avoid their statutory duties towards some of society’s most vulnerable members.

Inclusion, for us, is about recognising a child’s needs and providing an appropriate education to meet those needs. Sometimes that will be in mainstream, sometimes in a special unit attached to a mainstream school and sometimes in highly specialised schools catering for children with the most complex needs. Education is about giving children with special needs the skills to live as independently as possible in the world they so often find difficult to cope with. Inevitably, many of these children will require the expertise of specially trained professionals to teach those skills in settings that provide safety and security so that skills can develop hand in hand with confidence and self-esteem in an attempt to achieve whatever potential that all of these children have inside of them.

INCLUSION

When Baroness Warnock first published her report about inclusion, she was absolutely right to inform debate in our society about what was happening to our most vulnerable children, who were often being denied an appropriate education and their individual needs were being failed. Baroness Warnock was also correct to want to ensure that Parliament took actions through legislation to prevent discriminatory practices in the education system and that society had to protect children with special needs by compelling the local education authorities to address the individual needs of the child by ring fencing resource through the means of a statement.

No sensible commentator today would deny that many physically disabled children, who were intellectually able, were wrongly placed in residential schools away from their communities before and after the Second World War, when as a society we should have ensured their needs were met within a mainstream environment or within our own communities. Unfortunately we cannot change history only learn by it.

We should also reflect that during the 1970’s, we were experiencing a fundamental shift in social policy and society’s more tolerant views towards the rights of others. We have all benefited from the introduction of new legislation to protect the rights of others regarding equal opportunities for women and ethnic minorities. Many of us are able to recall the discrimination women and people from our ethnic minorities experienced after the War and still do. However, we now fully accept that the changes we now experience were not only about legislation, but about good practice, responding to the individual, and more importantly informing and re-educating people’s views. It was not about imposing an ideology or dogma that alienated people, but encouraging a gentle process of change.

In the 1990s we have seen great strides made by physically disabled people and the gay community in creating a more inclusive society, again by understanding rather than imposition, and with Parliament enshrining their rights through legislation to reflect society's changing views. None of us would pretend that we live in a perfect inclusive society, but we certainly have made substantial strides in our genuine attempts to encompass all members of our society within our community.

However, pro-inclusion educationalists are fundamentally opposed to parents' right to choose an appropriate education for their child, and are effectively imposing their values and ideology on others, without considering individual need. They do not appear to recognise that children with special educational needs represent a vast spectrum of need and that society should respond to those unique differences instead of adopting "a one glove fits all" approach and grouping every child with special needs collectively together.

Sadly, many following the mantra of inclusion represent groups who are physically disabled but are highly intellectual and very vocal. As such they bring their own perspective of disability into the debate, which in our view often distorts the true facts and diversity of need. For example a child with an autistic spectrum disorder may not want to be a member of society, because they have a social communication disorder and have to be formally taught those skills by highly trained professionals if they are to embrace society as adults. Understandably, given their communication disorder they often cannot express their views, so are effectively excluded from the debate, leading it to be dominated by experiences of physically impaired adults, whilst excluding the views of those who present with learning disabilities and impairments.

Our society is in fact highly sophisticated and knowledgeable about what is happening in their local communities. Indeed most sensible commentators now fully understand that whilst inclusion is right for one child it is extremely damaging to another child, because we have been able over time to inform and educate listeners. The benefit of which means we have a more receptive responsive society about the nature of differing disabilities and the impact it has on the individual. Sadly, our Government is failing to understand that society having acquired that knowledge, has led to a substantial shift in public opinion regarding how best to support children with special needs, which Government is simply not responding too.

No person would wish to return to a society whereby children are banished to residential schools, but the stark reality is that the current policy of inclusion that is leading to special school closure is now forcing parents of special needs children to place their children in independent special schools away from their communities, to ensure the child receives an appropriate education. In addition, there seems to be no appreciation that should a child fail in mainstream school, they are effectively denied a "safety net" to respond to their needs as the local authority has removed specialist provision for them to access.

Society understands from first hand experience that however noble the cause to include all children in mainstream school, it is simply unrealistic to expect our hard pressed mainstream teachers to meet the diverse spectrum of needs that all of our children who present with special educational needs have within the classroom, without having a detrimental effect to the other children's education. We are expecting too much to ask them to deliver a National Curriculum at such vastly differing levels in a busy mainstream classroom to appropriately meet children's special needs, especially without huge considerable financial and human resource.

Furthermore, it is a stark reality that we have a chronic shortage of specialist health professionals such as speech and language therapists available in the Country to support and help these children in mainstream schools. It is also a fact that there is not an endless bottomless pit of money from which schools or local educational authorities can dip into to fund the present system. Therefore, it appears clear to us that we need to re-evaluate how we can most effectively support, educate, nurture and integrate special needs children within their communities, within those human and financial constraints.

In addition, if we continue to close special schools and units down, we will begin to erode and water down the specialist knowledge we as a society have acquired over many years regarding the teaching of children with special needs. Without that specialist knowledge, mainstream teachers will be left floundering to meet the special needs of children.

Sadly, from our personal experiences there appears to be an ingrained generational culture within the DfES and the local educational authorities that is firmly stuck in their desire to "right the injustices of the past" rather than considering the present. It is also becoming evident that there is now an ever-growing backlash to the policy of inclusion by society. Government's special educational need policy and provision cannot just be developed solely from the most vocal contributors, some of who we accept were at one time denied an appropriate education as a result of their disability, but encompass a more universal approach. Indeed, the reality is their minority view is being imposed on others such as those children who are unable to express a view as to whether they are unhappy or dislike mainstream. This imposition is as fundamentally wrong today in much the same way as when they, or their peers, were wrongly placed in residential schools. We cannot justify one wrong with another.

We maintain that society's wishes are to insure all our children benefit from a high quality diverse education system that responds to the individual needs of the child. The current inclusive culture and agenda of "one-glove fits all" approach is effectively preventing us from developing a sensible cohesive education policy and infrastructure. As such the need is to ensure all children as adults reach their true potential and are empowered to play an active role in an increasingly more tolerant inclusive society, is alas being thwarted.

TRUE COST OF INCLUSION

There has in this Country, been no extensive independent research on the outcomes of all children with special educational needs that have been included in school. Research has often targeted small specific groups, in schools that have received high amounts of additional funding from the LAs to demonstrate inclusion works. No research has then followed to ascertain what happened to those children in adulthood.

Moreover, the increasing numbers of children being supported on the staged approach of the SEN Code of Practice are as a result not brought to the personal attention of the LA nor are the nature of their difficulties recorded properly, as it is a matter for the individual school to ensure the child's needs are met. The LA merely collects statistical data for the DfES regarding the total number of children their schools report as having special needs, on a yearly basis.

However, what DfES figures do show (Removal of Barriers for Inclusion) is that, of the 0.5% of the school population excluded from school, two thirds of the children and young people involved had special educational needs. Sadly, most were not subject to a statement. Given, that only 20% of children as noted by Baroness Warnock in her original report, will present with special educational needs at sometime during their schooling, children with special needs should not be accounting for the significant majority of pupils who are excluded from school. We are of the view that one of the direct consequences leading to their exclusion was because their individual educational needs were not being met or identified due to our current inclusive school approach.

It is noted by the Youth Justice Board that a recent study undertaken demonstrated that 80% of young people in a youth offender's institution experienced special educational needs. Again most of those young people did not benefit from a statement of special educational needs. The biggest risk factor for children to become involved in crime or to re-offend relates to those not attending school and as already noted the majority also have special educational needs. Finally, the vast majority of children truanting from school also present with special educational needs and are therefore exposed to the same risk factors as those children who are excluded.

Whilst we do not in anyway condone youth crime or vandalism, the Government's policy to address so called "yob culture" by the use of ASBOs or anti social behaviour policies are effectively being undermined. The fact is many young people becoming involved in crime do so because they are being denied opportunities to benefit from an appropriate education in the first place. Moreover, many parents of children with special educational needs have learning difficulties themselves and are ill-equipped to support their children's educational needs without support from others. Yet the Government's policy to this is to punish parents of problematic pupils rather than to address the child and parent's learning needs.

The Government policy of inclusion effectively leads it into direct conflict with its own educational policy of planning to show a "zero tolerance" approach to low-level disruption in the classroom by students. Yet, many children with dyslexia, speech language and communication disorders, and ADHD, have pragmatic language problems, poor concentration and attention skills and as such develop secondary emotional behaviour problems. It is inevitable that their frustration over their learning difficulties often not being addressed will lead to inappropriate behaviour in the classroom. Merely excluding them, and placing them part-time in an educational placement such as a Pupil Referral Unit, without addressing their special educational needs, is courting disaster for society and local communities.

We are of the view that this present Government policy to address the current "yob culture" has become reactive, rather than proactive. We feel given the ample statistical data available regarding youth crime and the clear links to poor educational attainment, the Government should be properly reviewing what is happening to students with special educational needs within our state educational sector and accounting for the true cost of the failure of the education system to appropriately address the special educational needs of our children both socially and financially to society, as a whole.

STATUTORY PROCESS

The Education Acts of 1981 and subsequently 1996 have enshrined in legislation the legal rights of a child to receive an appropriate education that their learning needs call for. For the first time LAs were compelled to meet the educational needs of our most vulnerable children. However, we believe on both the grounds of inclusion and cost LAs have actively attempted to avoid those statutory duties. The Government has for a substantial time now effectively turned a blind eye to it, and as a direct consequence LAs have been enabled to fetter their legal duties without recourse.

Our experience of the conduct of LAs should concern the Government. We have supported and represented parents from across the Country, against LAs led by all political parties. The vast majorities of statements of special educational needs we see are unlawful, as they simply do not detail the child's special educational needs, nor do they specify or quantify the support the child requires to ensure they are enabled to access the National Curriculum and are usually with very little resource. Furthermore, LAs are using unlawful banding policies to say a child with this "label" can have this much support only, when we all know that children's special needs impact upon them in an individual way and as such policies like this make it clear statements are not being needs led, but cost driven.

Parents are not, as the Government states, permitted to express a preference for a school of their choice, but have their local mainstream school imposed on them through dogma, and unlawful policies such as transport arrangements. Namely the LA refuses to transport the child to the local special school only to the local mainstream.

LAs are also now actively using policies that are not in accordance with the Education Act 1996 for its reason to refuse a statutory assessment of a child and therefore can effectively force the child into mainstream school through such policies. Of concern to us about the statutory assessment is that it did mean that as a consequence of the process children were brought to the attention of the local health service and underlying disabilities such as speech and language impairment or ASD were identified. Teachers are not qualified to identify these types of impairments and by not statutory assessing these children, needs are not being identified early, as is the desired intention of the Removal of Barriers for Inclusion.

We have personally witnessed LA officers physically and verbally abuse parents, especially if a parent is articulate and able enough to disagree with the LA's proposals. The unprofessional conduct we have observed is extremely concerning.

Despite making numerous complaints to the DfES about the conduct of LAs in failing to fulfil its statutory duties, in most cases the DfES, appears to actively choose to ignore them, as also noted by IPSEA.

It is a reality that one of the biggest causes of children not receiving an education their learning need calls for and one of the primary tension in the special educational needs system apart from inclusion, is the Education Act 1996, itself.

Although, vital to protect children with special educational needs, amendments to this primary legislation are needed urgently. The LA is both the commissioner and the provider of resources for statements of special educational needs and the Act creates a conflict of interest, which parents find they are caught up in the middle of.

It is clear from our experiences that LAs are reluctant to commission something that is effectively going to cost them money. Accordingly, if they are enabled by legislation to refuse to commission something and as a result of that refusal can save resources it probably will. It is evident to us that in a lot of cases we come across, the Authority under financial pressure, will act in this contrary way, whether it is appropriate or not. We also are aware of many financially hard-pressed LAs adopting unlawful policies simply to reduce the number of statutory assessment of a child's special educational needs it conducts, given the direct cost saving it experiences.

Moreover, the statutory assessments of children woefully minimise the extent and nature of the child's special educational needs, for exactly the same financial reasons and cost implications. Namely, the less needs an LA identifies as educational the less resource it will need to invest in the child's school placement and provision, so there is a cost saving. We are increasingly coming across statements that state an autistic spectrum disorder is a non-educational need and should be in part V and VI of the statement rather than an educational need, which is simply nonsensical.

SEN TRIBUNAL

The Government recently stated in the House of Commons that there is a robust system in place for parents to appeal against any Authority's decision regarding their child's educational needs, which we concur with. However, the Government did not seem to appreciate that most parents find this process beyond their financial resources and capability.

Indeed, the Government is fully aware the SEN Tribunal is a lower court of law, governed by complex legislation, which baffles most parents. Under the current system, parents regardless of income or ability (given many parents of children with special needs presents with learning difficulties themselves) cannot have legally aided representation, but must rely upon either representing themselves, securing Counsel or upon charitable organisations to help them prepare and represent their legal case. Legal bundles amounting to hundreds of pages have to be digested and considered within the context of the law.

Most parents struggle to access this system. The University of Strathclyde in recent research found only parents with considerable ability and resources access SENDIST or secure special provision for their child. Therefore, the sad reality is most special needs children from lower social economic backgrounds are being denied opportunities because the system is out of reach to their parents. The low number of appeals lodged from ethnic minorities is also extremely concerning. Although the appeal process is free parents need to commission independent reports to identify the exact nature of their children's special needs, the cost of which often runs into thousands of pounds.

The Government stated that the answer to the statementing process was to intervene early so that parents feel their children's needs are adequately met in school. This concerns us as it infers:

- I. Children with special educational needs are not entitled to an education "that their learning needs call for" as noted in the Education Act 1996, merely an adequate education. Most parents regardless of their children's ability expect more than just an adequate education for their child.
- II. As previously stated a parent can only express a preference for a special school if their child is subject to a statement of special educational needs. The Government's expressed agenda encourages LEAs not to undertake statutory assessments, which could lead to a statement of special educational needs, and therefore effectively imposes inclusion on the child whether appropriate or not.
- III. The majority of appeals (39.6%) to the SEN Tribunal in the year 2003–04 as noted in the SENDIST Annual Report, related to refusal to undertake a statutory assessment. Accordingly, given most parents are unable to access the SEN Tribunal in a meaningful way, it is likely that there are a considerable number of children currently being educated in mainstream school that are being denied an appropriate education.

PARENTAL PARTNERSHIPS AND MEDIATION SERVICES

The Government claims to have counteracted this flaw in the SEN Appeals system by ensuring LAs established parental partnerships schemes to help parents. However, it systematically failed to ensure that those working for parental partnership schemes were independent of the LA and/or policy decisions.

Accordingly, many parents we meet complain of the bias of parent partnership officers and directly relate it to the fact that they are employed by the LA and are such partisan. Moreover, their conversations are not subject to confidentiality and we have read in a number of case statements comments parents have made in good faith to the parent partnership officers believing it was confidential referred to in LAs case statements to the SEN Tribunal.

Parents are also concerned how little parent partnership officers know about primary legislation and parents legal rights in ensuring a child receives an appropriate education.

We are also concerned about the mediation services that LEAs are obliged by Government to offer to parents. Parents have no say whatsoever in which mediation service is used as the Authority has direct control as the commissioner of it. Again from personal experience we are concerned that there is a definite bias by the mediation services and that discussions always commence from a position that it is Government policy to include a child in mainstream school and an active hostility to specialist provision is invariably shown.

SEN REGIONAL PARTNERSHIPS

We have been concerned about these regional government established quangos for a substantial time now. They consist of LA officers from differing LAs meeting together. Their remit is to plan a consistent approach to SEN provision within their region. However, they are accountable directly to the DfES and not to elected local members, and are being actively funded by the Government. Officers are establishing policy and consensus about provision within their region, with no reference to the County Council itself.

We have also noted from minutes that the partnerships were set up to increase inclusion under National Government objective 2. However, the Government publicly insisted in the House of Commons, that special educational needs provision is a matter for local communities only, not them, when in fact it has actively created regional provision and policy, through these partnerships.

We are also concerned that these regional partnerships are according to minutes having direct contact with SENDIST lobbying it to change procedures. This body was established by Parliament to be totally independent from outside influence and we are disturbed by this contact, especially as that same ability is not afforded to parents.

Finally from minutes we have reviewed, much of the discussions taking place are not about enhancing provision and meeting need, but about how LAs can evade their statutory duties and share bad practices rather than good.

PROPOSALS

Short-term

1. We believe that the Government needs to express a clear proper view point as to whether their desire is for all children with special educational needs to be included in mainstream school or not, (even though this usually happens now) and if so should that occur against the expressed wishes of the parents. Its current guidelines policy document about inclusive practice merely reinforces that position. However, its public

statements to the House of Commons are vague. Ministers often report that it has no active policy of inclusion one way or the other. That position is simply no longer plausible or tenable and there needs to be proper clarification.

2. If it is the case that LAs have misinterpreted legislation as claimed by ministers recently in the House of Commons, then the DfES should in our view formally write to all LAs advising them of this and for LAs to adopt appropriate lawful policy. That letter should also be published.

3. The Government has widely spoken about parental choice for education. If the Government is pro-choice for parents it should apply that policy unilaterally across the educational spectrum including those children with special educational needs. Parents of special needs children should have the right to choose a unit, special school or mainstream school, providing the child's placement adheres to the current Education Act 1996, but are currently being denied that opportunity by most LAs.

4. The Government must ensure that LAs are held accountable for their actions and that they are prevented from adopting policies that are contrary to the Education Acts of 1981 and 1996. The DfES must also improve its performance in policing LAs unlawful SEN policies and ensure that it conducts proper prompt investigation, and actively find in the favour of the complainant or not. If the complaint is upheld then appropriate public criticism should be made. This public criticism is important to enable parents in the community to actually review whether or not their child's statement of special educational needs or refusal to assess has been made in accordance with primary legislation, moreover it informs parents that the LEA has been deemed not to fulfill their statutory duties.

5. The SEN Audit should evaluate all specialist provision available within the Country, not just encompass the narrow margin of low incidence special educational needs that it has commenced upon. Moreover, the Government should publish figures relating to just how many children in the Country is believes present with special educational needs including those on school action and school action plus, not just children with statements of special educational needs, given many children are now being denied statutory assessment.

6. It should also publish just how many children from each classification of special needs there are currently in education system, namely the exact number of children identified say with dyslexia, ASD, MLD, SLD, cerebral palsy, complex learning needs etc together with how many of the children from each of those groups have statements of special educational needs and how many are supported on school action and school action plus. Until society has those exact statistics we are unable to plan future specialist provision, invest in mainstream inclusion or meet those children needs in further education or into adulthood.

7. The DfES should disband the SEN Regional Partnerships. These groups are not reflecting local needs they merely conduct unaccountable regional discussions relating to National objectives. Moreover, it has not ensured good practice has "radiated out" as hoped, but has enabled officers to share advice in what policies their respective LAs adopt to avoid their statutory duties.

8. The SEN Tribunal must remain totally independent to both LAs and parents as noted in primary legislation. Therefore the current lobbying practises adopted by LAs as noted in SEN RP published minutes should cease forthwith and ministers should instruct LAs accordingly.

LONG TERM

Change to Primary Legislation

1. We would like the SEN and Disability Act 2001 amended to ensure that the assumption that a child must be educated in mainstream school is removed, and that parents should have the right to choose the provision they best think suits their child's special educational needs as in accordance with the Education Act 1996 and in accordance with the child's educational needs.

2. The purpose of Baroness Warnock's original report was driven by a genuine desire to ensure that local educational authorities were compelled unlike before to meet the needs of our most vulnerable children, through the introduction of statutory duties. She wished for children where it was appropriate to be included in mainstream, but at no stage did she argue for total inclusion, nor did she espouse all children's special educational needs could be met within mainstream.

However, since the introduction of the 1981 and 1996 Education Acts, LAs have unfortunately tried to avoid any statutory duties they have towards these children, either because of cost or as a result of inclusion. Whatever, the exact reasoning behind their failure to address these children's needs, the time has come for legislators to finally ensure that our vulnerable children's needs are met and addressed within the education system through in our view new legislation.

As stated, the current system is adversarial, legally complex to parents and grossly unfair to children from lower social economic backgrounds, given their parents or carers may not have the ability to understand legislation around special needs or have the financial resources to meaningfully access it. Therefore the system is failing to help vulnerable children, as it should.

As previously noted the current Education 1996 makes LAs both the commissioning agent and the funding agent thus creating a conflict of interest, which parents find himself or herself in the middle of. We propose removing the statutory assessment and statementing process away from the LAs, simplifying it, and placing it into the independent sector referring to it as the “Independent Assessment and Statementing Panel (IASP)”.

Accordingly, we lay out our proposals:

- (a) The IASP will replace the LA in the primary role of the identification, assessment and funding of children who are likely to require a statement of special educational needs.
- (b) The Government should set up local multi-discipline assessment centres, under the auspices of the IASP, to undertake the assessment, identification and statementing process of children with special educational needs.
- (c) The multi-disciplinary independent team of professionals would consist of an educational psychologist, a clinical psychologist, a community paediatrician, a specialised speech and language therapist and an occupational therapist.
- (d) The multi-discipline independent team will undertake a full one-day or, in more complex cases, a two-day assessment of the child’s special needs, having previously gathered reports from the child’s educational placement and from the parent(s). They will give the parent(s) at the end of the day verbal feedback of their findings.

Independent specials schools such as Moor House School, Oxted, Surrey have successfully been conducting these types of assessments for a substantial number of years as a method of insuring the child would be suitably placed educationally. Parents trust the findings, as the staff conducting them, are totally impartial.

- (e) The IASP will, under legislation, be responsible for identifying the child’s special educational needs, drafting the statement, which adheres to the requirement to specify and quantify support and after full consultation with parents the type of provision the child needs, whether it be mainstream, a special unit, or special school.
- (f) Parents, or the school, instead of requesting the local educational authority to undertake a statutory assessment of needs will contact their local IASP. When initial contact is made either by the parent or school, the IASP will ensure that an educational psychologist assesses the child in their educational placement within three weeks of the request. Should the child be out of school the child should be seen at the Assessment Centre.
- (g) If following that visit the educational psychologist believes there are educational concerns then the IASP will undertake a formal assessment, within three weeks of that visit.
- (h) However, if the educational psychologist feels that the school can meet the child’s needs within their delegated resources, (s)he will issue advice to the school in how best to address the child’s current special educational needs. Parents and the school should be advised within seven days of the visit that no statutory assessment is needed. Parent would be given the same right of appeal to the SENDIST as currently available.
- (i) If a statutory assessment takes place, and the IASP feel a statement is necessary, then a proposed statement should be issued within three weeks of the assessment for parent and school to consider and respond to.
- (j) The final statement, following consultation with the school and parents should be issued three weeks after the proposed statement. If parents disagree with the contents of the statement of special educational needs then, as now they will have the right of appeal to SENDIST.
- (k) If on the other hand the IASP feels a Notice in Lieu is more suitable it should send that out to parents within three weeks of the assessment and as now advise the parents that it has the right of appeal to SENDIST.
- (l) Parents wishing to seek an amendment of their child’s statement of special educational needs or seeking a statutory re-assessment would follow the above procedures.
- (m) The IASP will also re-assess the child when they need to transfer to secondary provision and further education and follow the above procedures.
- (n) Annual review reports will no longer be sent to the LA but the IASP for consideration.

We believe the removal of the statementing process out of LAs control will have the following benefits:

- It will actually reduce the initial request for a statutory assessment down from the current six week timescale to four weeks.
- Reduces the statutory assessment and statementing process down from the current 26 weeks to 12 weeks, saving valuable time in insuring intervention into a child’s education.
- The Assessment Centre will bring professionals from education and health together in a more cohesive manner for the benefit of the child’s education and well-being.

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- A one or two day visit to the Assessment Centre would be less stressful for the child than having to attend appointments for professionals on different days. Moreover, the parent will not have to keep repeating their concerns about their child to professionals as happens now.
 - Parents being given access to an independent assessment service are more likely to have trust in the system and less likely to turn to SENDIST.
 - We also believe an independent system will enable schools to be more open about the nature of a child's special educational needs, as the system for identification and assessment has been removed from their employer's remit.
 - Removal of the statementing process from the LA who is the commissioning agent and funding agent ends the tension in the system created by the Education Act 1996.
 - If LAs are aware that parents effectively have a 'funding package' in place either for a special school, unit or mainstream, which is going to bring resource into a maintained school rather than take resource out, the LA is more likely to want to actively engage with parents and ensure it has a diverse range of provision available to address the child needs to secure that funding. Parents are effectively empowered to be able to "purchase" high quality educational services from the LA, hopefully at a local level, if not then are likely to seek provision elsewhere, meaning the LA will lose potential investment in their education provision if it does not have choice.

Funding

Children with special educational needs who require statements account for a disproportionate amount of local authority funding and we believe that their education should be funded through Central Government as opposed to the LA. We genuinely believe that LAs are forced to make inappropriate decisions about children not based on need, but on cost, as they simply do not have the resources to meet the child's educational needs at that moment in time, particularly if a specialist residential school is required.

Medical advances has also led to a greater number of very premature babies surviving, 50% of who experience special educational needs. Moreover, babies who are ventilated at birth also have a much greater risk of having special needs.

When Baroness Warnock published her original report the number of children presenting with ASD, were considered only to be the very few children with Kanner's Autism. Today, through medical research and better understanding, we appreciate the autistic spectrum is wide and according to a Department of Health report published 31 August 2005, 1% of children now has ASD, a staggering 27% of which will be excluded from school.

Government investment in special education needs has simply not kept pace with medical advances and research regarding children with special needs and the LAs cannot meet the financial demands being placed upon them, to address this level of need.

Other roles of IASP

The IASP could also take on other roles to serve the local community such as:

- Mediate regarding claims of disability discrimination. Instead of a parent immediately appealing to SENDIST, as happens now, parents could ask the IASP to review the child's educational placement and provision, to ascertain if there is a genuine concern about discrimination or that teaching staff need more support and training.
- We also believe that any child permanently excluded from school must be subject to a statutory assessment by the IASP within two weeks of that exclusion to ascertain whether the child or young person has special educational needs that have not been identified or supported. This will ensure early intervention as opposed to merely placing a child part time in a PRU and hopefully reduce the risk of the child becoming involved in crime, as they can actively be re-engaged in education with appropriate support.
- Children who persistently truant should also be seen by the IASP to ascertain again whether the child has special educational needs or whether it is a case of poor parenting.

- We also believe that the IASP should also have its own specialised trained parental partnership officers to support parents and explain the procedures around statutory assessments and the statementing process.
- The officers should also help explain benefit entitlements to parents such as disability living allowance and carer's allowance and assist where necessary to complete the forms.
- If asked, the IASP should provide parents' access to trained officers who are able to prepare the parents' case statement for any appeal to the SENDIST and free representation at the Hearing.
- The IASP should have a statutory duty to liaise with social services and the local health authority to ensure a cohesive joined up approach to support vulnerable children and their parents in the community including access to respite care or befriending schemes.
- The IASP could also offer parenting skills courses.

THE ROLE OF EDUCATIONAL PSYCHOLOGY SERVICES

We believe that Educational Psychology Services are hindered in performing their core function, that is, the identification and assessment of children with special educational needs. This is because they are employees of LAs and are driven by the resources available within the LA. This again creates an obvious conflict. Therefore, EPs are forced into looking at the provision available within the LA and "boxing" children with special needs into that available provision rather than addressing need.

In order to perform their function efficiently we believe that Educational Psychology Services should also become independent and made into a National Educational Psychology Service (NEPS). A similar system currently exists in the Republic of Ireland. The NEPS would then be sub-divided into regional Educational Psychology Services responsible for children with special needs within that region and will work jointly with the Independent Assessment and Statementing Panel (IASP) for that region.

LAs or individual schools could then buy in other core EP services as demand dictates.

CONCLUSION

It is our experience that most parents of children with special educational needs fully accept their responsibility to their children and their only desire is to have an effective system in place that provides them with a proper choice of provision that is based upon an independent, impartial and easy to access system. We believe our proposals offer just that.

We feel they reflect the proper right of parental choice whilst supporting inclusion where appropriate and that most importantly of all they provide children with special educational needs full access to a range of educational opportunities. All children should regardless of ability have the right to fulfil their true potential and play an active role in society. Parents are paramount to that success yet current Government policy effectively excludes them from it and as such their valuable insight and knowledge of their child needs is lost.

What parents do not want is to be burdened down by Government policies that are driven by dogma and ideology based very much on the wrongs of an education system some 50 years ago, when society has moved on considerably since then.

Nor should financial accountants driven by the need to save cost ever again be permitted to seriously impair the opportunities given to a special needs child, especially as they are too often based upon short-term gains rather than longer-term objectives.

Baroness Warnock is correct to call on elected representatives to review primary legislation and the current special education system, which is causing such harm to some of our most vulnerable children. Public opinion now fully recognises inclusion is appropriate for some children and totally wrong for others and the time has now come for politicians from all parties to respond to that very pragmatic view.

Our document has been driven by a desire to contribute to a sensible and thorough debate about how to address our children's special needs in a way that does not polarise the issues and that any discussion formally undertaken ensures that children special educational needs are met in this Country through a robust diverse special educational needs sector that fully embraces the vital roles of both special and mainstream provision, and that both systems are finally properly funded by Government to ensure the success of these very special children, for the long term benefit of society.

We believe that the measures outlined above will deliver a more efficient and cost-effective statutory process for the identification and assessment of children with special educational needs where the needs of the child, in conjunction with parental wishes, is paramount and where there is no conflict between the commissioning and funding agents. This must be a better deal for our most vulnerable children.

Memorandum submitted by Maryla Carter

This submission concerns children who suffer from Attention Deficit Hyperactivity Disorder (ADHD) and particularly concentrates on:

- Provision for ADHD pupils in “mainstream” schools: availability of expertise.
- The system of statements of need for pupils with ADHD.

SUMMARY

Attention Deficit Hyperactivity Disorder (ADHD) affects around 3% of the child-hood population of this country and persists into adulthood. In a non-selective mainstream school, on average every class of around 30 children can be expected to have one such child. ADHD is a genuine neurological condition—an under-functioning of the frontal lobes of the brain. A child with ADHD is typically characterised by:

- impulsive behaviour—words as well as actions;
- being very easily distracted;
- excessive squirming, running about, or climbing;
- difficulty in sustaining attention/concentrating on tasks;
- short-term memory problems;
- interrupting the conversations and activities of others;
- serious disorganisation;
- a strong tendency to lose or break personal property;
- deficits in executive functioning; and
- a different perception of time and its passage.

In mainstream school classrooms, every teacher is nowadays expected to be a teacher of children with special educational needs. But ADHD is an extremely complex condition and even the way in which it is exhibited will be different from one child to another. The outplay of ADHD characteristics looks to the non-expert as though the child is deliberately being awkward, rude, lazy, mis-behaved, off-task, disorganised and, because of his/her different perception of time, may come across as though s/he is a liar. Neither LEAs nor teachers have been trained to understand the complexity of ADHD and how to deal with it. Indeed, it can only be properly addressed educationally by using teaching methods which are atypical to the mainstream environment, and a curriculum which is likely to differ significantly from the National Curriculum.

Getting a Statement of Special Educational Needs for a child with ADHD is fraught with difficulties. Even when a child does have a Statement, it is extremely rare for Part 4 to specify a Special School, which is the only kind where all members of staff are likely to have a thorough understanding of ADHD.

This situation is leading to more and more children with ADHD being “abused” by the system—a system which has not been designed to include such neuro-atypical human beings. And yet with the prevalence being around 3% one could argue that having ADHD is not particularly atypical, but merely different. The differences are not and cannot easily be accommodated in our mainstream schools, and as a result many children with ADHD are being excluded, with dire consequence for them and society.

The Government needs to investigate the true needs of children with ADHD and set up systems to ensure that these needs can be met by LAs, teachers and other school staff who have the necessary expertise in ADHD.

1. *About the Author*

1.1 Born in London in 1953, I was educated at Croydon High School. Later, I studied at the Universities of Cambridge, Reading, Cranfield and at Regent College, British Columbia where I read Natural Sciences, Earth Sciences, Agricultural Engineering and Theology. My work took me to many parts of England and Africa—to lecture-room, laboratory and field. Married to Richard Carter and living in the English Midlands, we adopted two children in the 1980s—a daughter Rosie, and a son Timothy who has ADHD. For some 13 years I worked as a full-time parent, snatching at spare moments to research ADHD, to understand our son better and meet his very complex needs. More recently I took up part-time work as a writer and technical editor and have just began studying with the Open University on their Flexible PGCE Course for Secondary Science Teaching. I have been a Beaver Scout Leader (mostly boys, aged six to eight years) since 1995. In 2003 I had my first book published, entitled *ADHD: A Challenging Journey*, under the pseudonym of Anna Richards, by SAGE Publications, ISBN 1-87394-284-2.

2. *The Characteristics of Children with ADHD*

2.1 Most, but not all of these children, are boys. If they have the hyperactivity component of the condition they are likely to be fidgety, physically very active (“bouncing off the walls”) and highly impulsive. Our son, prior to being medicated, would smash objects and hit other children for no apparent reason, and then not even know why he had done it. ADHD children without hyperactivity (mostly, but not exclusively, girls) are likely to day-dream a great deal, sit quietly in a corner, and even go unnoticed. Many ADHD children have co-morbid (ie co-existing) learning difficulties such as dyslexia or excessively poor or slow handwriting skills, although ADHD can occur right across the IQ spectrum.

2.2 Many children with ADHD exhibit serious or severe executive functioning deficits (EFDs). Executive functions (EFs) can be thought of as the decision-making and planning processes that help to control and direct our behaviour. For example, when a child has a long-term assignment to complete, the executive functioning tasks involved would include dividing the task into sub-tasks, making a plan for completing those tasks, and monitoring performance along the way. Although no single list of EFs is universally agreed upon, most experts would agree that important EFs include such abilities as planning, reasoning, working memory (ie, holding information in memory for later use), inhibiting behaviour that may bring immediate rewards in pursuit of a long-term goal, some aspects of attention, and shifting cognitive sets, ie, flexibility in thinking. EF skills are believed to be critically important for complex human behaviour because they serve to organise and guide behaviour in flexible and adaptive ways.

2.3 One of the main problems for children with ADHD in the school environment is that their lack of EFs come across to the staff as if the child were being lazy. As a consequence the necessary concessions are not made, neither is help given, but more commonly the child is punished in some form or other.

2.4 With a deficit of EF skills the child is frequently seriously disorganised. Another “give-away” sign is where the behaviour exhibited by the child is highly incongruous with his family background, that is, when he seems to come from a “good” home. He may well have a problem-free older sibling, whose exemplary behaviour and positive lifestyle indicate more than adequate parenting within the family. Why would the younger, difficult child so consistently behave in a way that is so much at odds with his family, the school and so much against his own best interests? Why would he go on generating more and more condemnation when what he desires above all else is everyone’s approval? The answer is that either he is unable to help it (a problem of inability to “self-regulate”), or it is an attempt to cover up what he perceives to be his continual failure in an orderly or academic setting. In the latter case, this failure to be able to give to the adult world what they require of him is probably not his fault either. It is because he suffers from a condition, ADHD, which, if untreated or inadequately addressed especially in the educational setting, is beyond his control.

2.5 In Text Box 1 you will see a summary of the most usually accepted set of criteria for determining whether a child has ADD or ADHD—the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, 1994, commonly known as the “DSM-IV™”.

TEXT BOX 1: SUMMARY OF DSM-IV™

A. Either (1) or (2)

(1) six (or more) of the following symptoms of inattention have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level:

Inattention

[Here follow nine specific examples of inattention, labelled “a” to “i”]

(2) six (or more), of the following symptoms of hyperactivity-impulsivity have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity

[Here follow six specific examples of hyperactivity, labelled “a” to “f”, and then three further specific examples of impulsivity labelled “g” to “i”]

B. Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before the age of seven years.

C. Some impairment from the symptoms is present in two or more settings (eg at school and at home).

D. There must be clear evidence of clinically significant impairment in social, academic or occupational functioning.

E. The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder, and are not better accounted for by another mental disorder (eg Mood Disorder, Anxiety Disorder, Dissociative Disorder or a Personality Disorder).

3. *Why Children With ADHD Behave as They Do*

3.1 Children (and adults) with ADHD have an under-functioning of the frontal lobes of the brain compared to the majority of the population. This is why stimulant medication can assist them to concentrate and thereby conform more easily. However, medication does not eliminate the problems completely.

3.2 In their brains, there is relatively little filtering and selection of incoming stimuli, so they are highly distracted by anything and everything which enters ears, eyes, nose, mouth or via their sense of touch. Moreover, many of these children have co-morbid Neuro-Developmental Delay (NDD) which exacerbates their incapacity to sit still for long periods. NDD (in which primitive foetal reflexes still persist) is fairly common in children who have been born prematurely or by Caesarean Section. To tell such children to sit still can sometimes be as unreasonable as asking me to stop kicking my foot into the air when my leg is being struck by a rubber hammer just below the knee-cap.

3.3 Children with ADHD have a very different perception of time, due to significant differences in the basal ganglia area of their brain. Many of them have sequencing problems (ie find it difficult to report events in an accurate chronological order) and end up being labelled as liars.

4. THE PROBLEM OF MIDDLE/UPPER/SECONDARY SCHOOLS

4.1 Another danger is that we design and implement compulsory education systems which are totally, or in great part, at variance with the way these children are “designed”. The Middle School and Upper (Secondary) School systems, I believe, are prime examples of this. I have come to this conclusion not only by experiencing what happened to Timothy when he changed from Lower School to Middle School, but also by observing the same thing happening to many other children with ADHD. Some children, like our son, may just about have “survived” at Lower School without being excluded or labelled severely problematical, on account of the tighter structure and control which these schools provide compared to a Middle School or Secondary School. (The Lower School child has one classroom, one place where he is expected to sit, one teacher who gets to know him very well indeed and will soon sort out the best place to position him, and the best way overall to deal with him). However, when the child gets to Middle School, as we found with Timothy, all this crumbles. In addition, the child is expected to organise himself, thus exposing his great lack of this particular life-skill. The majority of Timothy’s peers, who undertook this same transition as he, could, after an initial settling-in period, cope. Timothy, (despite being on medication), plus some of his classmates, clearly could not. I suspect that, broadly speaking, those without ADHD were the copers and those with ADHD (and/or other “invisible” disabilities) were the flounders. I am, through a large network of contacts, sadly aware that this is the picture across the whole of the UK.

5. DANGERS OF IGNORING ADD/ADHD

5.1 The ADHD child usually looks quite “normal”. When confronted by a static child of this type, the condition is quite invisible. If a child suffers from Down’s Syndrome, others usually make immediate concessions for his or her unusual or demanding behaviour, based on the child’s appearance. Children with ADHD do not have this “advantage”. On the contrary, they are frequently branded as naughty, unco-operative, lazy and defiant. All too often the child appears to come to fit this description more and more as he struggles with confusion, frustration and anxiety, plus a progressively plummeting self-esteem as he repeatedly fails to dance to the tunes called by the school staff. It is more than possible that ADHD underlies “that hard core of underachievers—the 7% who gain no qualifications at all” who were identified by this Government as long ago as 1999.

5.2 If ADHD goes undiagnosed and untreated (medically, socially and educationally) then by the time the child hits the teenage years he is often in big trouble. It is virtually impossible to keep these children playing nicely inside the home, and doing their homework as and when told. They are very vulnerable to getting in with a bad crowd, very easily led, very prone to substance abuse and to crime. Truancy is likely to occur. Whilst there is much talk now about “parent partnership” and parents being ultimately responsible for their truant children, how (may I ask), short of strait-jacketing them, can they possibly get their youngsters to school? Most of them are physically bigger and stronger than their parents by then. Even fining the parents several thousand pounds is unlikely to change the impulsive behaviour of a persistent truant. So by the time they are adults, with years of constant failure and rejection behind them, many become severely depressed and some commit suicide.

5.3 At the 2nd Annual ADD Information Services Conference, held in London in October 1998 (at which I was present), Doctor Alison Munden, a Child and Adolescent Psychiatrist working at the Birmingham Children’s Hospital, NHS Trust, presented the results of a study which she had been carrying out. The study had investigated ADHD plus behavioural and emotional problems in children who had been excluded from mainstream education. Her study team found that excluded children had a very high incidence of ADHD and Emotional and Behavioural Disorders. John Sanford, HM Prison Officer and parent of an adopted son with ADHD, gave a talk at this same conference in which he said that 90% of crime is committed by just 6% of the population. He estimates that half of that 6% have ADHD and do not know it.

6. THE ADHD TIME BOMB

6.1 It is clear that there are many of these children around (the prevalence of ADHD is around 3% of the population) and their condition will not just “go away” by being ignored. Unless and until every child is appropriately and successfully treated, the ensuing situations will explode in everyone’s face resulting in damaged children, dysfunctional families, dysfunctional schools and society. There is no other possible outcome. We are already seeing “explosion” after “explosion” in school after school in the UK, where children with ADHD are misunderstood and consequently being mistreated.

7. PROFESSIONAL IGNORANCE OF ADHD

7.1 Even after our son had a diagnosis of ADHD and a Statement, the majority of his teachers would write in his school report remarks like “Timothy must develop a much more positive attitude towards work and begin to recognise the value of concentrated attention”. Every other parent that I know of a child with ADHD also receives similar kinds of school reports. We don’t need to be told that our child has concentration problems, organisational problems and is impulsive. We already know that. What teacher would ever dream of telling the parent of a blind boy that their son has a problem with his sight? Who in their right mind would feel they need to inform the parents of a deaf girl that their daughter has a problem with her hearing? The fact that teachers are continuing to write reports such as these is a complete give-away that they do not grasp the true nature of ADHD, however much one tries as a parent to inform them. It is a very complex condition and teachers’ extent of such specialised knowledge and understanding in the mainstream environment is woefully and dangerously inadequate.

7.2 In our experience, the LA (Bedfordshire) were no better than the school at understanding what ADHD is all about. Timothy was Statemented in 1998. In May 2003 my husband and I had to attend a meeting with LA officers at County Hall, Bedford. Since Timothy was home for half-term break from his residential school, we thought it would be a good idea if LA officers had the opportunity to meet with him so we took him with us. Our daughter (then aged 17 years of age and extremely mature) came too, our idea being that she accompanied Tim into a brief meeting with the LA officers (without us, the parents) and then took him into Bedford city centre to occupy him until we could all meet up again. To our astonishment the LA officers asked whether our daughter and Timothy would wait (in an amusement-free waiting area) until after the meeting with my husband and myself, and then they would meet with our children. Now these were officers from the Assessment and Monitoring Team. They should understand the nature of various disabilities, and ADHD is by no means uncommon. Surely they should have known that it is extremely difficult for a child with ADHD to “wait his turn”. Even if they knew this in theory, they proved that they had no idea how to make reasonable adjustments in practice! It was an equivalent disability faux-pas to that of asking parents of a wheelchair-bound child to change the venue of the meeting to a room on a different floor in a building where there were no ramps or lifts.

7.3 Then again, at a meeting with LA officers (from the same Assessment and Monitoring Team) in January 2004, I had to bargain very hard with both Tim’s Statementing Officer and the Head of Educational Psychology regarding their wording in Part 2 of Timothy’s Draft Statement. They had put “Timothy is unwilling to take responsibility . . .” Given that Timothy does not have significant Emotional and Behavioural Difficulties, but does have very significant ADHD, the wording should be “Timothy is unable to take responsibility” The officers eventually conceded to my arguments and claimed that they could not be expected to understand every medical condition which existed. But if they are going to be making meaningful, appropriate Statements for children with ADHD, they absolutely must understand the condition—or “buy in” the necessary expertise. They did neither. Reports from parents of other children with ADHD in other parts of the UK indicate that their LAs are no better equipped than ours.

8. THE ECONOMICS OF TREATING—AND NOT TREATING—ADHD

8.1 Most people would probably agree that we have a moral obligation to treat ADHD children and adults with respect, justice and support, quite apart from any economic arguments. But even if one were heartless enough to argue the case on economic grounds alone, the case for early diagnosis and treatment as opposed to ignoring the condition is overwhelming. Treatment might include medication (where symptoms are sufficiently severe), but will certainly mean some kind of modified or alternative education.

8.2 The figures given below marked “*” were quoted by John Sanford, HM Prison Officer, at the 2nd Annual ADD Information Services Conference, October 1998.

Costs of ADHD Diagnosis and Treatment

ADHD diagnosis by a qualified professional	£500*
One year's supply of Ritalin tablets	£200*
Statement of Special Educational Needs (LevelG)	£2,330 pa (1998)
Total	£3,030 pa (approx)

Potential Cost of Not Diagnosing and Treating ADHD

Cost of supporting someone in prison	£26,000* pa
Cost of supporting someone in high security prison	£62,400* pa

Of course, the cost of all these items will have risen since 1998 but the underlying principles remain the same.

9. MISUNDERSTANDING OR PERSECUTION?

9.1 Jerry Mills, an American teacher and songwriter who has ADHD, and is now around 50-years-old, describes his experience of school as “a bizarre descent into a Living Hell”. At best he was misunderstood; at worst, he was persecuted. I have had the great pleasure of hearing Jerry speak at several conferences. He sums up his thoughts brilliantly and succinctly in his song entitled “The Ones Responsible”, reproduced in Text Box 2.

9.2 This song gives an insider's perspective of ADHD which can be more helpful than all the text books on ADHD put together in coming to a better understanding of what it is like to be an “ADDER” (ie ADHD-sufferer) undergoing compulsory mainstream education. In this regard, the situation is very similar in the UK compared to that in the USA.

TEXT BOX 2: THE ONES RESPONSIBLE

In my hometown there was a school that I attended as a child
Where I earned the reputation for bein' a little too wild.
And even though I left that place over twenty years ago
The memories of it haunt me almost everywhere I go!

I went there for nine long years, from kindergarten through eighth grade,
And I wish I had a dollar for every screw up that I made
Because maybe with all those riches I'd be able to make some sense
Of just what the hell was goin' on! What the hell was goin' on . . . ?

“Spare the rod and spoil the child.” But why couldn't they just let me rot
Instead of having to endure all of the punishment that I got
For not payin' attention, for bein' the class clown,
For not obeyin' orders when I was told to settle down,
For forgetting to do my homework, for not bein' ready on time,
For failin' to keep my way of life between their dotted lines?
For thirty years it's haunted me until I figured out
Just what the hell was goin' on. What the hell was goin' on . . .

Heaven help the children who live their lives with restless, achin' souls,
Always acting so impulsively and lacking self-control.
Heaven help someone to change the children's nightmares into dreams.
But God help the ones responsible for destroying their self-esteem.

It takes all kinds to make a world, and some can make the world unkind.
But there's no one in this world with the right to blow a young kid's mind
By treating them like trouble instead of trying to figure out
Just what the hell is goin' on.
What the hell is goin' on!
What the hell is goin' on?

The Ones Responsible

From the recording “Urgent Reply”

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For information contact www.jerrymills.com

10. WHAT CAN SCHOOLS DO ABOUT CHILDREN WITH ADHD?

10.1 Mainstream schools in the UK are by no means ADHD-user-friendly. Indeed, one could legitimately claim that the majority of schools are “user-hostile” to these children. Most of the “ADDer” children could probably thrive in an education system that was geared towards their brain type—an education system that was built upon their strengths rather than on their weaknesses—just as many children without ADHD can thrive in the current set-up.

10.2 But the only type of education which closely approaches this ideal which I have come across in the UK is the “Forest School” system, being pioneered from Bridgwater in Somerset and also by Oxford County Council. Even then, the proportion of time that any one child spends in the forest environment is relatively minute compared to the totality of their education. Moreover, the proportion of children in the UK who have access to Forest School is also minute.

10.3 Try to imagine the day-to-day school life for a child whose curriculum is centred on his weaknesses and not his strengths. Now think about what you know to be your greatest weakness in your profession (if you don’t know, a colleague could probably tell you!). Next, imagine an inspector repeatedly visiting you whilst you were carrying out duties based on this weakness, and the effect that it would have on your self-esteem. And finally, try to identify your greatest strength, which will probably be the part of your work which gives you greatest pleasure. Imagine now the inspector repeatedly visiting you whilst you were engaged in tasks based on this strength. What would your self-esteem be like now? This simple thought experiment is very revealing and can help one understand enormously the current plight of the ADHD child, whose education is centred upon his/her weaknesses. Just think how all this could be transformed if the curriculum were geared to their strengths.

10.4 One might argue that every school needs to support their ADHD children by pressing for a Statement of Special Educational Needs (in which the specific needs of each child are identified, with a programme of provision to meet those needs). Certainly this will be necessary where the child has co-morbid learning difficulties. Our son was extremely fortunate to get a Statement (back in 1988). But it turned out that even with a Statement, his needs could not be met in an in-county (Bedfordshire) mainstream school. He was given a Learning Support Assistant (LSA) to help him but only for seven hours a week. The Statement failed him both quantitatively and qualitatively.

- *Quantitatively*—the seven hours one-to-one support was insufficient. It left him free to roam either physically or mentally the rest of the time in class.
- *Qualitatively*—having a one-to-one LSA, untrained as a teacher, was not “scratching where Timothy itched”. Although she may have been doing an excellent job within her terms of reference, she was for the most-part having to keep Timothy on-task in academic subjects which were not his forte, and merely helping to squeeze him into a mould which by nature he did not fit. With no disrespect, and I have no proof, I suspect that there must have been times when all the LSA could do was provide a glorified baby-sitting service. One LSA after another resigned and he got through five of them in one year. This speaks for itself. I am virtually certain that Timothy wasn’t being given appropriately differentiated work to do all of the time. Despite Timothy having a Statement, the school clearly did not have the human resources available for this. It is no criticism of them, but rather a criticism of a system which promises to meet a child’s special educational needs but in practice is unable to do so. Inclusion is the name of the game, but maximum inclusion means maximum differentiation. Perhaps most important of all, Timothy’s Statement made no provision for the adapted or alternative curriculum which (was apparent to us) that he needed. Neither the school nor the LEA were able to meet this need. In the end Timothy had to be sent out of county to a (mainstream) independent school which had very small class sizes, Slindon College in West Sussex.

10.5 Timothy is just one of hundreds of thousands of youngsters with ADHD in the UK. We were so grateful that he was placed at Slindon, but the battle which we as parents were forced to go through was time-sapping, energy-sapping, health-destroying and, I hesitate but feel compelled to say, immoral. It is outrageous that parents of children with ADHD (not just ourselves, but thousands of others), who are as a result already severely disadvantaged in time, energy and even money, should be forced to fight their LAs which are so adversarial and so ignorant of the nature of ADHD.

10.6 It is clear that our education system needs to be adjusted—even re-designed, to cater for children with ADHD. At 3% of the population they can hardly be considered rare specimens. But how can their education be made compatible with their non-ADHD-suffering peers?

10.7 One suggestion is by setting up a rather different type of educational programme—a school within a school, perhaps, building on the successes of Forest Schooling and any other suitable systems that might be identified. Such special units could address the needs of children with ADHD whether Statemented or not, and be run along different lines to the current Individual Education Plan (IEP) system. I personally

know of no ADHD child whose needs have been adequately met by the current IEP method. This is not particularly surprising, as they are being offered more of the same, still in a group setting, rather than what they really need, ie an alternative curriculum. The nature of the problem which I am trying to explain is probably best illustrated by The Animal School, printed in Text Box 3, below.

10.8 Whatever education is being offered to children with ADHD, their teachers and all school staff must be informed by knowledge about the brain, neural sciences, and neuro-development as well as by the more traditional educational disciplines if these children's needs are going to be met in accordance with their human rights. The current situation in which children with ADHD are being expected to conform to the "norm" is, I believe, as barbaric as the now-abandoned practice of compelling left-handed children to perform in class as though they were right-handed.

TEXT BOX 3 THE ANIMAL SCHOOL

Once upon a time, the Animal State, having decided that education should be compulsory for all species between the ages of five to 16 months, set up a school. It was agreed that the curriculum should include

*running *climbing *swimming *flying

All animals were required to take all subjects, since it was politically correct to practise inclusion, regardless of the natural aptitudes of the different creatures. It was also decided to give a standard assessment test to all pupils at regular intervals.

The Duck obtained Grade A in swimming (and was even better than the instructor), Grade C in flying, Grade D in running and Grade E in climbing. Her webbed feet became badly worn from running, so her swimming grade eventually dropped from an A to a C. An average grade (C) for swimming was quite acceptable to the school authorities, so nobody worried about it—except the Duck, whose self-esteem and overall enjoyment of school life began to plummet.

The Rabbit, at his first assessment, gained a Grade A for running and was top of his class. However, he soon had a nervous breakdown because he was made to attend extra lessons in swimming in order to improve upon his low grade.

The Squirrel excelled at climbing (Grade A) and also did well at running (Grade B). But he became extremely frustrated at the school because the flying-class teacher forced him to start from the ground up instead of from the tree-top down. Consequently he persistently failed all flying tests (Grade F), whereas he knew that he could at least have achieved B+ if he had been allowed to do it his way. In addition, his climbing grade fell to a C and his running to a D. His doctor diagnosed him as suffering from a severe anxiety disorder, which had not been evident at the pre-school medical.

The Eagle came to the school as a reasonably happy pupil. Problems arose when, during the climbing classes, he beat all the others to the top of the tree but had insisted on using his own way to get there. He was labelled as suffering from conduct disorder and severely disciplined. Firstly he was made to stand on one leg outside the headteacher's study, and then he was forced to eat his lunch out of school.

At the end of the school year, the star pupil, gaining the headteacher's award, was an abnormal Eel who could swim exceedingly well, and could also run, climb and fly a little.

The Fox's parents withdrew him from the school because the administration refused to add digging and burrowing to the curriculum, even though they conceded that he might have a special need to do this. His parents were by then at their wits' end, since education was, by law, compulsory. Fortunately they happened to meet, and were very impressed by, the headteacher of another school, who was an open-minded Badger. Although his school was privately run, they felt that they had no option but to send their son there, joining an assortment of stoats, hedgehogs and sewer rats, and incurring an enormous cost to themselves of 12,000 chicken bones per year.

[Adapted for a British audience by Maryla Carter, 1999, (based on a story in Chapter 22, "Learning Disabilities", in *Fundamentals of Human Neuropsychology: Fourth Edition*. By Kolb, Bryan and Wishaw (1996).

11. CONCLUSIONS

11.1 There is a dearth of appropriate provision for pupils with ADHD in mainstream schools in the UK. The methods of teaching employed and the curriculum imposed are for the most-part ADHD-user-hostile. Even when such children have a Statement of Special Educational Needs, and even when they take medication, for as long as they are in a mainstream school with typical class sizes of between 20–30 children, their needs are very unlikely to be met. It is extremely rare for teachers and other members of staff in mainstream schools to understand the nature and complexity of ADHD, let alone know how to cater for it, even if the "system" were to allow for suitable adjustments. LA officers, too, are ignorant. Consequently many of these children are suffering fear, frustration and ultimately failure.

11.2 As things stand at present, the real needs of children with ADHD are being sacrificed upon the altar of inclusion. All too often the outcome is the complete opposite of this — exclusion, frequently followed by problems with addiction, mental health and the criminal justice system. Our society is paying an enormous price for this imposition of inappropriate education.

11.3 This situation needs to be addressed urgently as a matter of Human Rights.⁵³

September 2005

Memorandum submitted by Dr Sonali Shah

EXECUTIVE SUMMARY

This paper explores the recent policy concerning the education of disabled children and young people, and the debate of special education verses mainstream inclusion propelled by Warnock. It argues that the formal and informal practices, designed by non-disabled adults, to facilitate the inclusion of disabled students in mainstream schools may be the very same that disabled students perceive as barriers to their full participation in mainstream education. This paper presents empirical evidence to emphasise disabled children's individual perceptions and experiences of mainstream and special school, as well as their preferences towards both. In so doing, it suggests that disabled children are not a homogeneous group and constructing them as such often overlooks the diversity and richness of their everyday lives. Further, it highlights the importance of including disabled children and young people in developing policy that impacts their lives.

INTRODUCTION

1. Recent UK government legislation, including the Special Educational Needs and Disability Act (2001) and part 4 of the Disability Discrimination Act (2004), has promoted the idea that, where possible, children with special educational needs (SEN) should be included within a mainstream school so that they have a greater sense of integration, rather than being taught in separate special schools. These legal duties make it unlawful for providers of education to treat disabled people less favourably and require them to make "reasonable adjustments". Institutions have a duty to make reasonable adjustments to all aspects of school/college life, including policies, practices and procedures, so that disabled students are not placed at a substantial disadvantage (Wilson, 2005).

2. Barnes (1991) has argued that inclusion is imperative in the fight towards the elimination of discrimination and of disabled people being accepted as citizens by the social majority. Furthermore, being educated in mainstream institutions is positively correlated with the successful transition of individuals with disabilities into employment and wider society. Shah (2005) suggests that inclusive education can (for some people) facilitate the establishment of social relationships between disabled and non-disabled peers, as awareness and understanding of disability is said to engender an increasing acceptance of it. Moreover it presents disabled people with an equal training to their non-disabled counterparts and, therefore, qualifications to compete with them in mainstream economic society.

3. Therefore there is general agreement that the experiences of disabled children in the UK have changed rapidly as a direct result of social transformation in the past two decades. For example, there are now more disabled children educated in mainstream schools than was the case in the past, disabled children are sitting public examinations, and moving on into further and higher education. They are, in the main, no longer locked away in isolated, residential settings.

4. However, the integration and inclusion of disabled children is far from complete. Despite the UK Government's commitment to remove barriers to learning and increase staff training in mainstream schools so disabled students can be educated alongside their non-disabled peers (Department for Education & Employment, 1997; DFES, 2004), not much progress is apparent at grassroots level. Recent research, including the ESF funded study on which this paper is based, suggests disabled children have not been given the same educational opportunities, or been expected to achieve the same, as their non-disabled peers. According to official statistics from the Disability Rights Commission Educational Research study (2002–03), many young disabled people in England and Wales feel marginalized and excluded at mainstream schools for a number of reasons.

5. Therefore, the aim of this paper is to report on the preliminary findings, of a three year research project, Future Selves, on the educational experiences of students with physical impairments and how they perceive the formal and informal practices set up for disabled students help or hinder their social, educational and career related opportunities. For the purposes of this work the term 'young disabled people' defines males

⁵³ United Nation's Convention On The Rights Of The Child, 1989 (Article 23), Ratified by the United Kingdom of Great Britain and Northern Ireland in December 1991.

and females, aged between 13–25, who are in full-time education (in school or FE college) with physical impairments relating to mobility, dexterity and speech. Further the paper will reflect on the young disabled people's general accounts of mainstream and special education.

6. To date, very little is known about the way in which children, especially disabled children, make sense of their identities, and create a sense of their past and their imagined futures over time (Neale & Flowerdew, 2004). Although there is growing recognition of children's competence to be involved in decisions about their health, welfare and education, many social change policy initiatives are still designed, delivered and evaluated by adults. It is questionable whether insights derived from adult research are applicable in the context of children's lives. Christianson and James (2001) found a mismatch between the rationales for schooling held by teachers and how children themselves perceived experiences of school. Similarly, Tackett *et al* (1990) found, in their research with adults and children, that there were consistent differences between the two groups' accounts. Given this, it seems crucial to enable disabled children and young people to be fully included in the processes and procedures which have a bearing on their lives, including their education. Thus, one of the intended outcomes of the study is to present disabled children and young people as critical social actors. Through this it will allow the voices of young disabled people to be heard and listened to, informing policy and practice concerning the recent debate, triggered by Warnock, on the education of students with special educational needs.

WARNOCK'S INCLUSION DEBATE

7. The term special educational needs (SEN) emerged from the 1978 report of *Warnock's Committee of Enquiry into the Education of Handicapped Children and Young People* (Department of Education and Science, 1978). This committee was set up in response to a growing concern that the segregated system of special education was not providing disabled children with positive social and educational opportunities. The Warnock Report (1978) argued for special provision within the mainstream. It was also influential in establishing the term integration, distinguishing three main forms which it might take:

- *Locational integration*, where provision for children with special educational needs was to be made on the same site as their mainstream peers.
- *Social integration*, where children shared social spaces, in the playground or in extra-curricular activities.
- *Functional integration* (the most advanced form) where children with special needs and mainstream children were to be educated together, pursuing the same set of curriculum goals and activities.

8. Special educational needs replaced the former statutory categories of handicap and implied that as many as one in five children could experience special educational needs at some point in their school career.

9. Warnock introduced the notion of a continuum of need, ranging from temporary difficulties to those which are severe and enduring. It was envisaged that the special educational needs of approximately one in 50 children would be such that they required continuing review. A system of recording (or statementing in England and Wales) was recommended for these children, so parents could be assured that their children were getting their needs met in mainstream school.

10. However, a report in the Times Educational Supplement (November, 2004) headlined *Inclusion is just an illusion* stated that while schools are "talking the talk" they are still not "walking the walk" (p 18). Ofsted (2004) found that while there was a growing awareness of the need to treat all pupils equally, there was still a mismatch between school's aspirations and reality.

11. As disabled children often require additional facilities and support to function successfully, they often are considered to be disruptive and difficult to educate. In the regime of the "education market" (Ball *et al*, 1994) where the policy is to attract the ablest pupils, who are perceived to contribute the most to the wealth of the nation, the disabled child/young person may be perceived as having low value, or considered "damaged goods" (John, 1996). Davis *et al* (2001) argue that educationalist's preoccupation with national academic targets lead to the informal exclusion of disabled children from mainstream schools. They found one head teacher from a mainstream school who suggested that he could only have 15% of children with a learning difficulty in any year if the school was to meet its national targets. Their study also suggests that exclusion within mainstream schools, on the basis of academic and other criteria, often leads to disabled children being educated in separate "learning support units" or "impairment special units".

12. Ofsted (2004) reported that one of the weaknesses of inclusion preventing disabled students reaching their full potential is the use and quality of Teaching Assistants. Priestley (1998) found that for some young disabled people, the physical proximity of the helper could work against social processes of acceptance among other children in the class. Consistent with this, Allan (1996, p 222) suggests that all aspects of the child's interpersonal relationships can be brought under the vigilance of the staff, as disabled children are more comprehensively observed than their non-disabled peers. This promotes a divide between young disabled people and their non-disabled peers. Further, the former, who are the minority in mainstream schools, are perceived as 'different' and therefore a legitimate target for bullying (Wilson & Jade, 1999). The issue of Teaching Assistants will be explored in this paper via the perceptions of disabled students.

13. Other causes of social exclusion are the access and resource limitations of several mainstream secondary schools which may mean that young disabled people have to move to designated schools, with suitable facilities for disabled people, several miles from their home while their local non-disabled peers can make a straight transition to their local secondary school (Pitt & Cutin, 2004; Shah, 2005b). This is not only tiring for the young disabled people, as they needed to travel long distances, but also means that they may be separated socially from friends made at school and peers from their home locality.

14. Young disabled people in Britain are less likely than their non-disabled counterparts to pursue academic subjects that facilitate progression to future careers of their choice (Shah, 2005). This is often related to a number of factors connected with disability and how society reacts to it. Some young people are not able to access all school resources, and may have to forego certain activities and classes. Burgess (2003) maintained that despite the ongoing policy drive towards inclusion, mainstream schools are not fully accessible, as those responsible for developing inclusion still think of accessibility in terms of ramps and rails. In her study of disabled secondary school students throughout the UK, Burgess found that their curriculum choices were severely curtailed: 36% of young disabled people she talked to could not study subjects of their choice due to poor access to the curriculum and the disabling environment, including attitudes of teachers.

15. It can be argued, then, that as long as mainstream schools do not embrace the full process of inclusion, young disabled people still may have no real choice in deciding where to continue their education or what to do after school. According to a survey commissioned by the DRC (2002–03) on the aspirations of young disabled people, 24% of disabled people aged 16–24 have no qualifications compared to 13% of non-disabled people of the same age bringing exclusion throughout their lifetime. As early as 16 years of age, disabled young people are twice as likely to be out of work, education or training as their non-disabled peers (15% compared to 7%).

16. Evidence has suggested that young disabled people feel they receive insufficient support in school and are discouraged from taking standard educational qualifications required for university entrance (Martin, 2004). Too often, disabled students in secondary schools are being taught almost entirely by teaching assistants who are not fully qualified teachers, while non-disabled students are taught by the teacher (Warnock, 2005). This means there could be very little interaction between the teaching staff and the disabled students, again reinforcing the disabled/non-disabled divide. Further disabled students may not receive the same standard of tuition as their non-disabled peers.

SPECIAL SCHOOLS

17. The failure to include disabled children in mainstream schools has been noted recently by Baroness Warnock, a former advocate of mainstream education for all, who calls for a radical review of education for disabled children. Lady Warnock details her argument in a pamphlet published in July 2005 by the Philosophy of Education Society of Great Britain:

“Governments must come to recognise that, even if inclusion is an ideal for society in general, it may not always be an ideal for school”.

18. In her 2005 report *Special Educational Needs: A New Look*, Warnock expressed regrets about how the system of education operates in practice:

“Unless someone is brave enough to bring an end what I regard as our—my greatest mistake, namely statementing, money will still be squandered in the same way as now . . . the problems to do with statementing are almost insoluble and very expensive. The only way to solve it is to cut through the whole thing”.

19. However, although inclusive education as it stands in the UK is not an overwhelming success, the answer is not necessarily to return to the specialist institutions of the past, as recently suggested by Baroness Warnock. The principle of inclusion is the way forward, but as concluded by the Prime Ministers Strategy Unit report *Life Chances of Disabled People* (2005):

“The rhetoric of mainstreaming needs to be followed up by specific action to include disabled children”.

20. A number of arguments have been used by policy makers, professionals and parents to argue that segregated special schools are the best option for some disabled students, with their supportive barrier-free environment and specialist resources and support to meet the students’ needs. They criticise mainstream schools for failing to prepare adequately for a disabled child’s care, educational and social needs (Saunders, 1994). Further they believe that too often, only lip-service is paid to “integration”—whether in the classroom and curriculum or in wider social activities.

21. However special schools have their own shortcomings and have been criticised for restricting disabled students’ options in other ways. Disabled young people who attend the same school from their early infancy to early adulthood are being denied the experiences considered essential for the transition from childhood to adulthood, thus shielded from the realities of society (Barnes, 1991). This will only serve to reinforce the commonly held conception that individuals with impairments are eternal children.

22. Dr John Mary and the British Council of Disabled People (1986) believed that special education system is one of the main channels for disseminating able-bodied minded perceptions of the world and ensuring that disabled school leavers are socially isolated. This isolation results in disabled people passively accepting social discrimination, lacking the skills necessary to pursue the tasks of adulthood successfully, and not understanding about the main social issues of our time. Therefore, as well as reinforcing the myth that disabled people are “eternal children”, segregated education ensures disabled school leavers lack the skills for overcoming the myth (BCODP, 1986). This is supported by Jenkinson (1997) and Fuchs & Fuchs (1998) who believes that the lack of appropriate behavioural role models, the lack of feedback from non-disabled peers, and the removal from the common culture of childhood and adolescence contribute to later isolation in the community.

23. Mulderij (1996) agrees that the experiences of mainstream situations are essential during school years if disabled children are to develop the skills required to be successful in adult society. Furthermore disabled young people need to be in an environment where their career aspirations are fed and not suppressed by a system that lacks encouragement and flexibility, or a system that makes them feel they do not fully belong.

24. A further major criticism of special schools is of its isolated curriculum which focuses disproportionately on specific educational needs, preventing students from learning the wide range of subjects offered in mainstream schools and perceived to be important to successful economic participation. Furthermore, Jenkinson (1997) offers the opinion that the small number of staff in special schools, coupled with their significantly limited, if not deficient, curricula expertise, undeniably serves to restrict the range and content of the curriculum.

25. The above are, ethical, social and educational arguments for and against inclusive education, although not by disabled students themselves. This study highlights disabled students' experiences and opinions of special and mainstream education, therefore contributing to the segregation verses inclusion debate.

METHODS

26. The researcher talked to thirty young disabled people, in a selection of special and mainstream schools in the UK, in order to understand their educational experiences, and their views about education. Recruitment of students was, on the whole, based on the research sample criteria outlined in the research booklet which was sent to each school and college prior to the start of the fieldwork.

27. The sample of young people were from a mixture of social class, ethnic and cultural backgrounds, and had different types of physical impairments including congenital and deteriorating conditions which limited mobility, dexterity and verbal communication. The age range was 13–19 years in schools, and 16–25 years if at college. The young people attended special or mainstream school or both, and were either just choosing their GCSE or A-level options, choosing to apply for further or higher education or for jobs. The intended sample was of young people who were expected to participate in vocational decision-making, focussing on significant points of choice.

Interviewing and Life Stories

28. This research is about giving voice to the underdog in society (Becker, 1966/7): “people who are often the subject of research, yet whose voices are rarely heard.” Further is concerned with learning about the social reality of a group of people with varied values, beliefs and experiences. Therefore the means of enquiry needs to be open-ended, enabling access to groups such as disabled people and children. For this, semi-structured interviews were used, with prompts and follow-up questions to generate accounts of the young disabled people's educational experiences and their preferences with regards to mainstream and special school. Interviews were conducted within the young persons' educational environment, and typically lasted between 20 and 40 minutes. With the permission of the young people and, where they were under age 18, their parents, the interviews were recorded and fully transcribed. Each transcript was read through carefully several times, content analysed and encoded. This involved identifying emerging patterns, common themes and key points which were used to distil the findings.

29. The stories told by the young disabled people were guided by the topic-setting questions, so certain themes were explored with every participant. However, each story also generated sub-themes that the individual participant chose to identify: the aspects of current context they highlighted as significant and the ambiguities and contradictions within and between accounts (Jones, 1983). In this way, stories were both products and processes.

30. It may be argued that the acquisition of rich quality data, during this study, was facilitated by the fact that the interviewer and the participants came from the same minority group, that is, both parties shared experiences of challenging oppression, disablement, special and mainstream education. It was also thought that this shared culture and background was helpful in accessing potential respondents, building rapport with them, encouraging them to be more open. Further, it generates positive role-modelling effects, encouraging the young disabled people to ask the researcher questions about her own educational experiences and views of special and mainstream schools.

RESEARCH FINDINGS

31. In the context of the interviews, young disabled people described their educational experiences, including their preferences for special or mainstream education. They also reported on the various formal and informal practices put in place for disabled students, that they perceived as more of a hindrance than a help.

SPECIAL SCHOOL

Support and Facilities

32. Several young people who were based in special school but experienced both type of education systems, praised the support and facilities in special education institutions. They felt these were not available in mainstream school on the same scale. Facilities including physiotherapy, speech therapy, hydrotherapy etc were perceived to be crucial for the young people's physical development and future health and independence, and thus successful adulthood:

“the two really good things about this school are swimming and physio . . . I think it's very important for me to get out of the chair and have a good stretch.” (Cathy, special, age 14)

“when I came here I only looked like a newborn baby, ‘cos I was so small . . . The school has really helped me grow into an adult . . .” (Zoe, special, age 17)

33. Tison, a young woman of 19, who had been at the same school since the age of three, strongly opposes the Government's decision to close many special schools and comments on how crucial they are for young disabled people like herself:

“the Government just ain't got a clue, cos they think ‘Oh the special schools will be out in a minute’ but, but when you see pupils like some of the ones here, they wouldn't be alive if they didn't have special schools” (Tison, special, age 19)

34. Even the students based in mainstream schools used the therapeutic facilities of special schools as they were not available or accessible to them in their own schools:

“My physio is based at X special school, I go swimming every other week” (Allan, mainstream, age 13)

“There is a special school not far from here school X, they've got there own hydrotherapy pool . . . Its for these kids, who can't like go in cold baths, cold swimming baths, we use their pool, they let us use their pool”

“I used to go to X [special school] to swim when I was 8–10 years . . . I don't go swimming at this school” (Ikky, age 15, mainstream)

Friendships and Relationships

35. Friends were important to the young people, and often identified as one of the best things about special school. Those who had experienced both types of schooling considered it easier to build friendships and social networks in special schools/colleges than mainstream. This was the case for Hannah who moved to special school at the age of 16. Before that she lived in Africa and had home tuition after facing several disabling barriers at mainstream school. These included social and attitudinal barriers which prevented her from building friendships:

“I've finally got the chance to make friends and everything. I didn't have any friends when I lived in Africa” (Hannah, age 18, special)

36. Paul, who moved from mainstream secondary school to a special further education college, told a similar story:

“its easier to make friends here [at special college] because people always come up and talk to you . . . At my school [mainstream] it wasn't easy to make friends, I did have one friend but he left”

37. Noalga, who moved from mainstream primary to special secondary school, found the latter better in terms of building social relationships in and out of the classroom:

“We are all friends here, good friends [in special school], at my mainstream school I got picked on a lot because [they thought] I was funny looking . . . I didn't have any friends there . . . At my old [mainstream] school they [other kids] would not be my partner in sports lessons, they thought I can't do nothing and left me out.” (Noalga, age 15, special)

38. Both Jane and Schmacher have been in special education from an early age although had experienced mainstream school for a short period of time during their secondary education. They considered the supportive barrier free environment of special education to be important to the development of positive social relationships. The fact that every student at the specialist college had a disability of some description meant that they were not worried about being “disabled”:

“the one thing about special school is that we’re all in the same boat and people don’t look at you as if you’ve got four heads, I mean my brother’s experienced bullying and all sorts because his sister [me] is different” (Schumacher, age 18, special)

“I might have been the only one in a wheelchair you see and that wouldn’t have been very, well it wouldn’t have been very pleasant for me would it really?” (Jane, age 18, Special)

39. Although many young people favoured educational segregation, listening to their accounts of their personal experiences confirmed that there are definitely significant drawbacks to the special education system. Some mentioned the low standard of teaching and limited curriculum of special schools:

“they didn’t seem to push you. Like we didn’t do A-levels or anything . . . I would have liked to have a chance at some proper tests and see how far I got see how clever I was you know . . . they don’t seem to push you at special school” (Schumacher)

“Music and communications, I don’t like them . . . communications we hardly do anything in the lesson, and music is just like playing music and you don’t, you don’t learn anything from that” (Paul)

40. Jane, who mentioned some reservations of mainstream education above, also believed special school did not give her the opportunity to mix with non-disabled peers:

“I would have liked to gone to one in a way because I would be mixing with other people”

However in reality, mainstream education does not always permit social integration between disabled and non-disabled peers, as is evidenced by Cathy’s experiences:

“I felt as though I was shoved out and not with other people. I was put in a unit that people couldn’t talk you know like, have you seen Shannon and Liam, and with me being able to talk I was in a room of kids that couldn’t even talk.”

MAINSTREAM

41. Some of the young people perceived the lack of support was the problem of mainstream schools. They felt it restricted them from pursuing their own aspirations. As Hannah put it:

“I lived in Africa, it was [mainstream school], they just couldn’t cope with me they, they just didn’t have the facilities that they’ve got in a special school . . . my mum taught me to read and write at home . . . Here [in special school] I’m supported to do what I want”

42. Similarly Zoe, who had been partially integrated into her local comprehensive school, felt that her ambition to work in the childcare field would not be supported in mainstream education:

“At mainstream school I think they would not support as much they would probably say you’re not able to”

43. However, while some young people felt happier and more confident in the barrier-free environment of special school, others who were based in mainstream schools, expressed preferences towards the inclusiveness and perceived “normality” of mainstream schools:

“I’ve never . . . I’ve looked around them [special schools] but I’ve never actually gone . . . No I don’t think it would be the same because I want it to be a mixture of people not just people in chairs like me . . . I’d feel quite quiet ’cos I wouldn’t be able to say my feelings because people might be worse off than me” (Mille, age 12, mainstream)

“I got my laptop from the special school, I had to go there to see it, but I just saw all these like really ill people, you know like in beds and stuff, I don’t think I could handle that” (Mike, age 15, mainstream)

44. Sabrina, who has clearly defined goals to be a language interpreter, feels that she would be restricted from pursuing her aspirations in special school:

“I’ve seen special schools but I don’t really like them cos I don’t really like seeing all the people cos like, they can’t talk . . . I don’t think they do languages at special school” (Sabrina, age 14, mainstream)

45. Although disabled students based at mainstream school preferred it to special school, they identified several problems with their schools that prevented them from being fully included.

Support and Facilities

46. Several young people considered the physical environment of mainstream schools to hinder their independence, making them more dependent on its non-disabled population. Unfortunately this only reinforces the notion that disability is a personal tragedy and disabled people are different, dependent on, and passive recipients of, other people's charity:

"the bad thing is that I, I have to wait for people to open the door unless I try and do it myself, I can do a few doors myself but not all"

47. The overall lack of access available in mainstream schools included transport. This hindered students' inclusion in certain activities which were important for their personal and intellectual development:

"The work experience? There's a teacher, Mrs [Watkins] special needs she sorts it out the placement and the transport and stuff and then that's it I just do all the work, get there, but when I went that time school couldn't organise transport, and it was a 40 minute walk from my house so my dad had to take me and my mum picked me up, so because there wasn't any transport, proper one [with wheelchair access], we had to walk it, back and forth"

48. The recruitment and training of support staff including teaching assistants is done at local level—by LEAs and individual schools—and not directly by the Department for Education and Skills. The young people had different experiences with Teaching Assistants. Some admitted that although they used to have good support in Years 7 and 8, they only have a little (not enough) in Years 9 and 10:

"I do have support and that, but now, but more support goes to year 7 and I'm in year 10 so all the support is going to the year 7s and the year 8s . . . Would like a bit more but I'm leaving soon" (Ikky, age 15, mainstream)

49. Other students pointed out that the support they did have was not always very helpful and often a barrier to their learning:

"I have a TA in class who writes it down [things from the board] but sometimes they don't write it down they just stop, I can't see the board and I expect the TAs to write it down but sometimes [they] just talk to my [peer] about football or something, so what I do is I get the book out and I put it in front of his face and like 'do it' because, you know, because its, I'm not like telling them 'oh you have to do it' but its their job isn't it" (Mike, age 15, mainstream)

50. Adult support was also perceived, by young people, as an invasion of their personal space and relationships with peers of their own age:

"I don't like having a TA around me all the time because I want some of my own space . . . its not really fair on my friends having to sit next to a TA all the time when I want to sit with them" (Millie, age 12, mainstream)

51. Checka felt restricted, by adult support, from engaging in normal activities with peers, outside the classroom. This again can be seen to hinder the formation of friendships and social networks, and reinforce the powerful messages that disabled people are different and need "looking after":

"I'm not allowed in the playground I'm sitting in the classroom with the TAs, all day 'cause they think I'd run away." (Checka, age 15, mainstream)

"No, they [other girls in class] sit away from me. I think, I think they don't like me because all the attention from TAs"

52. Sometimes Teaching Assistants were required to teach disabled students, while the actual qualified teacher teach the non-disabled student. This means there could be very little interaction between the teaching staff and the disabled students who are thus receiving sub-standard tuition:

"If I'm stuck [in class] I put my hand up and ask the TA" (Jenny, age 14, mainstream)

53. So the very same formal and informal practices used to support disabled students in mainstream school are serving to create a divide between disabled and non-disabled students thus preventing mainstream schools from being fully inclusive.

Friendships and Relationships

54. Young disabled people reported feelings of isolation and loneliness in mainstream school generated by the access limitations and attitudinal prejudice which prevented them from building positive social relationships with non-disabled students. As Sabrina put it:

"its just hard at school 'cos they all [non-disabled pupils] go down the field and that's a bit stupid cos if they really want to see me and stuff they wouldn't go right down a grassy bank 'cos I'm not that stupid that I'd let my wheelchair go 'cos I'd tip down"

55. According to other young people, peers become a barrier to learning and thus future career success. For example, Mike has to force other students to work with him when they do group work at school:

"people don't actually come to me and say 'oh I'll work with you', but I'm in my class I'm actually like excluded when people are grouped and stuff"

56. Several young disabled people mentioned being victims of overt and covert bullying by non-disabled peers in mainstream schools:

“my general friends um in my class are nice but its other friends who just mess it up and um just ruin it for me, so one boy who was messing about and with my wheelchair so I had to stop going to that class for a bit, 'cos he was like a bully” (Mike, age 15, mainstream school)

“I don't like is when they do that, they [non-disabled peers] like just knock that (the joystick on electric chair) while I'm moving, and it knocks me out of the way and I don't like that, it's like pushing someone” (Xavier, age 13, mainstream)

57. On a similar note Zoe, who had spent some time at mainstream comprehensive as part of a link placement organised by her special school, found non-disabled peers difficult to handle:

“pupils was horrible, well they weren't horrible but when you asked them to move they used to give you such funny looks and things like that”

CONCLUSION

58. Disabled school children have a greater chance than their non-disabled peers of having decisions made for them, and of not being consulted about major questions that affect them. Further they have less freedom to make choices about their social and personal life (Beecher, 1998; Beresford, 1997; Russell 1998).

59. A body of research has argued that disabled children and young people are consigned to a passive role rather than being seen as active subjects who should be fully included in those processes which have a bearing on their lives (Priestley, 1998). This has often had the effect of objectifying and silencing disabled children. As a consequence, research has often concealed the roles of disabled children as social actors, negotiating complex identities and social relationships within a disabling environment, and as agents of change who can adapt to, challenge and inform the individuals, cultures and institutions which they encounter during their childhood.

60. All too often work seeking to further children's interests rely solely on the views of adults, be they teachers, parents or politicians. Adult conceptions of childhood are, at best, partial with limited connection to the views and experiences of children and young people in 21st century Britain (Prout, 2001; Hill *et al*, 2004). Children are referred to as weak, passive and impressionable, and rarely presented as “powerful, strong and competent” to express valuable opinions. This paper presents empirical work that clearly shows disabled children and young have insightful views of segregated and mainstream education which challenges recent policy and practice.

61. When discussing the best place for the education of disabled children, this paper emphasis the need for choice. Disabled children should have the opportunity to attend either mainstream or special school with this decision being made looking at a child's individual strengths and weaknesses (Stinson & Lang, 1994). The students interviewed believed that there were advantages and disadvantages inherent in both segregation and inclusion and that no single type of placement could meet all the needs of all disabled students throughout their educational careers. This is supported by Pitt and Curtin (2004) who believe that an appropriate school placement should depend on the physical, academic, psychological, social and emotional abilities, and needs of each student.

62. It is obvious, from the young people's experiences, that mainstream schools still have not embraced full inclusion and continue to disempower disabled students with exclusionary procedures and practices. While, it is true that every child should have the right to attend a mainstream school in their local area, the reality is a great deal of change is required within “mainstream” schools before disabled children will actually experience inclusion. Real inclusion is considered to be evident when there are genuine opportunities for all pupils to participate, to the best of their abilities, in all that college has to offer (Bishop, 2001; Corbett, 2001). Therefore, until this time comes, special schools should continue to exist so disabled young people can choose according to their perceived strengths and weaknesses.

63. However this should not be seen as evidence that policies of inclusion should be stopped as suggested by Warnock (2005). As other research (eg Barnes, 1991; Jenkinson, 1997) argue special schools have their own oppressive practices. In sharp contrast to the Warnock Committee (1978), which consisted of a few professionals with an interest in “special educational need”, this report demonstrates the fundamentally of communicating disabled children's own lived experiences directly to policy makers or as collected within empirical studies. It endorses the words of Davis & Watson (2001), “If real change is to occur disabled children and their allies must gain a share of the power in educational institutions”.

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Memorandum submitted by Astrid Hansen

1. SUMMARY

Provision for SEN pupils in “mainstream” schools: availability of resources and expertise; different models of provision

Over the last two decades there has been almost relentless Government interference in education which has served to undermine both the professionalism and autonomy of teachers and educationalists. Local Management of Schools (LMS); the Literacy and Numeracy Strategy; the “deskilling” of teachers; the move from “child-centred” to “target-driven” education; the general increase in teachers’ legal liabilities and responsibilities; the policy of inclusion and the increasing homogenisation of learning and school type have collectively “straight-jacketed” and bureaucratised school staff, to the detriment of pupils with special educational needs. This situation has been exacerbated by the lack of knowledge of SEN law on the part of Heads and teachers and lack of training to cope with the huge increase in the prevalence of SEN over the last two decades.

No policy or legislation, however well-meaning, will work in the absence of adequate centralised funding and effective mechanisms for ensuring that implementation is not hijacked by bureaucrats whose budgetary concerns override everything else.

Provision for SEN pupils in Special Schools

Any discussion on special schools must consider the effects of the Warnock report and the policy of “inclusion”. My position on inclusion is primarily that of a parent protecting my child. As such I question the morality of a policy in which SEN children are currently being used as “guinea pigs” in order to achieve some ideal in future. LEAs claim that they are closing down special schools in line with Government policy. Decisions are not being based on children’s needs, parents’ wishes or education law and no audits are being carried out to determine the range of provision needed in each area.

There is cross-party agreement about the value of mainstream units or integration classes but disagreement about who should ensure adequate capacity for all children who need these. Funding for the setting up and staffing of these units should initially come from the Government. Parents should not have to move to obtain better provision. There are several educational advantages for having unit provisions in almost every school.

Special schools should be retained for those children in need of them and there must be recognition for the excellent teaching and learning which goes on in them. MLD and SLD schools could be increasingly linked to mainstream schools so that opportunities for sharing of expertise and dual placements can take place.

Raising standards of achievement for SEN pupils

Many Government policies, introduced to raise standards, have resulted in alienation, disaffection, low self-esteem and poorer achievement for many SEN children (see Section 2.1). This process will not be reversed unless politicians accept that solutions must come primarily from those who are most affected—parents of SEN children, teachers, educational psychologists and others lecturing and researching in the field of education. As I see it, the role of the Government is to listen to these “experts” and ensure that funding is there to provide quality services on a national scale.

Issues of class size, the more efficient use of LSAs, early intervention and needs-based planning and a “joined up” approach are also essential in raising the achievement of children failing in the current system.

The system of statements of need for SEN pupils (“the statementing process”)

LEAs persistently evade their legal duties by concealing or providing inaccurate information about parents’ and children’s rights; by adopting policies which keep Parts 2 and 3 of statements vague; by insisting that Speech and Language therapy is a medical, rather than an educational, need and by stalling and delaying the provision a child needs until the parent seeks legal redress. Permanently excluded children and children removed from school by their parents for medical reasons represent two further groups who are failing to receive an appropriate package of full-time education.

I strongly support the creation of Independent Assessment and Statementing Panels (IASPs) as proposed by Julie Maynard and Allan Willis in “Beyond Warnock”. LAs should be relieved of these duties which they are unable to carry out effectively since they are currently both the commissioners and funders of educational provision, creating a fundamental conflict of interest. Educational psychologists should be placed within the IASP rather than under LA control and the Government should address the national shortage of EPs.

At present the opportunities for appropriate redress for the stress and injustice caused to parents by LA practices are extremely limited. The DfES shows a distinct reluctance to police LAs. Levels of compensation awarded following complaints to the LGO are paltry compared to the damage caused to parents and children by LA maladministration. SENDIST, although free to parents, is time-consuming and only an option for the most determined and able parents. SEN Regional forums are using public money to lobby SENDIST and disseminate “bad” practice and should be disbanded and legislation must be introduced to properly police LAs, making them accountable for their actions.

The role of parents in decisions about their children’s education

Parents of SEN pupils are often viewed by schools in a negative way. Unofficial exclusions are widespread. In some schools, parents are effectively “barred” and there is often poor and insufficient communication between home and school, with parents concerned about their child’s progress being viewed as ‘pushy’ by staff. Parents’ and children’s views must be sought for IEPs and statutory assessments but are rarely acted upon and there seems to be no recognition that a parent knows his/her child best. Schools should set time aside for talking to parents and staff should recognise the difficult job parents of SEN children do. Opportunities should be provided for parents to train together and learn from each other.

There is a mismatch between parents’ expectations of Parent Partnership and what this service offers. No service funded and managed by the LA can be truly independent and parents rely on charities such as IPSEA, which receive no funding from LAs or Government, for support. A growing number of individuals are now making a career out of the adversarial way in which LAs implement SEN legislation. Their wages are paid for with money which could be spent meeting children’s needs.

The “efficient education” continues to be abused by schools and LAs, often working in unison to achieve the LA’s and not the parent’s choice of placement. The law does not allow parents to request a place in a mainstream unit.

The legislative framework for SEN provision and the effects of the Disability Act 2001, which extended the Disability Discrimination Act to education

The relatively low take up for DDA claims at SENDIST may be explained by the fact that DDA: Part 4 legislation has no “teeth” and the statementing process is far more likely to obtain appropriate outcomes for the child. The lack of case law in this area means that the main beneficiaries of current DDA appeals are not the children on whose behalf the appeal is being made but their “successors”. Parents often fear repercussions if they make a DDA complaint against a school which a child is still attending. However, the low number of DDA appeals is no indicator of the widespread discrimination occurring in schools and LAs on a daily basis.

2.1 PROVISION FOR SEN PUPILS IN “MAINSTREAM” SCHOOLS: AVAILABILITY OF RESOURCES AND EXPERTISE; DIFFERENT MODELS OF PROVISION

In my opinion the following events have collectively served to create the current “crisis” in mainstream school and classrooms:

- *Increasing Government intervention in education*, eg the National Curriculum, SATs, league tables, Ofsted, QCA, all of which have imposed an ever-increasing number of targets on teachers and Heads. Not only do these detract from the “real” work which these professionals carry out, such targets are not valid measurements of a school’s success in the field of SEN. It is often schools that do not score well in league tables which have more expertise in this area.
- *Local Management of Schools (LMS)* was introduced in the late 1980s and schools were given increasing powers to “opt out” of LA control. LAs’ power to police individual schools and to ensure adequate SEN provision throughout their catchment was gradually eroded and school Governors (many of whom have no background in education) were given increasing powers over what happens within their establishment. This has been disastrous for SEN children. One example of this is Hertfordshire LA, which decided in 2003 (following an autism scrutiny) that many high-functioning autistic/Asperger pupils who were failing dismally in mainstream classrooms needed to be placed in “able autistic” units. Two years on and there is still not a single ASD unit in that county—not because of lack of funding—but because the Governors of each and every school the LEA approached refused to allow such a unit on their premises. Bedfordshire faces similar problems when attempting to expand existing mainstream unit provision.
- *The Literacy and Numeracy strategy*. The idea that children under eight, with or without special needs, are capable of following the timetable of a Literacy and Numeracy hour, flies in the face of what experienced teachers know about the concentration span of most children. I have much anecdotal evidence from teachers of pupils with SEN/concentration problems that these children are regularly “driven to distraction” during these sessions, demonstrating their frustration by crying, running around the room, screaming, banging their heads against the wall, throwing things and destroying work. This behaviour is not a demonstration of bad teaching, bad parenting or a fundamental “flaw” in the child’s personality—it is simply how pupils react to having the straightjacket of an hour-long lesson imposed upon them when they simply lack the maturity and skills to learn in this way.
- The “deskilling” of teachers, who are increasingly becoming little more than “operatives” whose sole purpose is to push through the Government’s education agenda. Until the late 1980s, teachers built up their knowledge base by attending courses of relevance to their pupils and by reading the latest educational research on how children learn; but most importantly, by observing what worked and didn’t work with each individual child in their class. The recent controversy surrounding dyslexia is a perfect example of how dependent the teaching profession has become on “labels”, when any teacher my age would find it obvious that all children who are failing at reading (or any other skill) require additional, targeted input to remedy the problem. We also know from experience that the best way to encourage a child to read is to instill in them a love of books and this is not achieved by presenting them with endless short texts, followed by a “test” of their comprehension. As the author and recently appointed Children’s Laureate, Jaqueline Wilson, correctly states, primary age children need to have that time at the end of the school day when they are simply read to by the teacher. Most schools simply no longer have the time to do this. My perception is that continuous professional development now centres around the latest Government initiative rather than the child.

There are also huge variations from school to school in the experience and commitment of the SENCO, ranging from excellent to virtually non-existent. In some schools the SENCO’s position is full-time whereas in other schools the role is covered by a full-time class teacher. LAs are now increasingly appointing individuals with no teaching qualifications as SENCOs. There is no doubt that this must impact on how well the needs of SEN pupils are met.

Ironically, this “deskilling” has been accompanied by the creation of a career structure within the school system and accompanying jargon (such as “middle management”) which did not exist two decades ago. Teaching is, and should be, a vocation—not a career—and no Government initiative should distract teachers from their primary duty, which is to help each and every child they teach to achieve their potential.

- *The move from “child-centred” to “target-driven” education*. No attempt to raise standards will succeed unless successive Governments realise that every child is unique and that, unlike market commodities, there is no direct correlation between “input” and “output”. Children’s performances on SATs will not improve year on year, if teachers simply follow the national curriculum. Learning is a complex process, in which lesson content plays a very small part. Experienced teachers are able to relate how, what and when they deliver new information to a child, based on his/her current level of understanding, concentration span, learning style and

interests. The Government's emphasis on instruction and lesson content, together with the constraints imposed by constant intervention, has created a new generation of teachers who often lack the imagination and sensitivity to do this.

The move away from topic work into subject-based lessons at the primary level has made it harder for SEN children to understand how facts relate to each other. For most autistic children learning must be child-centred with information presented as a topic of particular interest to them and based on their level of understanding. A search of the Internet reveals that many school districts and boards in North America still base their curricula on sound and proven educational research on how children learn and those involved in education in this country would do well to return to this practice.

In addition, the resulting move away from the concept of education of the "whole child", which was enshrined in the 1944 Education Act and the Warnock Report means that many teachers no longer see this as a priority. By their own admission, they are largely at a loss as to how to meet the psychological and mental health needs of the special needs children in their class. Given that 1 in 10 children now has a mental disorder, this has serious implications.⁵⁴

- *The general increase in teachers' legal liabilities and responsibilities* and the resulting increase in litigation has resulted in school staff shifting the "burden of guilt" for failure onto the pupil and parent in situations where there is a remote possibility of legal action. Teachers who trained before the mid 1980s accepted that their job was to teach every child and exclusions in primary schools were virtually unheard of. Once a culture is created where the blame can be shifted onto the parent or child and the child can be excluded, teachers are less motivated to try everything in their power to help a failing pupil. As a supply teacher I have personally witnessed, in school after school, teachers openly expressing their negative opinions about the parents of SEN pupils and the pupils themselves, sometimes within earshot of them. Schools now keep incident logs on "difficult" pupils with the sole intention of gathering enough evidence to satisfy an exclusion panel. Several secondary school teachers have openly admitted to me that they feel that the reason that two thirds of permanently excluded pupils have SEN is simply because schools find it "easier" to exclude them, since they have already gathered enough evidence on their behaviour during the statementing process. Recent NFER research confirms my observations that staff do not distinguish between SEN and "naughty" children and that unofficial, "benevolent" and "adult accelerated" exclusions are on the increase.⁵⁵

Interestingly, the term "challenging" was originally introduced to describe children who "challenged" the teacher to find creative ways to educate and motivate them. The way in which its meaning has been changed over time reflects the way in which these children have been increasingly demonised and excluded from an education system which is no longer designed for them. The inexorable rise in exclusions and the fact that $\frac{2}{3}$ of excluded children have special educational needs is testament to the extent to which this is happening. The Government's own statistics now show that 27% of ASD children have experienced exclusion.⁵⁶

- *The policy of inclusion.* Whilst there have been "winners" and "losers" since the introduction of this policy, the winners have tended to be those with physical and obvious disabilities whose compliant behaviour allows them to access the curriculum in the same way as the majority of the class. The losers have been those with "invisible" disabilities whose behaviour and/or lack of social skills prevent them from even functioning in a mainstream class, let alone accessing the curriculum. These children, whose special needs generally fall into the category of autistic spectrum disorder, ADHD, Tourette's, EBD, are the children no-one wants and increasingly, with the closure of special schools, there is nowhere for them to go. For many with ASD there is simply no way in which they can cope in classes of 30+ but this is what LAs are expecting them to do.

Teaching and support staff are invariably given "training" by an advisory teacher from the LA, which usually consists of a few staff meetings after school, so it is little wonder that they feel ill-equipped to deal with children who are too traumatised to learn, even with best will and expertise in the world. Bizarrely, in spite of the Government's drive towards increasing inclusion, teachers are not obliged by law to undertake any SEN training. According to the latest ONS statistics 80% of teachers (some 340,000 in England and Wales) will attempt to teach children with autism having received no autism specific training at all. We would not expect any other professional (eg doctors, lawyers) to widen their remit without insisting that they first achieve an acceptable level of expertise in the new area.

As a consequence what is happening in many of our schools is not "inclusion", but "integration", in which children with special needs are "bolted on" to the existing set-up, with or without some individual support. This practice usually results in teaching, learning and attitudes remaining largely unchanged and can lead to more social isolation for such children than they would experience in a specialist setting.

⁵⁴ Department of Health/Office of National Statistics survey "Mental Health of Children and Young People in Great Britain" 31.08.2005.

⁵⁵ "Admissions and Exclusions of Pupils with Special Educational Needs" National Foundation of Educational Research, January, 2005.

⁵⁶ Department of Health/Office of National Statistics survey "Mental Health of Children and Young People in Great Britain" 31.08.2005.

- *The increasing homogenisation of learning and school type.* Like inclusion, the introduction of comprehensive education was regarded by some as the panacea by which all educational injustices could be righted. However, instead of comprehensive schools combining the best that grammar, technical and secondary schools had to offer, the amalgamation has often resulted in huge, impersonal establishments in which all children work towards the same narrow set of (usually academic) goals, thanks to the National Curriculum. Children with special needs are much more likely to find it difficult in such schools. Whilst the Government pay lip service to vocational training and apprenticeship schemes, on the ground there is little evidence that lower achievers have enough (or any) opportunity to learn purely practical skills in many of our comprehensives. For example, cookery has now been replaced by “Food Technology”, which has a strong written element, preventing the child with poor written skills from even excelling in this subject!
- *The lack of knowledge of SEN law.* Teachers and Heads receive no training in SEN law and, whilst they may recognise that a child has special educational needs, they generally lack the knowledge and skills to identify, assess and make appropriate provision for such pupils. This is particularly alarming, given that LEAs are now delegating most of their SEN budget to schools in the hope of reducing the number of statemented children. Whilst it may be a simple enough matter to give schools additional funding for 1:1 LSA support for SEN pupils who need it, many children require Speech and Language therapy, Occupational therapy and other highly specialised resources which must in law be “arranged” by the LEA. Schools simply do not have the time or resources to carry out this function.

Parents are unlikely to be convinced that this arrangement is an acceptable substitute for a legal document which ensures a child’s right in law to having his/her special educational needs met—particularly since neither the Government (DfES) nor LEAs seem very interested in putting the checks and balances in place to ensure that the extra funding which schools are receiving will guarantee this, in the absence of a statement. It has been quite common for schools to spend money earmarked for SEN pupils on the SENCO’s wages; and parents with children on School Action and School Action Plus can testify to the appalling inability of schools to meet their children’s needs from their existing resources, forcing them to request a statutory assessment.

- *The huge increase in the prevalence of SEN over the last two decades.* The latest Department of Health/ONS statistics show that 1 in 10 children now has a mental disorder and 1 in 100 is on the autistic spectrum. The report reveals both the level of need related to autism alone and the system’s failure to address this need. Whilst the numbers of SEN children are inexorably rising, the inflexible and bureaucratic education system which we now have is increasingly unable to cater for the needs of a growing number of pupils, which is probably one of the causes in the increase in the numbers of children with a mental disorder!

Whilst some of the many government initiatives described above, may have been implemented with the best of intentions, it is self-evident that no policy or legislation will work in the absence of adequate centralised funding and effective mechanisms for ensuring that implementation is not hijacked by bureaucrats whose budgetary concerns override everything else.

2.2 PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS

One cannot discuss the role of special schools without referring to the Warnock report and Baroness Warnock’s own recent recantation of much of its content. Whilst no reasonable person would argue against the principle of inclusion, this cannot be realised in a climate of under-funding, under-resourcing and evasion of legal duties by LEAs. Party politics and dogma should never be used to justify a “one size fits all” policy, particularly one which central government is not prepared to fund and police.

During a House of Commons debate on SEN on 22 June, 2005, Tom Levitt mentioned the need for our children to live in an inclusive society after they leave school. Laudable as this ideal may be, British society is far from inclusive, as adults with disabilities will testify. The trauma which many SEN children experience in mainstream classes, where they are bullied or become disruptive, is hardly a preparation for the kind of society which we want our children to be part of. Using children who are currently in the school system as guinea pigs in order to achieve some greater goal twenty years from now is immoral and unethical. It is as a parent of a child in the present system, and not as a sociologist or educationalist, that I question the morality of inclusion for ASD children. I will not repeat here the cogent arguments put forward by Julie Maynard and Allan Willis in “Beyond Warnock” but merely refer you to this submission.

Paragraph 2 of “Inclusive Schooling” supports the Salamanca Statement to “adopt as a matter of law or policy the principle of inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing otherwise.” Is the effect which “inclusion” is having on the mental health and quality of life of thousands of our most vulnerable children and their families not compelling enough to ensure that alternatives to mainstream classes are provided? The term “regular schools” can in any case be broadened, as it is in other EEC countries, to include integral units within mainstream schools (or integration classes) and the Government should be providing targeted funding to ensure unit places for all children who need this type of provision. This would include funding for the training of many more specialist staff.

All MPs seem to accept the need for a range of provision to meet the needs of the SEN population and DFES Minister, Jacqui Smith, asserts that “the Government do not have a policy of closing special schools”⁵⁷ but, by adopting a *laissez faire* attitude to LAs’ interpretation of Government policy, this is precisely what is happening in Councils across the political spectrum. Special school numbers are deliberately being reduced by some LAs, which are openly admitting to parents that they intend to close them. Parents up and down the country are being offered nothing but mainstream places, regardless of individual need—but there is no great enthusiasm on the part of most mainstream teachers and Heads to welcome children with more “challenging” SEN into their establishments. Children who have no speech are being directed away from SLD/MLD (severe/moderate learning difficulties) schools and into mainstream in an attempt to reduce the numbers of new entrants to special schools which LAs have decided to close—regardless of what parents want.

LAs are either under the impression that this is one of the “hoops” they have to jump through in order to “prove” to the Government that they are becoming more “inclusive”; or they are carrying this out in a cynical attempt to obtain a sum of money for “inclusion” from central government. In 2004 Bedfordshire’s portfolio holder for education justified pressing ahead with the closure of special schools, against parents’ wishes, in this way: “We are working within the Government agenda and as far as the Government is concerned we are lagging behind other authorities in respect of looking at our special educational needs.”

Perversely, another reason put forward for the closure of special schools within Bedfordshire was that “197 pupils in special schools have attainment levels which are average . . .” suggesting that this is the only criterion for admission to a special school. If children with average IQs and social/behavioural impairments were thriving in mainstream classes, there would be no SEN debate! This argument also fails to recognise the quality of teaching and (very necessary) level of resourcing in special schools. It is unlikely that these children would have achieved so well in classes of 30.

It is of great concern that LAs, in pursuing an inclusionist agenda for less than “ideal” reasons, are overlooking the special educational needs of individual children within their remit. LAs have a legal duty to assess the needs of all SEN children (Section 323 of the Education Act, 1996) and (for children with statements) to “arrange that the special educational provision specified in the statement is made for that child” (Section 324(5)(1) Education Act, 1996) and it is these duties which should form the basis for planning. Therefore, before making any alterations to the range of provision for the SEN population, a county-wide “audit” would be imperative, in order to determine each child’s needs and calculate the resources necessary to meet those needs. Expert reports produced during the statementing process usually give strong clues as to what type of establishment is best suited to an individual child’s needs but considerable input would be required from local health and education professionals, such as Educational Psychologists, Speech and Language Therapists, etc. Bedfordshire County Council, like others up and down the country, does not appear to have carried out such an audit, apparently preferring to base its decision on criteria which seem to have nothing to do with children’s needs, education law or the views of anyone else.

There is general agreement amongst parents, professionals and MPs from all parties that specialist units (or integration classes) within mainstream schools, which provide pupils with a “half-way” house, is the best way to “include” many of our most vulnerable children (of all abilities) but there are too few of these nationally. Having visited a huge range of special schools and specialist provisions, I firmly believe that these units make inclusion possible for children who would otherwise be unable to cope in a mainstream setting. There are many reasons why these provisions are excellent—mainstream role models, specialist staff, small classes, respite facilities, a differentiated curriculum—to name but a few. However, attempts by LAs to set these up have been thwarted by school Governors’ refusal to allow such units in their schools. Another problem is the shortage of specialist staff to teach in such units. Establishments which offer accreditation in SEN-related pedagogy are limited. For example, until recently, only Birmingham University offered experienced mainstream teachers a Masters in the teaching of ASD children.

In addition to the £66 million, which Jacqui Smith recently announced had been earmarked for special schools,⁵⁸ the Government should consider further centralised funding for the national expansion of unit provisions attached to mainstream schools so that there is capacity for the ever-increasing number of SEN pupils who now require such placements. The “excellent able autism unit” in Ms Smith’s constituency should be provided for children on a national scale. There is a huge variation in the competence and commitment of local authorities and parents should not be forced to move house in order to obtain better services. Only the Government can legislate to ensure global and fair provision locally for all who need it.

There would be many advantages to a model in which almost every school had an integration class/unit:

- The transition of SEN children into mainstream lessons would be much less traumatic if they were already familiar with the school. Similarly, children in mainstream exhibiting difficulties would have specialist staff on hand to provide advice and support for mainstream staff. Such pupils could also have access to the differentiated curriculum and specialist resources of the provisions.
- Support for mainstream staff coping with special needs would be on site and ongoing. Training could be “hands on”, rather than the piecemeal approach taken at present.

⁵⁷ *Hansard*—House of Commons debate on SEN, 22.06.2005.

⁵⁸ *Hansard*—House of Commons debate on SEN, 22.06.2005.

- The transition of SEN pupils into mainstream could be supported and co-ordinated much more effectively than at present, with pupils receiving the support they need for as long as necessary.
- Expansion and contraction of class sizes in such units would be more easy to achieve, since staffing arrangements could be more flexible.
- Mainstream pupils would be spending time with less “stressed” SEN pupils, under the supervision of specialist staff, leading to a more positive experience of mainstream for everyone.
- Where this model is used in Europe almost all special educational needs can be met locally.

Special schools will always be necessary for some children—not only those with the most “severe” needs but also those who require a therapeutic or specialist environment. Teachers in special schools should be given the recognition they deserve. At present they are demoralised and in fear of losing their jobs. Parents of ASD/ADHD children have their suspicions about the “real” reason why LAs have so readily formed an alliance with the Government on “inclusion” and the closure of special schools. We believe it to be, not only short-sighted, but at odds with Part 4 of the 1996 Education Act, which requires LAs to arrange appropriate provision to meet the needs of every SEN child within their catchment. One way forward would be to link each special school to one or more mainstream schools so that opportunities for sharing of expertise and dual registration can take place.

2.3 RAISING STANDARDS OF ACHIEVEMENT FOR SEN PUPILS

Government intervention

In Section 2.1, I listed the ways in which teaching and learning for SEN pupils in mainstream school was being compromised by excessive government intervention in education. To some extent the education of pupils in special schools has also been affected by this. I can cite examples of SLD children learning about Tudors and Stuarts and children with very little speech being taught to say “Bonjour!” by Speech and Language therapists—not because this is appropriate—but in order that the school can tick boxes to show that the NC is being followed for that child! The Government should seriously consider relinquishing some of its stranglehold on education and allow teacher training establishments, educational researchers and teachers to become “the experts” once more. Heads and teachers must have the freedom to find creative and individualised solutions to facilitating SEN children’s learning.

Class size

It is now quite common for some mainstream classes to have almost 50% of their children on School Action, School Action Plus or statemented. Most SEN children require a huge amount of additional support which they simply do not receive in mainstream classes of 30 + . If the Government is serious about inclusion, then it must drastically reduce class size to a maximum of 20.

The Use of LSAs

I have not only observed this myself but have also heard many teachers complaining about the inefficient use which is made of LSA support in schools. LSAs are usually under-trained, underpaid “dogsbodies” who work with one or more SEN children in or out of the classroom. At best they are given targeted work to do with the least able and/or most disruptive pupils—at worst they are “babysitters” for these children, having been given no direction by the teacher about how they should occupy them. By the time children reach secondary school level they are often embarrassed by having such “minders”. The Government needs to have a complete rethink about the role of these individuals.

In my opinion, LSAs should all have a minimum standard of education (GCSE level), should be literate and numerate and have an active interest in SEN. They should all be willing to undertake training in areas of SEN (eg autism, ADHD) which will be of practical use to them in school. Teachers must be obliged to plan and explain to LSAs what is expected of them during each lesson and sensitivity should be used in how and where each child is supported. However, with the correct training, LSAs could fulfil another important role in schools, which would sit well with the current drive to allocate more funding to schools for special needs. Statements frequently specify that a speech and language or occupational therapist should advise schools on how to deliver the therapy a child needs. Whilst parents know that this is often simply an attempt on the LA’s part to “water down” provision and save money; where this level of input is appropriate, LSAs should have the opportunity to receive NHS training in the delivery of SALT, OT, etc, perhaps receiving a qualification at the end of the course, along with a pay rise. There would be several advantages to this:

- Unlike the current situation in which children often do not receive the provision in Part 3 of their statement because no-one in the school is competent to carry it out, children would have their needs met by an LSA qualified to deliver the therapeutic program. An LSA with such training could also provide “in house” support to children on School Action and School Action Plus.
- LSAs would become “experts” in a particular field within a school. This should be highly motivating, particularly if they also receive more pay for the increased responsibility.

- Closer links will be established between health and education, in line with Government policy.
- There would be less pressure on local PCTs for paediatric services if there were at least one suitably trained person in every school. Having gained practical experience, LSAs may even decide to complete their training as therapists, thereby partially solving the shortfall in the NHS.

NB The duties of LSAs and other non-teaching staff should run parallel to those of a teacher—not replace them. The current practice of employing unqualified SENCOs, for example, or expecting LSAs to teach classes implies that “anyone” can teach. Whilst it may be possible for “anyone” to deliver a curriculum; it requires training, experience, professionalism, sensitivity to the needs of all pupils and the concerns of parents, and a determination not to let any pupil “fail” to raise standards for SEN children.

Early intervention and needs-based planning

By law, LAs should identify the special needs of children as young as two. For children requiring statements, it is vital that the LA uses the information it has about the needs of each child to optimise his/her potential in terms of resources and placement. Unfortunately, parents’ experience of how well this is done varies wildly. For example, Hertfordshire has a peripatetic advisory and support service comprising one Senior Advisory teacher, four Visiting teachers and 12 Specialist Home-Support Workers (working directly with pre-school children and their families) to support a population of 369 (statemented) children with autism. Bedfordshire has two Autism Advisory teachers for the whole county and no early intervention programmes.

Some LAs see “resourced nurseries” as the solution to meeting the needs of most of the SEN population. Well-resourced as these nurseries usually are, having, for example, PECS symbols around the classroom is not a substitute for intensive Speech and Language therapy for a child with limited or no speech (see below). Children not only need to acquire language (preferably before the age of 7) to access the curriculum but also to decrease the likelihood of institutionalisation in later life. At present the education system, even at the early years stage is failing to provide the intensive therapies which underpin learning. It is little wonder that, with so many needs unmet, these children develop low self esteem and ultimately become disaffected with school.

If all LAs and PCTs practised early identification and needs-based planning in line with the 1996 Education Act and “Every Child Matters”, the whole country would have a range of provision with sufficient capacity and flexibility to cope with variations in demand. As a result many high profile issues, such as exclusion and ‘school refusal’ of children with statements could be minimised.

A “joined up” Approach

It is clear that a more “joined up” approach is required in meeting the requirements of SEN children who often have educational needs which require NHS services. However, the reality is that there is a massive shortage of professionals in the very services which our children require, ie. speech and language therapy, occupational therapy, physiotherapy, music therapy, drama therapy, educational psychology, child psychiatry, etc. The result of this is that children’s statutory right to these services is being compromised because of huge NHS waiting lists. Luton and Bedfordshire PCT announced in 2003 that no child over the age of seven would receive any paediatric occupational therapy services, regardless of the level of need. There are no offers of alternative private treatment for our children. Instead, parents are forced to battle for statements in order to secure funding for private treatment, arranged and paid for by the LA. One does not need to point out the effect on a child’s educational achievement when they are denied services which would enable them to speak or use a pencil. The paucity of provision also means that the parent and child become pawns in a protracted battle between the NHS and LA over which should provide the service—hardly the seamless provision the Government had in mind. There will be no real multi-agency working until all local service providers are adequately funded and have a full complement of staff to deliver services.

2.4 THE SYSTEM OF STATEMENTS OF NEED FOR SEN PUPILS (“THE STATEMENTING PROCESS”)

It is now almost common knowledge that the biggest source of stress for many families of children with SEN is caused, not by caring for their child(ren), but by the failure of LAs in their statutory duties towards huge numbers of SEN children for whom they are responsible. The 1996 Education Act sets out three specific duties which LAs have towards children with special educational needs; duties which form links in a “chain” that creates the legal entitlement for these children to receive the provision their needs call for. The specific duties are:

- A. The duty to assess (S.323 EA 1996).
- B. The duty to issue a statement (S.324(1) EA 1996).
- C. The duty to arrange the special educational provision set out in the statement (S.324(5)(1) EA 1996). This duty applies regardless of whether the Statement says that provision should be made by another body, (eg a school or Health Trust).

Where an LA is attempting to evade one of these legal duties, a link is broken and the legal entitlement is destroyed.

As a general duty, LAs must identify any child who “has special educational needs” and “it is necessary for the authority to determine the special educational provision which any learning difficulty he may have calls for”. (Section 321 EA 1996).

NB. Any child who is deemed by the LA as having SEN which is not severe enough to warrant a statutory assessment, is placed on School Action or School Action Plus. Although, in law, the Governors of a school must “use their best endeavours” to ensure that provision is made for these pupils (under S.317(1)(a) EA 1996), in practice, these school-based stages do not guarantee any specific entitlement in law and parents are aware that Governors are generally reluctant to take any effective action against a Head or teacher. In addition, parents often rightly fear repercussions for themselves and their child if they complain.

How LAs evade their duties:

A. S.323—the duty to assess

An LA must assess a child who has, or probably has, special educational needs and whose needs cannot be met by a school, using existing resources, eg. a child requiring Speech and Language therapy not available at the school. LAs commonly use the following tactics to avoid their legal responsibilities:

- neglecting to inform parents of their rights. This takes various forms:
 - school prospectuses, SEN policies and LA documents not indicating that parents have a right to request a statutory assessment for their child;
 - schools, LAs and Parent Partnership Services informing parents and local charities that “they’ll never get a statement in this LA”;
 - LAs informing parents and charities that, as they are now putting more funding into schools as part of their inclusion strategy, there will be less statements; and
 - limiting the information and support that Parent Partnership (which are not, as the name suggests working “with” parents!) can give to parents.
- making the criteria for who gets a statement unreasonably high, eg “only the bottom 2%”, “only severe and complex needs”. None of these are lawful but are widely believed by parents, school staff, charities and sometimes even LEA officers.
- minimising the child’s disability and insisting that they can “cope” in mainstream, despite overwhelming evidence to the contrary. This is a commonly used tactic for high-functioning ASD children, many of whom cannot survive in large classes.
- using Local Management of Schools (LMS) to absolve themselves of any responsibility when schools fail to identify or make provision for SEN children, even though Section 332B(2) EA 1996 states that LAs must “make arrangements with a view to avoiding or resolving, in each relevant school, disagreements between the parents of a relevant child and the proprietor of the school about the special educational provision made for the child.”

The only legal recourse parents have when an LA refuse to assess, is Tribunal, which is very stressful and delays the process for 5–6 months, during which time the child’s need remain unaddressed.

B. S.324(1) EA 1996—the duty to issue a statement

LAs attempt to evade their responsibilities by:

- having policies for keeping Part 2, but more often Part 3, so vague that the statement is rendered meaningless and the school receives no funding. Some LAs are issuing “templates” to produce statements with almost identical wording in Part 3 for every child. A parent, seeing a proposed statement for the first time, is unlikely to realise this. Other ways in which LAs do this is:
 - By failing to quantify the provision, eg “he may need the help of an LSA”;
 - By referring to a “band” of funding which is meaningless to the parent, since it is not linked to anything meaningful in terms of eg number of hours of LSA support;
 - By ensuring that the wording, particularly in Part 3, is vague, eg “access to . . .”, “opportunities for . . .” Parents who accept such wording in Part 3 have no legal recourse when their child subsequently fails to receive any provision.
- By convincing the parent that S</OT is a “medical” and not an educational need, and placing this provision in Parts 5 & 6 of the statement, which means that the child has no legal entitlement.

The result of this is further Tribunals.

C. S.324(5)(1) EA 1996 is the duty to arrange the educational provision set out in the statement

Often, even when LAs are ordered by SENDIST (Tribunal) to fully quantify the package of education in Part 3, they will “drag their heels” or simply stall until the parent employs a solicitor to carry out a judicial review. Many parents are unaware that this option is open to them. Although legal representation is free, parents must pay for the initial cost of the solicitor reading through the paperwork, discouraging parents on low incomes.

At present the Government is attempting to delegate more funding to schools to pay for SEN but the legal responsibility, when schools fail to deliver, is with the LA—and rightly so, particularly since Councils make ever-increasing financial demands on council tax payers. It makes much more sense to enforce the LA’s legal obligation to arrange provision and to empower them to do so, whilst at the same time relieving them of their duty to assess, but I also strongly support the setting up of Independent Assessment and Statementing Panels (IASPs) nationally, as proposed in “Beyond Warnock”, which takes responsibility for the whole of the statementing process completely out of LA hands.

Parents recognise that the credibility of educational psychologists’ reports is undermined when their salaries are paid by the LA. Many professionals are instructed by LAs to keep (statutory assessment) reports vague in terms of recommendations and quantification of provision. The transfer of EPs to a multi-disciplinary organisation, independent of LAs, provided that it was not under pressure to save money by downplaying a child’s disability, would help to restore some faith in the system of statutory assessment. The Government also needs to address the national shortage of educational psychologists.

In addition, there are thousands of statemented children who have been permanently excluded and who are receiving little or no education—let alone the provision in their statement—a legal document which is supposed to guarantee this right. Two thirds of these are SEN children with disabilities such as high-functioning ASD, ADHD and other conditions related to poor social skills and “challenging behaviour”. There is virtually no provision for these children, who are severely disabled—not academically—but socially.

The Government recently trumpeted the exclusion of almost 10,000 children in one year alone (the majority of whom fall within this group) as a sign that they getting to grips with the problem of disruption in schools. In its document “Behaviour and Attendance, Part 2: Removing Pupils from a School Site and the Decision to Exclude” the Government stated: “Since September 2002, all LEAs have been committed to ensuring that all permanently excluded pupils receive suitable full time education, either at school or, where necessary, making use of a Pupil Referral Unit or other alternative provision.” Why is no-one questioning what happens to these children, many of whom sit at home for months or even years receiving only a few hours per week of education? The latest ONS statistics show that one in four ASD children now face exclusion and, as David Cameron recently stated: “One in five people of school age affected by autism is expelled from school and never returns.” The lack of provision for this group of children, who should never be placed in PRUs, is a national scandal.

If the Government were serious about “inclusive schooling” and “removing barriers to achievement” they would not only publish details of exclusions by disability but also carry out a thorough investigation of what happens to these children and why they were excluded.

Another national scandal is the growing number of children whose parents remove them from school because they are becoming physically and mentally ill as a result of attending mainstream classes. Such parents, hoping to protect their child from further trauma, find themselves in a “legal limbo” in which they are threatened by the LA with attendance orders if they do not return the child to the very situation which made them ill or self-harm in the first place. These desperate parents and children are the ones we see in the media reported as “one off” stories—but in actual fact there is a growing number of them, increasingly prepared to take action to expose the failures of the current system.

LACK OF REDRESS FOR PARENTS

Taking on the LA as a parent is like David fighting Goliath for the following reasons.

- Complaints to the DfES (under S496 & 497 EA 1996) are seldom upheld and I wholeheartedly support the call for a National Audit Office or Parliamentary Ombudsman’s investigation into the activities of the DfES, which has for some time now shown a distinct reluctance to police LAs and schools.
- The local Government Ombudsman can sometimes award compensation but it is minimal compared to the financial loss and stress the parent and child may have suffered. I was told by the LGO that levels of compensation for parents of children who had been excluded from school and had been receiving virtually no education—sometimes for years—was between £200 and £2,000! My son was in this situation for two years, forcing me out of a career and onto benefits. Although the LA’s offer of £500 was insulting, in view of the financial impact on our lives, I accepted this sum because I was exhausted by the battle just to get that.

- SENDIST is the only effective option open to parents when the statement is not properly written. However, there are strict limitations on when a parent is able to appeal; and if a deadline is missed, it can be at least a year before the next opportunity presents itself. Also, the increase in the number of appeals means that the process can take much longer than it did a few years ago, made worse by the fact that LAs have become adept at further delaying the process by requesting one adjournment after another. Witnesses such as Heads, SENCOs and teachers, are “commandeered” as LA witnesses and told what they can and can’t say, and parents are regularly shouted at and bullied by LA officers immediately before, after, and even during the hearing. Whilst the Tribunal itself is free, parents rarely win without expensive expert reports and witnesses to back up their case. The stress and costs involved mean that Tribunal is effectively only an option for the minority of parents.

To make matters worse, changes to the Tribunal Regulations (as a result of SENDA) have made it even more difficult for parents, who no longer have the opportunity to read or respond to the LA’s grounds for opposing the appeal until they receive the case statement, whereas the LA knows from a very early stage what the parents’ case is.

In addition, the SEN regional partnerships, set up by the DfES to share good practice, are not being used for this purpose; the East of England SENDIST user group, being a case in point. The chair of this group has been paid considerable sums of money to provide training to LA officers in ‘interrogating’ parents at Tribunals. It has discussed how LAs can avoid the paying of transport costs for a child when SENDIST orders the parents’ choice of school to be named in Part 4 of the statement. It has recently tried to lobby SENDIST to change its procedures in favour of LAs. Anyone reading the minutes of this group’s meetings would be unlikely to come across anything of direct benefit to SEN pupils and I am not the only parent who feels that these quangos, paid for out of taxpayers’ money, should no longer be allowed to operate.

LAs are, of course, very aware that it is extremely unlikely that they will be brought to account for their actions and will continue to act in this way with impunity until the DfES, LGO and SENDIST are given more powers to police them. In May, 2000 the Government appointed Sir Andrew Leggatt to review the operation of the Tribunal system (including the SEN and Disability Tribunal). Leggatt found that Tribunals were well-placed to identify areas where departments’ primary decision-making needs to be improved, stating: “We want to make sure that a new system enables primary decision-makers to learn the lessons of adverse decisions.” In August, 2001 the Government published a consultation paper which considerably watered-down Leggatt’s recommendations, insisting: “The new tribunal organisation’s approach has to be co-operative: it will not be able to dictate to departments as to how they do their work.” The Government must seize the opportunity to make LAs and other public bodies more accountable for their actions because at the moment LAs are being rewarded for unlawful behaviour (by cost savings) and this will only change if it becomes more costly for them to evade their legal obligations towards SEN children than to fulfil them.

2.5 THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN’S EDUCATION

One of the most striking changes which I have observed over the last two decades is the way in which parents of the more challenging SEN children have become increasingly regarded as “the enemy” by Heads, teachers and LAs. The idea of these bodies working in partnership with many parents, in line with the SEN Code of Practice, is a pipedream.

Schools

As a teacher I had expected a real partnership between myself and staff in my son’s schools. Apart from a few notable exceptions, I have been treated with a mixture of suspicion and contempt. The more I tried to communicate with the school when things went wrong, the worse it became. Other parents would frequently express their views about my child (in front of him) directly to me in the school-yard and in the classroom. I was often asked by both staff and parents “Why don’t you just send him to a special school?” At the time I believed that I was the only parent that this was happening to and wondered what I had done wrong. I subsequently discovered that this is an experience shared by many parents.

Before my son was permanently excluded from mainstream school at the age of six, he spent six months attending mornings only. The school “covered” themselves by placing him on a series of Pastoral Support Programmes and claiming that he was unable to cope full-time. My only legal options as a parent were either to accept this situation or to take my child to school every afternoon and have a “showdown” with the Head. The NFER research shows that, again, that my experiences are not unique.

There are many ways in which schools can make it clear to parents of SEN children that their children are unwelcome and yet give the impression to outside agencies that the school is “caring”. I would suggest that the procedure for the monitoring of schools by Ofsted includes a questionnaire for the parents of pupils who have either been excluded or have transferred to other schools in the area at other times than phase transfer. At present their views are seldom heard and no lessons are learnt from schools’ failure to educate their children.

My experience of communication between home and school is mixed. Many schools consider “good communication” with parents as being two parents evenings and one school report per year. Any attempt to make additional contact with the school to discuss genuine worries and concerns over a child’s education is often viewed defensively and parents can be made to feel that they are being “pushy”. Many schools also have a policy of not allowing parents to enter the premises. The lower school ASD provision my son attended, actively discouraged parents from coming to see their children perform at assemblies, claiming that our presence was “disruptive” for the pupils. As a group we were denied opportunities to applaud our children’s achievements, whilst all other parents were actively encouraged to attend.

As a parent dealing with schools I have rarely had the feeling that my views were taken seriously or that there was any recognition that I knew my child better than anyone else. One example of this was one school’s failure to believe that my son required a “respite” area to retreat to when he couldn’t cope. Their insistence that he stay in the classroom during “meltdowns” was very damaging psychologically but enabled staff to gather the evidence which ultimately led to his exclusion.

Similarly, although the child’s views are supposed to be taken into account when writing individual education plans at School Action and School Action Plus or during statutory assessment, teaching staff often lack the expertise to “translate” these views into effective classroom management strategies. For example, my son (before his diagnosis of Aspergers syndrome) regularly used to draw himself “visual timetables” of his school day. At meetings, I would point out that I believed these to be significant in some way; but it was not until a senior educational psychologist attended a meeting shortly before my son’s exclusion, that these were interpreted as being his way of asking for help in interpreting the school day.

Creating positive relationships with parents is a crucial aspect of every teacher’s job—particularly in relation to children with special needs—and all schools should ensure that time is set aside to chat to parents who have concerns about their child. Whilst a home/school diary is helpful, it cannot replace a spontaneous face-to-face chat with the teacher.

Parents of SEN children should be given recognition for the difficult job they do. The majority of teachers admit that they lack the expertise to motivate these children. Parents of ASD and ADHD children do this all day every day—otherwise our children would simply refuse to get out of bed or do nothing but play on the computer! Perhaps school staff would be less hostile towards parents if more “joint training” in SEN took place, ie parents and teachers attending training together. This may help both groups to understand the difficulties faced by the other and encourage the idea of parent and teacher working together to help the child.

Parent Partnership.

There is a huge mismatch between parents’ initial expectations of the Parent Partnership Service and its actual role, with many parents believing that the service is there to support them. Whilst the quality of Parent Partnership services varies from one LA to another, generally, parents are quick to realise the limitations of a “disagreement resolution” service funded and line-managed by the LA. Those of us who have been involved in protracted battles with LAs to obtain appropriate provision for our children, are fully aware that, in some LAs, this service simply exists to satisfy Section 332B of the 1996 Education Act. Some Parent Partnership officers have limited knowledge of the law, adopt a partisan (pro school/LA) stance at meetings and breach their own confidentiality guidelines by reporting conversations with parents to their line managers in the LA.

In spite of S332B EA 1996 clearly stating that LAs must appoint “independent persons” to disagreement resolution services, there is no truly independent support on offer. Parents rely almost solely on charities such as IPSEA, ACE and the Childrens Legal Centre for impartial information and support, which is mostly provided by unpaid volunteers, many of whom are themselves parents acting out of a passion to see justice done for all SEN children.

What is extremely worrying is the number of individuals now making a career out of the increasingly adversarial and bureaucratic attitude on the part of LAs towards parents—Parent Partnership, mediation, consultants and experts representing LAs at Tribunal (sometimes at a cost of £1,000 per day). All of these individuals are being funded by the taxpayer through local or national taxes. At a recent Tribunal the LEA paid £2000 for Tribunal representation in an attempt to prevent a child receiving £500 of occupational therapy (which the parents won) making the total cost to the LA five times what it would have been had the LA simply given the child what he needed. In addition, both the LA and parents were berated by the Chair for not having brought expert witnesses (at an approximate additional cost of £500 each)!

The LA

The principle of Section 9 of the 1996 Education Act is that pupils are “educated in accordance with the wishes of their parents”. Section 316 and Schedule 27; paragraphs 3 & 8 give parents of statemented children further rights to “express a preference” for a maintained school (mainstream or special). However, the caveats invariably used by LAs to deny this right to parents is “that the attendance of the child at the school would be incompatible with the provision of efficient education for the children with whom he would be educated or the efficient use of resources.”

Paragraph 1 of “Inclusive Schooling” states that the efficient education and efficient use of resources caveats were open to abuse pre-1993 and in paragraph 43 repeats that “The efficient education caveat—within section 316—must not be abused”. These caveats continue to be routinely used by LAs and schools in order to achieve the result that LAs want for statemented children. Many Heads, with the full knowledge and support of LAs, are well-versed in the use of the “efficient education” argument when faced with a request for a place at their school for a statemented child. The receipt of such a refusal is not only hurtful to parents who already know that there is no appropriate “in county” provision for their child, but also unlawful, in the sense that LAs rarely use their powers under S.324(5)(b)EA 1996 to enforce the parent’s choice. This is tantamount to allowing schools to make the decision themselves about which SEN children they will and won’t accept. Until recently the Schedule 27(3)(4) letters which Bedfordshire LA send to schools for which a parent has expressed a preference, requested a response about whether or not the Head agreed to the school being named in the statement—the underlining of the word “not” sending a clear message to the Head about the response which was expected. Following a formal complaint, this LA have agreed to cease this practice.

An additional problem with parental preference and the current wording of the above legislation is that it does not allow parents to specify a preference for a mainstream unit place and parents are obliged to appeal for the school itself to be named in Part 4 of the statement. This puts the child at risk of being placed in a mainstream class when what (s)he needs is a unit place. The law needs to be changed to allow parents the right to request and appeal specifically for this type of placement, particularly if unit provisions are expanded nationally.

2.6 HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED.

No comments.

2.7 PROVISION FOR DIFFERENT TYPES AND LEVELS OF SEN, INCLUDING EMOTIONAL, BEHAVIOURAL AND SOCIAL DIFFICULTIES (EBSD).

This has been covered in other sections.

2.8 THE LEGISLATIVE FRAMEWORK FOR SEN PROVISION AND THE EFFECTS OF THE DISABILITY ACT 2001, WHICH EXTENDED THE DISABILITY DISCRIMINATION ACT TO EDUCATION.

My understanding is that the take-up for DDA appeals at SENDIST is relatively low. In my view, this is due to the following:

- DDA legislation has no teeth. If a claim is upheld, the most parents can expect is an apology for what has happened.
- The statementing process is more likely to obtain appropriate outcomes for the child than a DDA claim.
- The main beneficiaries of current DDA appeals will be future children who will benefit from new case law and not the child on whose behalf the appeal is being made.
- Parents fear repercussions if they make a DDA complaint against a school which a child is still attending. Due to the 6-month deadline within which a claim must be made, claims will be limited to those children who have changed schools shortly after the incident and those with parents brave enough to appeal while the child still attends the school.

NB. The low numbers of DDA appeals in no way reflects the extent of discrimination in schools. Many parents of SEN children all have examples of actions taken by schools which would merit a DDA claim.

3. RECOMMENDATIONS

Responsibility for delivering a high quality State education system which serves the needs of all pupils may lie in the hands of the Government, but the philosophy and ethics which underpin this delivery are a matter for all of us. As an increasing number of SEN children survive and enter the education system, it becomes crucially important for us, as a society, to consider what outcomes we wish to achieve for our most vulnerable citizens. It is my personal belief that the State has a duty to ensure that all children are given the resources to develop to their full potential. Whilst in the short-term this may be expensive, it should not be beyond the means of the fifth richest country in the world. The current system, in which huge numbers of SEN children (many of average or above average intelligence) are being denied the services which would enable them “to enter a world after formal education is over, as an active participant in society and a responsible contributor to it, capable of achieving as much independence as possible.”⁵⁹ will cost society far more in the long-term. The following recommendations assume that those with the power to change the system understand this and have the will to make the necessary changes:

⁵⁹ Chapter 1; The Warnock Report; 1978.

1. Qualitative decisions about education should be made by educationalists and based on sound and proven educational practice.
2. Decisions about the overall SEN provision within an LA area should be made by the body responsible for arranging SEN provision (currently the LA) and not by school Governors.
3. The Government should carry out an immediate evaluation of the impact of delegation of SEN funding and how it will ensure that both schools and LAs are fully accountable for their decisions.
4. The purpose of the national curriculum and the Literacy and Numeracy strategies should be limited to providing newly qualified teachers with useful guidance on lesson content. Teachers must be allowed the freedom to organise their classrooms and timetables to suit the needs of their class.
5. Teachers must also be encouraged to develop their own style of teaching based on the needs of their children. They should be allowed to make judgements about the appropriateness of different approaches, eg, whole class, group or individual teaching.
6. The starting point for learning is current understanding. Education, particularly for young and SEN children must be child-centred and based on what we know about children's development, learning style and concentration level. Topic work over a range of subjects could be reintroduced if timetables were made more flexible.
7. The culture of blaming parents/children within schools and LAs must be reversed. Advanced Skills Teachers could be brought into schools to where this is a particular problem.
8. Teacher training in SEN must be made compulsory and widely available if inclusion is to have any value at all. All education professionals should receive basic training in autism and the opportunity for teachers to specialise in the teaching of autism and other disabilities must be increased.
9. Similarly, teachers must be given a basic understanding of SEN law during teacher training, with regular in-service updates.
10. There should be a thorough evaluation of the different models of provision throughout the UK and a series of regional audits to determine the range of SEN and how well needs are currently being met. Decisions about how to ensure that a range of provision is delivered equitably across all regions, funding for the setting up of new provisions and the recruitment and training of specialist staff must be the remit of central Government. Capacity should be planned for the ever-increasing numbers of SEN children entering the education system.
11. Pupils' individual needs must be of paramount importance when planning provision. Autistic children, for example, require a whole spectrum of provision.⁶⁰ Some require dual placements and some need to be taught at home or in specialist residential schools. None of these should be dismissed.
12. There is general agreement about the efficacy of integral specialist mainstream units and satellite classes and these should be increased to meet demand. Special schools should forge links with mainstream schools.
13. The expertise of special school staff should be recognised and used as a resource in the training of mainstream staff in SEN.
14. Class sizes must be reduced to a maximum of 20 if schools are to raise standards of achievement for SEN pupils.
15. The qualifications and role of LSAs should be reviewed and courses developed to provide them with basic training in speech and language therapy, occupational therapy and other skills which are currently absent in mainstream schools. Teachers should be given a better understanding of how to make best use of LSAs.
16. The current shortage of NHS staff providing paediatric services should be urgently addressed so that all children receive the services they need.
17. Responsibility for the statutory assessment and statementing process should be removed from LAs and placed into the independent sector as recommended in "Beyond Warnock".⁶¹
18. Educational psychologists should be removed from LAs and given independence, as in the Republic of Ireland. They should work jointly with the above assessment centres. This would restore parents' confidence in their impartiality and professionalism.
19. The DfES must release statistics on the number of permanent exclusions by disability in order to throw light on which groups of children are being failed by the system.
20. Immediate measures must be taken to provide appropriate full-time education for the thousands of children currently not receiving this. This includes persistent truants, many of whom have

⁶⁰ APPGA Manifesto; National Autistic Society; 2003.

⁶¹ "Beyond Warnock—moving forward with Special Educational Needs" Julie Maynard & Allan Willis; 26.06.2005.

unaddressed SEN. All children who are failing to access full-time education (other than those whose parents have made alternative arrangements) should have their special educational needs assessed (or re-assessed) within two weeks of this happening.

21. The Government must ensure that the DfES, the LGO and SENDIST are given the authority and the motivation to police schools and LAs when they evade their legal duties. The National Audit Office and/or the Parliamentary Ombudsman should investigate the failure of the DfES to uphold parents' complaints under sections 496 and 497 of the 1996 Education Act.
22. The SEN Regional Partnerships represent a misuse of the public purse and should be disbanded and all LAs instructed to desist from lobbying SENDIST.
23. Joint SEN training for parents and teachers should be set up to improve communication and understanding and encourage joint working, focussed on the child's needs.
24. Parent Partnership must be taken out of LA control and PP officers allowed to operate without interference from LAs. Perhaps officers could be placed within the CAB or other charities, and funded by central Government, or else placed within the proposed independent assessment centres.
25. An audit should be carried out to determine the true cost of the adversarial approach taken by LAs, ie the cost (to the LA) of mediation, Tribunals (including expert witnesses and representation) and salaries for an ever-increasing number of SEN officers paid to act as "gatekeepers".
26. There should be a slight change to the law to give parents the right to express a preference for a mainstream unit place.
27. Part 4 of the Disability Discrimination Act must be strengthened, in line with other parts of the act.

September 2005

Memorandum submitted by R Wilkinson and J Rashleigh

CEREBRAL PALSY

1. THIS SUBMISSION PRIMARILY DISCUSSES THE DIFFICULTIES OF LIVING WITH CEREBRAL PALSY SINCE THIS IS THE MOST COMMON PHYSICAL DISABILITY THAT WE ENCOUNTER WITHIN OUR DAILY WORK. HOWEVER, CONDUCTIVE EDUCATION ALSO TEACHES CHILDREN WITH A WIDE VARIETY OF OTHER MOVEMENT DISORDERS.

CEREBRAL PALSY—MISUNDERSTOOD AND NEGLECTED

2. Cerebral palsy has a severe and profound effect on those suffering from it and their families. We see—first hand—how the birth of both children with cerebral palsy has a devastating effect on not only the children, but also their immediate and extended family.

3. Such children are born into a system which views their disabilities as creating purely physical problems and does not even begin to consider the huge impact that their disability has on their ability to learn, to motivate themselves, to create social relationships and to take control of their own lives.

4. We see how these misunderstandings in the system's current approach not only fails to address and ameliorate fundamental problems in children's development, but also puts additional pressures and problems on the families of those who already have the strain of living with a cerebral palsied child.

5. No matter how severely or mildly affected children with cerebral palsy may be, the biggest impact of their condition is upon their learning. From birth children with cerebral palsy are unable to access and interact with their environment in a functional way and thus their learning is dysfunctional. This dysfunction affects the ability and the desire to achieve, learn and succeed. "Access" to opportunities to learn is therefore not enough.

For example; children with cerebral palsy may have disabled 'access' at their local swimming pool but this does not automatically mean they can learn to swim.

CURRENT PRACTICE

6. Many children with cerebral palsy are allocated a learning support assistant. In the overwhelming majority of cases these assistants have little or no experience in teaching a child with a physical disability. In essence they are not sufficiently trained to facilitate a cerebral palsied child's learning. Similarly most class teachers have vastly inadequate training (in fact no training at all) in how to differentiate their teaching for these children.

7. How can one begin to teach children with cerebral palsy when one does not really understand what their problems are? This is like asking a general practitioner to perform surgery with no appropriate training! This may seem an extreme comparison but the consequences of providing inadequate or counterproductive teaching and learning can have a devastating impact on the life of a child with cerebral palsy.

A mother of one of the cerebral palsied children with whom we work spoke to us because her daughter is having problems at school. Her teacher knows she is intelligent and deems her 'lazy' because she never initiates the completion of her own work in class. In fact the child wants to take a greater part in the class work but lacks the basic skills to initiate her own learning. Her assistant—in trying to help or "support"—always takes the lead in completion of the child's work. No one within the classroom has the basic knowledge of how to motivate this child and in how to make her learn independently. In fact, she is being taught not to learn independently but to be dependent.

8. The learning difficulties of cerebral palsied children therefore, can not be solved merely by the provision of ramps, lifts, adapted seating, wheelchairs and hoists—nor simply by enlisting additional staff members within a classroom environment. Whilst these measures might offer some help in "managing" the children's condition, they do little to facilitate the multitude of difficulties that these children face in "learning to learn". However this is what the current system provides and what it seemingly views as sufficient and appropriate.

THE NATIONAL CURRICULUM AND CEREBRAL PALSY

9. The National Curriculum needs to admit explicitly that the developmental needs of children with cerebral palsy include learning basic functions such as self-positioning, mobility skills, toileting and hand-control and thus should be part of the curriculum like language skills are included for the deaf. Conductive Education can teach these explicit needs that the National Curriculum currently ignores.

For example; If a six year old child cannot grasp a pencil then the curriculum will not allow this lack of ability to be ignored and the child would be taught how to hold the pencil. However if a child with cerebral palsy finds it difficult to grasp a pencil then he is not taught how to hold it but is given an aid such as a computer. Whilst this aid may provide some help for the child in acquiring academic knowledge, his explicit developmental need to be taught to grasp a pencil is neglected.

WHAT CONDUCTIVE EDUCATION CAN OFFER

10. Conductive Education teaches people with physical disabilities (primarily cerebral palsy) to learn actively to achieve purposeful movement which can then be applied throughout their daily living. Conductive Education also works to improve people's social, emotional, cognitive and communication skills, helping them to become autonomous, valuable members of society. This in turn positively affects the morale and wellbeing of their families.

11. *Conductive Education offers*

- The only educational approach that is specifically directed towards the needs of children with cerebral palsy.
- Conductors who are the only teaching professionals specifically trained to an expert level in physical disabilities.
- An example of parental choice in operation.
- A system of teaching that can directly enhance a child's inclusion both educationally and socially.
- A system that improves a child's physical and academic abilities.
- A comprehensive system of teaching for people with any severity of physical disability and of any age.
- Teaching not only for the child but also for the parents.

12. RECOMMENDATIONS FOR ACTION

We urge that the Government:

- Recognises that cerebral palsy is a severe and complex disability.
- Seriously considers the conceptional inadequacies in the current provisions for children with cerebral palsy.
- Provides, at the very least, adequate training for teachers and learning support assistants in order to promote learning and inclusion for children with cerebral palsy.
- Pays serious attention to Conductive Education as an effective and necessary provision for children with cerebral palsy.
- Give serious consideration to real collaboration with the voluntary sector.
- Act upon their promise of increasing parental choice.

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- Listen to the growing number of parents who have felt it necessary to access Conductive Education due to inadequacies in the current system.

September 2005

Memorandum submitted by Sara Truman

1. INTRODUCTION

I am the parent of a 16 year old with special educational needs, and I run—on a voluntary basis—a large support group⁶² for families of children and adults with Autistic Spectrum Disorders (ASDs). Over 500 people receive the group's newsletter, and our annual conference is attended by 200—300 parents and professionals. I am writing to report the views and experiences of parents as expressed at support group meetings and through emails, and I am also attaching some members' case studies. I know through regular contact with parents from other parts of the country through internet support groups that the experiences of our members are not unique to our area, but are typical of parents' experiences across the country.

2. GENERAL POINTS

2.1 I can only comment on the experiences of parents of pupils with ASDs (such as autism and Asperger Syndrome), which are disabilities that affect the way a person communicates, relates to others and makes sense of the world. The situation may be different for pupils with other special needs, but in the autism community, whilst some families have a good experience of the SEN system, many find it extremely frustrating. This is in part due to the lack of knowledge of ASDs amongst education professionals, and the fact that it is not a clear-cut condition which is easy to recognise and understand. Every person with ASD will be affected in a different way, and have different needs. Because children with ASDs do not generally look “disabled”, their difficulties are sometimes unrecognised and/or mishandled, which can lead to very distressing situations with autistic pupils suffering from extreme anxiety, depression, school phobia, etc.

2.2 There is a perception that the drive for inclusion in education has been at the cost of our children's well-being, as was recognised recently by Baroness Warnock. Whilst some pupils with ASDs can do well in mainstream schools, many cannot, and suffer greatly by being in an environment which does not meet their needs. [See Appendix One—case studies] The ultimate goal should be inclusion in society, and often the best way to achieve this is education in a special school, where teachers have the necessary expertise to enable the pupils to achieve their potential.

3. MAINSTREAM SCHOOLS

3.1 The quality of provision for ASD children in mainstream schools is very variable, dependant largely on the attitude of the headteacher and knowledge of individual teachers. Lack of understanding of ASDs in school staff can lead to conflict between the family and education professionals. Problems are particularly bad in secondary schools. Many autistic children who have coped reasonably well in a mainstream primary school find that they cannot cope at secondary school. [See Appendix Two for further explanation of the problems for autistic pupils in secondary school.]

3.2 Overall, there is a great lack of training for mainstream teachers in ASDs. What training there is, is often very short and offered on a voluntary basis. Teachers have so many demands on their time, and so many different special needs to cope with, that many are reluctant to take up voluntary training. The lack of training causes many problems. Pupils with ASDs often appear to be rude and challenging, although the behaviours are usually caused by their disability: for instance, most people with ASDs have unusual senses, ie sounds or smells which would not be noticed by other people might be very unpleasant to someone with hypersensitivity. A teacher could be wearing a perfume which an autistic pupil found unbearable, perhaps nausea-inducing, and due to his poor communication skills he might say “you smell horrible” to the teacher without any awareness that he was being rude. However, the teacher thinks the child is being deliberately rude and she punishes him accordingly. The pupil might think that the quickest way to escape the unbearable smell would be to run out of the classroom, or even to hit the teacher in the hope that she would go away, without the social understanding that it was wrong to do either. These sort of situations can often lead to the pupil being excluded, but need not have occurred at all if the teacher fully understood the autistic child's disability. Pupils with ASDs are far more likely to be excluded from school than their peers.

3.3 Pupils with ASDs frequently misinterpret the actions of others. They cannot tell the difference between good-natured teasing and bullying, and due to their sensory and social understanding problems may experience a friendly tap on the shoulder as a punch. They “retaliate” to what they believe is a verbal

⁶² The support group is a branch of the National Autistic Society, but I wish to make clear that the views expressed here are those of individual parents from more than one LA area. This is not a submission from the National Autistic Society itself, and I do not speak on behalf of the Society.

or physical attack and get into trouble. Many, if not most of the exclusions of pupils with ASDs are likely to be because of behaviour rooted in the pupil's misunderstandings caused by his or her disability, and the school's misunderstanding of the pupil, rather than deliberately challenging or defiant behaviour. Again, proper training could alleviate many of these problems.

3.4 Outreach/advice from teachers who are specialists in autism can be very valuable, and often can make the difference between a pupils succeeding or failing in mainstream school. Local Authorities (LAs) need to ensure that Outreach is provided and that there is not a long waiting list for it. If a school has to wait 3 or 6 months to get the specialist advice, the pupil's placement may have failed in the meantime.

3.5 Bullying of pupils who are seen as "different" is a major problem which schools seem unable to deal with despite their best endeavours. Whilst children do not need to have special needs to be the victims of bullying, those who do have special needs are particularly vulnerable, and having autism makes one more vulnerable still because of the lack of social skills which are central to the disability. I do not know of many autistic pupils in mainstream secondary school who have not been bullied, and bullying can have very serious consequences, including driving the victims to attempt suicide.

3.6 Placing pupils in mainstream schools who cannot cope is not only unfair to them but also to the other pupils in the school. If a teacher has to spend a disproportionate amount of time dealing with a child who has special needs, the other pupils suffer from a lack of the teacher's attention. If a child is very challenging, it is unfair to the other pupils that their education is disrupted by the challenging student.

3.7 *Recommendations*

- (a) Training in ASDs to be compulsory for school staff, including support staff.
- (b) Outreach from autism specialists to be available to all mainstream schools.
- (c) More effective strategy to prevent bullying to be devised and implemented.

4. SPECIAL SCHOOLS

4.1 Autism-specific schools are generally very highly regarded by parents. Because the staff are experts in ASDs they understand the pupils behaviour and know how to help them. Generic learning disability schools are more mixed in their success with autistic pupils, again dependant on the level of understanding of the child's autism as distinct from their learning disability. In our own area we are lucky to have 2 excellent LA-run autism-specific special schools. However, demand for places outstrips supply, both locally and nationally, and parents suffer great stress trying to get their child a place at a special school. There are 90,000 children with ASD in Britain but only 7,500 places in specialist units or special schools. Whilst some of those 90,000 children will be able to cope in mainstream provision, more than 7,500 (approx 8.3%) will need specialist provision. Those children for whom specialist places cannot be found locally are likely to end up in unsuitable provision or having to board at a school a long way from their home.

4.2 Sometimes autistic pupils who develop challenging behaviour may be placed in a special school for children with emotional and behavioural difficulties (EBD). If the root cause of the challenging behaviour is that the pupil has an ASD, it is totally inappropriate for the pupil to be placed in an EBD school. The autistic child is very likely to be victimised by the other pupils and techniques for managing pupils with EBD are unlikely to help—and may even be counter-productive—for pupils with ASDs.

4.3 *Recommendations*

- (d) More special schools for autism, and autism units in mainstream schools to be provided.
- (e) No pupils with ASD placed in EBD schools

5. RAISING STANDARDS OF ACHIEVEMENT

5.1 There is a big gap in provision for pupils with ASDs who do not have a learning disability. Almost all special schools cater for pupils who do not have the ability to study for GCSEs. A pupil's degree of autism does not necessarily correlate to IQ level or ability to learn, and there are many children who, with the right teaching, would be able to gain qualifications. At the moment these pupils are often being failed by the system. They either have to attend a mainstream school where the lack of specialist teachers means that they are unlikely to achieve their potential and at worst their disability often leads to the placement failing and them being excluded or removed; or they are placed in a special school which cannot meet the academic needs of a pupil with a greater ability than the rest of the pupils. [My own son was in a mainstream school until year 10, but despite the best efforts of a good teaching staff the environment was wrong for him and he ended up suffering from extreme anxiety and unable to learn, facing the possibility of leaving school without qualifications. We were fortunate in being able to move him to one of the very few special schools in the country which could meet both his academic and his special needs, and he is now thriving and expected to do well in GCSEs next year.]

5.2 *Recommendation*

- (f) Ensure provision of special schools and units includes placements for ASD pupils who are academically able

6. THE SYSTEM OF STATEMENTS OF NEED

6.1 The current system seems very bureaucratic and cumbersome, and very long-winded. It has become a “battleground” with parents often in conflict with LAs who do not have sufficient funding to meet their responsibilities to local children with SEN. However, great concern has been caused by LAs developing new systems intended to do away with statements. The statement is the only means a parent has to ensure that their child’s needs are being met. Without it any money allocated to the school for that child can be spent on other things, and the parent has no way to insist that the school spends the money on the child.

6.2 EAs sometimes appear to make decisions about children’s needs before they have been assessed. Often the biggest battle the parent has is to get the child’s needs assessed in the first place. In some areas nearly all children who have their needs assessed get a statement, but the LA will often go to great lengths to avoid assessing the child in the first place—apparently having decided that a statement is not needed without any assessment. Parents have to appeal to the SENDIST Tribunal to force the LA to assess the child’s needs. Many also have to appeal to get those needs met. 1 in 5 of all appeals to SENDIST are about a child with autism. Appealing to Tribunal is an extremely stressful and difficult process, and many parents would not have the ability to take their case that far. Those that do frequently find that the LA withdraws their opposition just before the hearing. Parents see this as a cynical act by LAs who did not have a good case but which were hoping the parents would not have the ability to go to Tribunal, or would have to give up the fight earlier because of the stress and expense involved.

6.3 As part of its inquiries, I would urge the Committee to investigate the number of appeals to SENDIST by parents, broken down by type of disability, and look at the percentage of decisions in which the parents’ appeal is upheld, and the number of appeals in which the LA withdraw before the hearing. This would indicate whether LAs are making too many unreasonable decisions regarding children’s needs, and disputing an unreasonable number of appeals.

6.4 I have heard a number of anecdotal reports of professionals responsible for writing reports for assessments being told by their superiors not to include all the child’s needs, because the authority cannot afford to meet those needs. Whilst the professionals concerned are not prepared to go on record about this for fear of losing their jobs, I have heard it so many times from different people that I have to believe it is true, at least in some cases. This is a betrayal of the child, and it is extremely unfair that front-line professionals should be pressurised to do it.

6.5 Currently pupils are allocated help which is expressed as so many hours of support per week. Often parents are told their autistic children will have help for one, two, or three hours a day. But autistic children are autistic all day long, and frequently need help at meal and break times as much as in lessons due to their social and communication disability, but LAs don’t feel they have a responsibility to help the child outside lesson time. There needs to be recognition that LAs are responsible for the child’s needs throughout the school day.

6.6 Recommendations

- (g) Investigate ways to simplify the statementing process whilst retaining legal responsibility of LAs to meet the needs of the child.
- (h) Clarify that LAs are responsible for the child’s special needs throughout the school day.
- (hh) Investigate the outcomes of appeals to SENDIST to establish whether LAs are making unreasonable decisions.

7. THE ROLE OF PARENTS IN DECISIONS ABOUT THEIR CHILDREN’S EDUCATION

7.1 Parents have very variable experiences of making decisions about their child’s education. Just as any other parent, they will sometimes find that the school they want their child to attend is over-subscribed, and if the school in question is the only special school in the area the frustration is compounded by the fear that their child will be placed in an inappropriate school.

7.2 It is very important that parents have all the information they need to make an informed decision. Some Parent Partnership services are better than others; the fact that their funding comes from their LEA makes it hard for some to be as independent as they should be.

7.3 Although the SEN Code of Practice emphasises the importance of schools communicating with parents and involving them in the child’s individual education plans, schools vary a great deal in how much they actually involve parents. Some schools do not recognise the expertise in autism that some parents develop, and are reluctant to act on advice from parents on how to manage the child, even if the parents originally received the advice from a professional expert such as an outreach teacher. (The same advice, delivered first-hand by the outreach teacher, is much more likely to be acted on.)

7.4 I recognise that some parents are unreasonable and difficult for teachers to deal with. But parents of autistic children often feel that they are regarded as unreasonable because the child’s needs are not recognised ie the child’s behaviour is put down to poor parenting if they have not been diagnosed with ASD or the teacher does not understand the implications of the diagnosis. Experts in autism have shown that

parents of children with ASD are likely to have some autistic traits themselves, and these can also lead to poor relationships with professionals. Yet again, training in autism should make teachers aware of this possibility and better able to manage the teacher-parent relationship.

7.5 Recommendations

- (i) Make funding for Parent Partnership services independent of LAs.
- (j) Training in autism for school staff to include parental issues.

8. HOW SPECIAL EDUCATIONAL NEEDS ARE DEFINED

8.1 The current system still seems very reliant on low IQ levels and poor academic performance as a definition of SEN. This is not appropriate for autism. Some parents have been told that their child does not qualify for a statement because he/she has not fallen several years behind the peer group in attainment, but not only is this not always relevant for ASDs, but in falling that far behind the child has to go through much suffering. For the system to insist that a child has to suffer before they get the necessary help is unacceptable. A diagnosis of autism followed by an assessment of the individual needs of the child should trigger appropriate support regardless of academic performance, but this is not always the case at present. This is particularly a problem for pupils with Asperger Syndrome, who may achieve well academically but still suffer severely from the impairments caused by their ASD. Many pupils end up with major mental health problems because their needs have not been addressed, and depression, sometimes leading to suicide attempts, is considerably higher in teenagers with ASDs than in the general population.

8.2 Recommendation

- (k) Ensure that LAs recognise the needs of pupils with ASDs regardless of academic performance.

9. THE LEGISLATIVE FRAMEWORK FOR SEN—SEE COMMENTS UNDER THE SYSTEM OF STATEMENTS OF NEED

APPENDIX ONE

SOME CASE STUDIES FROM FAMILIES OF CHILDREN WITH ASD AT MAINSTREAM SECONDARY SCHOOLS

A

“My son is 13 and has been subject to bullying at his mainstream secondary school. Other pupils will slap his head or back when passing him, in front of a Teaching Assistant (TA), or call him names (unprovoked), hit or prod him frequently. He had his trousers pulled down in PE which exacerbated his stress and tics (he has Obsessive Compulsive Disorder, along with Asperger’s, which is worse when his stress is high). He takes anti-depressants. The school has never responded to the concerns we have raised about bullying. He is frightened to go to school and it is a battle for me to try and persuade him every day. When he does go in they call me up at least once a week to go and collect him as he is ‘feeling unwell’ or ‘not coping’. I think it is the other way round mostly—it is the school which isn’t coping. With a little understanding, he could make the most of his potential and be an asset to the school. As it is, the stress he experiences from bullying and lack of understanding of his needs leads him to be more disruptive in his behaviour (although he is not aggressive). He desperately wants to change to another school which will understand him. Although he has ‘support’ through TA’s at his current schools, they don’t understand his needs. There has been a lack of continuity of his helpers, which is so crucial to a child with Asperger’s, despite him having nearly full-time support needs. Why not employ just one or two TA’s who could work with him continually and avoid chopping and changing? Now, there is agreement that there is nowhere for him to go but an out-of-county placement.”

B

“It’s a continuing nightmare for us. My daughter just cannot cope with mainstream secondary school. She has tried, and is now at home, and has been for several months whilst the LA still refuses to assess her for a Statement of SEN. She is academically bright but cannot cope with the sensory and social aspects of the mainstream secondary school environment. She is now getting even more reclusive. We are having to increase our mortgage to raise the legal fees to fight the LA at tribunal at what is already a very stressful time. Her support assistant did not have any training whatsoever and was fooled by her clever masking of her disability—it is at home that she lets off steam and has wild and distressing tantrums, away from school—we had to cope with years of terrible behaviour and anger turned towards us at home once she returned from school. At school, she has always presented as docile and passive but inside has not been able to cope with rising levels of stress. We tried initially to have her assessed a couple of years ago but the LA would not agree, even though the request came from her school as well as ourselves.

I have never been able to go back to work because I never knew if she would go into school each day and each morning was an exhausting fight to get her up, dressed and at school throughout primary school and beyond. Now I have to deal with the guilt of knowing that things didn't get better and school was such a painful place for her that I will not make her go into mainstream again. What she needs are small classes with a kind ethos and structured, calm environment. An appropriate education will be a long-term investment in her future independence. She has visibly unwound and relaxed into her own person while she has been at home, but meantime we have still no access or promise of access to full-time education for her. I have missed out on getting a place for her in September as most are full already. It was only after two months that she was able to receive 5 hours a week education at home, which at least has given her some much-needed structure to her week and proper teaching. We feel life is just a battle and that no one at the LEA cares about our child."

C

"My son had coped fairly well at primary school, with the help of an excellent Special Needs Assistant (SNA). There was no transition programme when he left primary as the secondary school did not understand the need. Although some of his peer group had been in primary school with him and were reasonably accepting of his differences then, as he and his peer group got older they got less tolerant of him. This is one of the real changes at secondary school which make it so much more difficult for the ASD child. As he also matured, he became more aware of this intolerance of his 'difference' and it naturally started to dent his self-esteem. He just couldn't cope with the social pressure of the mainstream environment, and the continuous subtle taunting and ridiculing which the staff were unable to prevent. He got more and more stressed at school, sometimes breaking down in tears, and so they had to withdraw him from lessons more and more to work 1:1. He was put in one bottom set because it was a small class, although the staff admitted that his ability warranted him being in a higher set. But the bottom set was full of kids who were very disruptive and targeted my son. The special needs staff tried their best to help, but could not stop it. The bullying accumulated and the stress began to affect his academic work—he became too stressed to work effectively if he remained in the classroom, but you need to be in the classroom to learn for your GCSE subjects and not in the library doing 1:1 with your SNA. When he was bullied in class—for instance they would take his possessions or make fun of him—he just could not think and work in that environment. Sometimes he mistook good-natured teasing for bullying—to him it was all the same as he did not have the social skills to tell the difference. He eventually had a sort of breakdown and was extremely distraught. He is now in an out-of-county special school which is enabling him to relax and shed the debilitating effects of years of high-anxiety. At last he is amongst boys like himself. He feels accepted and is even starting to build real friendships and learn effectively. He is blossoming before our eyes, and we are now much more optimistic about his future, but he should never have had to suffer all that stress in mainstream."

D

My son has dropped out of his large mainstream secondary school as he could not cope any more. However, the EOTAS (Education Other Than At School) Service delayed his complete drop-out from school for two crucial terms. I think, with more resources, they may have prevented his total drop-out from school.

When D was about to go to secondary school, we asked for a meeting with the secondary school SENCO, but this was turned down, despite my son being on School Action for his literacy difficulties and being repeatedly bullied with a very low self-esteem. Within a few days of starting in Year 7, he was already struggling to cope. Things like having to organise his books into a locker were impossible with the result that he carried everything around, including his keyboard. He also became extremely anxious over making sure that he got to lessons on time. It was obvious that he was becoming very stressed. He became depressed and by the age of 13 had been on a whole range of different anti-depressants that did little to help the underlying issues. The school recognised this and moved him onto School Action Plus and to their credit made a number of changes that we all thought would help. However there was little recognition of the seriousness of the mental health problems which was due in part to him not showing any outward signs of having a problem whilst at school.

In my view things started to change once he threatened to slit his wrists in front of a carer from Social Services who were providing some support on account of our younger autistic son. I shall be forever indebted to her, as she was determined to try and get the school to take more notice of his difficulties. Over a period of a year or so changes were made. The school provided a person whom he could meet first thing in the morning to discuss problems. We also managed to receive help from the Child & Adolescent Mental Health Service. But unfortunately we still lurched from one crisis to another. Soon, the problems affected his attendance at school. We would drive him to school but he was unable to get out of the car and he was having panic attacks.

Eventually I came across—by accident—the Children with Medical Needs Service. I had not heard of this service before, yet it seemed clear that my son could benefit from it, so I passed the details on to the school. It was invaluable to him in helping him cope with school life. His school timetable was changed to allow him more time to concentrate on the subjects that he was good at and to give up subjects such as foreign languages that clearly he had no chance of achieving good grades in. It seems like the Children with Medical

Needs service has managed to do things that I was unable to as a parent. For example I had suggested that PE is a totally negative experience for D who is dyspraxic and has the co-ordination skills of a penguin on roller skates. It does nothing for his self-esteem and is totally counter-productive. But we were told that it was mandatory and nothing could be done. A year later, magically that was changed and he no longer has to do it. It is a pity that they couldn't have done that earlier.

Things have gradually got worse for him until he could no longer face the stress of being at school. He has been signed off by CAMHS from attending school indefinitely. He is currently receiving 5 hours a week home tuition from the Education Other Than At School service. We are supplementing this with an additional 2 hours private tuition. He still hopes to take 8 GCSE's this summer. It is unclear what his results will be. What is clear however, is that he cannot cope with further education within a mainstream school or college environment. His options are extremely limited. Whilst he is no Einstein, he clearly has the ability to do A levels, and perhaps even a degree. I feel angry that he will probably not be able to achieve these goals. It seems that there is nowhere in Surrey that can provide the kind of support he needs in order for him to achieve his potential. We are now investigating Satellite Virtual School—an Internet based teaching package. We hope that we can obtain funding for this post-16—either for resitting of GCSE's or for A-levels.

Surrey County Council currently funds an outreach service to primary schools who have children diagnosed with Autism and Asperger's Syndrome. More recently this has been extended to cover the transition to year 7 in secondary schools. However, from my experience and that of others that I know, the problems are just as great in secondary school as they are in primary—if anything, they are worse. What a shame that this service is not provided throughout the secondary schools years—as I'm sure that there are many like my son who could have benefited from the service. I certainly feel that many of the teachers my son has had during secondary school had little knowledge or understanding of the disorder. How do I know? By the number of times I have had to deal with the fall-out when he has arrived home upset following an incident caused by a teacher being unaware of the consequences of his actions.

E

“E had a Statement from being at Infant School—for Moderate Learning Difficulties—and was only diagnosed with high-functioning autism when he was 14. He was at a mainstream secondary school which has a very good reputation for academic attainment, but they did not understand my son's needs at all. He floundered and his autism was not picked up—an Ed Psych was never called to observe him despite his sometimes bizarre behaviour, or present at any of his reviews. He was excluded three times. When he was in school he was bullied continuously. In Year 10 he just dropped out, he just could not cope any more. No one—not even the SENCO or head teacher—called me to see where he was. He had gone ‘off the radar’. His behaviour to me at home became very aggressive. We were left without any knowledge of specialist colleges for his future but now of course he is school phobic and wouldn't go to another educational establishment after his dreadful experiences.”

F

“My son was in a special unit attached to a mainstream primary school but was expected to be included into mainstream a great amount of the time, despite his challenging behaviour in reaction to the stress he felt at this. We really wanted him to continue in some sort of mainstream setting at secondary level in the local area, but there is just nowhere he could have gone that would have worked. He was out of school for more than three months whilst a placement was sorted, during which I lost three months' pay as I had to take unpaid leave—luckily my employers were amenable. He has had to take up an out-of-county placement, some way away, on a residential basis. We would never have wanted him to board away from home at age just 11. He's been there for some time now and he's really blossomed, but we are now preparing to have to battle for acknowledgement from the LA that he should stay there for his sixth form education. What we really need in Surrey is some imaginative planning in ASD education provision.”

G

At first, everything went well at secondary school, with no transition problems. Towards the end of the year I became concerned that he was starting to struggle and told the school this. However, no help of any kind was forthcoming, and as far as we can tell the teachers made no attempt to accommodate his difficulties by presenting work in a differentiated way. When he went into year 8, nobody told any of his new teachers about his difficulties, so they all expected him to be able to learn in the same way as all the other pupils. Towards the end of the autumn term he started having screaming fits when I tried to get him into school. On the advice of the acting head I continued to bring him in each day, and left him with the head of year. He would calm down after a while and then went to lessons without problems. One day I was asked to talk to the Education Welfare Officer. On her advice, I tried giving him an incentive (bribery), which was about 90% successful in getting him into school without screaming. So for the rest of year 8 he was paid by me to attend school. The school obviously thought that nothing else was required, and on their part did absolutely nothing to find out what was distressing him, or give him any support with work. I subsequently found that

he was being bullied in PE lessons by the boys whom the junior school had warned them about. I mentioned this, in writing, to the head of year, and his response was that nothing could be done about it. The school took no action of any sort to investigate or address the situation.

In the meantime, my son was finding it harder and harder to cope with the work, although he gave no signs of this in school. However, he struggled with homework, and I had to give him a lot of help with it. In class his verbal proficiency gives a false impression; he is quite able to answer questions orally but really struggles to put his knowledge into writing. After a particularly bad period, I asked the school to consider getting him a Statement, so that he could be given additional help. I had my first, and only, meeting with the SENCO at this point, where she told me that he would be given some help and assessed to see if he qualified for a Statement.

The help amounted to one session with a SEN teacher to help him with some coursework. She decided that he was unco-operative (as people with ASD can appear to those who have no idea about how to work with them), and so she decided that he should not receive any more help. She refused to meet with me to discuss it. Eventually, they told me that he “did not need any support” because his work was “academically of a good standard” (even though there were differences of 3 National Curriculum levels between his written work and his verbal work in class), and that he “would never get a Statement”.

I was given an appointment with the Educational Psychologist at the start of year 9, to draw up an IEP. Two months after the meeting they produced the IEP—the first he had ever had. He was still given no in-school support, even though they had decided to put him on stage 3 of the code of practice (the old CoP was still in force at that time). By the end of the autumn term my son was starting to show signs of acute distress in school, as well as at home, and was starting to react to bullying by hitting back. At the end of the autumn term he had a major screaming fit in a science lab, which was precipitated by their trying to alter his routine unexpectedly (they wanted him to leave the class to do a test he had missed). During a meeting to discuss this it was agreed that he would not be removed from classes, but the ‘minutes’ produced by the school made no mention of this.

The school then decided that it would not be safe to allow our son to go on a trip to Spain that he had been accepted on the previous term. We were not happy about this as we had an inkling of the distress this would cause. Before we could tell him, there was a situation when the Head tried to remove him from a lesson, and he refused. The head forced the issue and this caused another tantrum and he was excluded for ‘defiance’. As we trusted the school we did not query this, although now we can see that it could so easily have been avoided. [Prior to this our son had never even received a detention, as his behaviour was normally exemplary].

When we told our son that he would not be going to Spain he cried almost non-stop for 3 days and then, unbeknownst to us, took a small craft knife into school with the intention of killing himself. He chose to do this at school as he saw it as the cause of his unhappiness. Fortunately he let his secret out and so they were able to prevent anything occurring. Despite my telling the head of the preceding days of distress he chose to punish the unacceptable behaviour of bringing a knife into school by exclusion. Whilst I accept that our son needed time away from the school environment, I think that this should have been as sick leave, not as exclusion.

A case conference was held, which included the EP and our son’s clinical psychologist. The school only half-heartedly tried implementing their suggestions. Further ‘challenging’ behaviour occurred, mostly as the result of bullying incidents. Our son was constantly accused of being defiant, disobedient and uncontrollable and there was another exclusion. However, he had not behaved in this way previously, nor did he at home, so we believe it was caused by the way the school were reacting and the complete lack of support.

During this time, the Head made it clear that he did not want our son in his school, and several times threatened him with permanent exclusion, as well as trying to persuade us that our son should be in a special school (although he had no Statement, so could not have been offered a place in one). They did tell us that they would be applying for a statutory assessment (remember that he was still receiving no support of any kind in school), but they took 3 months to get around to doing this.

Before the request for statutory assessment went to the LEA, an incident occurred in which another pupil was injured. Our son was immediately excluded again, and at the end of the exclusion period the Head told us that our son was not to return (he was not permanently excluded but was to be marked as sick in the register) and we should look for another school.

It took us more than half a term to find another school which had a place and which we felt was more likely to give our son the support he needed. The first question the new head asked was how much support our son had been receiving, and when told “none” declared “Well he ought to have some!”. Shortly after starting there, our son received a Statement specifying 15 hours a week of special needs assistance. Superficially this new school would appear to be very similar, it has a similar socio-economic catchment area and a similar attitude to discipline. However, the attitude of the head and the teachers to our son has been very different. They have demonstrated by both speech and actions that they care about him, and wish him to achieve his full potential, by supporting him socially and emotionally. They have taken the time to get to know our son and find out the best way to help him academically, which in his case has been one-to-one time with a teacher to do his GCSE coursework.

We have been treated as valued partners, listened to, and consulted over the (very few) behavioural incidents, before any action has been taken. Our son has felt secure and so has felt less distress, so he has not needed to resort to ‘challenging behaviour’ in order to communicate his distress. He has never been asked to leave a classroom so his routine is not disturbed. Making exceptions for him has not led to deterioration in the behaviour of others. There has been immediate and effective action when any bullying has occurred. We have regularly had ‘praise letters’ telling us how well he is doing, and several members of staff have told us that he is pleasure to teach. Life has been much easier at home because our son is a great deal less stressed. In fact it is now nearly 3 years since he has had a major meltdown at home. He gained 11 GCSEs, 10 of which were grade C and above, and is now doing A levels at 6th form college.

Inclusion can work, but it requires a Head teacher who has some understanding of autism (which is more than just knowledge), and a willingness to accommodate the ASD child. They need to be able to make some exceptions and show acceptance of differences to their staff and pupils. A strong Head will be able to maintain overall control of the school’s discipline, whilst at the same time accommodating some social lapses. It is vital that all ASD pupils, whatever their level of academic functioning, are given in-school support so that they can understand the work, and the social environment. Just because they appear to be coping, does not mean they are. All teachers need to be able to differentiate work appropriately. They should be aware that some lateral thinking may be required to best help an ASD child—they may not need an LSA to help with reading and writing or other things in the classroom, it may be more appropriate to give discrete support in the playground.

Teachers need to understand that ASD pupils often show their distress and confusion by becoming more challenging behaviourally, and that this may not be seen at school. They should not dismiss any concerns that a parent raises. Keep records—this is especially important in a secondary school. Be aware the way to alleviate an ASD pupil’s distress is likely to involve a change by the people surrounding the child. The child cannot change himself, and they are likely to not respond to normal methods of discipline.

APPENDIX TWO

THE MAIN PROBLEMS FOR CHILDREN WITH ASD AT SECONDARY LEVEL MAINSTREAM SCHOOLS INCLUDE

1. Secondary schools are very much larger than primary schools: ASD children are confused and over-stimulated by crowds of other children due to their social and sensory deficits. At secondary school there are maybe 10 or more teachers and support staff per year who they will take very much longer to even start to recognise and learn their different teaching styles; the noise of so many more, older children is often unbearably stressful to ASD children’s hypersensitivity and auditory-processing.

2. The built environment is much larger than that of primary schools. There is often a warren of corridors which will challenge the orientation abilities of any ASD child and add to their already high levels of anxiety. Children are expected to change classroom after almost every lesson and break.

3. There are more, unsupervised times where ASD children are vulnerable to bullying: now there are in-between lessons breaks, whilst pupils are moving to their next class, as well as breaks and lunchtime. What supervision is available is often too little, inappropriate or ineffective.

4. There is more equipment which students are expected to be able to manage independently, eg lockers which they can’t understand how to fit their things into.

5. There are more intricacies to the curriculum—having to remember what comes next and trying to think about what they will need for that lesson is more stressful.

6. Many teachers and support staff at a secondary school have little or no training in ASD and do not have the opportunity to get to know each child and how to adapt their teaching for that child.

7. Teachers often have little or no understanding of ASD children’s social needs or disabilities, especially if they are academically able and may not present with challenging behaviour.

8. Homework—every night, expected by different teachers and often extremely difficult to motivate an ASD child to do at home, especially when they are suffering from fatigue from sensory overload and processing difficulties.

9. Peer group developing at quicker rate emotionally and socially interacting in more complex ways, confusing and unfathomable to the ASD child who is “different”, perhaps naive, not interested in fashion or music or opposite sex, and is picked on by group.

10. Puberty brings added stress and vulnerability to mental ill-health.

11. ASD child becomes more aware of their ‘different-ness’ and often develops depression, reduction in self-esteem, bottled-in anger and stress requiring counselling and/or medication. Can develop behavioural disorders such as obsessive compulsive disorder.

12. Increased isolation of ASD child in school and at home due to the lack of focussed special activity/social clubs available for vulnerable ASD child to enjoy extra-curricular leisure time, alleviate stress and build self-esteem.

13. The above problems can lead to difficulties in getting ASD child to enter school on daily basis—developing school refusal and ‘school phobia’.

September 2005

Memorandum submitted by Dr Angela Ayios, Brunel Business School, Brunel University

This paper⁶³ will comment on the following terms of reference of the Education and Skills Committee Inquiry into Special Educational Needs Provision:

- Provision for SEN pupils in Special Schools.
- Raising standards of achievement for SEN pupils.
- The system of statements of need for SEN pupils (“the statementing process”).
- The role of parents in decisions about their children’s education.
- How special educational needs are defined.
- Provision for different types and levels of SEN, including emotional, behavioural and social difficulties (EBSD).

This paper summarises the views of 13 parents of children with an autistic spectrum disorder (ASD), including a number of volunteer branch officers of the National Autism Society, living in the Greater London area.

EXECUTIVE SUMMARY

1. Getting the best educational provision for their child is considered by parents to be their greatest achievement, and something they experience as a great relief.
2. Early diagnosis is crucial, especially for those at the higher functioning end of the spectrum.
3. Specialist provision, often not available at mainstream institutions, enables the child to develop key skills, eg cutting up food or communicating, that other children take for granted.
4. “Outreach” therapy arrangements for speech and language or occupational therapy cannot realistically serve a child through a once or twice yearly visit for “target setting”.
5. There are insufficient places or facilities to meet the wide range of ASD needs.
6. Parents feel they have to “fight for justice” to get the educational provision their child requires.
7. Officers of the LA charged with the “care” of these children are described as “the devil incarnate”, and “engaging in mind games with parents”.
8. Parents feel that their views are not taken into account, that their experience and knowledge of their child are not respected, and that LA officers may be actively hostile towards them.
9. LA officers are seen in many cases as not understanding ASD and driven heavily by financial priorities.
10. The notion of “out of borough” needs to be dropped in favour of “best fit”.
11. Statements are believed to be “written to resources”, “vague”, and parents feel they have little power to change them.
12. LAs must recognise private practitioner opinions of the child, not just those of their “own” specialists.
13. Across the board, there are unacceptably long wait times to see specialist therapists for speech and language, occupational therapy etc, despite their crucial role in permitting children to access education.
14. Lower level, community based support on a weekly or bi-weekly basis would help parents discuss ongoing practical difficulties on a frequent basis rather than wait months or years to see a “specialist” during which time a child’s challenges and needs may have changed 20 or 30 times.
15. It takes too long for changes to be made to a child’s educational provision to meet their changing needs, and meanwhile the child suffers with either an inappropriate placement or failing to access key services and therapies.

⁶³ This response summarises the results of 11 interviews conducted by Dr Angela Ayios of the Brunel Business School, Brunel University, Uxbridge. The interviews were held with parents of children suffering an autistic spectrum disorder (ASD) aged between four and 12; amongst these parents were five branch officers/secretaries of the National Autism Society (NAS), and two chairpersons of an autism support group not affiliated with the NAS. The responses were gathered during summer 2005, and represent the views of 13 respondents. The findings are part of a broader ongoing project studying social capital amongst parents of ASD children in the greater London area.

16. The personalities, competencies and training of face-to-face teaching staff, and those responsible individuals in the LA are viewed as essential.

17. Parents feel completely disempowered in accessing the most appropriate education for their child.

1. DIAGNOSIS AND PLACEMENT

For parents of children on the autistic spectrum, there is great relief from anxiety and stress when their child receives a diagnosis, and then enters what is hoped to be an appropriate setting for their education. When asked to identify their greatest achievement for their autistic child, parents will almost always refer to getting the most suitable educational provision for them, either in pre-school or at school age.

As this parent described it: "That first week, when he started at [the autism nursery], such a relief, this is reality, he actually is autistic, I'm not a bad parent, it's a relief. Oh yeah, I found it depressing, but my emotions at that time were more about it being real, and I had to deal with it, a weight had been lifted." (*Jodie, mother of Fernando, aged 5*)

Through their children being diagnosed and consequently entered into specialist provision, parents are able to leave behind some of the inevitable guilt and self-doubt inherent in the tricky world of parenting a child on the autistic spectrum, as well as regain some of their lives while giving their child the targeted support they need. This label, as well as permitting the child into an appropriate educational setting, also enables the parents to deal with their child as not being necessarily 'spoilt' or deliberately awkward, but as one suffering genuine difficulties: "Since John got into [the autism unit at a mainstream school], I know for a few years now I can relax and get on with life. It's much easier when you find out that the child has autism, I got so much strength, just the patience, patience, in the way I deal with him and the tantrums." (*June, mother of John, aged 5*)

June specifically identified "working with makaton and pecs" [signing language and communication cards] as key facilitators of her child's development as a result of the pre-school and school-age placements he received. Another parent highlights how easy it is to overlook the basic skills that children on the autistic spectrum require assistance with in order to function alongside their peers, a level of assistance that cannot always be provided in a mainstream setting, and yet which can make all the difference both at home and school. "He's done very well at [the special needs nursery], learnt a lot of skills, a lot of which I don't know about, like he cut up a banana, and can eat using a fork, using pens and stuff, so yeah, good progress. It's been exceptional." (*Kathy, mother of Michael, aged 4*)

2. THE "FIGHT FOR JUSTICE"

Both June and Kathy, however, would also be the first to admit that gaining these placements was far from easy. Kathy is looking to the future with some concern as she contemplates Michael's move into the school system: "Getting him into education properly, that's the thing, people find there's not enough places at the right time and they need more help than most." June for her part expresses concern for those who do not push for the most appropriate provision on their child's behalf: "Now I know that anything you fight for it", she states, "I've always had the possibility of choice to fight injustice. I feel so bad for parents who feel it all goes smooth." Kathy is more relaxed about her 'fight for justice': "They must have done assessments I suppose. As he's not going to a mainstream school, I'm not that pushy, and it's lots of form filling in and I don't have time for form filling. They know what he's like!"

But do they? Parents who assume there is a body of people in the local educational authority (LA) proactively looking out for the best for their children are in a minority, and as one NAS Branch Secretary describes it, this is most likely misplaced faith and optimism: "A lot of people don't realise how proactive you have to be; they wait for the LA to suggest the best educational provision for their child, while the LA's job is not to suggest!" (NAS Branch Secretary, London Borough 4)

Sadly, according to most of the parents interviewed, there is a good chance the assessments haven't been done and that those responsible have done nothing, even if they do 'know what your son is like', because, the harsh reality for parents of children on the autistic spectrum is that: "You've already got this child with a problem and then you've got to fight for everything." (Secretary, Autism Group (non-NAS affiliated), Home Counties) As a result, parents continually find themselves up against the "LA wall of silence and non-cooperation." (NAS Branch Officer, London Borough 2)

Time and time again, the "fight for justice" for their autistic child arises as the key issue for parents, with both "sides" seeming very much to cast themselves in adversarial roles. From every parent interviewed there came unflattering characterisations of the responsible officials in the LA. "Parents think [our local LA] are the devil incarnate" (NAS Branch Officer, Home Counties), describes one. "The LA engages in mind-games with parents" (NAS Branch Officer, London Borough 3) states another. "It depends on the clowns you get!" (NAS Branch Officer, London Borough 2), comments yet another.

3. LACK OF RESPECT FOR PARENTS' VIEWS

At its heart, many parents feel a deep lack of respect is shown towards them by those in the LA charged with their child's "care": "The problem is not being listened to It's snide, it's underhand, the autistic parents I know tend to be up on things, and it's awful to be so condescended to she [the responsible officer in the LA] doesn't do things by the book." (NAS Branch Officer, London Borough 1) There is notable concern that officers of the LA are exercising their duties neither properly nor knowledgeably: "They don't listen, they don't move on, they have their set opinion and that's it. The parents know what their children need, they go and look at the schools and then they come up against the LA! They [the LA] don't know they need occupational therapy, speech and language therapy, they're ignorant." (NAS Branch Officer, London Borough 2) Indeed, one shocked branch secretary recounted that professionals in social services and even within the disabilities team have asked her at what age autistic children get better!

The responsible officials in the LAs, already regarded as lacking both competence and care, are further seen as taking rather a dim view of parents. "They don't understand ASD so they don't understand the issues They do see parents as difficult—and some of them are! But with some of them it is taken for granted that parents will be difficult and unreasonable. You wouldn't believe the things they say about parents! . . . They believe it's too many middle-class parents who know their rights and the system They think all parents are troublemakers." (NAS Branch Officer, Home Counties) She goes on to characterise the local LEA officials as "very hard-boiled people, maybe it's the job that turns them." And then asks: "Why can't they have a bit of humanity?"

The "hard-boiled" metaphor is coined by another branch officer who sums them up thus: "Generally in this borough it is a group of very strong, left-leaning women, highly intelligent, highly educated, tough cookies." (NAS Branch Officer, London Borough 3) Even at the school level, respondents report how "Parents get shouted down by the headmistress." (NAS Branch Officer, London Borough 1) But respondents frequently ask why officers charged with responsibility for educating their children find it necessary to take this view: "It's whether you take that attitude of making a devil out of the parent—they lose sight of what it's all about." (NAS Branch Officer, London Borough 3)

What it's all about is, in the parents' mind, getting a diagnosis for the child, which then gives rise, hopefully (although this is far from assured) to access to education most befitting their child's needs. This is a trying process, undertaken by parents already under enormous pressure: "It's all been difficult to achieve. The constantly chasing of things does wear you down, feeling like a burden to people because you keep ringing. I'd have to pick my time of day for my emotional state before I rang, not just having Fernando there, but my emotional state." (*Jodie, mother of Fernando, 5*) And with no guarantee of success: "You have to argue about the stupidest things and they just go on and change things how they like." (*Ida and Dave, parents of Timothy, 6*)

4. GETTING THE STATEMENT

June describes her main challenge in the care of her son John as: "[t]he Guildhall fight, you know, just getting into [the autism unit], and throughout, again, it's just no one has helped me, but the parents and what I have read by myself, whether on the web site, or, with parents mainly because you find out what works and what doesn't." Looking back over her experience, June reflects: "Now when I look back it's not that difficult, you just sit on the phone and bother people, to remind them, especially with the statement you realise that they couldn't do the statement too early because they wouldn't have a place for children to go to, so they are trying to tell you "oh, we're working on this", while in actual fact they don't, and they're just playing with the time, then it's so frustrating, and eventually when you get that it moved for me."

Getting the statement issued becomes something of a holy grail for parents, yet local authorities are accused of being very careful in the wording—as one headmistress put it when reviewing the statement in front of her "that's nice and vague!". Without a statement of special educational needs, it is difficult to access good educational provision for an autistic child—and that is putting it mildly. Even if a child is known to a unit, and has been accepted there, without the statement, funds will not be forthcoming, and so the placement remains under a question-mark.

This leaves parents at the mercy of hopefully sensible responsible officers: "[The special needs nursery] started assessing for the statement in the July, it never appeared. Verbally the [autism unit attached to a mainstream school] had accepted him for September, but hadn't had his statement back. I visited the unit, and the speech and language therapist happened to be there, she said this is ridiculous, he's accepted, so they took him and I assume paid for him until his statement was through." (*Jodie, mother of Fernando, 5*)

Jodie was perhaps lucky in that regard; other establishments are not so prepared to go ahead without the paperwork—and in the case of a statement, this can take the best part of a year to complete. And that is if you are lucky enough to qualify for one. One interviewee's son was diagnosed with aspergers syndrome by a leading expert, but the diagnosis was not accepted by either the school her son attended nor the local educational authority. Why? Because she had paid privately to see the psychiatrist who gave her the diagnosis.

5. PRIVATE PRACTITIONERS' OPINIONS NEED TO COUNT

In the present system, children, to receive proper support, must be diagnosed “within” the system, ie they need to be identified either by their GP or nursery and passed “up” the NHS system to specialists and through to diagnosis; based on this, some form of educational support from the LA should be forthcoming (although, once again, this is far from guaranteed). Those parents who either cannot get their GP or nursery to understand that there is a genuine problem with their child (often a tricky issue in particular for those at the higher functioning end of the autistic spectrum, when parents tend to be blamed for difficult behaviour), and/or the parents choose to seek private opinions and therapies, then they inevitably find themselves frankly ignored by their LA when it comes to arranging suitable educational provision. By going privately, they are taking themselves ‘outside’ of the system. One reason for going privately are the long, long waiting lists of up to 18 months and more for essential services to support the child. These include, for example, speech and language therapy and occupational therapy—services which can make all the difference to a child’s ability to access the school curriculum or even function in an educational environment. Many parents, faced with a long wait, and then limited to perhaps only six appointments with occupational therapy across the lifetime of the child, choose to take up private therapy while they wait, or as an add-on. And then they are told that they are no longer entitled to these services, as they have chosen to take them up privately . . .

Here is Tonia’s account of the school system, as she has experienced, with “only” a private diagnosis to rely on:

“Andrew’s nursery teacher was unbelievably good, she had an autistic nephew. His first symptoms were very very poor eye contact, in his own world, we thought he had a hearing problem. She was excellent. That was until four and half when he went to reception. A lovely teacher, very sweet, she asked me to give her books about Aspergers when I told her about the diagnosis. Year one, this year, quite an awful teacher, the opposite, plus a big change anyway. She, the teacher, she took it as a personal thing to be arguing with my son, always made a point with him, punishments, being sent to the headmaster’s office, Andrew was crying, didn’t want to go. A challenging year, lots of me crying, depressed. I had this report from the private psychiatrist diagnosing aspergers, but the LA assessors couldn’t say for sure if he was aspergers. From April, I have been paying the school privately and confidentially to provide an assistant for him, and she has been very good. Big change and he’s only cried once since, he’s now starting to like his teacher a bit again. “Educational psychologists have been called in by the school several times and have now agreed a statement finally. We are paying for speech and language therapy privately—they have more time to dedicate and take through parents’ needs, be closer to the parents.”

6. “TRAUMATISING” THE CHILDREN

This is only a short excerpt to give a flavour of the terrible time Tonia’s child suffered without acceptance by the LA that he had anything wrong with him. There are a number of themes within Tonia’s account which recur within those of many other parents, but two in particular need attention. First is the trauma suffered by her child, which is actually mild in comparison to others, but which seems almost a necessary process to get progress. As one branch officer put it: “They [the children] have to fail first, they have to be traumatized before it can change—and then it takes ages. They need evidence for the right school. There are many times when they [the LA] could act sooner.” (NAS Branch Officer, Home Counties) Another branch officer is less circumspect in her description of what happens: “If they’re high functioning, they might go to a unit, but more likely mainstream the criteria they use often exclude high functioning, especially aspergers, as they don’t fulfil criteria. So you get these kids with a diagnosis from health, but no statement and having to go to mainstream. When these children get to secondary, these poor children having struggled through primary, how will they cope with secondary? They will fail, be bullied, have the confidence kicked out of them—this is the cost of this wait and see attitude, it’s rather bleak.” (NAS Branch Officer, London Borough 2)

7. THE NEED FOR COMPETENCE AND A POSITIVE ATTITUDE

A second theme to arise from Tonia’s account is how a capable individual, either knowledgeable in the special needs area or prepared to learn from and listen to the parents, can make all the difference. As one branch officer put it: “It is so much the people.” This applies at pre-school and school-age level, and also within the LA.

One branch officer had been involved in consultations by the LA regarding a new special needs unit. While the unit itself turned out to be well designed and thought out, less thinking seemed to have been applied to staff recruitment: “there were personality problems with the teacher, and yet I have to tell parents having problems that they have to communicate with her. She came from primary school teaching, no experience with special needs or autism, and has had a lot of training over the year. But parents found she was like a brick wall, couldn’t communicate with her There is this attitude we know best as the teacher. The teacher needs to not be isolating herself, contact other teachers and units in the borough, and she won’t. She might feel she’s being told she’s doing it all wrong. A partnership approach is what’s needed. It’s a shame, because the unit itself is set up well, but there are concerns about experience and training, including the other

teachers—from dinner ladies to cleaners, they all need to know of the difficulties. We watched the kids in the playground and the 2 staff there didn't interact with the children. Playtime is the hardest time, needs as much structure as the classroom. You need to be larger than life with autistic kids and communicate with them even if they don't communicate with you. With my son's unit, I had a very good relationship with the teacher which is so important. At the residential school he is with now, all the staff are trained for autism." (NAS Branch Officer, London Borough 2)

Attitudes of key staff are central to the success of even the best thought out initiatives. At the everyday level, parents tend to know their child best and when they have information about their child to share with their educational counterparts, they do expect to be listened to. Another autism unit, though, seems to share the same kinds of problems as described above: "She [the head of the special needs unit] is very possessive and is afraid you're criticising and she just says 'this is what we do'. With Timothy's headbanging—we thought we were doing [the special needs nursery] a favour telling them about it, and she dismissed it saying 'oh, that's what all autistic children do'. We were like 'that's not what Timothy usually does, it's a change'." (*Ida and Dave, parents of Timothy, 6*) At the same nursery, another parent commented how the person in charge "is protective and doesn't like criticism, probably just her personality. It's a very small team. You don't always know what's going on, you always have to ask, people don't have time. I suggested a white board, but it was not taken up." (*Jodie, mother of Fernando, 5*) Yet the individual in charge, so often criticised by parents, is also often credited by many in the borough as having turned around a failing special needs unit.

Jodie was in a position to compare two different nurseries in two different boroughs providing care to her autistic child. While the one described above did not inspire any confidence from her, the other nursery was so good, she even started working there: "At a time in my life when I thought I was being a really bad parent, [the head of the nursery] swept me off my feet and said 'we'll take care of it' . . . a lot of my loyalty to that nursery is because she helped me through a very difficult time in my life. She stands no nonsense from parents or professionals. Some parents don't like it, it is too structured. Some parents don't like her. It doesn't work for every child because they're all so different." Clearly in this account is the fact that a personality that works for one child, and a particular type of care, might not work for another, or their parents. The issue of "good" personalities is a tricky one indeed.

However, at the LA level, it seems a little more black and white. If these people are making decisions that affect profoundly the welfare and future learning and lives of these young children, it is not unreasonable to expect a positive attitude, competence, and knowledge. "People who met the previous officer felt that he seemed a fair bloke, who left his telephone number and told them to phone him with problems. The meeting with the different manager didn't go so well, early on it became clear he didn't understand ASD, and he stuck to the party line of 'we're not obliged to give a rolls-royce service'. It is so much the people. One guy high up in the LA I really hate, he doesn't understand the issues, and comes up with the most outrageous statements like 'it is discipline really, I do agree with the grandparents'." (NAS Branch Officer, Home Counties)

This is surely unacceptable—those in control should at least understand the nature of the problems faced by these children and the solutions that can best meet their needs. One branch officer is grateful that at least some of those she comes across in the LEA actually do seem to care: "We have someone who wants to make a difference—it is down to the professional and their personality, while in another area you might have a very different person." She further makes the point that at the everyday level: "Some are helpful in local officialdom. You get those that are, and they're very supportive, and those that are not, and they don't listen, don't understand. You only achieve things when you come across those who do want to help and support you Education has always been our main problem, that's not to say people working with children aren't good, some are good—teachers, sencos. It all comes down to training." (NAS Branch Officer, London Borough 2)

8. PARENTS FEEL DISEMPOWERED

These are powerful people. Particularly at the high-functioning end of autism, the LA officers' decisions on what resources and services to offer to these children via the educational system can make all the difference between developing a child who can access education and go on to lead a reasonably normal and productive life, and a child who will be excluded in one way or another from accessing the educational system and all it has to offer, and will be severely inhibited in their ability to lead a normal life thereafter. The parents are usually the mediators between their child and those making the decisions that affect their child. In this role, they feel largely disempowered; impotent even. It is this feeling of total disempowerment which seems to make parents feel they are failing their children.

"Most parents feel disempowered because they have no control a lot of the time. They lack sufficient knowledge and understanding of the systems, and feel the power is all in the hands of the authorities, which it is really. They have control if they have the wherewithal, knowledge to take them to tribunal, but someone else ultimately makes the decision." (NAS Branch Officer, Home Counties) This is backed up by parents who state: "from an educational point of view, no, there is no control. We were told not to even bother fighting for [the school of our choice], as it's not in our borough etc. I'm assuming we would have got nowhere with that one, we went along with what was offered, there is no choice really." (*Jodie, mother of*

Fernando, 5) Jodie raises a key point—go along with the LA’s suggestions, and things will be much easier, and this is a recurring theme: “They’re on your side when you have decided you want the provision they provide, otherwise you end up floundering in a black hole, non-answered calls and letters, and they’ll play you off for years.” (NAS Branch Officer, London Borough 3)

Play you off for years? Is this what they really mean to do while the child becomes traumatised? Flounders? It would appear so: “If you constantly ask for things and the answer is always no, then you feel your knowledge of your child makes no difference in the processing. You feel no control over processes directly affecting your child.” (NAS Branch Officer, London Borough 2) Again, parents’ views seem to garner little respect or support: “They [the LA] pay lip service to putting the client first, whereas you have no control in reality, and you know the child best.” (Chairperson, Autism Group (non-NAS affiliated), Home Counties) And for carers, this translates into an exhausting struggle at a testing time in their lives: “At the end of the day, you don’t have a choice, not without a battle. “When is all this gonna stop?” asked one parent, “It never stops’, I told them.” (NAS Branch Secretary, London Borough 4)

9. FINANCE DRIVING DECISION-MAKING

Many parents put their difficulties down to the fact that the issue of financing drives all of the decision-making. One interviewee, musing on the statistic that 90% of all moneys spent on autism are spent on long-term care, the other 10% on education, commented wryly: “The education budget couldn’t care less if you’re saving £1000s for the social care budget.” (NAS Branch Officer, Home Counties) Another put it in stark financial terms: They have £X000 to service all those statements. They’ll fight tooth and nail to keep each child’s amount down to pay for others.” (NAS Branch Officer, London Borough 3)

This leads to some odd outcomes. Those that do wish to do a good job in the LEA are seen by parents as few and far between, and likely to remain that way: “A good number of officers are extremely careful about “writing to resources”. They now have a brilliant educational psychologist who suggested my son went to residential care. She won’t last long!” (NAS Branch Officer, London Borough 3) Indeed, a number of parents have gone down the residential route out of borough, with a tribunal involved and high ongoing expenses for the LA, because there was no suitable provision within the borough, despite the borough’s insistence they could meet the child’s needs: “I never wanted to go down the residential route, I looked for a school for three years, and there was nothing here. They were all full up, he couldn’t get in.” (NAS Branch Officer, London Borough 2) Over and over again, parents find the LA insisting they can meet the needs of children within their borough, or that there is no need for particular kinds of provision, when this is simply and clearly not the case. Here is the detailed account by the NAS Branch Officer of London Borough 2 of her fight for resources, and what this leads to.

“We had to go to tribunal, I spent a year teaching him at home before the LA said that we can meet everyone’s needs—Mark’s needs can be met here. They never help you to find a school, you do all the legwork, you go to them and say this is the right school, they say no it’s not, we can meet all his needs here at such and such a school. When we went to tribunal, the panel were not impressed and could see there was a big difference between what we were saying and what they were saying. It’s ridiculous, you always have to go armed with a solicitor and barrister, they almost always go to tribunal and often lose. In one of the old cases, the parent lost the tribunal as there was just no school for her son to go to. She has now won after teaching him at home for five years, and has now won a second tribunal for an out of borough private autism school.”

Two issues emerge strongly in this account. Firstly, the issue of in or out of borough. “Boroughs like to keep things within boroughs to the point they’re quite secretive, don’t like to share, don’t even know what’s going on in the next borough. Everything should be more open to help, even if it’s from another borough.” (*Jodie*, mother of *Fernando*, 5) Many interviewees recount the availability of provision out of their educational borough which could best meet their child’s needs, yet there is no cooperation between LAs to enable this: “They should drop this idea of out of borough in favour of better fit, so you need a good range of provision regardless of location.” (NAS Branch Officer, London Borough 3) Parents do not feel inclined to pursue their chosen educational provider on account of the heavy burden of taking the issue to tribunals to achieve this.

And this is the second issue. Going to tribunal costs a lot of money, and time, requires great thinking and writing by the parents, and involves a lot of money. One parent is feeling great guilt at the fact she is now taking her six year old child’s education to tribunal. Her son has very little speech and language, and is on the autistic spectrum. After a year being kept at nursery while the borough said there was no space for him in an appropriate educational institution, he has started in a special school which caters for children with a broad range of severe difficulties and disabilities, many of whom have restricted mobility—not the case for her son who is a very active lad but requires occupational therapy to help hone his skills. To date she has spent £12,000 on solicitors’ fees and private educational psychologists’ reports, private speech and language reports etc. She feels guilty that this is time and money she should instead be devoting directly to her child’s therapy and care, instead of fighting a battle against children being shoe-horned into inappropriate provision that she could well lose. As another parent put it, commenting on the many similar cases: “I find people having to employ solicitors a bit much in this game—people have to spend so much money, where does that money come from?” (*Kathy*, mother of *Michael*, aged 4)

10. CONCLUSIONS

For parents, this is a big system with which to come to grips, lots of finance, medical language, education-speak, politics, all feeding into one individual—their child. And while the LAs are “playing parents off for years”, children fail to receive the provision they need, become “traumatised” and their chances for reaching their full potential ebb away—or perhaps are taken away by those ostensibly responsible for their “care”.

At the outset, getting a diagnosis is key to this—the longer a child is awaiting diagnosis, the longer they are not getting the support they need, support which makes all the difference to the child’s educational experience and progress, and their chances to succeed in later life. “There’s not much you can do with autism other than education; health is peripheral really.” (NAS Branch Officer, London Borough 3) But health is the enabler.

The nature of the autistic spectrum means that diagnosis can be difficult amongst those higher functioning children who may be believed to be nothing more than badly behaved, perhaps the recipients of poor parenting. And yet these children can benefit immeasurably from early diagnosis and intervention to permit their success in the “normal” world. This can be achieved perhaps through well-informed, competent and caring mainstream provision, or through a special unit, attached to a mainstream or standalone. However, in the current situation, many high functioning children with a statement in mainstream schools are under the care of “outreach” arrangements from specialists such as speech and language therapists who can only see them once a year to “set targets”. This is of little practical use.⁶⁴

For those with more complex needs, the issue is one of a variety of provision—shoehorning children into the one or two units on offer in a borough that offer some form of “special needs” care is not going to be applicable for children whose difficulties range from little more than poor speech and a little clumsiness, to those with much more impaired physical and mental abilities. These children, too, often find themselves subject to irregular “outreach” arrangements from horrendously overstretched and underfunded services while whiling away their days in an environment that would not motivate the best of us to succeed.

All of these children, at all of these levels of need, all require different support, different staff, with different training. It is little surprise, then, that parents are somewhat sceptical of the blanket provision implied in the term “inclusion”: “The inclusion thing is the real problem, the idea that inclusion is the best for all autistic children . . . That’s behind pretty much everything. All the LA categorise them as is with moderate or severe learning difficulties, as if autism isn’t the main difficulty, which it is.” (NAS Branch Officer, London Borough 2)

In this situation of complex individual needs, parents feel they “know their children best” and want to be listened to and respected. They are fed up of each encounter with an educational official being underpinned by an eye on the resource implications, and of statements that are “vague”, “written to resources” and leaving the parents constantly questioning: “how much the statement has an effect, they cover the bases but little else.” (*Jodie, mother of Fernando, 5*) Why are encounters with educational providers cast in such negative terms by parents—they can’t all be too paranoid or too middle class or too demanding surely? Why aren’t officials viewed as knowledgeable, competent, positive and working in the child’s best interests? What is it about the job that “turns them” into “clowns” or the “devil” with no “humanity”? In short, what has gone wrong with the system and the people working within it?

And in the meantime, while the parents find themselves on the receiving end of LA “mind games”, “black holes of unreturned calls”, and “being played off”, the children are losing their chances of reaching their true potential, and parents feel totally disempowered to remedy this—it is indeed “rather bleak”.

September 2005

Memorandum submitted by the Association of Educational Psychologists (AEP)

I ask you to note that the Association of Educational Psychologists (AEP) represents at least 95% of educational psychologists in England and Wales and is both a trade union and a professional association of educational psychologists. The AEP represents only educational psychologists and comprises solely of them. The AEP, therefore, speaks unequivocally for educational psychologists in England and Wales.

⁶⁴ As the branch officer of London Borough 1 expresses it: “The biggest challenge—for parents—is to have actual practical solutions to the challenging behaviour. And you want someone to talk to at home—a home programme is what’s needed.” This is reflected by the home counties branch officer who reflects on the fact that “key questions for parents are: Where should our child go to school? What therapies should they be having? What should we be doing about their behaviour?”

This author believes there is a pressing need for meso and micro level support for parents who need someone to talk to and talk things through with to help them work through the constantly changing daily difficulties they face with their child. As Jodie puts it about the help she received from her autism nursery: “The main gains were meeting [the head of the nursery] and doing the parenting course. It’s just having that lifeline. They understand that families don’t accept it, so they do an open forum for grandparents. After that, the family were all for it, couldn’t do enough.”

The message is don’t just look to the commanding heights of psychologists and specialists all the time, but invest in the everyday listening ear to support parents and empower them.

As I mentioned above, the role of the educational psychologist is unique in the roles of all professionals working for and with children. The role has always encompassed work that transcends the traditional boundaries between education, health and social services, working in combination with professionals from all those domains, but uniquely with a holistic view of the child that is centred on the child and the child's abilities as well as needs.

Local Authorities are obliged to seek advice from educational psychologists, along with paediatricians and Headteachers about children whom they are considering assessing for a statement of special educational needs. Within most Local Authorities, the view of the educational psychologist is the one most readily sought to help others understand the child within the context of her placement. The educational psychologist will have an independent view of the child and is likely to have knowledge over time. Again uniquely the educational psychologist is able to put her knowledge of the child's needs in the context of personal experience and a variety of types of placement a perspective that is not normally available to other professionals.

Perhaps I might quote from a bulleted section of a recent report the Association has produced for the DfES Review of the contribution and function of educational psychologists. Where in relation to the outcome of Enjoying and Achieving we outline some of our contributions.

"Almost all educational psychologists are involved in generic school work to ensure that:

- The context and curriculum is relevant and accessible to the Child
- There are no inherent learning, social, emotional or behavioural difficulties that remain unidentified and thus unmet
- That progress is regularly monitored
- That staff are aware of the most appropriate techniques to support particular children
- That the child is able to comment on his/her experiences of school and learning and contribute to future planning.
- That particularly vulnerable children eg Looked-After Children, Refugee children, children in situations of domestic violence, traveller children have their needs identified and met sympathetically.
- That equalities issues are addressed and needs met and that in so doing diversity is celebrated
- That the partnerships are effective
- That behaviour support is focussed and effective to promote the smooth running of schools, the support of teachers and the achievement of all young people.
- That inclusion is promoted and the rights of the child under the disability legislation are protected."

Hopefully, this brief note and synopsis conveys to you the role educational psychologists have in education and particularly with Children with Special Educational Needs. Given the breadth and unique nature of our role, we hope that, like us, you will feel we have a contribution to make that your Committee would wish to hear.

February 2006

Memorandum submitted by Christine Davies, Borough of Telford and Wrekin

Since its inception the Borough has worked to provide a stimulating and high quality educational experience for all children, including those with SEN. The Council's Inclusion Policy statement from July 2000 endorsed the view that children should be able to have their needs met in their local school but included a commitment to responding to individual need (and parental preference) through specialist provision where appropriate. There is an emphasis on the importance of partnership with parents to ensure effective practice.

1. PROVISION IN MAINSTREAM SCHOOLS

All schools provide support and intervention for children with a range of SEN, supported by professionals from the inclusion support services, therapists, school improvement advisors and the school and community clusters.

- Funding is delegated through school action/plus to provide additional staff, specialist equipment and teaching resources, and to purchase specialist teacher support and CPD. SENCO networks help maintain expertise in schools.
- Children with statements receive additional funding to enable objectives to be met

- Provision is subject to a comprehensive programme of monitoring and support
- Through the access policy an increasing number of children with severe and complex disabilities attend local schools
- Children with SEN (including behavioural difficulties) in early years settings are provided with advice, guidance, training and additional funding to provide early intervention through the EY inclusion panel
- Two primary schools have specialist language classes, supported by the PCT
- One primary school has a resourced provision for children with complex learning difficulties.
- A primary and a secondary school have resourced provisions for pupils with physical difficulties. With respect to the primary school, Ofsted, 2003 noted 'The provision for pupils with physical and other complex special needs is excellent.'
- One secondary school is CReSTed approved for its work with dyslexic pupils
- The primary and secondary national strategies have provided additional teaching materials and resources which have been welcomed by schools, including wave 3, SEAL, BIP, ISP and 'Leading on Inclusion'
- The termly forum for 'including pupils with complex needs' provides the opportunity for sharing good practice and developing a response to the new challenges posed by having a more diverse range of pupils in mainstream schools.
- The nurture group network is extending and includes successful parenting support groups

2. SPECIAL SCHOOLS, OUTREACH AND INCLUSION PROJECTS

There are four Special Schools which provide specialist teaching for pupils who have a range of learning difficulties or disabilities. The two all-age schools for pupils with moderate or complex learning difficulties will become a primary and a secondary school from September 2006. There is a school and attached assessment nursery for pupils with severe, complex or profound & multiple learning difficulties which will become part of the Hadley Learning Community and there is a secondary school for pupils with behaviour, emotional and social difficulties. Two of the special schools are considering applying for specialist status. The LA also has five PRUs within the Pathways Education Service. In September 2006 a new collaborative project will come to fruition in the form of a new residential independent special school for pupils with BESD.

- Outreach services are offered by the SLD and the MLD schools. The outreach is delivered by practicing teachers/TAs to enhance the capacity of the mainstream school as well as supporting pupils with ASD, learning difficulties and communication needs, including AAC.
- There are close links between local mainstream schools and the SLD schools in order to provide quality inclusion opportunities for pupils.
- Two medically trained nursery nurses provide care for pupils with medical needs (such as tracheotomies or gastrostomies) in mainstream schools
- The speech and language therapy project enables teachers and therapists to work together in the classroom to provide a language-enriched environment for pupils with expressive and receptive language difficulties. This has received national recognition.
- Dedicated occupational and physiotherapists work in schools to support children with complex needs
- Some pupils have joint placements in special and mainstream schools
- The SLD school provides training for mainstream schools on ICT and communication aids, Makaton, Sonrise Options programme, Moving and Handling, assessment (P Levels), producing ASD plans, the 'sensory in a box' resource
- Through an annual bidding process the educational psychology service provides dedicated time to develop a wide range of action research/training to schools via the 'inclusion support programme'
- Specialist out of school provisions cater for pupils with additional needs for intensive, focussed support including the playing for success projects

3. LINKS WITH CHARITIES

- The Early Support Programme provides targeted help and intervention to families where children have a disability or complex medical needs. A multi-agency working group, which includes professionals, parents and voluntary sector representatives, is developing procedures for providing support and information.
- The Early Bird (National Autistic Society) project for families and children with autism works across Telford & Wrekin and Shropshire

- Whizkids has provided wheelchairs
- The sensory Inclusion service had close links with various associated charities
- NACRO is providing a lead on the move of the key stage 3 PRU to a joint service site.
- There is a close working relationship with the Parent Partnership Service, which is managed by the CVS, including the development of parental support groups
- The West Midlands Autism Society has close links with the LA. It has provided tutors for a university accredited post graduate course, given training to secondary school staff and is working to provide a service to older young people with Aspergers Syndrome.
- Respite care is provided in collaboration with NCH
- Links with the Shropshire Dyslexia Association are well established and will increase with the focus on dyslexia friendly schools planned for the next year.

4. EXAMPLES OF SUCCESSFUL INCLUSIVE PRACTICE

Sensory Inclusion Service (SIS)—this is a joint service between Telford & Wrekin and Shropshire County Council in partnership with the NHS. Services are delivered for children and young people from the point of diagnosis, usually at the neonatal stage. In relation to visual and hearing impairment all children and young people in the Telford area are fully included in their local mainstream schools. Overall Key Stage results achieved in recent years have been above national expectations. SIS works closely with the voluntary sector, both locally and nationally. Locally it works with oneVISION (a support group for families of children and young people with visual impairment), the Shropshire Deaf Children's Society and the Shropshire Voluntary Association for the Blind. These charities raise significant amounts of money to enable SIS to ensure that children and young people continue to have 'cutting edge' technology to help them access school and the broader community. The Sensory Inclusion Service also works closely with the National Deaf Children's Society, the Royal National Institute for the Deaf and the Royal National Institute for the Blind, particularly in relation to broader strategic issues dealing with standards and initiatives aimed to improve facilities nationally. The service is also involved with a range of similar services throughout Europe and has been involved in recent years in many training, children and young people consultation and other activities with colleagues in European Union countries and elsewhere in the world.

Family Support Work (Outreach) provided by Sure Start has supported families in South Telford since February 2004. A significant amount of the team's work has been around early identification of developmental delay and appropriate referrals to other agencies such as Telford Child Development Centre via GPs. There is a budget to provide extra session of nursery provision which is often used for children who may be affected by developmental delay. Health for All Children (Hall 4) changes to health visiting practice have placed an increased focus on families who can be classed as "hard to reach" in that contact time with health visitors has lessened. Children who may be affected by developmental delay are being seen, assessed (Common Assessment Framework) and referred by Outreach and Family Support Team workers to appropriate agencies (including the voluntary sector) alongside direct work with families to support. Sure Start's Outreach and Family Support Team were all Portage trained by the Borough of Telford and Wrekin's Portage service in June 2004. The team has provided pure Portage, and elements of the portage model when supporting families with children where developmental delay may be a factor.

Wave 3 funding supports personalised learning for pupils with SEN. A conference for designated school staff was held which included key note speaker from the National Strategy and workshops. The workshops were led by teachers from schools which had undertaken wave 3 projects and enabled them to share good practice. This was a very successful event and evaluations were very positive. Schools with identified needs, as shown by CVA data, have again been targeted for support, which has included additional training, staffing and consultant support. This has included the implementation of the Fischer Family Trust intensive literacy programme and mathematics. All schools have had the opportunity to attend training on the use of the new Wave 3 Maths materials.

The Nurture Groups (for young children with challenging behaviour) have been independently evaluated and deemed to have significant impact on the vulnerable children they cater for. There are close links with the National nurture group network and the LA now has accredited trainers for nurture groups. A quote from the Ofsted report of an infant school (May 2005) said 'pupils whose self-esteem and confidence needs boosting get very effective support through the nurture group, where activities sensitively nurture these qualities, allowing pupils to blossom.'

March 2006

Memorandum submitted by The Fathers' Club

SPECIAL EDUCATIONAL NEEDS

The establishment of your enquiry into this complex subject has only just been brought to my attention.

Whilst I am Chairman of the Service Support Committee of a local specialist school for children on the autistic spectrum, run by The National Autistic Society, and have been involved with this school on a voluntary basis for almost 13 years, I write on behalf of members of *The Fathers' Club*.

My wife was an LSA for eight years, five of which she spent statemented to a young autistic boy in a mainstream school.

The Club is now in its third year of operation and holds monthly evening meetings in both Dartford and Folkestone. The aims of the club are set out within the enclosed documentation. Our "active" list of members currently stands at 56, four of whom are grandfathers seeking help and guidance on behalf of the family of their son or daughter.

Time precludes me from conducting a survey amongst our members. I shall confine myself to seeking to interpret and bring together their views and thoughts, which may be helpful to the enquiry and have been gained over the past three years.

Statementing

In general fathers appreciate obtaining a statement for their child. For some it brings a closure to the vexed and often long outstanding question of what is wrong with or affecting their child. It also brings a resolution, some say a label, to what is needed for that particular child and only then can they often begin the long process of obtaining support in all matters relating to the child's life and future.

Equally there are occasions when either the father or mother is unable, or finds it extremely difficult to accept, that there is a problem and enter denial.

There is a general consensus amongst the fathers, and a view widely recognised in the "trade", that "the authorities" have for some time been seeking to greatly reduce the number of statements issued, no doubt on the grounds of the high costs involved, thus denying parents this "key" to their child's future.

Inclusion

Whilst not directly featured in your bullet points, although relevant to several, inclusion is still something of a "hot potato" and a subject that will invoke lengthy and conflicting debate where meetings involve the combination of autism and education. Again a general view of this could be summed up as follows.

- Inclusion works but not for every child.
- Inclusion must never be forced upon the individual child.
- Parents must be properly consulted and their views respected.

Provision and Resources

Whilst "good words" are all very well they serve no purpose without the financial back up to put them into effect. Provision and Resources are not, however, all about money and Government really has to pay greater attention to finding, teaching and training the human resources needed to better cope with SEN.

It is all very well parents securing a statement that requires their child to receive say, S&L Therapy for "X" hours per week only to find that they have no access to Speech & Language Therapists in their area. I am aware of parents, already burdened with additional costs paying out hundreds of pounds for private consultations on a range of issues simply in support of applications for funding or special provision. The same applies to other areas of SEN provision.

Mainstream-v-Special Schools

Much the same general views apply here as with inclusion above. Listening to "my" fathers talking about their individual problems as regards education for their child or children it is clear that in a good many instances the child has been placed in an inappropriate facility often simply due to the lack of a suitable local school or lack of spaces being available.

Locally we have excellent examples of both mainstream schools with good autism provision and specialist schools albeit again with limited capacity.

Parents Involvement

I have already touched upon the role of parents and whilst there are many examples of good practice some fathers have commented about a feeling of being “side-lined” by the “experts” when decisions are made concerning their child’s education and health matters.

Ultimately the responsibility for the child and decisions as to the best course of action must rest with the parents, supported by good, comprehensive and carefully explained medical and educational advice.

September 2005

Memorandum submitted by the Confederation of Children’s Service Managers (ConFed)

1. INTRODUCTION

1.1 The Confederation of Children’s Services Managers (ConFed) is an umbrella organisation representing Directors of Education and Children’s Services, education and children’s services officers, advisers/inspectors and school governor support services in England and Wales.

1.2 This submission is based upon evidence provided by the regional representatives who form our national Special Educational Needs Committee. To a considerable degree, therefore, the following comments reflect the longstanding experiences and views of those Local Authority staff most involved in applying the statutory framework for special needs on behalf of local children and their parents. The Education and Skills Committee is asked to note that there is little confidence amongst these key practitioners in the present national framework. We believe that it is ripe for review and reform in the light of the positive recent developments in Children’s Services practice and the Every Child Matters Green Paper.

1.3 ConFed welcomes this Inquiry. It is timely and potentially very helpful following the rather heated, but not always well informed, national debate instigated last June when Baroness Mary Warnock once again raised her fundamental concerns about the current statutory arrangements for children with special educational needs.

1.4 ConFed supports Baroness Warnock’s criticisms about the present system for assessing and issuing Statements of Special Educational Needs. This system has indeed tended to raise rather than remove barriers to learning. It has also had unintended consequences in increasing bureaucracy over the years as the means of securing additional provision for individual children with complex needs. The current statutory special needs framework, which has been in place since 1983, has not turned out to be a success, nor has it proved to be very supportive of real inclusion for children and their parents. We would welcome, therefore, the initiation of the “radical review” which Baroness Warnock has suggested should be undertaken by an independent committee of inquiry akin to the one which she herself chaired in the late 1970s.

1.5 Education and children’s services professionals remain supportive of the Government’s commitment to securing the most inclusive arrangements possible for children who have additional needs. In reality, whilst there has been a gradual decline in the overall number of special schools in recent years, that is not reflected in an equivalent reduction in the number of pupils supported by such specialist provision. Bearing in mind the reducing number of primary age pupils across the country, there has not, therefore, been a wholesale move towards children with special needs being “forced” to attend mainstream schools inappropriately as a consequence of special school provision within Local Authorities. Nonetheless, the Government needs to support Local Authorities by allowing them to retain adequate central resources to deliver the provision required.

1.6 We would urge the Committee to seek up to date statistics on these matters from the Department for Education and Skills rather than to rely upon the often over-stated rhetoric of those who are either strongly for or against Government policies in this critical area of the education system.

1.7 This submission will refer to a number of key national documents which we believe should be central to the Committee’s Inquiry. These have been listed at the end of this paper.

2. SECURING INCLUSIVE EDUCATIONAL OPPORTUNITIES FOR ALL CHILDREN

2.1 ConFed continues to support the far reaching principles first set out by the Government in the Green Paper “Excellence for all Children: Meeting Special Educational Needs” of October 1997¹. The Green Paper’s section on “Increasing Inclusion” stated that:

“the ultimate purpose of SEN provision is to enable young people to flourish in adult life. There are therefore strong educational, as well as social and moral, grounds for educating children with SEN with their peers. We aim to increase the level and quality of inclusion within mainstream schools, whilst protecting and enhancing specialist provision for those who need it” (page 43).

2.2 The Green Paper went on to state that “inclusion is a process, not a fixed state. By inclusion, we mean not only that pupils with SEN should wherever possible receive their education in a mainstream school, but also that they should join fully with their peers in the curriculum and life of the school” (page 44).

2.3 ConFed believes that recent Government policy on special educational needs reflects very well the original definition of “functional integration” provided by the Warnock Report of 1978²—“this is achieved where the locational and social association of children with special needs with their fellows leads to joint participation in educational programmes” (page 101).

2.4 More recently, in November 2001 the Department for Education and Skills issued extremely positive and balanced statutory guidance on “Inclusive Schooling: Children with Special Educational Needs”³ which we would commend to the Committee. This guidance document, which accompanied the equally constructive and inclusive Special Educational Needs and Disability Act, 2001, provided practical support for schools, Local Authorities and others in the development of their cultures, policies and practices to include pupils.

2.5 In addition to some excellent key principles, the statutory “Inclusive Schooling” guidance indicated that “schools, supported by Local Education Authorities and others should actively seek to remove the barriers to learning and participation that can hinder or exclude pupils with special educational needs. Schools and Local Education Authorities that are successful in including pupils with special educational needs meet those needs in a positive and proactive way. They also approach inclusion as part of their overall improvement strategy. Inclusion is far more than just about the location of a child’s school placement” (page 2).

2.6 We have quoted liberally from these key DfES documents because of the cautious and balanced approach to inclusion which they provide, and which ConFed strongly supports. They give us a helpfully, child-centred and practical national framework for maximising the educational opportunities and consequent life chances of children and young people who have additional learning needs.

2.7 It is noteworthy that the best definitions of inclusion emphasise the importance of all children belonging to schools which address their very particular individual needs. Such truly personalised learning depends upon a positive school ethos which celebrates diversity and gives equal access and opportunity to those who happen to have special educational needs and/or disabilities. This is well reflected in the Government’s current strategy for special educational needs, “Removing Barriers to Achievement”. Increasingly, these central characteristics of educational inclusion are being evaluated by OfSTED during inspections of schools. This is most welcome.

2.8 Whilst they are broadly supportive of the present inclusive principles which inform Government policy on special educational needs, education service professionals do have significant concerns about the unintended and often non-inclusive impact of the present statutory framework for identifying, assessing and providing for special educational needs. Sadly, decisions of the Special Educational Needs and Disability Tribunal and conflicting national policy priorities, such as the undue emphasis still being given to school performance tables and the autonomy of individual schools within the Government’s Five Year Strategy, often cut across the achievement of inclusive outcomes for children who have additional needs.

3. KEY NATIONAL ISSUES

3.1 *Reviews of Progress*

We would commend to the Committee the report of the Department for Education and Skills’ new SEN Adviser Team of June 2005⁴. This provides a valuable national overview based upon initial visits to all Local Authorities in England between September 2004 and February this year. The report reveals that significant progress has been made across the country since the publication earlier in 2004 of the Government’s strategy for SEN, “Removing Barriers to Achievement”⁵. Similarly the report “Special Educational Needs and Disability: Towards Inclusive Schools”⁶, which was published by the Office for Standards in Education (Ofsted) late last year, provided a most helpful overview of national progress towards inclusive opportunities. It is based upon visits undertaken by inspectors between May and November 2003. We would ask the Committee to note in particular the following findings which unfortunately did not appear to inform the media debate on inclusion last summer:

- “i) The Government’s revised inclusion framework has contributed to a growing awareness to the benefits of inclusion, and response to it has led to some improvement in practice.
- ii) The framework has had little effect as yet on the proportion of pupils with SEN in mainstream schools, or on the range of needs for which mainstream schools cater. There has been an increase in the number of pupils placed in Pupil Referral Units and independent schools” (page 5).

3.2 *The Current Legislative Framework*

There is a grave danger of the stand alone statutory system for special educational needs, which has been in place since the Education Act 1981 came into effect on 1 April 1983, continuing largely unaltered. Meanwhile, otherwise welcome and fundamental changes are being sought in securing timely and integrated multi-agency support for individuals in need and their families. Given that virtually all other aspects of the education system in England and Wales have changed significantly since the mid-1980s, it really is quite remarkable that much of the special needs legislation set out in the 1981 Act remains fundamentally unchanged within the successor Education Act of 1996.

3.3 *Special Educational Needs and Disability Tribunal*

3.3.1 One of the great anachronisms within the present statutory framework for special educational needs, and the Government's associated, commitment to effective educational inclusion, is the role and impact of the Special Educational Needs and Disability Tribunal. In spite of the best efforts of Tribunal members, it is quite clear that the Tribunal has become a vehicle for the most articulate parents to seek to secure additional resources for their children.

3.3.2 Local authorities are working hard, in accordance with Government policy to reduce the overall need for Statements of Special Educational Needs, and to avoid the use of expensive provision in the private sector wherever possible. This is in line with the inclusive principles set out in "Excellence for All Children". However, the Tribunal in recent years has been increasingly over-ruling Local Authority decisions. This has resulted in the small minority of parents able to face the rigours of Tribunal hearings, supported by the significant increase in parental rights of appeal since 2001, being able to exercise their rights effectively but at the expense of the majority of parents whose children also have additional needs.

3.3.3 The Special Educational Needs and Disability Tribunal, on the basis of written evidence and advocacy at legalistic appeal hearings, is empowered to make decisions which for an individual child could cost the taxpayer up to £1 million in lifetime educational costs for an out-County school placement. This makes no moral or economic sense. It is quite clear to us that a simpler, more parent friendly and less legalistic system of local appeals is urgently required. This must allow for a balanced and reasonable consideration of an individual's needs within the context of cash-limited resources and local policies and provision.

3.4 *Integrated Multi-agency Working*

3.4.1 The Confederation of Children's Services Managers is highly committed to the Government's *Every Child Matters*: "Change for Children" agenda. However, we do have significant concerns about the lack of emphasis evident so far within national developments relating to the safeguarding and well-being of children, to the existing separate statutory framework for the 20% or so of all children and young people who have special educational needs and/or disabilities.

3.4.2 ConfEd believes that the five outcomes for children which are central to the *Every Child Matters* framework will prove to be a powerful lever for improved multi-agency provision on behalf of individual children and their families. However, the initial experience of the new Joint Area Reviews into Children's Services Authorities suggests that the present inspection framework will need some revision. This is essential if such reviews are to reflect more fully the particular impact of local services upon the outcomes for children and young people who have "learning difficulties and disabilities." This is a new Ofsted term which needs clearer definition.

3.4.3 The inspection framework should ensure that the quality of work for children across each of the five outcomes properly includes children with learning difficulties and disabilities. This can only be achieved if the key judgements in the inspection framework reflect the five outcomes for children as opposed to more traditional measures of Local Authority efficiency such as timescales for the completion of statutory assessments and Statements of Special Educational Needs.

3.5 *National Health Service Priorities and Provision*

3.5.1 A long term issue which cuts across the best intentions of both national and local government in this field is the lack of priority given to children by the National Health Service when it comes to improvement targets and priority of resourcing. Notwithstanding the recently published National Service Framework, children are still not represented within the overall key priorities for the National Health Service. This leaves Primary Care NHS Trusts being unable to fulfil adequately their prime obligations in relation to the provision of therapies such as speech and language therapy and Child and Adolescent Mental Health Services. Future NHS reorganisations need to reflect the need for viable, well-funded child and community health structures which are co-terminous with Children's Services Authorities. This would do much to make sure that the Government's "Change for Children" programme really is transformational.

The “Every Child Matters” agenda gives a real opportunity for the Government to resolve the unacceptable confusions and difficulties in this area which really should not be disguised any longer by talk of improved practice and partnership working.

3.5.2 What is urgently required is a clear and properly funded statutory framework which ensures that all children’s therapeutic needs are identified, assessed and provided for by the NHS as a central aspect of holistic support arrangements for education and social care needs. These issues are well known to the Department for Education and Skills but up to now the Government has been sadly “risk averse” when it comes to bringing forward long overdue primary legislation in this, as well as other, areas of special needs provision.

3.6 *Transport Issues*

3.6.1 Central government transport policy is causing a number of local authorities some concern. The August 2005 DfES “Update” to Local Authorities provided a new interpretation of recent non-statutory guidance to local authorities on SEN transport issues. It would now appear that the Department for Education and Skills expects local authorities to comply, without prevarication, in providing a vehicular means of transporting children with special needs, free of charge to the user. This is regardless of the family’s material or personal circumstances. It could therefore include situations where a family has an adapted car, funded under the disability living allowance, and provided to the family solely because the family has a child with a disability which makes such a vehicle a necessity.

3.6.2 Apart from the potential budgetary implications for Local Authorities of this recent guidance, ConfEd would ask the Committee to note how such practical aspects of national policy guidance can run counter to the inclusive principles set out within the Special Educational Needs and Disability Act, 2001.

3.7 *Special Schools*

3.7.1 The Green Paper, “Excellence for All Children”, 1997 indicated that there was a need to redefine the role of special schools to bring out their important contribution in working with mainstream schools to support inclusive opportunities for pupils, school staff and parents. ConfEd supports the stance taken by the Department for Education and Skills Working Group, which duly reported in March 2003,⁷ that “special schools should have an important and continuing role in supporting children and young people with the most severe and complex SEN, and working in partnership with mainstream schools to assist them to deliver the wider inclusion agenda” (page 14). Recent improvements in special school standards and links with local mainstream schools provide a strong basis for the steady development of truly inclusive local provision for children across the full range of special needs.

3.7.2 Attempts by Local Authorities to reshape the pattern of their specialist provision so as to improve the range and quality of placement opportunities locally for children and their parents, are being hampered by financial constraints. The Targeted Capital Fund remains the route for financing a significant proportion of the capital costs of refurbishing or re-building special schools in accordance with the welcome, but much more generous accommodation schedules contained in the latest DfES guidance which will supersede Building Bulletin 77. However, the Targeted Capital Fund constraints are such that increasingly only single special school improvements are feasible. What is usually needed, however, are strategic area or Authority-wide developments. These are vital if reinvigorated special schools are to be at the heart of new extended/full service school or Area Improvement Partnership arrangements alongside partner mainstream schools.

3.7.3 ConfEd believes that real opportunities are being lost in the development of the best possible learning environments for children with complex needs in modern, outward-looking special schools as a result of the current restrictions on capital approvals. This is at the very time that new DfES guidance is showing the extent to which many special school pupils are being educated in accommodation which is no longer fit for purpose.

4. CONCLUSION

4.1 It was no surprise to ConfEd that Baroness Mary Warnock should state last June that the current statutory process is “wasteful and bureaucratic” and “must be abolished”. She first expressed such severe doubts in the early 1980s when she criticised the new statutory framework arising from the report of the Committee of Inquiry in May 1978 into “The Education of Handicapped and Young People”, which she chaired. ConfEd has long supported her viewpoint. Our members would welcome, therefore, the establishment of a new committee of inquiry into all aspects of the current special needs framework in the light of the findings of the Education and Skills Committee.

4.2 In 2002 the Audit Commission published two highly regarded reports^{8,9} based upon its major research project on children with special educational needs in England and Wales. ConfEd is concerned that many of the most far-reaching proposals contained in the reports published in the Summer and Autumn of 2002 were not addressed with any conviction within the Government’s “Removing Barriers to Achievement” strategy document of 2004. We know that this is mainly due to the potential controversy that reviewing, updating and amending key aspects of the current statutory framework might bring. We believe that this is

not a valid reason for inaction by central government on these fundamental issues. The continued neglect of the fundamental tensions within the present statutory framework for SEN will continue to have a detrimental impact upon the progress made on behalf of the 20% or so of children and young people who have special educational needs and/or disabilities.

4.3 The full inclusion of special needs within the very positive national “Every Child Matters: Change for Children Programme” is essential. A multi-agency Common Assessment Process, rather than the proposed welfare driven Common Assessment Framework, is urgently required as the basis for a single “child’s plan” which each agency is required to support. Last year, the summary report of the Cabinet Office’s Special Educational Needs Bureaucracy Project 10 gave a short term task to the DfES—“to review the use of the different plans for children with the aim of consolidating and integrating into a single child plan” (page 5). ConfEd members would warmly welcome such a development. We believe that parents and schools would be equally supportive of such a positive development in joining up all provision made for individual children.

4.4 Above all, ConfEd would ask the Committee to revisit the widely supported recommendations contained within the Audit Commission reports of 2002 and, in particular, the following key recommendation set out in the initial report on “Statutory Assessment and Statements of SEN : In Need of Review” 8 of summer 2002:

“the tensions in the statutory framework are significant and are likely to become more acute as increasingly SEN resources are delegated to school level. For this reason, we urge Government to initiate a debate about possible changes to the statutory framework in the longer term, by establishing a high-level independent review. Such a review could pave the way for a fairer, more sustainable system—enabling schools to respond quickly and effectively to all children’s needs and making better use of the available resources; ensuring that all those who need it, receive advice and support from other agencies; and giving parents greater confidence that their child’s needs will be met in school” (page 66).

4.5 In summary, the position of ConfEd, representing education and children’s services staff in Local Authorities across the country, is that the exciting opportunities presented by the move towards integrated children’s services must no longer by-pass the 20% or so of all children who have special educational needs. In this context, the failure of central government in recent years to address the well-known fundamental flaws within the present statutory framework, which gives separate legislative arrangements for addressing educational, care and health needs, has been damaging and unjustifiable. It has hindered the achievement of genuinely inclusive practice which can only be achieved through effective personalised learning. It has also provided a climate of litigation and disputation as opposed to genuine partnership between Local Authorities, schools, individual children and their families.

4.6 We can assure the Committee of ConfEd’s strong support for any moves which would lead to a fundamental, rigorous and far reaching review of the key issues set out above in order to improve the life chances of thousands of children in this country. Much is at stake here for the most vulnerable children in society and it is our view that the necessary concerted central government leadership is long overdue.

4.7 During parliamentary discussions about the Bill which later became the Education Act 1981, a senior MP commented to the effect that the new legislation “was good as far as it goes but, like Brighton pier, it is no way to get to France”. Some 25 years on, and thousands of children later, it is not only Brighton pier but the whole national special needs system which is showing its age and its need for significant restoration or, indeed, replacement.

4.8 Education and children’s services professionals are highly committed to meeting the individual needs of children who require extra help in order to thrive in school and move successfully into adult life. Vulnerable children who have additional needs deserve a statutory framework which truly removes barriers to achievement and fosters partnership between schools, parents and the statutory agencies.

4.9 The initiation of another full, independent review of the present position would enable the Government to establish during the lifetime of this Parliament the best way forward. ConfEd believes that there would be overwhelming public support for any Government which has the vision and conviction to address the major challenges set out above. Members of ConfEd would be delighted to work within a truly inclusive, properly funded, less bureaucratic and more child and parent-friendly national special needs system.

REFERENCES

1. Government Green Paper “Excellence for All Children: Meeting Special Educational Needs”, 1997.
2. “Special Educational Needs: Report of the Committee of Inquiry Into the Education of Handicapped Children and Young People”, 1978.
3. “Inclusive Schooling: Children with Special Educational Needs”—Department for Education and Skills Statutory Guidance, 2001.
4. “National Overview of ‘Removing Barriers To Achievement: The Government’s Strategy for Special Educational Needs’—the SEN Adviser Team”, Department for Education and Skills, 2005.
5. “Removing Barriers to Achievement: The Government’s Strategy for Special Educational Needs”,

Department for Education and Skills, 2004.

6. “Special Educational Needs and Disability: Towards Inclusive Schools”, Office for Standards in Education, 2004.
7. “Report of the Special Schools Working Group”, Department for Education and Skills, 2003.
8. “Statutory Assessment and Statements of SEN: In Need of Review”, Audit Commission, 2002.
9. “Special Educational Needs: A Mainstream Issue”, Audit Commission, 2002.
10. “Special Educational Needs—Bureaucracy Project”, summary report by Cabinet Office and Department for Education and Skills, 2004.

October 2005

Memorandum submitted by Essex County Council

I am delighted that the Select Committee is now able to examine special education needs provision over the coming months and I would like to invite you and the committee to an Essex School to examine innovations in our services.

Given the amount of debate in recent months about the role of mainstream and specialist schools in supporting children with special needs, the sort of rational overview that a Select Committee can bring to this issue is immensely welcome. Indeed I believe that the mainstream/specialist debate is at least partly out of date and we really need to be examining how schools can best support the wider range of needs of children and parents.

For many children education is just one of many areas in which they need support from the state and voluntary sector. Health care issues such as speech therapy or physiotherapy can be as significant for particular periods of a child’s development and it is important that we make these as readily available as possible if we are to support families effectively.

In Essex we have been establishing new model special schools which bring together services around the child and parents, rather than obliging them to travel to a variety of places for different services. The schools have been praised in several quarters and, I feel, illustrate one of the ways in which SEN provision is likely to develop in the future.

I would be delighted to arrange a visit for the Committee to one of our schools if you think it would help you in collecting the information you need about the issue.

January 2006

Memorandum submitted by Peter Gordon, Headteacher, Hazel Court School

My most sincere apologies for contacting you now, when the Committee is well into its enquiry. It has been strongly suggested that I should contact the Committee, given my SEN experience and recent NCSL research work, and I do apologise for not having done so before.

I am the headteacher of this East Sussex County Council SLD special school for pupils/students aged 11–19. Hazel Court School has the first purpose built co-located (SLD/mainstream) premises in the country, with eight years of very positive experience.

We then designed the first purpose built co-located FE (16–19) premises in the country, and have six years of very positive experience.

We are often asked to talk about co-location to LAs and schools across the country, and welcome visits (including from abroad).

We firmly believe that for pupils & students with severe and profound learning difficulties, co-location is the way forward. It provides “the best of both worlds”, with all of the specialist teaching and provision that the pupils/students need, and then superb inclusive opportunities “on tap”.

The arguments for SLD/mainstream co-location, and the different ways in which co-location can be organised (ie; the “two schools under one roof”, or the “mixed” models), are included in my NCSL research report, a pre-publication copy of which is enclosed.⁶⁵

One final comment which I should make! I have been teaching in SLD schools for some 27 years, and a headteacher for 12 years. However, I also have a 21 year old son with profound learning difficulties, so I very much have a parental as well as a professional perspective.

February 2006

Memorandum submitted by Blackpool Council

High levels of transience and lack of socioeconomic prosperity in Blackpool

The current guidance on SEN does not take social deprivation or family background into consideration. Whilst it is accepted that some of the approaches to addressing underachievement as opposed to low attainment may differ, where transience and an impoverished home background are features of the profiles of significant numbers of pupils in a school, the impact of this upon the children and the school are at least as great. Children who are continually moving, living in households with multiple occupancy, suffering abuse, have one or both parents who misuse substances (as a significant number of our children do) are highly likely to have a “greater difficulty in learning than the majority of children of the same age” and are, likely to need their schools to make a number of additional arrangements to ensure they make progress. However, social deprivation and family factors are not categories for PLASC SEN data collection, nor do they feature as areas of need in the SEN Code of Practice and schools are therefore not able to have their work recognised in this way, nor justify any expenditure of their SEN funding on meeting such needs. We have already moved a significant distance away from locating learning difficulties within the child by looking at what barriers to learning there may be in the school environment. Surely we need to take a truly holistic approach and allow these other more social factors to be considered?

The term “SEN” has probably outlived its usefulness. We should be trying to demystify the terminology we use and the approaches we suggest. What used to be deemed “special” is increasingly argued to be what should be the norm. In this sense, the term actually works against inclusion. Perhaps it is time to find another term such as “additional needs” and to reorganise our thinking to address the full range of children and young people who need additional and/or different arrangements/systems etc to be put in place for them. Some of our schools have already appointed Inclusion Managers or Co-ordinators and have set up Inclusion Registers, or ECM Registers.

Cost of certain models of provision

We are some way along the journey towards having a continuum of centrally funded provision in Blackpool, with special schools, a PRU that has 8 centres, Special Educational Resource Facilities (SERFs) and some central support services. The 11 SERFs include two that formalise the links between a mainstream and a special school. The work of both these SERFs has been recognised as very good practice by Ofsted. Although the benefits to both staff and pupils have been enormous, in the majority of cases the arrangements have not led to children from the special schools transferring to the role of the mainstream school, as was originally envisaged. Therefore, extra capacity in the special schools has not been created to any great extent. Because the schools have developed such good collaborative working arrangements, and have been so creative in the way they have pursued this agenda, larger numbers of children and staff have benefitted than was originally envisaged, but this has taken up a lot of staff planning and travelling time. These arrangements work both ways and constitute the sort of model being proposed within the new role for special schools agenda. However, the financial cost of such arrangements are high. The funding formula uses the appropriate special school bandings, with some additional money in recognition of the lack of economies of scale. In addition to this, transport costs are soaring. Whether the cost of transport between sites to allow access to the most appropriate parts of the curriculum is met by the school or the authority, it is huge and will continue to grow as the two-way exchanges increase, particularly at K54.

⁶⁵ Not printed.

Recognising inclusive schools

Three years ago Blackpool developed a process by which local schools and settings could share and celebrate their inclusive practice. This was an effort to recognise that many of our schools and settings work very hard to improve outcomes for pupils whose achievements are not always made obvious through the publication of examination and national test results. We wanted to identify and encourage innovative practice in removing barriers to learning and participation and to this end the Blackpool Schools Inclusion award was developed. Schools used a template to describe aspects of their practice that had led to improved attendance rates or engaged a child from a particularly vulnerable group in an activity they had previously been excluded from or demonstrated how they had adapted the curriculum to meet a particular child's needs. Two schools received the award in the first year. Last year and the year before, the Blackpool model was taken by the NW and Greater Merseyside SEN Regional Partnerships and used as the basis for regional recognition of how far schools and settings have travelled on the journey towards more inclusive practice. This year inclusive practice from participating schools from across the 22 LEAs in the two regions was celebrated in a publication with the work of seven Blackpool schools highlighted. We believe that this work is vital and that some kind of inclusion kitemark for schools and settings should be developed nationally. This is not to suggest that schools should be required to submit evidence or engage in a bureaucratic process. However, we feel that although there are some efforts by Ofsted to check on inclusivity and inclusion issues are being addressed by the national strategies, there is a need to introduce a national benchmarking mechanism that will enable schools like ours, who work creatively and successfully with children living in some of the worst areas of deprivation in the country, to be able to publicise their good work alongside the outcomes of other national indicators.

Pupils who arrive in Blackpool with a statement of SEN issued by another authority

An issue for some of our schools that accept a higher than average number of non-routine admissions, is that some children arrive with statements of SEN for high incidence needs, such as MLD, SpLD or EBSD. These statements often specify the number of support hours the child must receive. Blackpool GSA delegated the money to meet these stated needs to its schools several years ago and there is therefore no centrally retained funding with which to meet these requirements. It would be very unusual for a statement to be issued to a child with SpLD, MLD or EBSD whose needs could be met in a mainstream school in Blackpool. Our schools often meet such needs through group arrangements and interventions without the need for 1:1 support. However, they find themselves required to attach specific teaching or support hours to these children, often at the expense of much needier children. This works against the notion of interpreting the SEN Code of Practice within the context of the school, since the receiving school is bound by the statutory nature of the statement to continue to treat the child as if it were still in the context of its previous school. The statement can, of course be amended through an annual review, but this takes time and does involve cost. In addition, parents are entitled to have their views taken into account and altering the provision or ceasing to maintain the statement is not straightforward.

Parental involvement

We recognise the value of working with parents as partners. However, statistics show that Blackpool has higher than average numbers of adults with mental health issues and drug or alcohol problems. Coupled with this is the fact that few adults in the town have experienced education at a higher level. Given that we know that there is a link between social indicators and performance of children in school, it is probably fair to say that at least some of our children with SEN are likely to have parents who are not the most capable of acting as informed advocates for their child. This has implications for our children.

Provision for SEN pupils in mainstream schools: availability of resources and expertise; different models of provision.

PROVISION FOR SEN PUPILS IN SPECIAL SCHOOLS*Raising standards of achievement for SEN pupils*

It is recognised that there are strong links between outcomes for children and socioeconomic prosperity. Blackpool was ranked 24th worst out of 354 districts on indices of multiple deprivation. (2004 figures). 1,306 children transferred schools in 2004–05. 4,409 children were eligible for free school meals.

*System of statements of need for SEN pupils**Role of parents in decisions about their children's education*

It is generally understood that many parents of children with SEN have special educational needs themselves. We know that in Blackpool, levels of higher education of adults living in all wards are lower than national average figures. There are therefore likely to be many children with SEN in Blackpool without strong parental advocacy.

*How special educational needs are defined**Provision for different types of SEN, including EBSD**Legislative framework for SEN provision and effects of Disability Act 2001*

February 2006

Letter to the Chairman from the Special Educational Needs and Disability Tribunal

Looking at the uncorrected transcript of Lord Adonis's recent appearance at the SEN Select Committee, it seems clear that the Committee has received some misleading information about what is involved in appealing to SEN DIST.

Last week's Times Educational Supplement repeated some of the false statements made at the Committee, and you may be interested to see the enclosed copy of the President's letter to the Editor.

I hope this is helpful. If the Tribunal can be of further assistance to the Committee, do please let me or the President know.

April 2006

Dear Sir

May I set the record straight as regards appeals to SENDIST? As Lord Adonis said in evidence before the Parliamentary Education Select Committee last week, there is no cost to a parent in registering an appeal. If a parent chooses to be represented by a lawyer either throughout the appeal process or only at the hearing, there will be a cost unless he or she is eligible for legal aid. This cost will vary according to the type of lawyer used. A number of solicitors' firms now also offer representation pro bono with a nil cost.

In recent years we have seen greater use of legal representatives, but it is misleading to present it as the norm. Our last Annual Report notes that parents were represented by a lawyer at the hearing in 25% of cases and by a non-legal representative, for example from one of the special needs support groups, in a further 23% of cases. One in five had legal representation throughout the appeal process. Local Education Authorities were legally represented in 23% of cases.

I do not know the source of your quoted percentage figures for parental "success" or "failure" in an appeal, but they cannot be accurate given the high rate of parental success overall. A recent publication by the DCA Research Unit states that the success rate among represented cases brought to SENDIST was 7% higher than among non-represented cases (82%–75%) although even this difference is discounted in regression analysis.

The Tribunal aims to be clear and helpful in its advice to parents, giving guidance at all stages. Tribunal panels are considerate and patient when an unrepresented parent comes to a hearing and will take time to ensure that the procedure is fully understood. Many panel members tell me that they prefer to have unrepresented parents before them so that communication is direct and to the point. Unless there are complex areas of law to be explored, factual and relevant evidence is better than unnecessary legalese and most parents are well able to argue their cases effectively.

Yours faithfully

Rosemary, Lady Hughes

President, Special Educational Needs and Disability Tribunal

Memorandum submitted by the Special Educational Needs and Disability Tribunal

INTRODUCTION

The Committee has invited the Tribunal to provide a memorandum on matters arising in its recent discussions with Lord Adonis, in particular the costs that parents may incur in using the Tribunal.

TRIBUNAL AIMS

SENDIST aims to provide an accessible, supportive and helpful service to parents of children with special educational needs.

The tribunal regulations state explicitly that we should seek, as far as it seems appropriate, to avoid formality in our proceedings. Inevitably a legal process involves some complexity, but we aim to guide parents through each stage of the process. The Secretariat provides full and clear written guidance, and deals with many telephone enquiries where parents need clarification.

The service receives positive feedback from parents. In a recent survey 91% of parents responding rated our literature as good or very good. Satisfaction with the telephone service (88%) and support at hearings (97%) was also high.

ACCESSIBILITY

There are no direct costs in appealing to the Tribunal. The service is free and we reimburse parents and their witnesses for travel expenses. Witnesses can also receive a standard allowance towards loss of earnings.

We recognise that many parents will need help making and pursuing an appeal to SENDIST. A number of voluntary organisations provide advice which may range from informal advice on the telephone to representation at hearings. Some law firms also provide support pro bono. Details of some organisations that can help parents appear in our appeal booklet.

The Tribunal provides information in a range of accessible formats. We can provide Braille, tape and large print versions of information, and send all parents a video designed to give them an idea of what a tribunal hearing will be like. The video seeks to dispel any notion that parents are coming to a court, and reassure them that the panel will guide them through the process.

WHO APPEALS TO SENDIST?

There are no data on the socio-economic backgrounds of parents appealing to SENDIST. In our annual report we include, for the last two years, a breakdown of appeals by LEA.

We have not undertaken any analysis to look at any correlation between the socio-economic make-up of LEA populations and the level of appeals. Appeal levels tend to be highest in the Home Counties. However, if one looks at LEAs with relatively high and relatively low levels of appeals, one cannot see any clear link to economic circumstances.

<i>LEAs attracting most appeals, 2004–05</i>		<i>LEAs attracting fewest appeals, 2004–05</i>	
<i>LEA</i>	<i>Appeals per 10,000 of school population</i>	<i>LEA</i>	<i>Appeals per 10,000 of school population</i>
Lewisham	21.76	Blackburn/Darwen	0.79
Lambeth	20.38	Doncaster	0.79
Hackney	15.61	Newcastle	0.79
Richmond	14.37	Nottingham	0.74
Croydon	12.55	Coventry	0.40
Southwark	12.46	Warrington	0.31
Wandsworth	11.78	City of London	0.00
Bromley	11.27	Hartlepool	0.00
Kingston	11.14	Havering	0.00
City of Bristol	10.72	Isles of Scilly	0.00
		Redcar/Cleveland	0.00
		Rutland	0.00

The Tribunal can only report the number of appeals against LEAs. Parents' own educational backgrounds and their confidence with administrative systems may affect their ability to access the tribunal. However, LEAs are bound legally to inform parents whenever the right to appeal arises with details of how

to make such an appeal. A variety of other factors may help to explain the very different levels of appeals across LEAs. These may include the nature and perceived effectiveness of local provision, local policies, the relationships between authorities and schools, the capacity and capability of special educational needs departments, the transparency of funding arrangements, and the quality of relationships between local authority officers, parents and other local stakeholders.

REPRESENTATION

The Tribunal asks all parties to provide details of any representatives and witnesses and we collate data for the annual report. According to our records 20% of parents whose appeals we heard in 2004–05 had the help of a legal representative throughout the process. At hearings, 25% had a legal representative and a further 23% had a non-legal representative, usually a person working for a voluntary organisation supporting parents.

We have no data on the costs parents incurred engaging either legal or non-legal representatives, nor do we have any analysis correlating the use of representatives with the distribution of parental appeals across LEAs or across appeal types. Recent research published by the DCA Research Unit (Tribunals for Diverse Users, January 2006) found that among parents they interviewed legal representation was most common where the appeal concerned the contents of a statement. It might be reasonable to assume that the more at stake in the appeal, the more likely parents will be to engage a lawyer.

The quality and usefulness of legal representation varies. Where the appeal turns on difficult legal argument it may particularly assist parents. A representative may also help negotiate concessions from local authorities and isolate points of dispute before a hearing. Some parents need help articulating their case and identifying appropriate questions to ask. However, sometimes the involvement of legal representatives can make hearings more adversarial than necessary, and may tend to delay or prolong proceedings.

SENDIST panels will vary their approach to hearings depending on who is taking part. If parents are unrepresented and unfamiliar with the relevant law, good panels can compensate with patient questioning, clear summaries and frequent checks that points have been fully covered and understood. The necessary skills feature heavily in our training of chairs and members.

When questioning Lord Adonis a member of the Committee cited figures on the success rates of represented and unrepresented parents. Like the Minister, we do not recognise those data. However, the figures quoted can only have been based on a small and unrepresentative sample of cases.

The Tribunal has no data on how representation may affect success rates. However, the Research to which we refer above conducted thorough statistical analysis on over 1,100 cases and concluded (page 278) that “whether or not an applicant was represented had no impact upon outcome”. Although represented parents were more likely to be successful, the differences were not found to be statistically significant.

REPORTS

Apart from engaging representatives the other significant costs which parents may incur arise from commissioning expert reports to counter the assessments of professionals advising the LEA. We do not collect data on how many parents commission such work or the level of costs they incur although a single report is likely to cost several hundred pounds. Even if it is not a necessary part of the tribunal process for parents to commission such reports, we would have to recognise that there are cases where an alternative professional opinion will be necessary to sway the Tribunal against the advice of the relevant LEA professional, especially if there significant amounts of public money at stake.

It is for others to consider whether or not parents should receive any assistance if they decide to commission professional reports. It is not easy to see how the Tribunal itself might help.

OUTCOME STATISTICS

Our annual report records the outcome of special educational needs resolved in 2004–05. Nearly two thirds of all appeals were either conceded by LEAs or withdrawn by parents, and we know that the great majority of withdrawals arise because parents are satisfied with LEAs’ response to their appeals. A majority of the remaining 35% of appeals resolved by tribunals were at least partly upheld.

In 2004–05 the Tribunal upheld 58% of appeals against LEA refusals to carry out statutory assessments. In cases involving the contents of statements 87% of appeals were upheld at least in part—that is, the resulting statements included some if not all of the provision parents were seeking. Given that only a quarter of parents bring a lawyer to hearings, the high proportion of appeals upheld or settled in advance would seem to contradict any impression the Committee may have gained that parents have little chance of success without representation,

CONCLUSION

It is important to dispel myths and encourage people to use SENDIST. As a legal process it will inevitably involve some complexity, but efforts continue to make the service genuinely accessible and provide support unrepresented parents. We hope that this memorandum is helpful to the Committee.

May 2006

Memorandum submitted by BBC Radio 4: You and Yours

You and Yours is BBC Radio 4's flagship consumer and social affairs programme broadcast between 12 noon and 1pm every week day lunchtime.

The programme has 3.181 million listeners per week. Their average age is 59. 56.1% of *You and Yours* listeners are female. 43.9% are male.

The social grading of listeners breaks down as follows:

- A and B: 36%.
- C1: 36%.
- C2: 14.2%.
- D and E: 13.6%.

INTRODUCTION

Between 8 and 22 February, working in conjunction with The Education and Skills Select Committee members, we gave our listeners the unique opportunity to contribute directly to the committee's inquiry into special educational needs.

Our phone in programme "Call You & Yours" which invited listeners to air their views on special needs education was broadcast between 12.00–13.00 on Tuesday 14 February 2006 on BBC Radio 4. We specifically asked our listeners to respond to the following question:

"Do we need to rethink the way in which we educate children with disabilities and other special needs?"

RESPONSE

The response was overwhelming; within two weeks we received 701 emails, calls and letters. For this report we have used sample of 350 of the calls and emails. They break down into six broad categories:

- 36% (127 listeners) has serious concerns about inclusion as a policy. Some were worried that it was not fully supported or was just unworkable in principle. Many supported special school as the most appropriate method of educating pupils with special needs.
- 13% (46 listeners) were in favour of inclusion and saw it as the best method to achieve integration of disabled people into society. There was a particularly high number of parents of younger children and children with Down's Syndrome who were in favour of inclusion. Many still felt however that inclusion need to be properly financed, supported and resourced to be effective.
- 15% (54 listeners) had serious concerns about the level of training given to teachers and professionals. Many disabled people and parents also complained that they felt excluded from the process.
- 13% (45 listeners) thought that funding was the most pressing concern.
- 10% (33 listeners) saw the merits of both mainstream and special schools and advocated a flexible system which offered the benefits of both.
- 9% (30 listeners) felt they had to fight the system to achieve a decent standard of education for their children and were concerned that many parents wouldn't have the time or ability to do this.
- 4% (15 listeners) other.

1. *Examples of those concerned about inclusion*

The most common worry was that if LEAs followed a policy of inclusion many children would be denied the opportunity of special schools. Many listeners felt that a special school was the only setting which could adequately provide appropriate teaching backed by a level of understanding and expertise from the teachers. They also felt that they should have the option of choosing between mainstream and special schools.

Parent of a 16 year old boy with Aspergers

He struggled in mainstream secondary school and experienced considerable bullying for his disabilities—as well as a lack of understanding of his problems by constantly changing staff. He learned to conceal his difficulties . . . he has dropped out of school, is very unhappy, has a drugs problem and is in trouble with the police. Mainstream education is less appropriate for those with emotional and behavioural difficulties.

Parent of son with severe learning disabilities

Inclusion has an emotional appeal, but it has to be realised that more severely handicapped children require care and provision that can never be provided in normal school environments.

A girl who's elder brother went to a special school

It was the best place for him, where he could fulfil his potential with specialised staff, instead of always being the kid who could not keep up with the rest of the class. My parents made a point of ensuring he mixed with kids without the same difficulties by sending him to youth groups with me, swimming and gym lessons, church group, scouts etc. They had to spend time with the leaders to explain his difficulties but most were very sympathetic and very supportive.

Blind university student

In my case specialist education was essential so that my A levels and GCSEs could be resourced as in normal mainstream education resources are frequently not available. Going to RNIB New College in Worcester taught me the life skills I needed to survive . . . if I hadn't been through specialist education I would be unable to survive at university.

SENCO of a state primary school

It is common for all types of problems to be included in whatever school is local to the child. This means that there is no level of expertise in dealing with particular condition and as the special schools close the expertise is lost.

A lady who has worked in resource bases for children with hearing impairments for 25 years

It is all too easy for mainstream schools to pay lip service to the needs of children, taking the money but not providing adequately for their needs. The tension (is) between the needs of the children and the need to hit targets & consider the schools place in the League Tables.

Academic researcher and Deputy Director, Torrens Park South Australia

I have spoken to the first and current generations of “mainstream” students. A small number have felt they have done as well in the mainstream as they would elsewhere. Most (93% of N = 486)) feel that they did not receive the support or assistance they required and that the socialisation potential was limited. They are also afraid to make these comments publicly for fear of being labelled “ungrateful” for what they have been consistently told is such a wonderful opportunity.

Anonymous

(Children with special needs) may not be statemented but will still suffer as they try to fit in to a system which demands too much of them and punishes behaviour they cannot help. Why can't the education department give the parents a voucher equivalent to the cost of educating their child which could be used to pay towards the school of their choice. Often a small private school with smaller classes is better, but many parents cannot afford this, to the detriment of their children.

2. Examples of those who support inclusion

Many of those who supported inclusion also stressed that it could only work if it is properly funded and that education professionals had been properly trained. There was a higher proportion of parents of younger children and children with Down's syndrome who reported positive experiences of mainstream education.

University student

As I cannot speak or control my movement, I was not allowed into an ordinary school class until I was 14. I had had almost no formal education before that at either special school or in a “special needs” unit of a mainstream school. Inclusion is...essential for disabled young people like me. Most people I meet in the world are scared of me, as they have never met somebody like me before.

Mother of disabled son who attends fully inclusive pre-school

He is thriving from playing and learning alongside his non-disabled mates. I believe that all children learn tolerance and respect from each other through encountering difference.

Mother of 17 year old severely disabled son

Schools will only learn to educate children with special needs by having them in school. Resources and training must also follow children into mainstream schools. This is no more expensive than maintaining high cost special schools. Schools need commitment and confidence more than they need finance.

Mother of 11 year old daughter on the autistic spectrum, now “thriving” in a mainstream school

It took a lot of effort on my part and on the school’s to get her a Statement of Educational Needs which provided her with the level of support which she required. Without this level of support I am convinced that she would never have made the wonderful progress that she has achieved.

Mother

Unless my daughter, who has Down syndrome, grows up with her peers in a mainstream school she will be excluded from society for the rest of her life.

Lady with Down’s Syndrome

I am Kitty Gilbert. I am 23 years old and I have Down’s Syndrome. I went to my local secondary school along with my sisters. I got eight GCSEs and made lots of friends. I am glad I wasn’t sent to a special school.

Teacher and parent of child with special needs

I fully support inclusion as a choice. However there needs to be more equality of opportunity across the country. I live in Northumberland and my child has been refused a statement of special needs on the grounds of his academic ability. He is on the autistic spectrum and is visually impaired.

3. Examples of those concerned about training and professional support

Teacher in South West

I have not encountered any classroom teachers or L.S.As who have received what they consider to be adequate training to deal with any of the children they are in charge of. In fact the vast majority of teachers and L.S.As have received no training at all. My training, as with most teachers, did not prepare me to teach children with special needs and I have received no training at all from either schools or local authorities. The only training that I have received has been on the job and through my own reading.

SENCO

There are still too many occasions where it is obvious that the idea of “joined up” services linking health, social services and education is not happening. This means that there is always the risk of children “falling through the net”.

GP

I am a GP. In my area there is a three year wait for a child with a problem like possible autism to be assessed and get a diagnosis. Till then they do not get a proper statement of educational needs. Vital missed years for a young child. Will the health resources be considered in this review?

Teacher

I am a secondary English teacher, and in my opinion, inclusion has been a disaster.

I have had no training in how best to serve those pupils with SEN, and as a result they are failed. But (more importantly) those pupils without SEN are failed because of all the disruption.

Teacher

When I trained as a teacher in the late 1960s special needs teaching was a specialisation requiring a year's extra training. Before I retired in 2004 we were expected to be effective with pupils with a range of needs but without the requisite training.

Lynne Gilbert parent of son with Aspergers Syndrome

There is little or no training available in some areas of the country for teachers or teaching assistants to understand what special needs are, let alone learn how to deal with them. Special needs policies are present in every school, but there are no unannounced spot checks by an outside agency to ensure that each individual class teacher is actually implementing them.

Anonymous mother who questions whether it is appropriate to teach the National curriculum to her two children with special needs

They are unable to hold a conversation . . . while it is laudable to try to teach them to read and write it might be better to get them to a level where they are actually able to communicate with peers, teachers, etc, before introducing all the Nat Curriculum stuff.

4. Examples of those concerned about funding

Many listeners were concerned about the lack of funding available to schools and also the cost of going through the tribunal process.

Mother of two children with SEN but who do not have statements

. . . because they are not statemented the school receives little if any extra funding for them . . . little of their SEN programme will be implemented, not because of a lack of willingness on the school's behalf, but because they do not have the staff to implement them.

Mother of child with special needs who thinks the statement system needs to be reformed

Many parents end up at tribunal costing them and the tax payer large amounts of money. At present the system for assessing their educational needs is too vague, which highlights the LEA's lack of knowledge of ASD needs, and their needs for cutting costs ie their costs for educating children out of borough. This is a false economy, because the less you spend on them now the more they will need as an adult. These children are all potential tax payers with the right education. With the wrong education their will be benefit receivers.

Teacher of a Foundation course for students who have not done well in their GCSE's at a college in Norfolk

Many of these children have complex special needs but there seems to be no funding to provide extra learning support to help them once they are 16.

SENCO in secondary school

Unless parents go through long and expensive Tribunal process the LEA will usually always go for the cheapest option.

5. Examples of parents fighting the system

The vast majority of listeners within this section reported specific problems of obtaining a statement for their child.

Parent who spent two years wading through the process of statementing

I taught him at home for the two years—because otherwise he would have missed two yrs completely. I am sure he would not have got his place at his current school if I had not been as assertive, well-educated, and motivated as I am.

Anonymous

Each child has individual needs and we as parents fight constantly to have each child seen as an individual. There is a tendency to try to make all children fit into the same box. A statement is a useful weapon to fight for better provision but it is hard to obtain and I am sure that many children do not receive one as their parents are less well equipped to fight for one. This inequality remains financially beneficial to the education authorities.

Mother whose son has social communication problems

The statementing process is too long with no real interim support for the child and parents. There needs to be more qualified people actually helping the children and parents cope. You feel that you are totally isolated with an out of control child to cope with at home nearly all day.

6. Examples of listeners who advocate a range of options from inclusion to special schools

Special needs teacher who advocates the “Golden Curriculum” used in her mainstream school in Luton

Although they are taught in small teaching groups for most subjects, they are in mainstream form groups and they join mainstream PE and DT lessons. In KS4 most pupils take five GCSEs and take part in work experience. The Golden Curriculum is not a rigid programme, if a child shows progress and that they are ready to go into mainstream education then we can reintegrate them.

Father of a son with Down’s syndrome

I think there is a case for special needs units attached to certain schools which would specialise and have the resources. This might also lead to a concentration eg of children with Downs Syndrome in a particular school giving more of a chance to have peers they could form friendships with.

Anonymous teacher and mother of a child with an Autistic spectrum disorder who began his education in a special school and successfully transferred to mainstream with support

We need a variety of quality special and mainstream provision and a flexible system where children, classroom assistants and teachers can move between provisions. This seems a lot easier to move towards in a small unitary local authority than in other situations.

Anonymous

There will always be a need for Special Schools to look after the severely handicapped children, but many less severe children’s needs can be taken care of by setting up a Unit as part of the mainstream school. This integrated Unit can serve children who need help in part of the curriculum but can benefit from sharing resources and staffing with the mainstream school for other parts of the curriculum.

Student who has dyslexia says he was able to progress well in mainstream primary school with weekly visits to a dyslexia institute

When I got to Comprehensive school, there were no systems to help me learn and no-one who knew how to help. Because of this I had to move to an independent school, which specialised in dyslexic children . . . there has to be more choice when it comes to special schools.”

You and Yours feedback

This programme prompted one of the largest responses we have had on “Call You and Yours”. The vast majority of listeners who contacted us had direct personal experience of the issues and were clearly extremely keen to be involved with the radio programme because of the potential to help shape the Select Committee’s final report.

May 2006

Memorandum submitted by Parent for Inclusion**POINTS ARISING FROM THE “YOU AND YOURS” PROGRAMME—BBC RADIO 4
14 FEBRUARY 2006**

Jo Cameron: Director of Parents for Inclusion (and SEN Governor of Kings Avenue Primary School, Lambeth.)

Parents for Inclusion (Pi) is a national voluntary organisation of 20 years standing. It runs a national helpline and many local projects aimed at supporting parents and schools to work collaboratively towards the development of inclusive policy and practice. Pi informs all its work by continuous debate within the disability movement and the views of young people.

I accompanied Micheline Mason to the “You and Yours” debate in relation to the select committee. It was useful and informative, but here are some comments.

We need to understand what lies behind Baroness Warnock’s assertion that the SEN System has become bureaucratic, and stifles achievement.

- It is true that attitudes towards the rights of young disabled children and children with the label SEN have barely begun to shift, but any really radical change in law and practice takes decades to evolve and it is this that drives attitudinal change. Those of us who work closely in supporting schools to be inclusive know that the barriers to developing inclusion successfully remain immense. There are philosophical, social and attitudinal barriers which are the legacy of this country’s long history of segregation. Ofsted has reported that it is teacher’s attitudes, which block good inclusive practice. When Micheline Mason was discussing these barriers Peter White said he wanted to discuss quality of education, not philosophy. These are NOT mutually exclusive, rather inextricably linked. It is critical that any discussion of quality of education is grounded within a wider philosophical framework. This should value and respects each individual child, take account of their individual needs and support their right to self-determination.
- It is for this reason that disabled people need to be involved in the debate about how the education system can serve them to take up their rightful place as fully valued citizens. It is they who know how a system that supports segregation, undermines their own education and that of others. No-one knows this better than disabled people themselves. It is they who are campaigning for an inclusive educational system alongside those parents who believe in equality for their children.
- The programme was not on long enough for the full spectrum of views to be heard. I have no idea how many parents sent emails. We feel it is most important for the select committee to seek out schools who work together with parents, and which have inclusion policies with adequate training, inset days, and knowledge of disability equality alongside race equality. These schools will talk with pride in their school’s achievements, knowing that value, respect and equality has remarkable benefits for all children. It is well documented that disabled children intrinsically support young people with emotional and behavioural difficulties. There was not time on the programme for head teachers to share their pride in this achievement, and to discuss the positive aspects of inclusion. An excellent example of such a school is Cleaves School in the London Borough of Newham.
- In the London Borough of Lambeth, at the close of ILEA in 1989, there were 14 special schools bussing children across London. There are now four special schools, and three new build accessible primary schools. They have become centres of excellence. For instance one mainstream school is a centre for excellence for partially deaf and deaf children, and all children attending the school are learning to sign which is a real tool for inclusion. There is a diversity of SEN in all of these schools. The teaching team says that inclusion and the principles behind inclusion support all children. All around the country there are excellent pre-school provision, nurseries, and schools, who are doing excellent work in relation to the inclusion of disabled children. These need to be showcased and become beacons of excellence for all schools.
- The progressive green paper which was overseen by David Blunkett in 1997, went a considerable way towards developing inclusion further, but did not resolve the resource issue. Baroness Warnock is quite right to say that the system is bureaucratic, but it has been since the 1981 Education Act, and many LEAs still take an inordinate length of time to decide what funding they will provide -often woefully inadequate- to support the child’s needs. LEA’s must take some responsibility for this, and a new and simplified method evolved. Is it any wonder that teachers get frustrated and disempowered? All this leads to parents trying to find an individual external solution rather than working collectively towards good inclusive practice. It will be very important not to use parent’s often justified discontent in the slow progress of implementing inclusive practice successfully, as an excuse to curtail the progress towards further inclusive schools. We also recognise that much improvement is needed, but we would put that into the context that it is the schools which need to change, not the groups of children who have been excluded. Italy has a very impressive inclusive system, where disabled children are welcomed from birth. Their method was to close all special schools down overnight!

- Barry Sheerman stated that this is a passionate debate, with two sides of parents wanting different systems. The important question to be asked is this: if schools were properly resourced schools—if schools changed to accommodate all children—if attitudes to disabled children were based on equality as opposed to pity, rejection and containment—if resources were placed at the school base—if disability rights were as strong as race equality rights, would parents be opting for segregated schooling?
- Perhaps more importantly than any of this parental debate, young people have said that they want to be in their mainstream schools and their communities.
- It is Pi's experience through our inclusion helpline, training and work in schools that no parent wants their child or children segregated. They want them to be properly supported, and well educated. Ultimately they want what all parents want for their children—a life. A life begins at school, where the community comes together and friendships begin. It is from that platform of security that educational achievement is attained. As Micheline said, disabled children have been losing out for centuries. A caller stated that there is nothing special about special schools. It is important to recognise that educational achievement is also stifled in special schools.
- We have had 26 years of steady progress towards inclusion, what is needed is more of real inclusive practice, not a return to the mistakes of the past. Why not look at the whole of the education system as failing many young people, and start from there, not just disabled young people and children with special educational needs? We should be talking about all schools as centres of excellence including all children. Barry Sheerman was right to state that SEN must not remain on the sidelines and that it must be part of the whole. That is the essence of inclusive practice: that all young people whatever their race, background, ability or impairment be valued. Inclusion is an equalities issue, just like race, gender, sexuality and religion.
- Pi runs grassroots projects with parents and schools and has built up a wealth of experience and expertise that can help the committee to recognise how many parents want to and do work with the educational system to improve inclusive practice. Those parents opting for inclusion do so because of the outcomes for their children, which go way beyond academic achievement. They often also know of the perils of exclusion and segregation, because they have listened to and learnt from disabled people. We know how damaging it is for the perception to continue that parents are divided into two camps, one for and one against inclusion. All parents want inclusion. They all long for their child to be welcomed, understood, educated and valued. It is true many don't believe inclusion is possible and too many people in and out of the system don't believe it either. The fact remains that in this country alone, there is an example of a child with every sort of impairment and difficulty successfully included somewhere. The shame is that this remains so hidden and that there is such a high level of tolerance of bad practice by law makers, policy deliverers, educational professionals and parents. Too much time has been devoted to debating the ifs and whys of inclusion instead of listening to young disabled people, disabled adults and committed teachers about the how's. Pi's experience is of parents and schools successfully working together for change and improvement, with people learning the art of the possible. That is why we have such a valuable contribution to make to the Select Committee's understanding of the issues.
- We hope that Barry Sheerman will not be influenced by the Conservative interim report particularly in relation to categories. This would be a retrograde step and completely against what disabled people themselves are asking for. Categories define the young person by their impairment. Disabled people want people to see them as people first and recognise that it is social and physical barriers, which prevent their educational attainment, social inclusion and community involvement.

Our experience as parent allies in this field makes us believe we should be called to give evidence to the select committee.

September 2005

Memorandum submitted by David Ruebain and John Wright

Warnock: A Response

Last year, Baroness Mary Warnock published a monograph entitled "Special Educational Needs: A New Look" as part of the Impact series of policy discussions, published by the Philosophy of Education Society of Great Britain. Subsequently, Baroness Warnock has spoken publicly, including in evidence given before the House of Commons Education and Skills Select Committee in their current enquiry on SEN, on 31 October 2005, at which she reiterated and expanded on a number of the points raised in her monograph.

Baroness Warnock is legendary in SEN circles, having chaired the commission of enquiry whose report informed the Education Act 1981; the forerunner of the current statutory framework governing educational provision for disabled children and others with learning difficulties. To that extent, Baroness Warnock's reputation and long involvement make her views important and her paper and subsequent comments

received widespread coverage. Indeed, arguably, her views, in part, lead both to the Education and Skills Select Committee determining to establish an enquiry into SEN and also the Conservative Party to set up their own enquiry.

Much has been said about Baroness Warnock's paper and, in many respects, time has moved on. However, in light of its impact and ongoing debates and, some might say, confusion, over inclusion and the merits of the current SEN framework, we wish to present our response.

First, we should state that we mean no disrespect to Baroness Warnock whatsoever. However, we are astonished that her paper is, at least, premised on a number of fundamental factual errors and, in our view, is ill argued. By way of example (page numbers refer to her monograph):

- Baroness Warnock states that “the criteria for entitlement to a statement are far from clear” (pages 7-8). This is not true. A child is entitled to a statement if he/she has a learning difficulty which calls for provision which is additional too or different from that available in local mainstream schools for children of that age in his/her area (Sections 312 and 321 of the Education Act 1996). Whilst this does not mean that one can straightforwardly list disabilities or learning difficulties for which statements should be provided, to the exclusion of others, it does not represent a lack of clarity.
- Baroness Warnock argues that, for some children, statements have been “detrimental” (page 8). However, she gives no evidence to support this challenging view, least of all explain against what standard the detriment is being measured.
- Baroness Warnock states that around 20% of children receive statements (page 12). This is roughly 10 times the actual number.
- She goes on to state that “since 2002, heads and governors have been liable to a criminal charge if they exclude a disruptive child from a mainstream school against the wishes of the parent” (pages 12-13)—a point repeated in her evidence before the House of Commons Select Committee. This astonishing assertion is not only alarming but completely untrue.
- Baroness Warnock appears to misunderstand comprehensively the meaning of inclusion when she states that “the desire to “include” children in single institutions is a desire to treat them as the same.” (Page 13.) As we will seek to explain, if anything, this is what many disabled people call “integration” (and which, in another context, may be called “assimilation”) and is in fact why disabled people have called for inclusion rather than integration.
- Then, Baroness Warnock seeks to argue that there are some “needs” which can be more effectively met in separate institutions, and, by way of example, refers to such children as including those who are in care (page 13); again, an assertion repeated in her evidence before the House of Commons Select Committee. Again, this somewhat astonishing assertion is not backed up by any evidence or argument at all. (Later she argues for the need for small schools for children in care which is, we contend, a materially different point from her argument against inclusion.)
- Then, she asserts that disabled children are “not as vulnerable to bullying [in special schools] as they inevitably are in mainstream schools” (page 13) without any evidence to back this up and in contrast to the numerous reports and evidence of disabled children and young people themselves, who have illustrated that bullying can take place in special schools as much as mainstream schools. Moreover, the assumption underlying her point is that a victim of bullying should be removed rather than the bullying addressed. We wonder whether she would take the same view in respect of bullying or harassment based on any other ground, such as racism, sexism or homophobia.
- Baroness Warnock refers to the “The Disability Discrimination Act 2001”, presumably referring to the Special Educational Needs and Disability Act 2001. She then goes on to refer to the Special Educational Needs and Disability Act “2002” (at page 33). Whilst this is, of course, a small point, her paper is shot through with such errors and lack of precision.
- Baroness Warnock asserts that Tribunals were established in 1992. They were established by Part 3 of the Education Act 1993, to come to force from September 1994. She then goes on to say that this lead to “a painful and extremely long drawn out process” without any regard to the appellate procedures which prevailed before Tribunals which, frequently, went on for years. She also states, completely incorrectly, that Tribunals are chaired by local authority officials (page 29).
- Baroness Warnock talks about the tendency of a statementing procedure to “antagonise parents” (page 31). We would argue that this rather misses a point. Statements, when operated effectively, can determine essential provision but antagonism, certainly as often as not, arises because of improper practices or unlawful behaviour.
- Baroness Warnock talks about the inequity of disabled children who do not have statements being “excluded from school with no clear duty to find them suitable alternative provision”. We have no idea upon what basis she asserts this.
- We are afraid that in some cases, Baroness Warnock is frankly patronising. By way of example, she states this: “Adolescents form and need strong friendships, from which a Downs Syndrome girl, for example, who may have been an amiable enough companion when she was younger, will now be excluded; her contemporaries having grown out of her reach.” (Page 33.)

- Baroness Warnock asserts that the current system “is wasteful and bureaucratic and causes bad blood between parents and local authorities and schools” (page 49) as if lack of statements or a lack of inclusion would be widely accepted by all!
- She states that “an emotionally disturbed child in a mainstream classroom may effectively exclude others from the process of learning” (page 8) but this is also true of a non-statemented or non-disabled child. Equally, she states that an Asperger’s child who is subject to bullying in a mainstream school classroom will feel emotionally excluded but again, this is true of a non-disabled child.
- Baroness Warnock states that “there are many children, and especially adolescents, identified as having special educational needs, who can never feel that they belong in a large mainstream school.” (Page 40.) We agree but this is equally true of young people who don’t have special educational needs. She goes on to state, and here we consider that Baroness has an important point, that “one of the main defects of the present education system is the size of schools” (page 44) but this is an entirely separate matter from Special Educational Needs and statementing and debates about inclusion.
- Baroness Warnock wrongly asserts that “every school now has to appoint someone as a special educational needs coordinator (or SENCO) whose responsibility is to ensure that all the procedures of assessment and statementing are properly followed”. Assessments and the drawing up of statements are, of course, the responsibility of the local education authority.
- Baroness Warnock makes claims about the contents of her original 1978 Report which exaggerate its influence on the current legal framework, for example, stating in her monograph: “We (the 1978 ‘Warnock’ Committee) invented the statement of special educational need. This was to be a document . . . which would list the extra support that (the child) would need in order to make progress, the provision of which would be a statutory duty laid on the local authority.” In fact, the 1978 Report does not contain the term ‘Statement’. Nor did it recommend that LEAs should have a statutory duty to provide the help a child needed. What “The Warnock Report” recommended (in paragraph 4.73) that parents should be able to use their general right to make representations to the Secretary of State if they believed their child was not getting appropriate Special Educational Provision, but this is a very different (and a much weaker) right than the right to seek Judicial Review in the High Court when your child is denied the provision specified in his or her statement. In fact the Statement, and its mandatory nature, was the creation of the drafters of the 1981 Education Act and Parliament, receiving unanimous cross party support at the time.

Most profoundly, Baroness Warnock does not critique the current system in any meaningful way. Indeed, to do so would require that we remember how we got to where we are today. In particular, prior to 1981, a disabled child had one of a prescribed list of labels given to them, which saw the child throughout their school and beyond, some of which bore some general relation to a medical or quasi medical condition (such as “physically handicapped”) whilst others were either curious (“delicate”) or downright offensive (“backward” or “mentally subnormal, severe or moderate”). Those of us who were disabled at that time were invariably placed in a school which was meant to correlate with such a “label”. In other words, we were no longer just children, we were, effectively, placed outside of the moral sphere of childhood into some defective nether region. Bullying (in the special school) was sometimes rife. Quality education was, often, non-existent.

Conversely, the introduction of the SEN regime—with its “child-centred” approach—and, indeed, inclusion, was an effort to challenge this marginalising and, to our minds, has been greatly successful. We agree with Baroness Warnock that current mainstream provision may not meet some disabled children’s needs (though they may also not meet some non-disabled children’s needs) and both of us work with families who are struggling to figure out what is right for their child, given the provision available, but mainstream today certainly meets many more needs than hitherto and, in that regard, we view inclusion as a “work in progress”. Further, no understanding of inclusion can arise without an understanding of the effects of segregation and the transforming effects of human relationships; about which much has been researched and written, none of which is referred to by Baroness Warnock. If what she is arguing for is a diverse mainstream system with large and small schools, then all power to her peerage. But to ignore the nature and history of segregation is to contribute little to ending the marginalisation of disabled people. Baroness Warnock’s paper does not advance this debate.

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