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Educational Interventions for Children With Autism: A Literature Review of Recent And Current Research

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Glossary of terms

ABA	Applied Behavioural Analysis
ABC	Autism Behaviour Checklist
ADI	Autism Diagnostic Interview
ADOS	Autism Diagnostic Observation Schedule
AIT	Auditory Integration Training
APA	American Psychiatric Association
asd	autistic spectrum disorder
ASL	American Sign Language
CA	Chronological Age
CABAS	Comprehensive Application of Behavior Analysis to Schooling
CASPA	Coding of Active Sociability by Preschoolers with Autism
CARS	Childhood Autism Rating Scale
CDC	Child Development Centre
CEO	Chief Education Officer
DLT	Daily Life Therapy
DQ	Developmental Quotient
DSM	Diagnostic and Statistical Manual
EBD	Emotional and Behavioural Difficulties
EFS	Emotional Support
EP	Educational Psychologist
ES	Independent pointing
FC	Facilitated Communication
FFS	Full Facilitator Support
GP	General Practitioner
HV	Health Visitor
ICD	International Classification of Diseases
IEP	Individual Education Plan
IFS	Information Support
IQ	Intelligence Quotient
INREAL	INter REActive Learning
LAS	Local Autistic Society
LEA	Local Education Authority
LEAP	Learning Experiences: an Alternative Programme for Preschoolers and their Parents
LGA	Local Government Association
MA	Mental Age
MANOVA	Multivariate ANalysis Of VAriance
MLD	Moderate Learning Difficulties
MMR	Measles, Mumps and Rubella
MS	Mainstream
NAS	National Autistic Society
NIH	National Institute of Health
NOS	Not Otherwise Specified
PDD	Pervasive Developmental Disorder
PECS	Picture Exchange Communication System
PEP	Principal Educational Psychologist

PEP	Psycho-Educational Profile
PEP-R	Psycho-Educational Profile - Revised
PFS	Physical Facilitator Support
PMA	Prorated Mental Age
PPVT	Peabody Picture Vocabulary Test
SEN	Special Educational Needs
SIB	Self Injurious Behaviour
SLD	Severe Learning Difficulties
SQ	Social Quotient
SW	Social worker
TEACCH	Treatment and Education of Autistic and related Communications handicapped CHildren
TTA	Teacher Training Agency
VABS	Vineland Adaptive Behaviour Scales
WPPSI	Wechsler Preschool and Primary Scale of Intelligence

Executive summary

Part 1: The research context

Background to the review

The DfEE commissioned this review in order to set out what is known and what gaps exist in our knowledge about educational interventions for children with an autistic spectrum disorder (asd). It is intended as an aid to future research in this field and, more particularly, forthcoming research which the Local Government Association is commissioning into some of these interventions. It will also be of interest to those who make provision for children with autistic spectrum disorders (asd) and autism support groups.

Objectives of the review

- to collect information from relevant professionals, researchers and support groups on the questions they have about educational interventions and the research they have planned or completed
- to provide a description of each intervention in terms of its aims, target group, costs, parental involvement and training implications
- to describe and comment on the research studies conducted to date (or planned)
- to identify gaps in the research evidence and suggest ideas and methodologies for future research

Key findings

- LEAs were most interested in the comparative effectiveness of different approaches and, in particular, Lovaas, the Higashi school at Boston and TEACCH.
- Most approaches had some evidence of their effectiveness, but this was variable in quality and no approach had yet been entirely successful in producing a methodologically sound evaluation.
- There was no well conducted study of the effectiveness of any of the approaches that controlled for intensity, so that the effectiveness of the particular approach itself was not measured.
- There were sufficient consistent positive findings, however, across all the studies of early intervention, to suggest that some form of early intervention is warranted.
- Approaches that relied on integration as part of the approach showed promising results both for the children with autistic spectrum disorders (asd) and their normally developing peers, but more rigorous control of some of the variables is needed.

Key recommendations

- Research studies should use standard measures for assessing the children and measuring progress and standard research designs for the timing and nature of the measures.

- Approaches should be independently evaluated, preferably with double blind techniques. The use of video-recording may make this possible.

- Approaches need to be compared with one another in well designed studies that allow for control (or statistical accounting) of all key competing variables, including intensity. Failing a direct comparison study, standardised design and measures would allow comparison through a meta-analysis.

- There needs to be an examination of the construction of eclectic curricula in UK schools - their rationale, process of operation, and effectiveness, compared to single approaches. This is most important in school studies but also affects the way different approaches are adopted concurrently by parents and the interactive effects that might result.

- Integration and inclusion of children with asd in UK schools need to be studied as a process and effectiveness of placement in mainstream, special and specialist schools evaluated in terms of outcomes (for children with asd and their peers), access to a relevant curriculum, school and child characteristics, timing and preparation.

- Parental choice needs to be researched in terms of the availability of information and then the degree of choice following diagnosis, factors affecting choice of school or approach, outcomes for all the family of following different approaches, and reactions to apparent success or failure of approaches in terms of parental expectations.

- Research is needed on the child characteristics that lead to success in different approaches and to parental characteristics that lead to the adoption of one kind of approach over another. Factors influencing the degree of direct parental involvement need to be researched as does the number of parents whose circumstances or choice would preclude direct teaching involvement.

- Across approaches there are areas of small scale research that can be identified, such as research on the most effective way of teaching communication and language, or concept development, or independent versus dependent styles of learning as long-term effects of different approaches.

Methodology

There were two main components:

- a **postal survey** with questionnaires sent to relevant professionals and support groups

- a **literature review** of research done or planned on educational interventions with children with an asd

The nature of autistic spectrum disorders
(Chapter 2)

As our understanding of autism increases, so definitions, diagnostic criteria and ideas on which approaches may be most useful, change. This, in turn, affects the research that is done. The two major diagnostic systems now have common criteria for a diagnosis of autism based on a triad of impairments in social interaction, communication and a lack of flexibility in thinking. Recently, the term autistic spectrum disorder has been used to include other conditions and pervasive developmental disorders which have the same triad of impairments. Accounts from able adults with an asd suggest that they have a different (and not necessarily a deficient) world view and way of being and that others should not be focused on making them behave and act as people without an asd.

It is likely that as interventions and support systems become more appropriate, the better the outcome for people with an asd will be. There are difficulties in defining success and measuring quality of life and these assessments will vary depending on whose perspective is taken. Research in the 1970's suggested that having an average or above average IQ and useful speech were two key predictors of a favourable outcome. Others, though, point to the fact that many will need lifelong support and try to identify factors which can be altered to provide supportive environments in which people with an asd can function successfully.

Educational provision and approaches for children with autistic spectrum disorders in the UK
(Chapter 3)

Within the autistic spectrum, there is a range of educational needs which requires different forms of provision and intervention. In the UK, children with an asd may attend mainstream schools, a generic special school or a school or unit specific to autism. Some of these children will require support and resources additional to those usually provided within the school, but others will not. A variety of pre-school provision also exists and outreach services are developing to support children, parents and staff.

Most practice in schools in the UK is eclectic in that a number of approaches might be used within a school in whole or in part with some or all of the children with an asd.

Results from the postal survey
(Chapter 4)

Questionnaires were sent to LEA personnel, researchers, principals of services offering particular approaches, support groups and child development centre staff. These asked respondents to comment on the research they had done or had planned on educational interventions and the research questions they had. The response rate from LEA personnel was 52%.

Twelve of the 95 LEAs which replied were funding one or more children in full or in part at the Boston Higashi school (5) or for a Lovaas programme (22). Sixteen LEAs knew of families who were financing Higashi (1), Lovaas (14) or the Option approach (4) themselves. These figures under-represent the true number of children following these programmes, as not all questionnaires were returned and not all respondents would be party to this information.

Twenty-two (32%) researchers made returns with details of the research in which they were engaged or planning. A total of 12 (57%) returns was received from Principals of particular interventions or their UK support groups and 67 (37%) questionnaires were returned by staff within child development centres. Twenty three questionnaires (32%) were completed by personnel within local autistic societies. Some of these return rates are low, but we did not expect responses from those who were not engaged in research into educational interventions.

The main questions respondents raised on educational interventions were:

- how effective are the different interventions?
- what is their relative cost?
- for which group within the autistic spectrum is an approach most appropriate?
- what are the implications for staff training?

Part 2: Review of the research on approaches

Approaches and research studies are described in a standardised way, and then the research in that area is analysed. Finally, in each section, suggestions are made for further research. The analysis of the research in each section covers the following points:

- a brief description of the approach or programme being studied
- a description of the sample with an asd that constitutes the group being studied. This description is in terms of age, diagnosis, IQ or adaptive behaviour measure, language level, criteria for exclusion from the study, any additional special needs and, finally, the number of individuals studied.
- a similar description to that of the sample is given for any control or comparison group, plus an indication for what variable they serve as a control. Where other measures are taken to compensate for a lack of a control group, these are given.
- a note of any additional treatment the sample received.
- note of the variable that was being used to measure the effect of the programme and the ways that variable was measured.
- a record of whether the evaluator was blind to the study or was part of the treatment team.
- the cultural variables that will affect the meaning of the research are noted and the relationship of the study to integration or inclusion, where this is part of the study. The nature of the particular contexts in which the study has taken place and any measures of generalisation.

- the time scale of the research and its level of intensity is noted.

- any measures taken to ensure that the programme was delivered in the way intended throughout the duration of the study, is noted, as is the way the programme was integrated into other aspects of the child's education or environment.

- the ethical issues that are raised are the relationship of the programme to the overall quality of life of the person with an asd, the costs of the programme where a cost-benefit analysis is part of the research, the extent of the family involvement in the programme, the rationale for the approach in relation to autism, and the respect given to individuals with an asd as individuals, where this is a feature.

- research results are given, including the levels of significance of any changes.

- the training implications of the approach used in each study is noted.

- any identified factors within the child that are predictive of success with a particular approach, are given.

Interactive approaches
(Chapter 5)

Interactive approaches emphasise the importance of developing a relationship and communication between the child and their parents and/or staff. Six different interactive approaches are described and six research studies presented. There is research evidence for some of the principles underlying the approaches but much of the research on the approaches themselves has been limited to small case studies. Many studies report gains made within the sessions but they often lack a control or comparison group and do not ascertain whether the skills displayed in the sessions are shown in other settings.

Approaches to communication
(Chapter 6)

There are several approaches designed specifically to encourage and develop communication skills. Other approaches within the review also address this area as a part of their programme. Three particular approaches are described and ten research studies. The two studies conducted on children attending the Delaware Centre using the Picture Exchange Communication System (PECS) have shown gains in the children's communicative abilities and that the system may aid language development, but there was no control group or independent evaluation. No systematic evaluation of augmentative communication systems in autism using samples of five or more children with an asd were found. A few of the many studies on Facilitated Communication (FC) were selected for this review. Much of this latter research centres on the authorship of what is written but some studies were presented which evaluated the possible benefits of facilitation as a technique. Almost all scientifically controlled studies showed that the facilitator was the author of the communication, although some argue that this does not necessarily negate the value of FC as an educational tool through which communication and academic ability might be fostered.

Integration approaches
(Chapter 7)

Three pre-school programmes are described where the children with an asd are included with normally developing children and taught to participate in varying ways. In these approaches, the integrated experience is the learning medium. It is not just where other skills are practised. All three studies given show gains in many areas of development and successful mainstreaming of at least half of the children, although only one study had a matched control group.

Division TEACCH
(Chapter 8)

TEACCH (Treatment and Education of Autistic and related Communications handicapped CHildren) is a structured teaching approach based on visually mediated learning and the prosthetic structuring of the environment to cue behaviour. It was developed in North Carolina but is widely used in UK schools through a training programme of short courses. TEACCH has parental involvement at its heart, but in the UK it is used more in school than in preschool settings. Eight studies were found but only one short-term study had a matched control group. Even in this study, the effects of intensity were not controlled so the evidence for specific TEACCH effectiveness is not strong. The outcomes reported are very encouraging and there appears to be a high rate of parental satisfaction, but more rigorous research is needed to eliminate possible bias in the results and to compare TEACCH with other approaches in a well-matched design.

Daily Life Therapy as practised at the Boston Higashi School
(Chapter 9)

This is a programme for children with autism that originated in Japan but which is now also practised in a school in Boston, Massachusetts which some children from the UK attend, often from an early age. It is a totally integrated 24 hour curriculum comprising a concentration on daily living skills, physical education, music and craft. The teaching approach is embedded in the Japanese culture of group performance and identification with the group. The curriculum content and mode of delivery is based on age rather than developmental level and the aim is to teach the child at a level that will allow integration into mainstream. The Boston school now has an overlay of the American system (eg individual educational plans and the use of computers) and there are plans to establish schools in the UK following Daily Life Therapy principles. There has been almost no published research on outcomes of Daily Life Therapy and no well matched controlled study. One study with a comparison (not control) group showed differential improvement in the children undergoing Daily Life Therapy in just those areas focused on in the curriculum.

Behavioural approaches
(Chapter 10)

Many approaches to autism use behavioural techniques as part of their programme but this section looks at approaches where this is the sole methodology used. Even within this group, there is a division between those who follow a strict Applied Behaviour Analysis (ABA) with discrete trial learning (as Lovaas has done in his work) and those who use other behavioural techniques. The methodology of behavioural approaches has a long history in special education in the UK, including work with children with autism. The ability to train specific behaviours has been well documented in the research literature with a range of subjects, including children with an asd. More recently, however, it has been criticised on educational grounds for producing dependent learning styles and a failure to generalise. The Young Autism project conducted by Lovaas seemed to address these shortcomings in a controlled study that showed a significant advantage for the group of children with an asd receiving ABA for 40 hours a week over those who had 10 hours a week and those who had other non-specified treatment. Follow -up studies suggested the effects were retained over a long period. Careful analysis of the studies, however, shows that these results demonstrate the effects of intensity rather than the treatment itself and, moreover, the original experimental group also had contingent aversives (a slap and a shouted 'No!') whereas the control groups did not. Thus, since modern versions of this approach do not use such aversives, there is no scientific basis for the approach. Nevertheless, all the reported studies do show gains in the children, some with less than 40 hours a week and some starting later, but research is needed to see whether this modified methodology is as effective and to identify the features that distinguish those children who benefit substantially and those whose progress is less marked.

Comparative research on different approaches
(Chapter 11)

It would be surprising if consistent and systematic work with a child with an asd did not produce at least some beneficial results, whatever the approach. The real research question, then, is whether one approach is better than another and for that, research which compares different approaches is needed. There is also a need to examine the effects of most educational settings in the UK for children with autism, where a variety of approaches may be used. There has only been one recent attempt at this kind of comparative research but the study had methodological weaknesses which make it difficult to interpret the results. Some of the difficulties inherent in this kind of research are explored.

Discussion of research findings and implications for the future
(Chapters 12 and 13)

This chapter concludes that there is no really strong evidence to suggest that one approach for a child with an asd is better than another, although there is a consensus of findings that early intensive education that involves the parents and includes direct teaching of essential skills with an opportunity for planned integration, can produce significant changes in children with an asd. Some children were reported to move out of the diagnostic category of an asd, but there needs to be further research to determine the validity and reliability of this finding. Certainly, there is evidence of improvement, but not yet 'recovery'. Within all the studies, however, there are always some children who do well and others who do not. Research is needed to pinpoint the variables that lead to that difference because the evidence at the moment is not clear. Long term comparative and detailed research will be difficult to conduct, but suggestions are made for the kind of research that is still needed for that analysis and for smaller scale research projects to address specific questions that have arisen through the review. A plea for consistency of methodology and measures across research is made so that results of one study can be more readily compared with that of another in a form of meta-analysis.

PART ONE: RESEARCH CONTEXT

Chapter 1: Introduction

The DfEE commissioned this review in order to set out what is known and what gaps exist in our knowledge about educational interventions for children with an autistic spectrum disorder (asd).

Parents and professionals working in the field are keen to have information and research evidence on the rationale and effects of these approaches. There are currently a number of approaches which are not offered by the majority of LEAs in the UK (notably, Daily Life Therapy as practised at the Boston Higashi school, USA (Kitahara, 1984); intensive, exclusive discrete trial behavioural interventions as promoted by Lovaas (Lovaas, 1987); and the Option approach (Kaufman, 1976)), but which some parents of children with asd are asking the LEA to introduce or to fund. There are other interventions which are being used increasingly in schools in the UK (eg musical interaction (Christie et al., 1992); the Picture Exchange Communication System (Bondy and Frost, 1994); and TEACCH (Schopler et al., 1980)), about which parents and professionals would welcome advice and research evidence.

1.1 Objectives of the review

- to collect information from relevant professionals, researchers and support groups on the questions they have about educational interventions and the research they have planned or completed
- to provide a description of each intervention in terms of its aims, target group, costs, parental involvement and training implications
- to describe and comment on the research studies conducted to date (or planned)
- to identify gaps in the research evidence and suggest ideas and methodologies for future research

1.2 Context of the review

There are three key factors influencing the current pressure for particular approaches to be adopted by LEAs. The first stems from the increasingly early age at which autism is now being identified (Howlin and Moore, 1997). A recent development of an early screening measure for autism, the CHecklist for Autism in Toddlers (CHAT) (Baron-Cohen, Allen and Gillberg, 1992) is liable to further lower the age of diagnosis. Earlier diagnosis, however, is not necessarily matched by earlier educational provision and there is considered to be a wide gap between diagnosis and the provision of an effective system of education for the child and support for the parents (Howlin and Moore, 1997; Jordan and Jones, 1996). In such situations, parents naturally search for treatments they feel will benefit their child. They may lack good information on the value of these approaches and so be vulnerable to claims for success.

The second factor relates to the dissemination of information about educational or other approaches to autism. The media continue to give publicity to particular approaches or parents' efforts to obtain funding for certain approaches. These do not always present a balanced picture of the provision made in the UK either nationally or locally. Several approaches now advertise on the Internet and parents engaged in particular interventions may contribute to this, as they are keen to share the benefits they feel they have received from a particular approach. Parents, then can obtain some kinds of information for themselves, but this may lead to still further confusion about which approach is best for their child.

Strong advocacy for certain approaches can lead, in some cases, to parents gaining the impression that only one programme will benefit their child and may then feel that their child will miss out if not following the particular programme advocated.

> Schopler (1998) has noted in the USA that,
>
> '... *an ever increasing number of advocates are using the courts not just to resolve some legitimate procedural questions, but increasingly to judge research questions, appropriately resolved only through existing research structures. This has resulted in what Feinberg and Beyer (1997) describe as a "veritable growth industry", with funds sorely needed by special needs children, going to the legal system and elsewhere'* (p. 91).

Schopler (1998) goes on to say,

> *'... There are considerable negative consequences to having research judged in the courts. Individual children may be denied the most appropriate intervention ...'* (p. 92).

Part of the function of the review, then, is to make an objective analysis of the research evidence on the value of interventions so that LEAs or special needs tribunals (where LEA decisions are not accepted) will have access to reasoned debate. It will also highlight areas where evidence is lacking and suggest research that might be conducted to provide that evidence. It is hoped to prevent further misdirected research where no further evidence is required, or where research would just repeat inadequate designs. To this end, the review will evaluate the findings of published research but will also comment on the research design of planned studies or those in progress to highlight where further research is needed.

In spite of the controversy over particular approaches, there is an almost universal consensus in the UK that education, rather than therapy, is the treatment of choice (Jordan, 1996a). Further, there is

> *'now agreement that, in the present stage of knowledge, developmentally influenced behavioural and educational approaches should constitute the mainstay of intervention. '* (Rutter, 1996, p258).

The current controversies, however, have also highlighted the need for careful and appropriate evaluation of these approaches, which is not the usual situation with respect to educational methods. Harris and Handleman (1994) make the case not just for evaluation but for effective communication so that knowledge is shared.

> *'There is a serious risk of drift away from the data-based treatment models toward those founded on administrative convenience, intuition or misinterpretation unless communication among educators and administrators is kept at an optimum level and programmes are challenged to document the effects on their young students.'* (p2)

The final purpose of this research review, then, is to provide a form of communication between professionals, researchers, administrators and parents.

It should be pointed out that this review was conducted over a period of ten weeks only. The authors have done their best to gain accurate and up to date information from all known sources. Inevitably, however, there will be errors and omissions. We apologise for these omissions in advance and hope that they will not bias the review in any particular direction. Because of limits of time and space, and the constraints of the original brief, this review is concerned with major research only. This has been taken to mean research involving 5 or more children with an asd. Case studies of individuals can provide accumulative support towards answering a research question, but cannot, of themselves, offer definitive evidence.

1.3 Methods used to collect information for the review

A postal survey, using questionnaires, was conducted as was a review of the recent literature on research in interventions in autism, which consulted several databases. There were eight groups of respondents:

Chief education officers in LEAs in England and Wales*
Principal educational psychologists in LEAs in England and Wales*
Heads of psychology departments in higher education establishments
Researchers in the field of autism in the UK and internationally
Consultants in child development centres in England and Wales
Heads and principals of establishments which follow a particular approach
(eg Higashi school in Boston) in the UK and abroad
Support groups for these approaches
Secretaries of local autistic societies in the UK

*two members of the research team had completed a study of educational provision in Scotland for children with autism in 1996 and so questionnaires were not sent to education authorities in Scotland (Jordan and Jones, 1996).

In addition, a web page was set up with links to other autism pages to publicise the research. This had an email address for anyone to forward information. Publicity for the review was also sent to three relevant journals.

Chapter 2: The nature of autistic spectrum disorders

As our knowledge and understanding of autism increase, so the ideas on definition, diagnostic criteria and interventions which may be effective change. This in turn affects the research that is done. There are now several accounts written by adults with autism (eg Grandin, 1992; Sinclair, 1992; Williams, 1996) which provide fresh and valuable insights into autism. These accounts suggest that we should view those with autism as having a different world view, rather than a deficient world view. The major implication is that professionals and parents should not necessarily be engaged in trying to change a child or an adult with autism into a 'normal' individual but to appreciate their perspective and to provide strategies for them to function and manage within situations in which they need to participate (eg their families, schools and workplaces). Such strategies might include teaching them ways of understanding others, communicating effectively, and managing situations which they find stressful.

This section provides brief details on the current diagnostic criteria and terminology for autism, including Asperger syndrome, discusses some of the labels which are still used with reference to individuals with autism and presents the views of some adults with autism.

2.1 Definitions and diagnosis

There is now

> '*a high degree of consensus on the diagnostic criteria for autism and consistency in the evidence on the validation of autism as a diagnostic category.'*
> *(*Rutter, 1996, p. 257).

Kanner (1943) first identified a condition in eleven cases that he felt had sufficient in common, and were sufficiently different from other conditions, to merit a separate syndrome. He referred to this disorder as a disorder of affective contact and identified criteria in terms of interpersonal development, communication and imagination deficits that have largely stood the test of time. Wing and Gould (1979) established the fact that the condition often co-occurred with learning difficulties. The two major diagnostic systems now have common criteria for a diagnosis of autism based on a triad of impairments in social interaction, communication and a lack of flexibility in thinking and behaviour (DSM IV: American Psychiatric Association, 1994; ICD 10: World Health Organisation, 1992). This same triad of impairments underpins other autistic like conditions said to form 'autistic spectrum disorders' (Wing, 1996) or 'pervasive developmental disorders'. The spectrum may contain a number of different medical conditions with different diagnostic criteria, but sharing those common developmental difficulties.

2.2 Asperger syndrome

Asperger, in 1944, first wrote about children having characteristics similar to those identified by Kanner, but with at least average levels of intellectual ability and good structural language skills; these individuals are now said to have Asperger syndrome. Some have maintained that Asperger syndrome is a distinct syndrome (Trevarthen, Aitken, Papoudi and Robarts, 1996) and this is supported by current diagnostic formulations (DSM-IV: APA, 1994; ICD-10: WHO, 1992). When reviewing research, however, it is important to realise that it is only the latest diagnostic systems that have identified Asperger syndrome separately and that some earlier systems (DSM-IIIR: APA, 1987, for example) included a far broader category within the label 'autism'. Nevertheless, educational distinctions between the groups may not be valid and Wing (1996) has maintained that autism and Asperger syndrome are more alike than different. In practice, there is considerable overlap between people diagnosed as having Asperger syndrome and/or as having 'high functioning autism'. There are, naturally, differences arising from good general intellectual ability and good structural language skills. The existence of motor disturbance, often in the form of dyspraxia, can be associated with autistic spectrum disorders. The authors of this research consider that these features (ie intellectual ability, language ability, motor difficulties) are best seen as individual characteristics that need to be considered when determining individual needs, but which are not helpfully ascribed to any particular diagnostic label.

Theoretical confusion and debate over differential diagnosis, plus the fact that diagnosis is more difficult at the extreme ends of the intellectual range (Wing, 1996), means that it is likely that many intellectually able children with autism or Asperger syndrome are undiagnosed. This is also because definitions of special educational need stress 'learning difficulties' and many of these children will not have difficulties in academic learning, at least of the more easily recognisable kind. If, in addition, they are socially active rather than withdrawn, their difficulties are more likely to be misinterpreted in terms of conduct disorders or emotional difficulties, not associated with autism. The term 'mild autism' which is sometimes used for such children, gives a misleading impression of the extent of the child's difficulties and so the use of the term 'Asperger syndrome' for those of higher ability is likely to help professionals and parents identify able children with autism and to provide more appropriately for their education.

2.3 Range of labels

Because of difficulties in diagnosis, a range of descriptions might be used by professionals to describe a child on the autistic spectrum. Such descriptions will include 'autistic tendencies', 'autistic features', 'Kanner's syndrome', 'Asperger syndrome', 'autistic behaviours', 'atypical autism' and so on. Sometimes, one of the diagnostic features is emphasised ('semantic pragmatic disorder', for example, or 'rigid and obsessional behaviour') and then it will be necessary to look at the other two classifying features to determine whether this is an autistic spectrum disorder or whether the difficulties are limited to that one area of functioning. It must be remembered that autism is diagnosed by the existence of the full triad of impairments and the particular manifestation of the triad will vary among individuals. There are no behaviours per se that by their presence or absence indicate autism; it is the overall pattern and the underlying difficulties that define autism. Bishop (1989) wrote a useful paper discussing the boundaries between autism, Asperger and semantic pragmatic disorder which describes areas of overlap and difficulties in definition.

2.4 Personal views of adults with autism

Some adults with autism or Asperger syndrome reflect on their own condition and develop and express strong views on its nature and the way it is to be viewed. An examination of Internet forums on autism will give a sample of views, culled from a lively debate on some current issue. Personal views are as their name suggests, but professionals, researchers and parents should pay attention, especially when the views are in accord. A debate on the Internet on what it was like to have autism produced the following comments, typical of many of the others.

> *'Autism isn't something a person has, or a 'shell' that a person is trapped inside. It is pervasive, it colours every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person - and if it were possible, the person you'd have left would not be the same person you started with. This is important, so take a moment to consider it: autism is a way of being. It is not possible to separate the person from the autism.'* (Jim Sinclair, 1993)
>
> *'People do seem to have trouble realising that we can learn a compensatory skill, but not how to be 'normal' (even if we wanted to be totally normal). They can't realise that our brains and thought processes are different and that we can't change that any more than the blind can learn to see with their eyes. Or that what is adaptive for normal may be maladaptive for us (and vice versa), and that, in most cases, our ways can be better for us (and can allow us to function quite well in certain situations and at certain tasks). I think a cure for 'normalcy would be a much better goal than a cure for autism; normalcy is much more prevalent!'*
> Jared (1993)

Sperry (1998) makes a similar point (through her interview with a man with Asperger's syndrome) about autism not being an illness and not needing a 'cure'. Of course, this is a biased sample of individuals who are able enough to express their views in this way and who feel strongly enough to do so. It is also true that some people with autism work hard at diminishing the effects and promote ways of facilitating other children with autism to do the same (Grandin, 1992; Sinclair, 1992; Williams, 1996). Nevertheless, it should be recognised that approaches to autism might be judged on criteria other than their 'success' at making children appear less 'autistic'. It need not be assumed that a difference is automatically a deficit to be remedied, and current quality of life should be as important as the less certain future quality, presumed to flow from being 'indistinguishable from the norm'. The values underpinning the educational system will have an influence on what treatment is considered 'effective' and from whose perspective.

2.5 Prevalence, identification and early diagnosis

The results of surveys in England, Scotland and Wales (Newson and Jones, 1992; Jordan and Jones, 1996) and that of Howlin and Moore (1997) appear to show rates of identification that significantly under represent the numbers of children with autistic spectrum disorders, calculated from prevalence rates. There are many reasons why children with an asd are under-identified.

As Wing (1996) recognises, diagnosis is more problematic in those children with good language and general intelligence (often, although not exclusively, falling under the diagnostic criteria for Asperger syndrome) and for this group it is frequently not made until the late primary or even the secondary stage. Failure to diagnose an autistic spectrum disorder such as Asperger syndrome in the early years may not be just because of difficulties in diagnosis, but also that some forms of autism may not manifest themselves in early childhood.

The age at which the diagnosis of autism is being given to parents is decreasing (Howlin and Moore, 1997) with children of two or three years of age being identified and diagnosed. Much of the literature on interventions in autism and in other areas of disability, stress the importance of early intervention (Jordan and Powell, 1995a). In some parts of the UK, there are well established preschool services which can offer information, support and particular interventions to preschool children with an asd, yet in other parts of the country such services are insufficient in terms of the numbers of children they can support and/or the level of service they can provide (Jordan and Jones, 1996). Parents often report a gap between receiving the diagnosis and then being given information on what autism is and how best to help their child. In the preschool years, professionals working in health and education services are often involved and the voluntary sector can offer support in terms of linking parents with other families and giving them information on local services and an increasing number have parent helplines.

2.6 Prognosis in autism

It is likely that as our understanding of autism develops and the interventions and support systems become more appropriate, then the better the outcome for people with asd will be. Several studies have been conducted which have investigated the long-term outcome for children and adults with autism (eg DeMyer et al., 1973; Freeman et al., 1991; Gillberg and Steffenburg, 1987; Goode et al., 1987; Lord and Venter, 1992; Wolf and Goldberg, 1986), but these may be of limited value as our interventions and social policies change. There are also value judgements involved in terms of how 'success' or a 'good quality of life' are defined and criteria will vary depending on whose perspective is taken (eg the individuals themselves, their parents, teachers, support workers, psychologists).

In evaluating the effectiveness of a particular approach in terms of its impact on the development of the individual in the long-term, it is clearly of value to have data on how well children with an asd function in adolescence and later life and what seem to be the main contributing factors to their success. Given the diversity of conditions within the autistic spectrum, not least differences found in the degree of additional learning difficulties, such data is not straightforward to obtain. There does seem to be a consensus though that individuals with an asd continue to have autism throughout their lives and that there are few examples of individuals who have 'recovered' from their autism.

Typically a good outcome has been viewed as achieving independence and having a normal social life (Ruble and Dalrymple, 1996). As stated earlier, prevalence studies suggest that there may be many more people with Asperger syndrome or who are high-functioning individuals with autism than previously thought. If a person has not been recognised as having an asd or has not been in receipt of particular services, then they will not be available for research samples on outcome. So, there may be many more successful people with an asd who are in open employment, and/or who have succeeded in finding a partner and in having children of their own, than is reported. Having said that, it is known that there are many adults of well above average ability with an asd who are not able to live independently or hold a job in open employment. They continue to have major difficulties in understanding other people and in 'reading' situations and thinking and behaving flexibly and appropriately.

It generally follows that the more intelligent the person, whether or not they have an asd, the more able they will be to understand and manage situations. However, for some people with an asd, and particularly those with Asperger syndrome, being of average or above average intelligence might lead to an increased awareness of their difficulties and increased anxiety and distress which will then affect the quality of their life. In some cases, they may have succeeded well academically, gaining University degrees or other qualifications, but nevertheless may require support in their everyday lives to live happily and successfully. They may live independently but have regular contact with a support service or they may need to live and/or work within a supported community or with their family.

Researchers have tried to elicit the key variables which might be used to predict a successful outcome in later life. These variables include IQ, the severity of the autism, early language and communicative competence, gender and social understanding. Lotter's studies in 1974 and 1978 suggested that IQ and useful speech were two key variables. Ruble and Dalrymple (1996) argue that these variables tend to be stable over time and that for parents and practitioners, it may be more useful to consider other (environmental) factors which are important but which can be altered to the benefit of the individual. They argue that,

> *'defining outcome as the relationship between an individual's challenges and strengths, environmental stressors and supports, and others' perceptions of competence and self-perceptions of quality of life is more likely to yield a better combination of predictor variables than simply measures of IQ and language'* (p.13).

This view is borne out by the experience of parents whose children are now adults with an asd (Allison, 1998) and of professionals who work in adult services (Howlin, 1997; Morgan, 1996) who report that significant progress is often made throughout adult life both in terms of the acquisition of new skills and the reduction of behaviours which are seen as challenging. The key factors contributing to these positive changes seem to be the nature of the environment created for that person, the opportunities offered and how sensitively the person is supported, taking into account their strengths, interests and sensitivities.

Chapter 3: Educational provision and approaches for children with autistic spectrum disorders in the UK

As the review concerns interventions which may take place in a school or be followed by children who also attend a school or preschool group, it is useful to consider briefly the current educational provision made in the UK for children with an asd. Given the differences between children within the autistic spectrum (eg in terms of the severity of their autism and their intellectual functioning), it is clear that they will have different educational needs. However, all will have the fundamental needs in common, arising from their autism, and staff within all schools (both mainstream and special) will require knowledge and understanding of these. The three areas of communication, social understanding and relationships and flexibility of thought and behaviour will underpin and inform the approaches used and indicate areas to make a priority for a child with autism.

Not all children with an asd will require a Statement of Special Educational Needs. Whether they have a Statement will depend on their level of need and how the LEA allocates resources. Some children with an asd will be at Stages 2 and 3 of the assessment procedure set out in the Code of Practice (DfE, 1994) and will not need to proceed beyond those stages. As such, the child will have an Individual Education Plan which sets out the priority areas and how these are to be addressed. If the child requires additional adult support for some activities, then this may be provided from within the school's or LEA's resources without the need for a Statement. In some LEAs though, the need for adult support from outside the school's resources (eg from an outreach teacher, primary support teacher or special needs support assistant) may have to be established by a multiprofessional statutory assessment which concludes on the child's Statement that extra adult support is necessary to meet some of his/her needs.

In educational terms, it is viewed as neither conceptually valid nor practically possible to use medical diagnoses within the autistic spectrum to differentiate educational needs. Yet it may be important in research terms to subdivide the spectrum to determine differential outcomes for children with different characteristics. Even here, however, it is more important to detail individual characteristics of the sample used (level of intelligence, language ability, for example), rather than to give global terms associated with sub categories (such as 'autism', 'Asperger syndrome', 'atypical autism' and so on).

The characteristics of autistic learning and thinking should also underpin and inform the approaches used and indicate areas that will be a priority for a child with autism. Knowing a child has autism does not mean one knows exactly what his or her difficulties are, or how to teach, but it provides a signpost for explanations of the kinds of approach that are likely to succeed. The teacher will still need to observe the child as an individual, but knowing about autism will guide those observations in more fruitful directions (Powell and Jordan, 1993). Staff also need to be aware that these children may have additional needs which are not specific to autism (eg dyslexia, dyspraxia, language disorder or factors arising from their family life at home).

3.1 Educational placement for children with an autistic spectrum disorder

The provision made and funded by education authorities varies from one LEA to another. The options for a preschool or school age child may be:

- mainstream school
- a school for children with moderate or severe learning difficulties
- other type of special school or unit (eg assessment unit; language unit; EBD school)
- specialist unit or school for autism run by the authority
- specialist school run by an independent organisation
- support from an outreach advisory and teaching service
- home-based programmes (eg Lovaas ; musical interaction; Option; Picture Exchange Communication System (PECS); Portage)

These options differ on a number of variables including staff expertise and experience, staff-child ratio, the nature and amount of individual teaching, the curriculum and the focus of the work, characteristics of the peer group, the distance from home and the nature of parental involvement, whether they are residential or day, opportunities for spending time with children without autism, access to information on autism or to specialist advisory support, additional therapy/ resources available (eg speech and language therapy, music therapy), teaching approaches used, size of classes and of the school, flexibility and differentiation to meet individual needs.

All of these may need to be considered when determining the most appropriate placement for an individual. These variables will be weighted differently by different professionals (and parents) depending on their own experiences and views and also on the authority's policy, thus leading to a situation where professionals and parents might make very different recommendations for the same child with autism.

It is acknowledged that within the autistic spectrum there are subgroups of children whose needs are different and it is likely that some children with an asd are more appropriately placed in a mainstream school, whilst others would benefit from being within a school specifically for autism. But, just as we are not yet clear which interventions suit which of the subgroups within the autistic spectrum, so we do not yet have clear evidence on which children with an asd are best suited to which type of placement. It is likely that the more intellectually able the child, the more likely s/he is to be in a mainstream school than in a special or specialist school, but this is not always the case. Practice within a particular LEA can be very different from the practice within a neighbouring LEA. So, it is possible to find children from throughout the autistic spectrum within mainstream, within special and within specialist placements. The recent SEN Green paper (DfEE, 1997), while reaffirming that the needs of the individual child are paramount, promotes the goal of inclusion in mainstream for an increasing number of children with special educational needs. It is likely then that a growing number of children with an asd will be placed in mainstream schools and special schools will be working to arrange time for their pupils with normally developing peers.

3.2 Preschool provision for children with an autistic spectrum disorder

Several authorities in the UK operate the Portage model (Bluma, Shearer, Frohman and Hilliard, 1976) for preschool children with recognised special needs, including those with an asd, where the families are visited at home weekly or fortnightly by a Portage teacher who works on particular targets and skills with the child and the parents. It is felt by some that the Portage materials need to be adapted and extended for some children with an asd and there is a project currently underway to develop the materials for this population (Smith, 1997).

In recognition of the importance of the early years, there are a number of preschool projects specifically for children with asds designed to support families and to enhance the development and progress of the children themselves. It is important at this early stage (and later) to coordinate the services given to families as there may be several professionals involved. Appointing a keyworker who has information on all inputs to the family may help. Some families may have as many as 20+ different professionals involved and there is a need to ensure that these families receive clear and consistent advice and are not further confused.

Speech and language therapists are often involved in the treatment of children with autism as the delay or absence of speech might be one of the key concerns of parents. The diagnosis of autism might have been made at a Child Development Centre and staff within these centres may offer once or twice weekly groups for the children and parents to attend. Children might attend for individual therapy and assessment sessions and/or attend a weekly group where parents may observe a range of professionals working and playing with their child or may be directly involved in the group themselves.

Some speech and language therapists (Addenbrooke, 1998) have been using the Hanen programme developed in Canada, whereby parents attend 6 to 8 weekly group sessions and comment on videos taken of themselves and other parents working with their children (Girolametto, Greenberg and Manolson, 1986). It focuses on developing the child's skills within natural contexts and combines group sessions with individual consultation using video records. It is not a programme which is specific to children with asd and it is currently being adapted to better meet the needs of this population. There has been no research conducted on the benefits specific to those children with asd. Research has been conducted on the effectiveness of the programme and consumer satisfaction with other groups of children (Girolametto, 1988), which will have included children with asd, although some of the studies deliberately excluded those with autism or PDD (Girolametto et al., 1996). Harris and Handleman (1994) have edited a book which contains details of ten preschool education programs in the US for children with autism, focusing on each program's structure and content, diagnosis and assessment, staffing and administration, curriculum, integration, use of behaviour modification techniques, family involvement and outcomes.

3.3 Number of schools and units specifically for children with an autistic spectrum disorder in the UK

There are 12 schools solely for children with an asd run either by the NAS (5) or by Local Autistic Societies (7) in England and an increasing number of independent schools offering places for children with an asd. The NAS is about to open another school in Scotland. In addition, some LEAs have set up their own specialist provision - usually a day unit for between 10 and 20 children attached to a mainstream or a special school. The majority of these units are for primary-aged children. Taken together, these provide about 2, 000 specialist places for children with an asd. Given a prevalence of 5/10,000 children with Kanner's autism and a child population of 13 million, there would be a total of 6,500 children with autism in England and Wales. On these figures then, about two in 3 children with autism will attend mainstream or generic special schools. As yet, there is no clear evidence on the relative benefits of different types of school placement or on which groups of children with an asd might be best placed in a mainstream school, generic special school or a school or unit solely for children with an asd. Schools in each of these categories are likely to have a set of advantages and disadvantages for a particular child and their family. The task for parents and professionals is to assess which of these is most likely to be appropriate at a particular stage of a child's life and to ascertain how to minimise the potential disadvantages (eg through staff training in autism; providing access to children without an asd; improving home-school communication).

Further, if Wing and Gould's (1979) figure of 22/10,000 is taken, to include all those children who have the triad of impairments, then there will be approximately 28,600 children with an asd and so 1 in 14 children will be in a school or unit solely for children with an asd. In addition, studies by Gillberg (1991a) and others suggest that there may be 36/10,000 children with Asperger syndrome giving another 46, 800 children. The vast majority of children with Asperger syndrome will be in mainstream schools but there are some in special schools or autism specific schools. There is now an independent school which specialises in the education of children with Asperger syndrome which currently has over 50 pupils on roll.

So, in an LEA with a child population of 100,000, if there are an estimated 58 children in every 10,000 with an asd, then there will be a total in the region of 580 pupils between the ages of 0 and 19 years with an asd. Recent figures given by the NAS suggest that there may be as many as 91 children per 10,000 with an autistic spectrum disorder. Clearly, the vast majority of these children will attend schools which were not set up specifically for children with an asd and most will attend school on a daily basis from home. In recognition of this, many LEAs are enhancing the resources (eg in terms of staffing and training) of some of their special and mainstream schools to meet the particular needs of these children. In addition, in the last five years, many LEAs have appointed outreach teachers specifically to support and advise staff working with children with an asd in mainstream and special schools. This would appear to be a potentially effective way of sharing knowledge and expertise and worthy of evaluation.

3.4 Educational approaches used in schools and units in the UK with children with an autistic spectrum disorder

In terms of the practice in UK schools, including those specific to autism, it is extremely rare for a school to adopt and follow just one approach or intervention. An eclectic approach is usually adopted and practice is influenced and develops as a result of the experience and expertise of the staff and of visiting professionals such as speech and language therapists, educational and clinical psychologists, paediatricians, occupational therapists, and physiotherapists. So it is possible for a school or unit to be using parts or the whole of a number of approaches which may include the following, given here in alphabetical order:

aromatherapy
art therapy
behaviour modification for teaching skills and/ or managing behaviour
computer assisted learning
Daily Life Therapy
diet
drama therapy
Geoffrey Waldon approach
Hanen programme
Lovaas programmes
Makaton signing and symbols
massage
music therapy,
musical interaction therapy
Option
PECS
sensory integration
Sherborne movement
speech and language therapy
TEACCH

In addition, all schools in the UK (with the exception of those in the non-maintained and independent sector), both mainstream and special, have to follow the National Curriculum and are subject to regular inspection of overall quality through the OfSTED inspection process (DfE, 1993) . There is also an accreditation process in the UK (under the umbrella of the NAS, but functionally independent of it) which, unlike other systems that measure the extent to which an organisation is fulfilling its aims and objectives, attempts an evaluation of the quality of what is provided for individuals with autism (Morgan and Reynolds, 1996). Through a process of peer review, the autism-specificity of a school or service is assessed. Specific criteria have to be achieved before accredited status can be gained and services are revisited to ascertain whether these are maintained.

Chapter 4: Results from the postal survey

A postal survey, using questionnaires, was conducted. There were eight types of respondents in five categories:

- LEA personnel
- Researchers
- Heads and Principals of particular approaches
- Support groups and local autistic societies
- Child development centre staff

4.1 LEA personnel

A total of 182 questionnaires were sent to Chief Education Officers (CEOs) and 162 questionnaires to Principal Educational Psychologists (PEPs) in all LEAs in England and Wales. Questionnaires were returned from 95 LEAs, giving an LEA response rate of 52%. These were completed by either CEOs (55 (30%)) or the PEPs (33 (20%)) or by both (7).

4.1.1 Funding by LEAs for children following a Lovaas programme or for attending the Boston Higashi school

Twelve of the LEA respondents who returned questionnaires reported that they were funding a child with an asd to follow a Lovaas programme or to attend the Boston Higashi school either in part or full (see Table 1). It must be noted that these data are not complete as not all LEAs replied to the survey and so there will be other children who are being funded who are not included in the tables. From the data returned, 27 children were being part or fully funded by LEAs for DLT at the Higashi school in Boston (5) or for the Lovaas approach (22). One London borough was paying for a child to follow the Option approach.

Table 1: Number of children known to LEAs (who returned the questionnaire) who were attending the Boston Higashi school or engaged in a Lovaas programme, paid for in part or full by the LEA

LEA area	DLT at Higashi	Lovaas approach	Full or part fees paid
NW	7 year old		part
North		6 children	part
North	4 year old		full
Midlands		2 children	part/full
Midlands	4 and 5 yrs		full/part
Midlands		3 children	full for 30 hrs
London		7 yr old	part
London	14 year old	one child	full/part
London		3 children	full
London		two 5 yr olds	3 mth trial
London		4 and 5 yr old	part/full
London		3 and 4 yr old	full/part
Total children	5	22	8 part 19 full

One LEA was trialling a 3 month Lovaas programme with two five year old children - one programme being school-based and another being home-based prior to completion of the statutory assessment. Sixteen LEAs, including 4 of the LEAs above who were paying for programmes, knew of families who were paying themselves for their children to follow particular approaches (see Table 2). These figures under-represent the true number of children following these programmes, as not all questionnaires were returned and not all respondents would be party to this information. It is known, for example, from the questionnaire return received from the Boston Higashi school that there are currently 26 children from the UK on roll at the school. Similarly, the returns from two groups of researchers, showed that the progress of more than 100 children following a Lovaas programme in the UK was being investigated.

Table 2: Number of children known to LEAs (who returned the questionnaires) who are involved in a Lovaas or Option programme or attending the Boston Higashi school, paid for by the family

LEA	DLT at Higashi	Lovaas approach	Option approach
NW		5 yr old	
NW		3 presch. chdn.	
NW		5 yr old	
Midlands			10 yr old
Midlands		4 yr old	
Midlands		3 and 4 yr old	
East	5 year old	7 yr old	
London		3 yr old two 4 yr olds two 5 yr olds	
London		3 and 4 yr old	
London		3 yr old four 4 yr olds 6 and 7 yr old	
London		5 and 6 yr old	9 yr old
London		4 and 5 yr old	
South		8 yr old	
SW		4 yr old	5 yr old
SW		4 yr old	
Wales			9 yr old
Total children	1 child	30 children	4 children

4.1.2 Research or surveys conducted by LEAs into children with an asd

Some LEA respondents reported that they had done research or surveys specific to autism. These included:

- setting up a working party on educational provision for children and young people with autistic spectrum disorder.

- the production of a statement about methodology in educating pupils with an autistic spectrum disorder as part of their SEN policy

- research which had been conducted into interventions being followed by children with autism during the last 3 years
- research into the inclusion in mainstream schools of children with an asd
- research on the Picture Exchange Communication System (Bondy and Frost, 1994)
- the collation of data and research on the Lovaas approach

A number of LEAs had conducted surveys to ascertain how many children with an asd with special educational needs they had in the area. Some had conducted small scale projects of children with an asd following particular approaches such as TEACCH, Option or Lovaas.

4.1.3 LEAs research interests

Respondents were asked to specify what their research interests were in the field of asd and interventions. Their replies are grouped under topics below.

Prevalence:
- why are more cases of autism being diagnosed?
- what is the incidence of asd in mainstream schools and is it increasing?

Educational placement
- what benefits do children with an asd obtain from placement in a mainstream school ?
- is there evidence to say mainstream school placement is more effective than segregated placements?
- which interventions are most effective in enabling inclusion in a mainstream school?
- what are the essential elements of effective educational provision?
- how is it best to meet the needs of children with severe learning difficulties and autism in a special school for children with SLD?
- what are the components of models of good practice within an LEA?

Interventions
- what is the relative effectiveness of different interventions?
- what should be the essential features of any adopted approach?
- what is the influence of interventions on parental beliefs, attitudes and an understanding of the condition?
- how much is progress a product of habit and how much is real learning?
- under what circumstances is speech and language therapy effective?
- is there evidence that a thought-out selection of appropriate methods is more effective than any single approach?
- which of the 'new' interventions should an LEA pursue?

Matching the intervention to the child
- which intervention matches which type of autism and/or Asperger's syndrome?
- how can we best assess children to match them to appropriate interventions?
- what is the effect of various interventions when considered in relation to:

general ability level
age at start of the intervention
theories held about the cause of the condition?

Implications for schools and units

- what implications are there for staff training?
- what are effective environmental supports for learning?
- how best can a school deliver the National Curriculum to pupils with an asd?

Long-term effects

- what are the benefits of very early interventions?
- which methods help sustain gains made?
- which interventions help the individual in adult life?
- what are the long-term outcomes for children in the main approaches?

What is meant by effectiveness/success?

- which behavioural and cognitive effects of an intervention should we measure?
- what do we mean by an effective intervention?

4.2 Researchers

Two different questionnaires were sent to this group. One was designed for those known to be engaged in research in the field of autism in the UK and abroad (n=69), although not necessarily in the area of educational interventions and the other for heads of psychology departments in higher education (n=141). Both asked for details of any research which was being done on educational interventions or approaches in autism which had a sample of at least five children with an autistic spectrum disorder. Twenty-two questionnaires (32%) were returned from researchers and a further 10 e-mailed the research team with their response (14%). The response rate from heads of psychology departments was less than 15%, which is perhaps not surprising, given the range of research activity within the field of psychology. It is assumed that if staff had been engaged in relevant research, then a return would have been made.

4.3 Principals and support groups for particular approaches

A total of 22 questionnaires was sent to Principals of particular approaches and their support groups in the UK. Questions were asked about the rationale, practice and costs of the approach and details of any research that had been done or planned. This list included people engaged in the Boston Higashi school, Facilitated Communication, Holding therapy, Lovaas programmes, Music therapy, the Option approach, and Division TEACCH. A total of 12 (57%) returns was made which included the questionnaires from the Boston Higashi school, Division TEACCH and professionals and parents involved in Lovaas programmes and the Option Institute.

4.4 Local autistic societies

A brief questionnaire was sent to 73 local autistic societies in England, Scotland and Wales and Northern Ireland asking for details of research being carried out in their area and for their research interests. Twenty-three (32%) of these were returned, 10 from the London area, two each from Scotland, North West, East, South and the South West of England and one from the Midlands, North of England and Wales. Many of these mentioned that the TEACCH approach was used in their special schools and units. They also knew of families following the Lovaas approach or the Option approach. Usually two or three children were mentioned, although one Northern society mentioned that 10 children were following the Lovaas approach.

Many expressed great interest in the review and said their main questions involved the efficacy of the approaches and ways in which parents could access information on the approaches themselves. One society from the London area commented that,

> *'Far too much reporting seems to concentrate on the very early years - one rarely hears about teenagers or adults. '*

One society had a three year part-time research project being conducted on the needs of children and adults with Asperger Syndrome, funded by the health authority, in year one.

4.5 Child development centres

A total of 183 questionnaires was sent to CDCs in England, Wales and Scotland and 67 (37%) of these were returned. There were 5 from Scotland; 6 from the North of England; 7 from the North East; 10 from the North West; 8 from the Midlands; 4 from the East; 4 from Wales; 16 from the London area; 3 from the South and 4 from the SW of England.

4.5.1 Child development centre research into asd

Staff in eight of these CDCs had research underway or planned into some aspect of working with children with an asd, as follows:

- the incidence of asd
- the effects of Lovaas work
- evaluation of a group run for the siblings of children with an asd
- early intervention
- value of anti-fungal therapy with preschool children
- intensive interaction therapy

4.5.2 Child development centre research interests

The research issues respondents would like to see addressed were:

Diagnosis and definitions

- how useful are diagnostic tools for predicting outcome and differential diagnosis?
- can we arrive at a national definition for asd and the different subgroups?
- how do we define and diagnose children with Asperger syndrome?

Prevalence of asd

- are the numbers of children with an asd increasing?
- are there racial and ethnic differences in prevalence?

Causation of asd

- genetic causes and tests
- prevention of asd

Particular areas of development or functioning

- management of obsessional behaviour
- sleep disturbances
- effect of diet
- behaviour management
- communication development

Interventions

- are intensive approaches more effective?
- do different children need different interventions?
- effectiveness of multidisciplinary working
- what are the respective benefits of individual versus group work?
- which early interventions are beneficial?
- use of video for developing skills

In addition, some staff wanted to know what type of educational placement is needed (6); how best to help parents (4); what the prognostic indicators were (3); the effects of mainstreaming and which factors influence educational attainment.

PART TWO: REVIEW OF THE RESEARCH ON INTERVENTIONS

Introduction

Factual information on the approaches and interventions are presented below - each described within a common framework. Most of these approaches are specific to autism, but some are included because of their widespread use with individuals with autism, even though they are not autism specific. The NAS has produced a booklet (NAS, 1994) which gives a brief summary of each of the approaches used with children and adults both within the UK and abroad. In addition, Knott has written a report on some of the approaches used in the USA (Knott, 1996). Data was requested by the research team from the major centres and this updates and supplements the information on the Boston Higashi school, Division TEACCH, the Lovaas approach and the Option approach.

Many schools highlight music therapy and speech and language therapy among the specialist provision made for pupils with autism (Jones, Meldrum and Newson, 1995; Jordan and Jones, 1996). Other therapies such as occupational therapy, art therapy and physiotherapy are also sometimes available to the child with an asd, plus relaxation therapy, aromatherapy and reflexology. There is strong experiential evidence for the benefits of speech and language therapy, although the researchers are not aware of any formal research evaluation. Trevarthen et al (1996) make a strong case for the value of music therapy. A short section on music therapy is included, but generally, this review is concerned with educational approaches and the researchers have concluded that it is beyond the scope of this report to attempt an analysis of therapies as such. It may be assumed that most children with an asd would benefit from access to the expertise of a speech and language therapist, although this may be more effectively delivered through such a therapist's influence on, and support of, other teaching staff. Even so, the value of the therapist's involvement will depend on his or her understanding of autism.

In the same way, other approaches identified by schools are not therapies as such, but neither are they particularly relevant to autism. Thus, children with an asd may gain specific benefits from the particular way that drama, swimming and outdoor pursuits are taught, but the same might be said of any curriculum activity and the benefits will lie as much in the method as in the activity. Finally, diet, medication and auditory integration therapy were considered medically based approaches and also beyond the scope of this report.

Smith et al (1996) review scientific studies on interventions other than behavioural treatments. Non-behavioural special education classes, which are the main service-providers for most children with autism are discussed first, followed by descriptions of individual therapies, which often supplement classroom instruction. Three kinds of individual therapies, each having several variants, are considered:

- speech and language therapies
- sensory-motor therapies
- psychotherapies.

Biological interventions, such as medication and special diets, are examined. Special education (eg project TEACCH, other public school classes, the Boston Higashi school), sensory-motor therapies (sensory integration therapy, auditory integration training, facilitated communication), psychotherapies (psychoanalysis), and biological treatments (megavitamins, prevention and treatment of infections) are discussed.

Format for the analysis of the research

The studies for each of the approach groups below, are presented in a standard format, wherever possible, to make comparison easier. This has meant that in some cases information is not available or that a category (eg use of a control group) is not applicable to the research design used. In the latter case 'none' is used to indicate absence of that variable or measure, but the actual method used instead is indicated in note form. An explanation of the categories used is given below.

The first line gives the number of the study within the particular grouping of approaches. The next line gives the title of the study either as it appears in its published form or as indicated by the authors on the questionnaire returns. For published research there is then the reference and for research in progress or planned there is the name of the contact person.

Programme: This is a brief description (perhaps just a label, for familiar approaches) of the approach being researched.

Sample: This describes the participants with autistic spectrum disorders who form the 'experimental' (or main treatment, for non experimental research) group. The description is in terms of age, diagnosis (including any tests or measures used to confirm diagnosis), IQ and/or adaptive behaviour measures (including any tests used), language level (including tests or measures), any criteria for excluding children from the study, any additional difficulties characteristic of the children, and finally the number in the study. As mentioned above, only studies with at least 5 children in the treatment group were included in this analysis.

Control: This indicates whether or not a control group was used and, if so, the characteristics of the group under the same headings as for the sample above, where these are known, and the basis for the matching of the controls. This includes the variables for which the group is a control. Where there is no control group as such, but there are other measures taken to control for the experimental manipulation (ie the treatment or approach being studied), these measures are outlined.

Additional treatment: Where the information is given, this indicates any additional treatment the treatment group is or was receiving at the time of the study.

Dependent variable: This has the conventional meaning of the variable(s) that were used to evaluate the effects of the treatment being studied.

Measures for dependent variable: This section describes briefly the measures (tests or techniques or criteria) that were used in the evaluation. An indication of the timing of these measures is also given.

Evaluator: This records whether the person or team conducting the evaluation is or is not independent of the treatment being evaluated and the extent of that independence (eg are they blind to the status of the treated versus non-treated groups and/or the purpose of the study).

Context: The 'meaning' of any intervention and its evaluation will vary according to the context in which the intervention and the research has taken place. Where information is available, the following issues will be commented on:

- culture:
  Educational interventions reflect the cultural contexts in which they are developed and the educational and social aims of that culture. Comment is made where the cultural ethos of the intervention differs from the cultural norms which predominate in British education.

- integration and inclusion:
  This indicates where the treatment approach depends on, involves, or is inimical to, integration and inclusion, where this is part of the research study or a stated part of the treatment.

- generalisation:
  This concerns whether the research demonstrates improved functioning within particular contexts, and the question of generalisability across settings. Where known, the characteristics of any 'maintenance' environment are given.

Time scale: This indicates both how long the study lasted (or is planned to last), how long the children were (or plan to be) undergoing treatment and whether there are any longer-term follow up measures.

Intensity: This indicates how long the treatment was given in terms of hours per day or week as appropriate.

Integrity: This is not related to the integrity of any individuals involved, but rather to the integrity of the approach itself as it is translated into different contexts, with different personnel, and to see how far the effects are modified through time or through association with other (perhaps conceptually contradictory) approaches. The issues addressed are:

- standards of delivery:
  This considers how far the standards of delivery of the researched intervention are monitored and/or maintained and reflected in the interpretation of the results.

- curriculum management and integration:
  Approaches that are delivered in isolation are likely to have a very different effect to those delivered as part of an integrated curriculum structure. The review will examine how far the research has attempted to disentangle these factors and to allow for the effects of other parts of the curriculum on the results obtained.

Ethical concerns: All published (and, one hopes, most undertaken) research should meet ethical standards, although these will vary in different cultural contexts. There are some particular ethical issues that will be addressed. These are:

- quality of life:
  If there is any restriction on the individual's quality of life as a result of an intervention, then this must be borne in mind in assessing the implications of the research evaluating that intervention. In general, the more restrictive an approach, the clearer needs to be the evidence of a positive outcome to 'balance' this restriction.

- costs:
  Evidence of any cost-benefit analysis is given

- family involvement:
  This includes whether it is a necessary part of the intervention or a contaminating variable that might be mitigated with the provision of more local resources and family support. Any known effects on families that are a part of the study, are given.

- nature of autism:
  This examines the extent to which current research on the nature of autism is taken into account in the evaluation of an intervention. This is not to claim that the research on the nature of autism is uniform and uncontroversial, but there is a current consensus on certain key features and it will be important to note the theoretical account of autism that underlies each intervention and the extent to which it accords with this consensus, in so far as the researchers make this clear.

- differentiation:
  British educational practice emphasises respect for individual differences. The extent to which the intervention reflects this and the extent to which it is directed at compensating for and/or overcoming difficulties as opposed to building on differences and strengths will be discussed. The evaluation of an approach should address this issue and be clear about how what is being counted as a 'successful' outcome relates to this, without any necessary judgement about which is 'better' in any case.

Results: This gives the results obtained, including any levels of significance.

Training implications: This indicates, where it is given in the study, the training and skill requirements of those who conducted the treatment being studied.

Identified precursors for success: To the extent that the research addresses this issue, any factors (of the sample characteristics or the context of the treatment), that are predictive of success, are given.

The final section of each group of approaches pulls all the research together in an analysis of the research findings, the methodological issues that affect the interpretation of the results, and an indication of research questions that remain unanswered. The number of studies in each section is variable as is the extent and depth of this final evaluative analysis. This reflects both the number and the nature of the research studies in each area. Where there has been little or no research, there may be little to comment on, beyond the fact that further research is needed. Where there are research studies with limited aims and cautious interpretation of the results, the same may apply. There is little point in criticising research for not doing something it was not intended to do, although it may be pointed out that further research is needed to address a neglected issue.

Research with broad aims that makes claims of demonstrating the success of an approach through rigorous scientific methodology will naturally of itself attract greater scientific scrutiny. If this scrutiny concludes that there are significant reservations about the nature of the results or their interpretation, this does not necessarily mean that the research related to that approach is of less value than research of other approaches that has attracted less controversy and consequently less analysis. The issue is taken up again in the final chapter of the review which compares the research across the different approach groupings and makes recommendations for future research.

Chapter 5: Interactive approaches

Interactive approaches are based on an understanding of autism as rooted in difficulties with intersubjectivity (Christie et al, 1992; Hobson, 1993; Trevarthen et al, 1996) and emphasises the importance of building relationships with teachers and carers which can then be used as the basis for further educational development. It is also rooted in the building of pragmatic understanding and the development of communication.

5.1 The Playschool curriculum

Rogers et al. (1986) used interactive approaches within a developmental play curriculum. They characterised the curriculum as follows,

> *'The developmental approach implemented in this program incorporated the children's needs for high levels of structure, adult attention, and consistency, into a curriculum which placed major emphasis on 1) increasing cognitive levels, particularly in the area of symbolic functions, 2) increasing communication via gestures, signs, and words, and 3) enhancing social/emotional growth through interpersonal relationships with adults and peers. The primary vehicle for enhancing development in these three areas was play in all its variety'* (p.143)

Thus, the specific developmental difficulties associated with an asd are taught directly and emotional warmth is explicitly fostered, as part of the methodology, rather than assumed. Because the medium of instruction is play, the approach is called 'The Playschool'. The first emphasis is to identify an activity which the child clearly enjoys and to use that engagement with the task to focus the child's attention and to build up the relationship with a key adult (kept constant in the first few weeks of the programme). Emotional engagement should also aid memory.

Language development is based on a pragmatics orienting programme called INter REActive Learning (INREAL) (Weiss, 1981). The reasons for using INREAL are because:

- it emphasises communication rather than language or speech per se (signing is used with those without speech),
- it uses the natural environment to foster spontaneous communicative intent,
- it is incorporated into the child's experiences and not seen as a separate activity to be learnt in isolation,
- it uses the child's own actions and developing capacity to respond, rather than imposing an 'alien' system,
- it develops non-verbal communicative understanding and puts the child in control of integrating and co-ordinating his or her own language and communication experiences.

Since these are all key areas of difficulty in autism, the programme only works through adults trained to be facilitatory. There is a 40 hour training programme in which the adults are taught to impute communicative intent to the child's actions or sounds, to clarify and reflect back to the children their own communicative attempts, and to gear their own linguistic input to match and just extend that of the child.

Social interaction is started by joining in with the child rather than expecting the child to conform to adult demands. The adult gradually extends the child's actions, changes them into social games, and works to become a focus of fun and attention for the child. If the child engages in solitary or even socially excluding activities, the adult gradually intrudes on that, changing them gently into social games. This might, for example, involve imitating the child, turning stereotyped actions into chasing games or rough and tumble play and building up mutuality and pleasurable anticipation. Once relationships with key adults have been established, the programme concentrates on developing social interactions with peers. Children were then encouraged into activities alongside other children, the key adult would take a low profile, cue the child into the actions of the other children, and prompt developmentally appropriate social behaviours. If social conflicts occurred, the adult would verbally prompt socially acceptable 'negotiating scripts' and use simple cause and effect statements to clarify each child's actions to the other. Ultimately, the adult would ensure the success of prompted or cued social behaviour.

Behaviour management is very positive, focusing on building the child's repertoire of behaviours, rather than getting rid of 'unwanted' ones. Where behaviour needed to be stopped (because it was dangerous or was seriously interfering with the child's development) the behaviour was blocked and the child re-directed to an attractive alternative. Some dangerous behaviours were treated through operant training techniques, without the use of aversives.

The physical environment is planned to remove distractions and enable the child to focus on the task in hand. Staff interventions are planned and timed with precision, to enable flexibility in the child. This is not a laissez-faire programme, which might be associated with the name. It involves highly skilled professional intervention, and additional training in specific techniques (eg INREAL). To that extent, it is not easily transferred to a home-based programme, although parent training is included. If parents are able to be trained in the techniques, however, it is potentially very powerful, because it could then use the child's environment 24 hours a day.

Aims: To enhance the development of social/emotional, cognitive and communicative development
Target population: asd
Ratio of adult to child: 1:1
Cost: Staff training and implementation costs
Funded by: Health in the USA
Setting: Special nursery setting and/or home
Hours per week: 11 hours per week at nursery, training parents extra
Who carries out the approach? Nursery staff adopting a generalist role
Assessments used: Early Intervention Profile and Preschool Profile, Play Observation Scale, Parent-Child Play Interaction (Rogers and Pulchalaski, 1984)
Staff training and qualifications: Staff and parents need to have an understanding of the principles behind the interactive approach and to undergo extensive training in the techniques, particularly in the INREAL (Weiss, 1981) method of communication.
Parent involvement: Parents are involved in receiving training in the work of the 'Playschool' approach and are given support and encouraged to observe and take part.

Compatibility: Compatible with other interactive approaches. It would fit well with a developmental/ integration approach and could be used with elements of the TEACCH approach. It could also be used with behavioural approaches as long as these did not damage the relationship (eg by the use of aversives), but discrete trial learning would be counter to the cognitive learning fostered here.

5.2 Infant development programme

Dawson and Osterling (1997) put forward the idea of a very early programme for children with autism, becoming more necessary as diagnosis gets earlier. The programme is based on studies of assisting early interactive aspects in children with autism, carried out by Dawson and her colleagues (Dawson and Adams, 1984; Dawson and Galpert, 1990; Dawson and Osterling, 1997). Dawson and Galpert (1990) discuss the rationale for this in terms of the difficulties inherent in autism. They point out that imitation of the child serves to put the child in control of the interaction, and thus makes the adult (and the entire interactive sequence) more predictable and salient. It also enables the child to regulate the interaction in terms of the stimulation to be dealt with, so that it never becomes overwhelming (leading to the child becoming distressed and turning away) or confusing (leading to the child 'switching off'). Because such simple interaction is developmentally appropriate to the socially and emotionally delayed child, then it is also meaningful and pleasurable, leading to a sense of shared emotion or intersubjectivity.

The characteristics of the programme are given by Dawson and Osterling (1997) as being:

- modelled on early social interaction and facilitated through play
- based on typical developmental sequences
- incorporating 'scaffolding' (the normal developmental process whereby adults structure interactions to facilitate the child's contribution), but augmented by exaggeration and simplification
- sensitive to a narrow range of optimal stimulation
- and having the child as initiator.

The goals of the programme would be:

- self regulation of arousal
- shared affect with carer; shared attention with carer
- promotion of social play through ritualised games
- the acquisition of communicative intent.

Aims: To enhance the early social/emotional, cognitive and communicative development
Target population: Very young children with an asd
Ratio of adult to child: 1:1
Cost: Parent training and monitoring costs
Funded by: Not known
Setting: Special nursery setting and/or home
Hours per week: As part of curriculum or everyday life
Who carries out the approach? Parents or nursery staff
Assessments used: Coding frame for videos of interaction

Staff training and qualifications: Staff and parents need to have an understanding of the principles behind the interactive approach and to undergo some training in the techniques.
Parent involvement: Parents are an essential part or they may be the sole participants.
Compatibility: This could also be used as a pre-cursor to another approach, including a behavioural one. This kind of programme is also at the heart of the interaction curriculum designed by Nind and Hewett (1984). It is the base on which musical interaction (Christie et al., 1992) rests, and it forms a significant technique within the Option programme (Kaufman, 1994).

5.3 Musical interaction therapy (Christie et al., 1992)

Musical interaction therapy (Christie et al., 1992; Prevezer, 1990; Wimpory et al., 1995) is an autism-specific approach that has been developed over a number of years at a local autistic society school. It forms part of the school's curriculum which prioritises the development of communication skills. It is also being used in clinical practice with families by a clinical psychologist in North Wales (Wimpory et al., 1995) and has been adopted by many speech and language therapists as part of their practice in working with children with autism. The intention of the work done in these sessions is to develop early communication and interactive skills. The child's keyworker or parent works with the child and a musician plays an instrument to support and facilitate the interaction between the two.

Aims: To develop a relationship with the child and to enhance their pragmatic understanding and communication skills
Target population: asd
Ratio of adult to child: 2 adults to 1 child
Cost: Staff salaries for the session
Funded by: Education or the health authority
Setting: At the child's home or in their school or other setting
Hours per week: One or two one-hour sessions formally within the school. Some of the strategies may be used outside the session within the school or at home.
Who carries out the approach? Musician plus the child's keyworker or parent
Assessments used: Measures devised by the staff
Staff training and qualifications:
One of the adults should have some musical skills to support the interactions of the other adult with the child. This second adult may be the child's parent or keyworker at school. Both adults will need to be told the principles of the approach and will usually learn by watching others and/or receiving feedback on their own sessions.
Parent involvement:
For some children, the parent may be the sole person engaged in the approach with the child and musician in the home or school setting. For others, the approach may be used only at home or in the school with the child's keyworker who may be a nursery nurse, classroom assistant or teacher.
Compatibility: This is compatible with other approaches which prioritise the building of relationships and communication skills and which acknowledge the particular needs of children with an asd

5.4 Interactive curriculum (Nind and Hewett, 1994)

The interactive curriculum developed from work in a hospital setting with adults with very complex needs and is based on techniques gleaned from early dyadic interactions between parent and child (Nind and Hewett, 1994). The actions of the child or adult with autism are imitated and incorporated into turn-taking routines with the teacher and sessions are geared to build relationships which can be used to foster learning throughout the curriculum. Staff will imitate and build on the individual's responses. Once an imitation 'game' has been established, staff will try to alter and extend the individual responses but will always be ready to retreat back to established patterns of interaction if the individual shows any signs of stress or distress.

Aims: To develop a relationship with the child or adult and to encourage two-way interaction
Target population: Children or adults with severe communication difficulties and often severe learning difficulties, with or without an asd.
Ratio of adult to child/adult: 1:1
Cost: Staff salaries for the session
Funded by: Education or the health authority
Setting: In the child's/adult's school or other setting
Hours per week: Varies
Who carries out the approach? The keyworker for the child or adult
Assessments used: Video analysis framework developed (Davies, unpublished MEd thesis)
Staff qualifications and training:
The member of staff is usually a keyworker for the child or adult concerned and, as such, may be a teacher, a classroom assistant or an instructor, for example.
Parent involvement:
For some children or adults, the parent may also be engaged in the approach with their child in the school or home setting.
Compatibility: This is compatible with other approaches which prioritise the building of relationships and communication skills.

5.5 Music therapy

Music therapy provides a framework in which a mutual relationship is set up between the child and the music therapist. The growing relationship enables changes to occur, both in the child and in the form that the therapy takes. It is suggested that music may afford opportunities for expressing emotions and may open up channels of communication (Storr, 1993). Music therapy includes directive and non-directive strategies.

Aims: To develop the relationship and the communication between the therapist and the child
Target population: Children or adults with social and communication difficulties, with or without an asd
Ratio of adult to child: 1:1
Cost: Salary of the music therapist for the session
Funded by: Education or the health authority or parents
Setting: In the child's school or other setting
Hours per week: Once a week for 15 to 60 minutes

Who carries out the approach? Qualified music therapist
Staff qualifications and training:
The therapist is a trained music therapist.
Parent involvement:
Parents may be invited to observe the sessions either directly or through the use of video.
Compatibility: This is compatible with other approaches which prioritise the building of relationships and communication skills.

5.6 Option approach (Kaufman, 1976)

The Option approach is an interactive approach which started through the intensive work of parents with their child with autism through which they claimed to effect a 'cure' (Kaufman, 1976; 1994). While not promising this as the goal of intervention, the approach emphasises hope and uses intensive 1:1 intervention in which the child is put in charge of the situation, but is continually enticed to join in interaction with the adult. In the system as practised in America, the child will spend months or years away from the disturbing influences of the outside world, in its own suite of rooms into which volunteers come to engage with the child for one or two hours at a time, throughout the day, seven days a week.

Option puts more stress than other interactive approaches on the adult showing complete acceptance of the child and their actions. The approach includes staff debriefing sessions in which they are taught to recognise moments when they were not comfortable with the child and, therefore by implication, not as responsive as they should be. Staff and parents are taught the difference between wanting change (which is acceptable) and needing change in order to approve of the child (which is not). Every action of the child is accepted (although some extreme actions may be re-directed or ignored) but the adult uses enthusiasm, energy and excitement to involve the child in the interaction.

The Option approach is used by some families in the UK largely in the home setting, but there are examples where parents have asked the staff if they will work in this way for part of the school day. Some schools which have developed an interactive, child-centred approach, offering choice and letting the child take the lead, have ascribed their practice to the influence of the Option approach.

Aims: To motivate the child to want to interact with others and to encourage the development of social and communication skills
Target population: asd
Ratio of adult to child: 1:1
Cost per child per year: Not known
Funded by: Parents (often from fund-raising; a few LEAs pay for volunteers)
Setting: Home-based and some schools may use the approach for part of a child's day
Hours per week: Ideally all the child's waking hours
Who carries the approach out? Parents and volunteers
Staff training and qualifications: Therapists at the Option Institute are usually graduates who have undertaken two years training in the approach.
Parent involvement:
Parental involvement is essential and staff at the Option Institute spend several hours talking to parents about their views on the child and the ways in which they interact, play with and manage their child. Parents are able to watch staff work with their child and then are

observed themselves and given feedback. Follow-up appointments at the Institute are offered to families.

Compatibility with other approaches:

Any approach which encourages the child to interact with others and which values the child's interests.

5.7 Research on interactive approaches

5.7.1 Study 1: on interactive approaches

An approach to enhancing the symbolic, communicative, and interpersonal functioning of young children with autism or severe emotional handicaps

(Rogers, Herbison, Lewis, Pantone and Reis, 1986)

Programme: Approach emphasising the development of symbolic thought, communication and interpersonal relationships

Sample:

Age: i) mean 47.92 months ii) and iii) mean 51.3 months

Diagnosis: i) autism or ii) PDD or iii) EBD (DSM III) CARS

IQ: Bayley, Leiter, Merrill Palmer: i) mean IQ 72.23 mean MA 32.07 months ii) and iii) mean IQ 81.44

Language level: 53% with useful language

Exclusion: MA less than 12 months

Additional difficulties: some learning difficulties

Number: i) 13 ii) and iii) 13

Control: No control group

Additional treatment: Augmentative sign language and gestures

Dependent variable:

Cognition, language, motor/perceptual, gross motor, social/emotional and self care
Play
Social and affective interaction
Educational placement

Measures for dependent variable:

Early Infantile and Preschool Profile
Play Observation Scale
Parent-Child Play Interaction
Follow-up data

Evaluator: Not independent of programme nor blind to treatment status

Context: Prediction index analysis used to partial out the effects of maturation from treatment gains.

Time scale: 6 to 8 months and 2.5 year follow-up

Intensity: 11 hours/week

Integrity: Treatment team trained and closely monitored by project staff

Ethical concerns: Emphasis on child and autism-focused treatment, with individually tailored programme

Results:

Statistically significant gains in pre and post tests were found in cognition, language and social/emotional development. Changes in perceptual fine motor skills approached significance. Self help and gross motor skills improved but not significantly so.

In symbolic play skills, there was significant change in some levels of some scales (eg child acts out another's activity; substitutes realistic item for real one; substitutes ambiguous item for real one; links two or three related actions; and plays out whole life scene). Other areas improved, but not significantly so. These were group scores containing all diagnostic groups.

In social/communicative play skills, there were significant improvement gains in attempts to continue interaction, in the engagement in turn-taking games, and in playing with others in shared play schema. There were gains in other areas, but not at a significant level.

In parent-child interactions (data from eight children with autism, and five who did not have autism), there were statistically significant changes in the demonstration of positive affect to mother, social initiations to mother and decreased negative responses to mother's interaction attempts. Other improved interaction skills did not reach significance. Mothers' behaviours did not change statistically across the two videoed time periods.

At follow-up, there were 7 children in mainstream, 7 in EBD settings or classes specific to autism, 5 in classes for children with SLD, and one child in a language class. The remaining six children stayed in pre-school for a further year.

Training implications:

Theoretical training and hands-on practical training of staff, including 40 hours of reactive language training (INREAL)

There is a generalist staff model so that all staff teach everything, or anything.

Identified precursors for success:

IQ scores were not a good predictor of outcome. The group with autism made more improvements than the PDD group.

5.7.2 Study 2: on interactive approaches

An effective day treatment model for young children with pervasive developmental disorders (Rogers and Lewis, 1989)

Programme: Use of positively affectively charged experiences, play and a pragmatics-based language therapy model

Sample:

Age: i) mean 44.68 months ii) mean 40.67

Diagnosis: i) autism or PDD (DSM III) and CARS: 13 severely, 9 mild/moderate, 4 not autistic (but PDD) ii) autism or PDD

IQ: Bayley, Leiter, Merrill Palmer: i) mean IQ 68.7 mean MA 32.07 months ii) mean IQ 65.5

Language level: 53% with useful language

Exclusion: MA less than 12 months.

Additional difficulties: some learning difficulties

Number: i) 31 ii) 15

Control: No control group

Additional treatment:

Use of sign (ASL) and gestures for mute children

Sorting activities for concept formation

Sensory management of the environment to increase saliency and focused attention

Dependent variable:

Cognition, language, motor/perceptual, gross motor, social/emotional and self care

Play
Degree of autism

Measures for dependent variable:
Early Infantile and Preschool Profile
Play Observation Scale
CARS

Evaluator:
Not independent of programme nor blind to treatment status

Context:
Prediction index analysis used to partial out the effects of maturation from treatment gains.

Time scale: i) 6.5 months ii) 12.75 months

Intensity: 13 hours/week

Integrity: Treatment team trained and closely monitored by project staff

Ethical concerns:
Emphasis on the child and autism-focused treatment, with individually tailored programme
Child initiating periods

Results:

i) Statistically significant gains in pre and post tests were found in cognition, language, social, emotional, perceptual fine motor and gross motor skills. Self help improved but not significantly so. 53% improvement in language attributable to treatment. 43% improvement in cognition attributable to treatment. 42% improvement in the social/emotional domain. 41% in the perceptual fine motor domain. 33 % in the gross motor domain. 19% in the self-help domain.

ii) Same gains as for i) in first time period and four of these domains remained at that level. 2 domains (social/emotional and self-help) continued to make statistically significant gains in the second 6 months.

53% had useful speech at start of study; 73% had useful speech at the end - 47% who began without any useful speech had acquired it by the end.

Statistically significant increases in symbolic play and in social communicative play.

Total CARS score dropped from mean 35.12 (moderately autistic) to 28.96 (not autistic). Eight subjects dropped to a non autistic category at Time 2 and seven subjects decreased from severe to moderate range. All bar one child reduced their autism score.

Training implications:
Theoretical training and hands-on practical training of staff
Generalist staff model so all staff teach everything.

Identified precursors for success:
IQ scores not a good predictor of outcome. The group with autism made more improvements than the PDD group.

5.7.3 Study 3: on interactive approaches

Mothers' use of imitative play for facilitating social responsiveness and toy play in young autistic children (Dawson and Galpert, 1989)

Programme: Imitation of a child's actions to encourage social responsiveness

Sample:
Age: i) mean 44.68 months ii) mean 40.67
Diagnosis: autism (CARS)
IQ: Bayley, Leiter, Merrill Palmer: i) mean IQ 68.7 mean MA 32.07 months ii) mean IQ 65.5,

Adaptive measures: Uzgiris-Hunt Scale of Gestural Communication/ Developmental play rating scale/ Stanford Binet/ Wechsler Full Scale IQ/ Leiter/ VABS and CARS
Language level: ,not given
Exclusion: CA more than 7 years, not able to sit opposite mother for 5 minutes, no toy behaviour
Additional difficulties: some learning difficulties
Number: 15
Control: No control group
Additional treatment: Some children already attending TEACCH classes
Dependent variable: Mutual gaze and joint attention
Measures for dependent variable:
Videotaped sessions
Gaze and joint attention assessment
Parent interview
Evaluator: Not independent of programme nor blind to treatment status
Time scale: 2 weeks
Intensity: 20 minutes/day
Integrity: Mother trained and 'checked' by project staff over the 2 weeks
Ethical concerns: Emphasis on the child and autism-focused treatment, with individually tailored programme.
Parental involvement: Child's mother an essential part of the programme
Results:
Significant immediate increases in gaze at mother's face (average duration) compared to gaze at actions with toys (either familiar or novel)
Significant cumulative increase in differential gaze at mother's face (average duration and total gaze) after 2 weeks programme (with familiar or novel toys)
Non significant increases in total gaze time at mother's face under differential initial conditions but no increase in frequency of gaze between sessions or over time.
Mothers reported programme as easy, enjoyable, and helpful to the children
Training implications: Parent training - brief
Identified precursors for success:
Applicable to a wide range of ability. Neither their IQ, general imitative level, social quotient nor autism level predicted successful outcomes.

5.7.4 Study 4: on interactive approaches

Autistic children and music therapy: the effects of maternal involvement in music therapy (Muller and Warwick, 1993)

Programme: Music therapy sessions with and without the child's mother
Sample:
Age: 3 yrs 4 mths and 14 yrs 7 mths
Diagnosis: autism (Rutter's criteria)
IQ: severe learning difficulties to average ability
Language level: 4 had no speech; 3 had echolalic or repetitive speech and 2 had good expressive language
Additional difficulties: 3 had Fragile X syndrome
Number: 9
Control: Two similar groups chosen in terms of age, gender, prior experience of music and holding therapy and language development. Each group had ten weekly sessions of music

therapy with their mother and ten weekly sessions of music therapy without their mother, the two groups varying in the order in which the block of ten sessions was presented.

Dependent variable: Communication skills

Measures for dependent variable:

Child behaviour checklist

Orlik's self concept (Orlik, 1979)

Communication questionnaire

Video records

Parent and staff interviews

Context:

Music therapy sessions home-based, but children also attended units specific to autism

Time scale: 20 weeks

Integrity: Sessions were carried out by a qualified music therapist who also worked in the children's schools

Ethical concerns:

Based on an understanding that music therapy might be useful for children with autism in developing communication skills and the mother's involvement might help generalisation of these skills.

Results:

There was an increase in turn-taking and musical activity and a decrease in stereotypic behaviour in the music therapy sessions, but the mother's participation did not have a particular influence on their children's behaviour. No carry-over effects in a free play session nor changes in mother-child interaction (with the exclusion of mother's request and children's avoidance) could be measured in the short time span of the study.

Training implications: Parent training.

Identified precursors for success:

None mentioned.

5.8 Research planned or in progress on interactive approaches

5.8.1 Study in progress 1: on interactive approaches

Home-based musical interaction study

(Chandler, Newson, Christie and Prevezer, in progress)

Programme: Musical Interaction

Sample:

Age: 2-3 year olds

Diagnosis: asd (using play-based assessment)

IQ: Cattell scores

Language level: from observation and parent interview and checklist

Additional difficulties: none reported

Number: 12

Exclusion: more than 33 months at the start

Control group: Retrospective control on entry to school at 4 years - asd who have not had musical interaction

Dependent variable:

Play development

Language and communication development

Social/emotional engagement

Parental satisfaction
Measures for dependent variable:
Direct observations
Interview with parents
Behaviour checklist
Social interaction measures
Parent satisfaction scale
Context:
Parents trained
Effects on siblings monitored
Process of intervention monitored
Time scale:
Data collection period 1997-2000
Duration of programme 2+ years
Intensity: 7 hours a week minimum
Integrity:
Programme based at a diagnostic centre and school - supervised by the project team
Ethical concerns:
Based on an understanding of the difficulties in early development including communication. Enabling and child-centred rather than restrictive.
Results: None reported, as yet
Training implications: Training needed in method, trained musician needed

5.8.2 Study in progress 2: on interactive approaches

Evaluation of Coding of Active Sociability by Preschoolers with Autism (CASPA) as a way of developing social interaction in children with autism
(Wimpory, in progress)

Programme: Social interaction, using CASPA as a guide

Sample:
Age: 24 months
Diagnosis: DSM-IV (1994) further verified by CARS
IQ: DQ range 23 to 117 Griffiths Mental Development Scales
Language level: not given
Additional difficulties: not given
Number: 12
Exclusion: not given
Control group: Looking separately at the effectiveness of imitation compared to self repetition
Dependent variable:
Clinical strategies which facilitate sociability in young children with autism
Measures for dependent variable:
Direct observations
CASPA
Time scale:
1998-2000
Duration of programme 2 years
Intensity: Not given

Integrity: Programme based at a university centre - supervised by the project team
Results: No data available, as yet
Training implications: Training needed in the method

5.9 Evaluation of research on interactive approaches

The Option approach has been evaluated in terms of its rationale and practice, but not its outcomes (Jordan, 1990), although the proponents have published some detailed case studies (Kaufman, 1976; 1994). Similarly, musical interaction and the interactive curriculum have only been subject to small case studies with respect to people with autism (Nind and Hewett, 1994; Wimpory et al., 1995). Many of the ideas within these approaches, however, can be seen to parallel principles which underlie the procedures of behavioural intervention (Jordan, 1991) and particularly those used in Gentle teaching (McGee et al, 1987). There is research evidence for some of the principles underlying these approaches and, thus, what might be considered, a priori reasons to try them. Dawson and Adams (1984), for example, and Koegel, Dyer and Bell (1987) found that the quantity and quality of social responsiveness in children with autism improved considerably when strategies similar to following the child's lead were employed. Lewy and Dawson (1992) found that children with autism under six years spent more time socially engaged when adult play behaviour closely followed and was contingent on their own behaviour.

The research of Dawson and Galpert (1989), reported above, lends further support to the rationale behind these approaches, but does not offer convincing evidence that any whole approach is, or even would be, effective. There was anecdotal evidence in their study, for example, that one child became fixated on gaining his mother's eye contact and the danger of distorting the overall development of a child by focusing on a single aspect, is always present when dealing with children with an asd. The research in progress by Wimpory is potentially interesting in evaluating an instrument that can serve as a guide to structuring social interaction. It is an in depth qualitative study, which is appropriate methodology for attempting to investigate the process of interventions and it will be valuable if it can answer such questions as the relative effectiveness of two particular strategies (imitation and self-repetition in improving social interaction).

When imitative play and affective engagement are part of a well structured total curriculum, as they are in the Playschool programme, then this seems more fruitful. Rogers and her colleagues (1986) present evidence of considerable gains in important areas of development and a good rate of mainstream placement. There are, however, problems with the studies. The technique of assessing actual gains against a statistical calculation of projected gains without the treatment (based on pre-treatment scores) is a neat way of getting round the fact that there was not a control group, but it is not as convincing as if there had been. What makes the studies even more difficult to interpret in terms of the education of children with an asd is that some of the children in the study appear not to have met diagnostic criteria for autism nor scored as having autism on the CARS. The results are further confounded by treating the group as a whole, so it is not always clear which results apply specifically to those with autism. With such methodological weaknesses, the results can only be regarded as indicative at present.

Musical interaction has also only been evaluated through small case studies, but a larger study is now in progress. This should provide some rich data on the processes involved but it is unlikely to produce any definitive evidence on the value of the intervention. The group receiving the intervention will be 'controlled' retrospectively by looking at a group of children who have not received this treatment. It is presumed that the two groups will be matched on some criteria, but it is hard to see what would be appropriate, unless there were measures dating back for two years (when they could be matched against the pre-intervention measures of the intervention group). Since it is not known what other interventions the control group will have had (if any), it is not clear what they are controlling for, except perhaps non-specific versus musical interaction interventions. It may just lead to the conclusion that giving some intervention makes a difference. Even this will only stand if there are pre-intervention matching measures, forming a baseline for the control group. A further potential difficulty with the study is the apparent reliance on non-standardised measures for much of the data; it is hoped that this can be clarified.

Radhakishan (1991) reviewing music therapy in general concluded that the literature on music therapy research showed consistent methodological weaknesses, principally the absence of a neutral control and the presence of observer bias. This leads to unanswered questions about whether the changes reported in the sessions would have occurred anyway or were seen outside the sessions. In response, experienced practitioners point out that while each child's individuality and the subtle aspects of emotional expression and creativity within the dynamics of relationship are paramount considerations in music therapy, these features do not lend themselves readily to measurements by scientific research methods that are designed to compare treatment groups and to make 'blind' assessments of behaviour defined 'a priori'. In recent years, this dilemma has begun to be addressed: on the one hand, by psychological researchers whose collaborations with music therapists have produced data within a quantitative perspective (Aldridge, 1991) and by practitioner researchers who have adopted qualitative methodologies to examine the relationship and various phenomena of the music therapy process (Forinash, 1993).

The Muller and Warwick (1993) study provides some evidence of effectiveness but it is not designed to test the effectiveness of music therapy itself but rather of the presence or absence of the mother during sessions. The measures taken are limited and are made by the therapist involved in the treatment. There is no comparison with a non treated period.

5.10 Research needed on interactive approaches

The two studies under way should provide some evidence for the processes that may be effective within interactive approaches. A further process study would be to compare two models of early interaction, one which uses music to structure the interaction, the other which just relies on carefully structured input (perhaps following CASPA). Since a live musician is an expensive and scarce resource to provide on any scale, it would be important to know which, if any, aspect of musical interaction was essential to its effectiveness. At the moment, of course, there is no real evidence that it is effective as an intervention, so perhaps the first step would be to investigate that. The Chandler et al. study under way could begin to answer that question if objective measures could be introduced and an adequate control group found.

The methods used in the Playschool have a good rationale and the results reported are encouraging, if not definitive. A properly controlled study, involving a clearly defined diagnostic group of children with an autistic spectrum disorder, would offer better evidence on which to judge effectiveness. It should also give more data on individual characteristics so that profiles of development can be seen and tied to the individual characteristics of the children. At present, there is no identical system in the UK, but it fits with much accepted nursery school practice so it might provide a good model to try if new pre school provision is being established.

Chapter 6: Approaches to communication

6.1 The Picture Exchange Communication System (PECS)

PECS was developed within the Delaware Autistic Program in the USA based on observations that 80% of the preschool children they admitted had no functional communication skills (Bondy and Frost, 1994). The PECS involves the use of pictures in a different way from other picture or photograph schemes such as those which might be used in the TEACCH programme. PECS starts with requesting and not labelling, requires interaction with others from the outset and encourages the child to initiate communication rather than respond to a prompt. The aim of PECS is for children to acquire key communication skills, especially initiating communication, in a social exchange (Bondy, 1996). It teaches those who may not have any functional communication skills how to give a picture of a desired object to another person in exchange for that object. A critical part of the early teaching is not to pre-empt by asking, 'What do you want?' or 'Do you want a drink?' but waiting for the child to hand over the picture card first, so the child initiates the communication (Baker, 1997).

PECS is currently being used in the West Sussex Portage Services in the UK to help develop communication skills in preschool children with autism (Baker, 1997). Evaluative data are being collected on the benefits of this.

Aims: To acquire key communication skills, especially initiating communication, in a social exchange (Bondy, 1996).
Target population: asd
Ratio of adult to child: 1:1 or 2 adults to a child when PECS trials being done
Cost: Salaries of professionals involved
Funded by: Health or education authorities
Setting: Home-based or school-based
Hours per week: As appropriate
Who carries out the approach?: Parents and others who have frequent contact with the child
Assessments used: Functional communication checklist devised by Bondy and Frost
Staff qualifications and training:
Speech and language therapists or other professionals introduce the approach to parents and others.
Parent involvement:
Parental involvement is essential, although in theory, the system might only be used in a school or other setting.
Compatibility with other approaches: Approaches which encourage the development of communication, particularly those which focus on encouraging the initiation of contact with others.

6.2 Augmentative communication

Although augmentative systems of communication (eg sign, pictures, symbol or written words) are generally used as an alternative to, or a precursor of, speech in children who have no or inadequate spoken language skills, they have an additional role in autism. Even where children with autism have apparently good speech, comprehension may be poor and speech may not focus attention or be as meaningful to the child with autism as a visual form of communication. Of course, written language may serve the same purpose for the more able child with autism or Asperger syndrome. Augmentative systems of communication in autism, then, would be used not just to replace speech but to assist learning and communication, regardless of the level of speech.

Signing is the most common form of augmentative system and, at least in those with additional learning difficulties, Makaton (Walker, 1985) is the commonest form used. The use of signing with people with autism has been advocated (Jordan, 1985) but there are also reservations (Jordan, 1993) and it is generally regarded as only marginally easier than spoken language for many with autism (Peeters, 1997). Symbols, pictures, photographs and objects of reference, however, are all well established as helpful for people with autism in supporting the comprehension of what is said and in getting needs met. In the UK, Golding (1997) is conducting a study investigating the value of teaching parents to use Makaton with their children who have an asd.

Aims: To help the child to understand others and to provide a means of expressing their needs
Target population: Children or adults with severe communication difficulties, with or without an asd.
Ratio of adult to child: 1:1 or group teaching and use of the system
Cost: Salaries of professionals involved
Funded by: Education or health authority
Setting: In the child's school or home and other settings, as appropriate
Hours per week: As appropriate
Who carries out the approach? The child's keyworkers and/or his/her parents
Staff qualifications and training:
A person trained to use Makaton generally holds group training sessions for staff and/or parents and signs and symbols are introduced to individual children and their parents and keyworkers, as appropriate.
Parent involvement:
Workshops are often held for groups of parents and they will usually be kept informed of the signs and symbols that the staff are using so that they can use these at home.
Compatibility with other approaches: Approaches which encourage the development of communication

6.3 Facilitated Communication

Facilitated Communication (NAS, 1994) arose from the work of Crossley with people with cerebral palsy, teaching them to communicate by physically prompting them to form a pointing finger, supporting the hand as a point is made and assisting withdrawal from the point. Its rationale was based on the difficulty experienced by people with cerebral palsy in making and controlling movements. The claim that the communicative purposes and thoughts can be revealed if sensitive support is given to directing hand movements has received widespread publicity and led to considerable controversy.

The person with autism is facilitated to point to a communication board or (more commonly) to type using a word processor and under such facilitation people with autism without speech have 'written' about a range of esoteric topics, including their distress at being 'locked inside their own body'. The aim is usually not to produce independent typing or pointing but to 'release' the hidden potential through a facilitator. Many professionals and parents initially believed (and some still do) that the child was the author of the work. Others had strong doubts, however. At the peak of its use in some states in America, children with autism, who had been assessed as having additional severe learning difficulties and who had no speech, were being taken out of special schools and put into mainstream classes to follow an age-appropriate mainstream curriculum with the help of their facilitator.

Aims: To facilitate the child or adult to communicate his ideas and thoughts
Target population: Children and adults with an asd or other communication difficulty
Ratio: 1: 1
Cost per child per year: Salary of the facilitator
Funding: By the state
Setting: Home-based or school/setting based
Hours per week: As appropriate
Who carries out the approach? Parents, teachers, assistants, or other keyworkers
Assessments used: Output, usually via a portable Canon communicator
Staff qualifications and training: Training in the approach
Parent involvement: A parent may act as a facilitator with their own child
Compatibility: It is compatible with other approaches which seek to develop an individual's ability to communicate

In the UK, FC has been tried by some schools and parents as another tool to foster communication. Other parents (not involved in Facilitated Communication) have reported anecdotally, that their child appears to be helped to write if they place their hand on their arm or shoulder. At least one university department is researching the processes involved (Grayson, 1997).

6.4 Research on communication programmes

6.4.1 Study 1: on PECS

Outcome of the Delaware Autistic Programme (1)
(Bondy and Frost, 1994)
Programme: Pre-school programme based on behavioural interventions, play experiences and training in the use of PECS
Sample:
Age: pre-school children
Diagnosis: autism (DSM III-R)
IQ: 47% DQ less than 50; 21% DQ more than 80
Language level: non-communicating / functionally mute
Additional difficulties: some with severe learning difficulties
Number: 20
Control: No control group
Dependent variable: Main communication system used
Measures for dependent variable:
Direct observations

Interview with parents
Behaviour checklist
Social interaction measures
Context: Parents trained but intervention at pre-school nursery
Time scale:
Data collection period 1987-1992
Duration of programme 2+ years
Integrity: Programme at a university centre - supervised by Bondy and Frost
Intensity: Daily across all situations whenever the opportunity arises
Ethical concerns:
Based on an understanding of the difficulties in autism in producing spontaneous communication
Enabling and child-centred rather than restrictive
Scientific rationale from Skinnerian (1957) concept of the development and maintenance of 'mands'
Results:
14 (70%) use speech as their main mode of communication.
6 (30%) use speech + PECS
Training implications:
Training needed in PECS, but training short and no professional skills required

6.4.2 Study 2: on PECS

Outcome of the Delaware Autistic Programme (2)
(Bondy and Frost, 1994)

Programme: State-wide programme based on training in the use of PECS in pre-school settings
Sample:
Age: pre-school children
Diagnosis: autism (DSM III-R); Autism Behavior Checklist (Krug et al., 1980)
IQ: 47% DQ less than 50; 21% DQ more than 80
Language level: non-communicating / functionally mute
Additional difficulties: some with severe learning difficulties
Number: 66
Control: No control group
Dependent variable:
Main communication system used
Number of PECS signs used spontaneously
Number of autistic behaviours
Measures for dependent variable:
Direct observations
Interview with parents
Autism Behaviour Checklist (Krug et al., 1980)
Social interaction measures
Context:
Use of public school pre-school programmes
Parents trained but intervention at pre-school
Time scale:
Data collection period: 1986-1992

Duration of programme: 2.5 years
Intensity: Daily across all situations whenever the opportunity arises
Integrity: Programme part of university research, supervised by Bondy and Frost
Ethical concerns:
Based on understanding of difficulties in autism in producing spontaneous communication
Enabling and child-centred rather than restrictive
Scientific rationale from Skinnerian (1957) concept of the development and maintenance of 'mands'
Results:
41 (62%) used speech as main mode of communication.
13 (20%) used picture and word system to augment speech
80% acquired speech and used it solely or as augmentation
90% acquired 2+ PECS symbols used spontaneously
Almost 100% learnt at least 1 PECS picture within 1 month of starting programme
Training implications:
Training needed in PECS , but training short and no professional skills required
Identified precursors for success:
Those who acquired speech had 11 months training in PECS, were using 70 PECS symbols and were using PECS symbols to label as well as request. Those who acquired speech showed reduction in autistic score on Autism Behaviour Checklist

6.4.3 Study 3: on PECS

Outcome of the Delaware Autistic Programme (3)
(Bondy and Frost, 1994)

Programme: State-wide programme based on training in the use of PECS in preschool settings
Sample:
Age: pre-school children
Diagnosis: asd (Autism Behaviour Checklist, Krug et al., 1980)
IQ: from sld to average
Language level: non-communicating / functionally mute
Additional difficulties: some with severe learning difficulties
Number: 26
Control: No control group
Dependent variable:
Main communication system used
Number of PECS signs used spontaneously
Number of 'autistic' behaviours
Post programme diagnosis and educational placement
Measures for dependent variable:
Direct observations
Interview with parents
Autism Behaviour Checklist (Krug et al., 1980)
Social interaction measures
Evaluator: Not independent of programme, nor blind to research design
Context:
Use of public school pre-school programmes
Parents trained but intervention at pre-school

Time scale:
Data collection period: 1986-1992
Duration of programme: 2+ years
Intensity: Daily across all situations whenever the opportunity arises
Integrity: Programme part of university research, supervised by Bondy and Frost
Ethical concerns:
Based on an understanding of the difficulties in autism in producing spontaneous communication. Enabling and child-centred rather than restrictive. Scientific rationale from Skinnerian (1957) concept of the development and maintenance of 'mands'
Results:
10 (38%) declassified from autism or re-classified as learning disabled
8 (31%) placed with mild disabilities
7 (27%) started school with PECS support
18 (69%) no longer needed centre based programme
Training implications:
Training needed in PECS, but training short and no professional skills required
Identified precursors for success:
Those with (or who developed) speech (62%) were the ones who had a reduced autism score.

6.4.4 Study 4: on augmentative communication

Pragmatic analysis of the communicative performance in autistic children
(Bernard-Opitz, V et al., 1991)

Programme: Case study of 10 children and their parents in a communication programme
Sample:
Age: less than 5 years old
Diagnosis: autism
IQ: 5 'low functioning'; 5 'high functioning'
Language level: not given
Additional difficulties: some with severe learning difficulties
Number: 10
Control: Comparison groups of low-functioning vs high functioning
Dependent variable:
Differential responses of parents and a clinician to the children's protesting, responses, and initiations
Child's communicative attempts
Measures for dependent variable:
Direct observations
Social interaction measures
Pre and post tests
Context: Communication programme with therapist/ parent training
Time scale: 20 months
Ethical concerns:
Basis for obtaining more effective interaction with therapist and/or with parent
Results:
Children interacted differently and showed a different level of behaviour problems when with their parents compared to a clinician. Both groups of children reacted quite sensitively to different interaction partners and their communicative feedback. Children with less ability mainly used nonviable protests when interacting with their parents.

Parents tended to respond to appropriate communicative acts with new demands, while the clinician explicitly acknowledged the communication. Post intervention measures showed significant reduction of protests and non-compliance and an increase in parents' positive feedback.

Training implications:

Parents needed training to recognise communicative attempts and respond appropriately

6.4.5 Study 5: on FC

Facilitated Communication: a failure to replicate the phenomenon

(Erberlin, McConnachie, Ibel and Volpe, 1993)

Programme: Facilitated Communication.

Sample:

Age: 11.5 to 20.2 years old

Diagnosis: autism and learning difficulties

IQ: not given

Language level: various from full speech and writing to mute with minimal signing

Additional difficulties: moderate, severe or profound learning difficulties

Number: 21

Control: Own control with baseline communicative ability and pre and post-test FC
post- tests using either FC or FC control (with earphones) condition

Dependent variable:

Vocabulary level
Answering personal questions

Measures for dependent variable:

Typed responses on communicator
Vocabulary sub-test of Stanford-Binet 4th. ed.
Personal interview

Evaluator: Objective, but familiar to clients

Context: 10 familiar facilitators (6 months + with clients or 2 weeks familiarisation period)

Time scale: 20 hours FC training

Intensity: 40 sessions

Integrity: Programme based on Biklen (1990) procedure, monitored by project directors

Ethical concerns:

Research to evaluate effectiveness
Based on idea of autism as a motor difficulty

Results:

20 of 21 clients less able to answer questions at post test than at baseline level of communication (mean 8 questions correct at baseline, 0 correct at post-test)
1 client scored 21 at baseline testing and 24 at post test
Evidence for facilitator influence with 8 clients and 5 facilitators

Training implications:

Biklen approved 3 day training given

6.4.6 Study 6: on FC

Facilitated Communication: the contribution of physical, emotional and informed support (Konstantareas and Gravelle, 1993)

Programme: Facilitated Communication
Sample:
Age: 7.6 to 21.7 years (mean 14.4 years)
Diagnosis: autism
IQ: not given
Language level: 5 mute, 6 echolalic with some functional words, 1 sentences
Additional difficulties: moderate, severe or profound learning difficulties
Number: 12
Control:
Independent pointing (ES)
Physical support (PFS)
Emotional support (EFS)
Information support (IFS)
Full facilitator support (FFS)
Additional treatment:
Modified school curriculum appropriate to age
Previous use of FC 13-33 months
Dependent variable:
Literacy level
Answering personal questions
Measures for dependent variable:
Typed responses on communicator
Pointing to pictures/ words/ letters
Letter recognition, single word comprehension, labelling task, sentence comprehension task
Evaluator: Objective, but familiar to clients
Context: Most effective usual facilitators
Integrity: Programme based on Biklen (1990) procedure, monitored by project directors
Ethical concerns:
Research to evaluate effectiveness
Based on idea of autism as a motor difficulty
Results:
FFS produced 100% success
ES no literacy skills in spite of 2 years FC (1 child who did show some success, performed less well than outside FC conditions and he resisted FC training)
No independent typing and 4 could not point (after 2 years FC)
In IFS, facilitator's knowledge crucial to correct responding
When motor requirements constant, performance varied as function of 'informed support' of facilitator. Neither emotional nor physical support relevant to FC output, regardless of task complexity.
Training implications: Biklen approved 3 day training given
Identified precursors for success: Performance either at ceiling or floor level, depending on support conditions, thus no precursors for success could be identified

6.4.7 Study 7: on FC

Effectiveness of Facilitated Communication with children and youth with autism

(Simpson and Myles, 1995)

Programme: Facilitated Communication
Sample:
Age: 3 to 20 years: 4 pre-school, 10 primary, 4 secondary (mean age 9.5 years)
Diagnosis: autism (DSM III-R)
IQ: PEP-R scores 12 - 48 months
Language level: non-verbal or very limited single words
Additional difficulties: moderate, severe or profound learning difficulties
Number: 18
Control: Own control via baseline communicative ability, pre and post-test with FC post tests using either FC or FC control (with earphones) condition
Additional treatments:
All bar 2 pre-schoolers in special schools for autism. Two in SEN nursery
Dependent variable:
Answering questions
Open-ended communication
Measures for dependent variable: Typed responses on communicator
Evaluator: Objective, but familiar to clients
Context: Children's familiar teachers (13) as facilitators
Time scale: 1 semester (15 weeks)
Intensity: 40 sessions
Integrity: Programme based on Biklen (1990) procedure, monitored by project directors
Ethical concerns:
Research to evaluate effectiveness
Based on idea of autism as a motor difficulty
Results:
14 (77.8%) of clients had no meaningful responses to information questions over 15 weeks
4 (22.2%) had fewer than 1 meaningful response per day to information questions
No correct responses if facilitator ignorant of answer
12 (67%) no meaningful response to affective questions
11 (61.6%) no meaningful responses to opportunities for spontaneous communication
All meaningful responses at rate of less than 2 per day
9 students showed some minimal ability to type under FC conditions but 5 of these were able to do this independently prior to FC
Training implications:
Biklen approved 3 day training given

6.4.8 Study 8: on FC

Evaluating the impact of Facilitated Communication on the communicative competence of fourteen students with autism

(Bomba, O'Donnell, Markowitz and Holmes, 1996)

Programme: Facilitated Communication
Sample:
Age: 8.6 to 14 years (mean 10.5 years)
Diagnosis: autism

IQ: Developmental Profile (DP II) score communication mean, 20.8 months; mean academic performance 26 months.
Exclusion: parental unwillingness
Language level: prior to FC, 6 communicated through limited verbal ability, 6 used augmentative system, 1 used simultaneous communication, 1 used sign alone. Pre-level: none able to score at basal level. Expressive one word vocabulary test - mean 33.5 months.
Additional difficulties: some with severe learning difficulties
Number: 14
Control:
Set work versus open ended 'conversation'
Apology for 'simple' questions and tailoring to child's language level
Facilitator wore earphones and listened to white noise and on some trials, ring-binder block used
Dependent variable:
Answering questions,
Engaging in conversations
Measures for dependent variable: Typed responses on communicator
Evaluator: Objective
Context:
3 familiar facilitators (all 2+ years with the child) except for pre and post tests where speech and language therapist used. Apology for 'simple' questions and tailoring to child's language level
Time scale: 10 weeks
Intensity: 5 to 25 minutes x 5 days
Integrity: Programme based on Biklen procedure
Ethical concerns:
Research to evaluate effectiveness
Based on idea of autism as a motor difficulty
Results:
13/14 pre and post tests identical. One child who responded only did so within pre-treatment capacity. FC communication far more limited than for other more familiar means
Training implications: Biklen approved 3 day training given

6.4.9 Study 9 on FC

Multiple method evaluation study of Facilitation Communication: II. Individual differences and subgroups result (Bebko, Perry and Bryson, 1996)

Programme: Facilitated Communication
Sample:
Age: 6 to 21 years (mean 13 years)
Diagnosis: autism
IQ: Developmental Profile (DP II) score, communication mean 20.8 months; mean academic performance 26 months.
Exclusion: parental unwillingness
Language level: prior to FC, 6 communicated through limited verbal ability, 6 used augmentative system, one used simultaneous communication, one used sign alone. Pre-level: none able to score at basal level. Expressive one word vocabulary test , mean 33.5 months.
Additional difficulties: some with severe learning difficulties
Number: 20

Control :
Auditory or visual input
Set work versus open ended 'conversation'
Apology for 'simple' questions and tailoring to child's language level
Facilitator wore earphones and listened to white noise and on some trials, ring-binder block used
Dependent variable:
Answering questions
Engaging in conversations
Measures for dependent variable:
Typed responses on communicator
Pointing to pictures or words
Evaluator: Objective
Context:
3 familiar facilitators (all 2+ years with the child) except for pre and post tests where speech and language therapist used. Apology for 'simple' questions and tailoring to child's language level.
Time scale: 10 weeks
Intensity: 3 sessions per day, 54 trials per session
Integrity: Programme based on Biklen procedure
Ethical concerns:
Research to evaluate effectiveness
Based on idea of autism as a motor difficulty
Results:
Wide variation in performance across designs but little support for FC facilitating beyond student's independent abilities
Less facilitator effect than reported in other studies
Evidence that facilitator effect increased over time of facilitation
For some students, an abdication effect was found (ie students' accuracy decreased under facilitation compared to independent performance)
Training implications: Biklen approved 3 day training given

6.4.10 Study 10: on FC

Impact of Facilitated Communication combined with direct instruction on academic performance of individuals with autism (Myles, Simpson and Smith, 1996)

Programme: Facilitated Communication
Sample:
Age: 12.3 to 28.1 years (mean 19.4 years)
Diagnosis: autism by independent person to DSM IV criteria. ABC score
IQ: severe or profound learning difficulties. PEP-R given
Exclusion: parental unwillingness
Language level: none or extremely limited verbal expression
Additional difficulties: severe or profound learning difficulties
Number: 20
Control:
Independent pointing (no FC)
Facilitated communication (FC)
Facilitator wore earphones (FC control)

Additional treatments:
Specialist day centre service curriculum
Teaching by direct instruction discrete trial learning
Dependent variable: Answering questions
Measures for dependent variable:
Typed responses on communicator
Pointing to letters, pictures or numbers
Evaluator: Objective
Context: 12 familiar trained facilitators
Time scale: 14 weeks
Intensity: 3 days per week
Integrity: Programme based on Biklen procedure and monitored by project staff
Ethical concerns:
Based on idea of autism as a motor difficulty
Research to evaluate effectiveness
Results:
No significant differences within subjects for different task performance (letter recognition, sound/symbol correspondence, number recognition, one to one correspondence, positional words and positional concepts)
Significant difference across subjects between FC condition and FC control condition.
Multiple regression analysis showed no significant effect of time on performance for no FC and FC conditions, but a significant effect with the FC control condition
In FC control condition, significantly poorer performance for first 15 days, then performance returned to level of other conditions
Results do not support FC use as an educational tool
Failure to demonstrate knowledge of the basic academic tasks taught
Training implications: Biklen approved 3 day training given

6.5 Research on communication programmes planned

The outcome of all the research reviewed on FC was so uniform that it was decided not to give details of further planned research on the same topic (see section below for a discussion of this point). No research on other aspects of augmentative communication was found.

6.6 Evaluation of research on communication programmes

The Delaware programme using PECS has not been evaluated in comparison with other programmes, nor in relation to the value of any particular component (including PECS), its duration or intensity. The studies reported above show gains in communicative ability (including the development of speech) and in the medium term, placement of children in schooling independent of support from the centre. This is particularly impressive, given that nearly half the children appear to have severe learning difficulties, in addition to autism. Thirty eight per cent of one study moved from a classification of autism to one of learning disabled (mild or specific learning difficulties) and a further 31% to what in the UK would be termed moderate learning difficulties. This reduction in 'autism scores' was dependent on the acquisition of speech and so it may be something of an artefact of the scoring on the Autism Behavior Checklist. In other words, it is clear that the children improved but improvement in language scores may predict a lower 'autistic' score and so these cannot be viewed as independent, separate gains from the programme. On the other hand, the fact that a level of facilitation with PECS predicted the development of speech, is evidence for the likely connection between the two, enhancing the view that experience of communicating with PECS, aided language development, at least in these children. Unfortunately, no details of the actual language levels are given, so it is not clear exactly what these gains comprise.

There are no controls in these studies, nor are they evaluated by independent assessors, so they can only be suggestive of the benefits of the programme. Given that limitation, it appears to be a low-cost system (although no cost-benefit analysis is made) and does not depend on extensive training or monitoring of staff. It fits in well with normal pre-school provision and involves parents as co-therapists, without giving them the burden of the entire programme. It does not require residential provision, nor segregation into special classes.

No systematic evaluation of augmentative communication systems in autism using groups of five or more children (beyond PECS in the context of the Delaware programme) were found. Bebko (1990) has conducted a review of the literature on the indicators of the effectiveness of language intervention programmes for children with autism and conducted a meta-analysis of the results. This showed that the ability of the child to change key terms (such as pronouns) in echoed speech, to fit the context, was a critical characteristic in predicting the success of the programme. He suggests that the ability to modify their echolalia in this way implied that the prerequisites for language were accessible through speech and that children who had no speech or only unmitigated echolalia were less likely to do well with speech-oriented therapies.

The one study given (Bernard-Opitz et al., 1991) is not an evaluation of a particular augmentative communication system but rather a qualitative study of the different patterns of interaction found in dyads comprising children with autism and their parents and those comprising children with autism and language therapists. The findings offer suggestive data which might be important in research involving parent versus professional training of a child. In studies involving a relatively small number of children, interpersonal differences between dyads might affect the findings or might suggest variables that could be tested for their effect on outcome (eg familiarity of adult, history of the relationship, levels of intrusiveness and sensitivity and so on).

The research reports found on Facilitated Communication are so numerous and the findings so similar, that only a few were selected here as indicative. Most of the research in Facilitated Communication has centred round the issue of establishing the author of what is typed or 'written' during facilitation sessions. Examples of this were given, as were examples of research evaluating different possible benefits from facilitation as a technique.

This review has not detailed the extensive literature on the evaluation of Facilitated Communication, because most of it is concerned with testing the sole issue of the authorship of the apparent 'communications' during FC. This is clearly relevant to the evaluation of FC as an educational approach, but the studies given above address that issue more directly. There is, nevertheless, an extensive literature on the issue of authorship (Cummins and Prior, 1992; Jacobson, Mulick and Schwartz, 1995). Almost all scientifically controlled studies show that the facilitator is the author of the communication, rather than the person with an asd being 'facilitated', although Donnellan, Sabine and Majure (1992) argue that that does not necessarily negate the value of FC as an educational tool through which communicative and academic ability might be fostered. Hence, the studies detailed above are used to address that issue.

Three of the studies (Bomba et al., 1996; Erberlin et al., 1993; Simpson and Myles, 1995), investigate the effects of training in FC. As with all the studies given above, great care is taken in the design to provide uncritical, dignified, trusting conditions for the client to demonstrate optimum performance (meeting criticisms by proponents of FC to explain the failure of scientific studies to replicate their reported effects: Biklen, Winston-Morton, Gold, Berrigan and Swaminathan, 1992). Nevertheless, none of the studies were able to demonstrate any substantial beneficial effects as a result of FC training and in the Erberlin et al. study, the clients were performing at a lower rate after FC training than before. Erberlin et al. (1993) comment,

> *'..At the present time there has not been one scientifically valid confirmatory finding supporting the claims that FC produces independent client-generated communication...' (p.52)*

Konstantareas and Gravelle (1993) set out to investigate the influence of the different aspects of facilitation on the performance of the clients and found that the physical and emotional support offered were not crucial to the success of the clients, but shared information with the facilitator was. This is further evidence against the idea that the difficulties in communication in individuals with autism stems from some expressive speech problem only and that FC works through compensating for those motor problems and offering emotional support to give confidence. On this evidence, FC does not appear to 'work' at all, so the question of the mechanism through which it operates is redundant.

The study by Bebko et al. (1996) investigated the effect of FC training on a multi-stimulation study using a graded sequence of responding, designed to range from minimal to advanced communicative ability. Once more, the results of this carefully controlled study were largely negative, in terms of the effectiveness of FC, but there were some interesting findings. The facilitators in this study entered the programme for the purpose of the research, although they were well trained and demonstrated a positive and open-minded approach to the use of FC. The consequent facilitator effect in this study was less than that found in other studies, especially for the first 15 sessions, and increased as the programme progressed. The authors suggest that this may result from the facilitators needing time to 'learn' how to predict (albeit unconsciously) the clients' responses. Of even greater interest was the finding that some of the students showed what the authors call an 'abdicator' effect, whereby their performance under FC was less accurate than their pre-FC performance. They suggest that this may be a form of prompt dependence, with the students learning to hand over responsibility for communication to the facilitator. If this is true, it would mean that FC was not just unhelpful but was actually having a negative effect on the development of spontaneous communication.

Finally, Myles et al. (1996) investigate the wider application of FC by investigating its usefulness as a teaching technique in academic subjects. No success was shown in using FC on a range of simple academic tasks. The authors of this study conclude,

> '... *we contend that it is now time to acknowledge FC as an interesting phenomenon that has claimed its 15 minutes of fame, and to move on to more functional and potentially useful tools for improving the lives of individual with autism....'* (p.43-44).

Howlin (1998), in a review of treatments in autism, is equally dismissive of the claims arising from FC work.

6.7 Research needed on communication programmes

The innovatory aspect of the Delaware programme is the PECS. Small scale research could be undertaken making comparisons between PECS and alternative methods of teaching communication. This might be the use of Makaton signing and/or symbols, TEACCH picture based systems (without the 'mand' approach) and/or speech training through discrete trial learning as in the version of ABA advocated by Lovaas. The design could be a within subject cross over design, using each child as his or her own control and using measures of spontaneous communication outside the training situation as the dependent variable. Alternatively (and more convincingly) there might be a separate matched group design using standardised pre and post measures for all the children. Such a study might look for long-term as well as short-term measures of outcomes and look at comparative changes in IQ scores, measures of communication, measures of social interaction, diagnostic status and school placement. The learning style in learning PECS requires further study.

The suggestions made above for evaluating PECS could be used for other systems such as Makaton. Within larger studies of the effectiveness of certain approaches, there could be detailed analysis of a sample of dyads to assess levels of communication, sensitivity and intrusiveness either to ensure compatibility across groups or to correlate such measures with treatment outcomes.

The situation with the research into FC is almost unique in that it is an area where there has almost been too much research. Certainly there has been a large number of anecdotal and ethnographic case study reports detailing its supposed benefits, followed by an even greater number of controlled scientific studies, all showing that the phenomenon fails to materialise once facilitator effects have been controlled. It would be hard to justify further research on this, given the many areas where there is insufficient, or no, research. It is interesting to speculate on why FC should have attracted such disproportionally large numbers of evaluative research projects. We suggest it may be because it offers the possibilities of short-term, discrete programme operation with clear variables that are amenable to research designs. Most interventions in autism are not like that and it can be difficult to extract specific programme effects when the programme is embedded in a school curriculum with possible multiple influences and approaches. Where possible in this review, we highlight areas where some short-term discrete areas of research might yield some worthwhile results, because we recognise that that kind of research is easier to fund and carry out.

Chapter 7: Integration approaches

7.1 Learning Experiences: an Alternative Programme for Preschoolers and their Parents (LEAP)

The LEAP programme began in 1982 in Pittsburgh, Pennsylvania and serves children with autism and normally developing children between the ages of three and five years in an integrated project (Strain and Cordisco, 1994). At the time it was one of the few preschool programmes which was committed to inclusive practice for young children with autism - many others were segregated. It has three main components:

- an integrated preschool (two classes each with 16 children, 6 with autism)
- a behavioural skill training program for parents
- national outreach training activities

Aims: To develop play and social interaction skills and provide parent training
Target population: Preschool children with an asd integrated with normally developing children
Ratio: 1:5 plus a speech and language therapist
Cost: Salaries of the professionals involved
Funding: By the state
Setting: Preschool class and home-based
Hours per week: 15 hours
Who carries out the approach? Teachers and assistants and a speech and language therapist in close collaboration with the child's parents
Assessments used: Not known
Staff qualifications and training: Staff are teachers or assistants and receive training in the approach
Parent involvement: Parental participation is a requirement for enrolment
Compatibility: This is compatible with other approaches that involve children with an asd and normally developing children together and which stress the development of play and interaction skills and the importance of working closely with parents.

The training curriculum teaches parents the basic principles of behaviour management. Learning activities are selected based on the needs, interests and the developmental levels of individual children. Play and social interaction are developed through peer modelling, prompting, fading and reinforcement. Guiding principles of the LEAP programme are that early, inclusive intervention is beneficial, that parents and professionals working together at home, school and in the community is very important and that the normally developing children benefit too.

The physical environment of each classroom is arranged so that there are clearly defined interest areas (eg bricks; home corner; table toys; sand and water; books) that support child-initiated, child-directed play. Weekly themes (eg dinosaurs, transport, families) are used to help children learn about the world and acquire information and concepts. The classroom has a daily timetable which is designed to provide a balance of activities that include quiet/active, individual/small and large group and indoor and outdoor activities.

7.2 Walden preschool programme

This programme was set up in 1985 and offers early education, social integration and incidental teaching to children with autism (n=7) together with normally developing children (n=8) (McGee, Daly and Jacobs, 1994). The programme is based on the assumption that other children are excellent intervention agents for children with autism. They are active and interesting and provide invaluable learning opportunities. Walden assumes that learning how to learn from peers is best accomplished when children are as young as possible. But staff acknowledge that merely exposing the children to each other is not sufficient. True social integration does not occur without direct teaching. In a free choice classroom, staff work to keep all areas and activities constantly integrated. Traditional education for children with autism has consisted of highly structured sit-down activities that are offered in distraction-free settings. Incidental teaching, as in the Walden programme, offers an alternative. The main components of the approach are:

- a natural environment is arranged to attract the children to desired activities
- the child initiates the teaching process by indicating an interest in something
- the teacher uses the child's initiation as an opportunity to prompt an elaboration
- the child's response to the teachers prompt results in a confirming response.

Aims: To use the child's interests to encourage interaction and the development of expressive skills and to learn how to learn from peers
Target population: Preschool children with an asd integrated with normally developing children
Ratio: 1: 3
Cost per child per year: $24,000 (McGee et al., 1994).
Funding: By the state
Setting: School within a University
Hours per week: 30 hours
Who carries out the approach? Teachers, assistants and parents
Assessments used: Video records
Staff qualifications and training: Information not available
Parent involvement: Parents are given information and skills to blend the teaching naturally into family life
Compatibility: It is compatible with other approaches which value the child's interests and use these to encourage the development of social and communication skills.

Staff must continually track the children's interests to identify the perfect timing of the 'teachable moment'. Verbal objectives and expressive language are the main priority for children in their first year. An incidental teaching environment provides frequent opportunities to make choices and to experience the natural consequences of language. In the second year, the broader goal is to prepare children to learn how to learn from peers. Behaviour management stresses the promotion of engagement by highlighting children's preferred materials and activities. Increasing fun decreases behaviour problems. Each child is videotaped each day for 5 minutes, whatever they are doing, at preset times. Due to the intensity of the work, staff have only four hours contact time each day.

The format options for parents include:

- weekly individualised programme for 6 months
- ongoing consultation
- biweekly parent seminar
- school communication

7.3 The Douglass developmental disabilities centre

This consists of 3 classrooms at Rutgers University wherein three stages of 'integrated' provision have been set up for children with an autistic spectrum disorder (Handleman and Harris, 1994). Children with an asd enter the 'prep' classroom where they are directly taught the skills needed for integration through applied behaviour analysis techniques. Parents are also taught to follow this programme so that the child is consistently managed through the day and has the maximum hours of training per day. The staff ratio in this class is 1: 1 and discrete trial methodology is used. Once the child has acquired sufficient skills to cope, and his or her behaviour is under sufficient control, the child moves to the small group class. Here the staff: child ratio is 1:2 and the child begins to learn how to learn in small groups. In this group the child is taught more specifically the entry behaviours he or she will need to enter the third integrated class. The child with autism usually takes 3 years to progress through the 3 classes.

The integrated class works on the incidental training model that is also used in LEAP programme (Strain and Cordisco, 1994). The other aspects of the LEAP classroom also feature in this model. The staff structure the environment and their own interactions so that the child with autism is cued to behave more spontaneously and socially. Other children are trained in ways of encouraging play and social interaction, not formally, but in ways they have seen demonstrated by staff.

Aims: To systematically teach the skills necessary for integrated learning by direct teaching and graded experience
Target population: Preschool children with an asd are progressively integrated with normally developing children
Ratio: 1: 1, 1:2, 1:5
Cost per child per year: Information not available
Funding: By the state
Setting: School within a University
Hours per week: 25 hours
Who carries out the approach? Teachers, assistants and parents
Assessments used: Video records
Staff qualifications and training: Training in applied behaviour analysis and incidental teaching techniques
Parent involvement: Parents are given specific ABA training and required to carry out a home based programme in the first year. Parent support groups and regular information exchange.
Compatibility: It is compatible with other approaches which use behavioural techniques or which offer integrated experiences.

7.4 Research on integration approaches

7.4.1 Study 1: on integration approaches

LEAP preschool (Strain and Cordisco, 1994)

Programme: Integrated pre-school with traditional varied curriculum and use of peer modelling with concurrent parent training behavioural programme
Sample:
Age: mean 43 months (30-64)
Diagnosis: autism or PDD-NOS (DSM III-R/ CARS) CARS scores: mean 37 (30-49)
IQ: 6 to 119; mean 61 (McCarthy Scales of Child Ability)
Language level: speech 0-48 months, receptive language 4-44 months: Sequenced Inventory of Communication Development
Exclusion: less than a score of 30 on the CARS
Additional difficulties: some with learning difficulties
Number: 48
Control :
Comparison group: No integration programme, just behavioural training of parents
Dependent variable:
Placement outcomes
Developmental gains
Communication scores
Degree of autism
Family satisfaction
Measures for dependent variable:
Parental interview and school records
McCarthy Scales of Child Ability
Sequenced Inventory of Communication Development
CARS
Parent survey and rating scale for stress
Observations across settings
Evaluator: Not independent of programme nor blind to treatment status
Context: Pre-school based with concurrent parent-training programme
Time scale: 2-3 years
Intensity: 15 hours/ week at preschool plus home treatment programme run by parents
Integrity: Treatment team trained and closely monitored by project staff
Ethical concerns:
School-based programme based on peer modelling and cueing of appropriate social and communicative behaviour and individual teaching of 'entry' skills.
Home based programme based on family centred approach on behaviour management and the teaching of skills - allows easily transferred teaching skills without professional training.
Parent involvement essential to maintain intensity but parents also supported with meetings and attitude of 'parents as partners'
Results:
In the LEAP group, the majority 'outgrow' the qualification for an 'autism' diagnosis after two years of treatment. Most of the comparison group though retain the diagnosis.
Both groups make developmental gains, but the LEAP group consistently do better.

The LEAP group behave more appropriately, socially, and are more actively engaged in academic work
Normally developing programme peers show no negative and some positive outcomes (eg better social skills, fewer disruptive behaviours).
50% LEAP children placed in mainstream education up to 5th. grade
Few outcome measures of parents initially distinguish the two groups, but two to three years after the programme, LEAP parents show less depression and stress
Initial cognitive, communicative and behavioural improvements of LEAP children are maintained. Control children do not improve after treatment, but do not regress.
No difference between groups on appropriate behaviour in home setting
Training implications:
Staff qualified professionals but also trained and monitored by University project directors
Parent training programme part of the intervention
Identified precursors for success:
No precursors for success identified but not related to initial level of functioning, family income and educational level, nor severity of autistic symptoms.

7.4.2 Study 2: on integration approaches

The Walden preschool (McGee, Daly and Jacobs, 1994)

Programme: Early education, social integration and incidental teaching programme focusing on language and social development
Sample:
Age: mean 44 months (30-66)
Diagnosis: autism (DSM III-R)
IQ: mean 57 (29-91) Stanford-Binet/ Kaufman Assessment Battery for Children/ Brigance Inventory of Early Development and VABS
Language level: PPVT Expressive One Word Picture Vocabulary Test
Exclusion: no exclusion criteria but no psychotropic medication on programme
Additional difficulties: some learning difficulties
Number: 14
Control: No control group
Dependent variable:
Language development
Social development
Educational placement
Measures for dependent variable:
Ongoing videotaped observations and coding
Assessment probes during teaching
Receipt of social bids from peers by children with autism. 43% of children with autism improved in peer interactions.
Evaluator:
Partly independent of programme and blind to condition status
Context:
School based with parent training programme as accessible modules
Time scale: 2+ years
Intensity: Full day/ full year
Integrity: Treatment team trained and closely monitored by project staff in university setting
Ethical concerns:

Based on incidental teaching model of maximising naturally occurring teaching opportunities. Child centred and behaviour management through education and opportunity. Parent involvement essential to maintain intensity

Results:

Successful verbal language by most leavers at all levels of ability. The mean level of verbalisation changed from 4% (0-14) on entry to 13% (1-37). Verbalisations tripled, often outstripping that of the normally developing peers (27%). Twelve out of 14 children were mainstreamed with varying levels of support.

Training implications: Staff trained and monitored by University project directors

Identified precursors for success: Initial speech predicted good outcome

7.4.3 Study 3: on integration approaches

Changes in language development among autistic and peer children in segregated and integrated preschool settings

Harris, Handleman, Kristoff, Bass and Gordon (1990)

Programme: Segregated versus integrated preschool programme

Sample:

Age: i) mean 58 months (49-66) ii) mean 55.8 months (52-60)

Diagnosis: autism (DSM III) 2 diagnoses agreed CARS i) Mean 34 (30.5-38) ii) 30.4 (23.5-38)

IQ: Stanford-Binet IV i) mean 62.6 (43-71) ii) mean 69 (59-83) iii) C group mean 108.5 (96-125)

Language level: PPVT i) mean 68.2 (46-97) ii) mean 60.4 (41-90) iii) mean 97 (83-109)

Exclusion: epilepsy or severe learning difficulties

Number: 10

Control: E1: 5 children in segregated class; E2: 5 children in integrated class; C group: 4 normally developing peers

Additional treatment: Pre-school programme

Dependent variable: Language ability

Measures for dependent variable: PPVT

Evaluator: Not independent of programme nor blind to treatment status

Context: School based

Time scale: 1 year +

Integrity: Treatment team trained and closely monitored by university based staff

Ethical concerns:

Based on application of operant conditioning theory (Skinner, 1957) which is assumed to be universally applicable (ie no account of autism other than in content of programmes, but also on model of incidental learning and the cueing of behaviour).

Parent involvement essential to maintain programme

Results:

All children made significant progress

i) Segregated children made most progress. All progressed. Pre-treatment developmental rate: 0.66, post-test 1.37

ii) 4/5 integrated children progressed. Pre-treatment developmental rate: 0.73, post test 1.52

iii) Normally developing peers all progressed. Pre-treatment mean, 1.15, post test 2.09

Significant difference between all autistic children's pre and post treatment scores and those of the normally developing children. All children gained in developmental age. No significant difference between segregated or integrated children with autism at pre or post level.

Training implications: Staff trained and monitored by project directors

7.5 Research planned on integration approaches:

None reported to the research team.

7.6 Evaluation of research on integration approaches

The research conducted by Strain and Cordisco (1994) offers interesting and reasonably reliable evidence of the effectiveness of the LEAP approach. The study has a comparison rather than a control group, which is its main weakness, since there is no evidence of the adequate matching which the small numbers make essential. The results are impressive, with gains in all developmental areas and 50% being mainstreamed on leaving the pre-school, some into the 5th. grade (end of primary). The gains in all the key developmental areas were also substantial, with some achieving a doubling of the developmental rate over the course of the programme.

If the comparison group reported had been a properly constructed control group, the results would have been yet more impressive. Both the experimental and the control group received parent-training in ABA. The main difference between groups was that the comparison group did not enter the LEAP programme and so they did not receive training in key social skills nor the incidental teaching that would allow access to learning in mixed environments. The LEAP children scored significantly better than the comparison group on all the measures taken at school, although there were no differences in their behaviour at home. This fits with what is known of the generalisation difficulties in autism and also suggests that training skills and managing behaviour may not be enough to bring about significant and long-term changes in autism; there may need also to be ways of enabling access to the learning that is occurring in integrated settings. It was also interesting to note that differences in the parental condition did not occur until 2 to 3 years after the programme had ended for their child. This will be important to take into account when planning research; long-term judgements of parents may be more significant than immediate reactions. Unfortunately, the person collecting the evidence was not independent of the programme, and so there may be many reasons for a comment or rating other than an objective evaluation.

The Walden programme (McGee et al., 1994) offers an even higher rate of children mainstreamed (12 out of the 14 studied), albeit with different levels of support. It also showed the children making remarkable developmental gains over the 2 years of the study, especially in the area of language. Unfortunately, no control group was used, so it is difficult to be certain that the results were the direct result of the intervention, rather than some other extraneous variable, or the simple passage of time. Nor was there a qualitative or pragmatic analysis of the language used so it is not clear whether increased verbalisations (to a rate often exceeding that of the normally developing group) are of themselves a fair measure of progress.

The third study in this section (Harris et al., 1990) did have a well matched control design, but the control group were normally developing children so are not a control for the efficacy of the treatment. Once more results showed marked improvement after 1 year in the programme. There were smaller rates of integration, but this measure is hard to interpret, given that it is so sensitive to political policy and local views. There was a large gain in the IQ scores (19 points) of one group while the scores of the normally developing children did not change over the same period (as would be expected). A regression analysis on the IQ scores showed that the gains were not attributable to regression to the mean effects. The second group tracked were measured on a language scale and showed increased scores over the year but the gain was not significantly different from that shown by the normally developing group. This does not mean that the programme was ineffective, but rather that the normally developing peers gained from the language programme in this integrated setting almost as much as the children with autism.

Overall, the results of these studies offer substantial, if not conclusive, evidence that integration (effectively managed with trained staff) can enhance the development of children with autism and that normally developing peers do not suffer, and may gain, from the experience.

7.7 Research needed on integration approaches

Although many children with autism are offered integrated education as their provision in the UK (especially at the pre-school stage) there has been no research on the effectiveness of this approach compared to the model of offering early specialist provision to teach the key 'entry' skills needed for effective education. There also needs to be research on which skills are the 'key' ones and the kinds of organisation of the environment that foster integration at the same time as meeting the educational needs of all the participants. The practice of offering untrained support to children with an asd in mainstream schools needs research of both a qualitative and quantitative kind. We need a large pool of data from outcome variables (in terms of both academic and social development) related to data at time of diagnosis (CARS scores, IQ measurements, language scores) with time and type of support in mainstream settings as the independent variable. There is also a need for survey research on what kinds of support there are in terms of how much, for how long, for what activities or periods, with what training and so on. Qualitatively, we need to identify working practices of support assistants, how they facilitate (or prevent) social integration, how they support the role of class and subject teachers or to what extent they de-skill teachers and prevent them taking full responsibility for an inclusive curriculum.

The models above suggest inclusive practices (such as training and cueing incidental learning) that require trained staff to make them effective. Research on the key skills that staff need to possess and models for training staff in those skills would also be useful. Again there is a need for survey research to identify the level of skill and knowledge already available and the training models that exist, but there is also a need for evaluative research of the training both for support assistants and for staff of all kinds. Specialist training courses are still uncommon, but they are increasing. Some local authorities have developed their own; others buy into those provided in Higher Education. A survey of what is available, who is being trained, and the aims and content of such courses would help planning. Even more important would be research into outcomes in terms of practice, perhaps comparing baseline with post course practice or comparing short single method training (as in TEACCH courses) with professional development courses in terms of staff confidence and attitudes at least. The need for specialist training is contrasted with the Teacher Training Agency (TTA) initiatives requiring a large generic element in all special needs professional development courses. This would be an opportune moment, therefore, to research how this initiative affects the training that is available and the take up of such training by professionals.

Chapter 8: Division TEACCH (Treatment and Education of Autistic and related Communications handicapped Children)

A questionnaire was completed and returned by Division TEACCH. Division TEACCH was founded in 1972 at the University of North Carolina (Lord and Schopler, 1994). The programme is a state-wide, community-based programme for children and adults with autism and communication disabilities. In 1992, there were 6 TEACCH centres in cities where the University of North Carolina has a base to assist with staffing and research activity across the state. TEACCH services are both centre and outreach-based. There is a demonstration preschool classroom within the medical school, but other educational services are provided within school and programmes in the communities within which the children and adults live.

A major goal is to provide continuity of services from preschool to adult life. Lord and Schopler (1994) describe the characteristics of the services provided by TEACCH centres to preschool children across the state. A total of about 250 new preschool children a year are seen at the 6 TEACCH centres, so at any one time, about 650 to 700 preschool children are receiving TEACCH services. Over 4,500 children and adults have been served by TEACCH during the first 20 years of its existence. Most were first seen during their preschool years and have moved through the programme. The age of referral to TEACCH has been decreasing over the last ten years. They may be referred by the age of three and quite a number at the age of two years. Types of intervention include structured teaching, communication training, leisure and social skill development and stress reduction.

The major feature of the TEACCH approach is structure. Schopler et al. (1971) showed that children with autism learned better in a structured learning environment and that children at earlier developmental levels needed structure more than children at higher levels of functioning. Some of the difficulties in autism which the TEACCH programme identifies and addresses are organisational difficulties, memory problems, difficulties with auditory processing and making transitions from one activity or topic to another. The environment is organised to help the child or adult understand and remind them what they are to do. The emphasis is on positive strategies of behaviour management and visually rather than verbally mediated teaching strategies.

TEACCH aims to develop communication skills, and to help individuals work and play independently of adults. Developing a student's communication skills in terms of their understanding and their ability to express themselves is a key part of the approach. A number of ways of communicating are acknowledged and taught depending on the individual concerned, which include using objects of reference, photographs and pictures, symbols and words. The programme has a long-term perspective, from child to adulthood and focuses on the student's strengths and interests and works on emerging skills. The staff believe there is value in providing learning and play experiences with normally developing children and set up reverse integration opportunities and full inclusion into mainstream classes.

TEACCH does not address the autism directly, but provides what might be called a 'prosthetic environment' for people with autism whereby many of their difficulties can be circumvented and they can be enabled to live and learn without undue stress and anxiety. There is a detailed assessment which identifies 'emerging skills' and uses these as the first teaching goals. Children are taught functional (even vocational) skills from the start and are taught good work habits which enable them to function semi-independently, as long as there is a structure. It is one of the most widely used approaches in autism. European (Flemish) versions of TEACCH incorporate a cognitive element (Gillberg and Peeters, 1996) and prefer to call the approach 'visually mediated instruction'. Later versions from America also involve a cognitive element, at least for the more able child (Schopler and Mesibov, 1995). Parents are involved as equal partners in the programme throughout.

Aims: To provide visual information, structure and predictability to help the child understand what s/he has to do, and where and when this should be done and in what order.
Target population: Children and adults with an asd (from 8 months to 55 years old); PDD (APA, 1987); severe communication disability
Ratio of adult to child in class: 1: 3 school age. When TEACCH methods are first introduced and taught to a child, this may require 2 adults to 1 child or 1:1, until the method is understood and established.
Cost per child per year: $5,000 to $15,000
Funded by: The state in the US and by schools which use parts or all of the approach
Setting: School; home; college; adult placements
Hours per week: As appropriate
Who carries out the approach? The child's keyworkers and their parents
Assessments used:
APEP Adult and adolescent Psychoeducational Profile
Psychoeducational Profile-Revised (PEP-R) (Schopler, Reichler, Bashford, Lansing and Marcus, 1990)
Staff qualifications and training:
Therapists have a first degree or a Master's degree
Therapists have 'substantial' experience with children with autism (Lord and Schopler, 1994) and are required to have at least two years experience prior to interview for a post
Each TEACCH centre is headed by a Clinical Psychologist
Therapists are supervised by another therapist for their first 6 - 12 months in post
There is no working distinction based on a person's initial training or discipline - all are expected to work on any aspect of the programme.
Parent involvement:
Parents are viewed as central to the process and the aim is to promote a feeling of well-being and competence. They are invited to be co-therapists and to work alongside staff. Strategies can be used in the home situation and TEACCH staff make home visits
Compatibility with other approaches:
It is compatible with approaches which provide structure and visual clues. Diluting the programme with different interventions often compromises the effectiveness of each one (Mesibov, 1998).

With the preschool children, the emphasis is on clarifying the diagnosis, developing learning skills and appropriate social and communicative behaviour. Parents are more closely involved than later in the programme and there is more emphasis on the organisation of the classroom. Parents are encouraged to maintain some contact with TEACCH after an assessment even if they do not participate in a formal treatment programme. They can work as co-therapists with their child on goals they choose (eg toilet training; increasing communication; independent play). They are also given information about parent support groups. Strategies and activities for parents are provided in two publications by Schopler, Reichler and Lansing, (1980) and Schopler, Lansing and Waters, (1983). There is a publication on communication at school and home by Watson, Lord, Schaffer and Schopler, (1988). Children in the TEACCH programmes may attend mainstream or special schools and units or may be at home full-time with their parents. TEACCH therapists visit school settings to advise staff on the children.

Division TEACCH has supported over 100 adults with autism through its supported employment programme ((Keel, Mesibov, and Woods, 1997). Three models of supported employment are used including individual placements, a dispersed enclave and a mobile crew model. The retention rate is 89% which is largely due to the long-term support services offered to individuals and employers.

Many of the specialist schools and units in the UK have adopted some TEACCH ideas and of the major approaches, this is the one most likely to be evident within UK schools and units, both mainstream and special. Staff from Division TEACCH have visited the UK regularly over the last eight years to provide three and five day training courses on TEACCH for practitioners and parents. The most commonly seen TEACCH strategy is the use of visual timetables and the use of other visual clues (eg pictures, photographs, symbols, sequenced diagrams) to clarify what it is the students are to do, in a work, home or leisure setting.

8.1 Research on the TEACCH programme

Details of eight studies on the TEACCH programme are presented below, in chronological order, followed by a discussion on their value and ideas for further research on TEACCH.

8.1.1 Study 1: on TEACCH

Treatment outcome for children with autism and their families

(Schopler, Mesibov, Devellis and Short, 1981)

Programme: Based on TEACCH programmes.
Sample:
Age: Preschool to adult
Diagnosis: Information not available
IQ: Information not available
Language level: Information not available
Additional difficulties: Some with severe learning difficulties
Number: 348
Control: No control group
Dependent variable:
Rate of institutionalisation,
Academic achievement
Quality of life
Measures for dependent variable: Parent questionnaire
Intensity: Various
Integrity: Programme part of university research, supervised by TEACCH personnel
Ethical concerns:
Based on an understanding of the difficulties in autism in communication, social interaction and flexibility and recognises them as visual learners. It enables development towards

independence but the adult is in control and sets goals. It involves the family and assesses for stress

Results:

96% of adults still functioning in the community (compared to 39-74% in institutions in other studies (DeMyer et al., 1972; Rutter et al., 1967)

Quality of life measures showed good level

High level of reported satisfaction (from parents) with the TEACCH programme.

Training implications: Training needed in TEACCH methods - 3 day minimum

8.1.2 Study 2: on TEACCH

Treatment outcome for children with autism and their families

(Schopler, Mesibov and Baker, 1982)

Programme:

Based on TEACCH programmes. 1. diagnostic evaluation only 2. evaluation and parent training 3. evaluation and placement in TEACCH class 4. evaluation, parent training and TEACCH class

Sample:

Age: 2 to 26 years old at study time
Diagnosis: 51% with autism - DSM III/ DSM III-R/ CARS
IQ: Information not available
Language level: Information not available
Additional difficulties: Some with severe learning difficulties
Number: 348 (53% of questionnaires sent)

Control: No control group

Dependent variable:

Rate of institutionalisation
Academic achievement
Quality of life

Measures for dependent variable: Parent and staff questionnaires

Evaluator:

Parents who are part of the programme
Staff not blind to the treatment or part of it

Context: TEACCH schooling received, various

Intensity: Various

Integrity: Programme part of university research - supervised by TEACCH personnel

Ethical concerns:

Based on an understanding of the difficulties in autism in communication, social interaction and flexibility and recognises them as visual learners . It enables development towards independence but adult in control and sets goals. It involves the family, but assesses for stress

Results:

93% of adults still functioning in the community (compared to
39-74% in institutions in other studies (DeMyer et al., 1972; Rutter et al., 1967)
Quality of life measures showed good level.
High level of reported satisfaction (from parents) with the TEACCH programme.

Training implications: Training needed in TEACCH methods - 3 day minimum

8.1.3 Study 3: on TEACCH

Short-term treatment outcome using parents as co-therapists for their own autistic children (Short, 1984)

Programme: Piedmont programme based on TEACCH pre-school and parent-training programme and later school provision
Sample:
Age: 2.3 to 7.5 years; mean 4.7 years
Diagnosis: Rutter (1978) - 4 criteria
IQ: 20-106 , mean 54 (Merrill-Palmer; Bayley Scales and the WPPSI)
SQ: 25 to 97 mean 57.9
Exclusion: more than 9 years of age, more than 2 hours travel from the clinic
Language level: information not available
Additional difficulties: some with severe learning difficulties
Number: 15
Control: Own control with baseline design
Dependent variable:
Parental guidance and management behaviours
Appropriate/ inappropriate child behaviour
Family stress
Measures for dependent variable:
Behaviour checklist
Interviews with parents
Questionnaires to parents
Evaluator: Not independent of programme, nor blind to design
Context: Parent training at the TEACCH clinic
Time scale: Duration of programme 6 to 8 sessions
Intensity: 1 session of 60 to 90 minutes, every 2 to 3 weeks
Integrity: Programme part of university research - supervised by TEACCH personnel
Ethical concerns:
Based on understanding of difficulties in autism in communication, social interaction and flexibility and recognises them as visual learners
Enables development towards independence but adult in control and sets goals
Involves family, but assesses for stress
Results:
Compared to the baseline period, the children whose parents received training in TEACCH methods showed a significant increase in appropriate behaviours, especially in the areas of appropriate play or work and communication.
Social interaction increased throughout, but the difference for the treated versus untreated periods was not significant. Treatment gains generalised outside of the training setting.
Training implications: Training needed in TEACCH methods - 3 day minimum

8.1.4 Study 4: on TEACCH

TEACCH Services for pre-school children (Lord and Schopler, 1989)

Programme: State-wide programme based on TEACCH pre-school and parent-training programme and later school provision

Sample:
Age: 3 or 4 years
Diagnosis: DSM-IIIR; CARS (Schopler et al., 1986)
IQ: 30 to 50
Language level: Non-verbal
Additional difficulties: All with severe learning difficulties
Number: More than 50
Control: No control group
Dependent variable: IQ pre and post scores
Measures for dependent variable:
Behaviour checklist
Interviews with parents
Questionnaires to parents
Evaluator: Not independent of programme nor blind to design
Context: Parents trained but intervention at pre-school/ school
Time scale: Duration of programme: 4 or 5 years
Integrity: Programme part of university research, supervised by TEACCH personnel
Ethical concerns:
Based on an understanding of the difficulties in autism in communication, social interaction and flexibility and recognises them as visual learners
Enables development towards independence but adult in control and sets goals
Results:
3 year olds - mean increase by age 7 years of 22 to 24 points in nonverbal IQ
4 year olds reassessed at 9 years gained an average of 15 to 19 IQ points
Both groups remained mildly retarded.
Training implications: Training needed in TEACCH methods - 3 day minimum
Identified precursors for success: Gains in pre-school years greatest for youngest non-verbal children and those who acquired language between first and second testing

8.1.5 Study 5: on TEACCH

A follow-up study of high functioning autistic children

(Venter, Lord and Schopler 1992)

Programme:
Follow up of children, over 8 years, who had TEACCH educational programmes
Sample:
Age: Pre-school and primary, then follow-up mean age, 15 years (range 10 to 37 years)
Diagnosis: Autism, DSM-III (pre), DSM-IIIR; ICD 10 (follow-up); ADI/ADOS
IQ: At pre-school, more than 60, mean 80.2: Merrill Palmer, Leiter. At follow-up Ravens/ WISC-R/ WAIS-R
Exclusion: IQ less than 60
Language level: early and follow up language comprehension (PPVT); 39 had useful speech at 5 years old
Additional difficulties: four with epilepsy, two with a degenerative disorder
Number: 58
Control: No control group
Additional treatment: All children were in school, of varying kinds, or in work at follow up
Dependent variable:

Social adaptive behaviour - VABS and parent interview
Academic achievement - standardised achievement tests
Cognitive and language development

Measures for dependent variable:
VABS and parent interview
Standardised achievement tests

Evaluator: Not independent of programme, nor blind to design

Measures for dependent variable:
VABS
Raven's Matrices
PPVT
Neale's reading test

Context:

Time scale:
Duration of programme - approx. 9 years continuous education
8 years follow-up

Intensity: Various

Integrity: Programme assumed part of university research - supervised by TEACCH personnel, but not specified

Ethical concerns:
Based on an understanding of the difficulties in autism and recognises them as visual learners. Enables development towards independence but adult in control and sets goals
Involves family, but assesses for stress

Results:
28 in special schooling (at follow -up or for their last year of school); 17 in technical schools with support; 13 in mainstream school with little or no support. Significant difference in one group in segregated schools and more with full time aides came from other area. 66% developed useful speech as only method of communication

Training implications:
Training needed in TEACCH methods - 3 day minimum

Identified precursors for success:
Language scores and verbal IQs above median predict mainstream placement. Verbal skills best predictor of academic achievement and social adaptation.

8.1.6 Study 6: on TEACCH

Evaluation of a TEACCH training programme (Durnik, 1996)

Programme:
Practical and theoretical TEACCH based programme for practitioners and parents

Sample:
Number: 75

Control: No control group

Dependent variable:
Attitude to training received
Confidence and opinion on own skill in teaching and managing children with autism

Measures for dependent variable: Questionnaire (anonymous)

Evaluator: Programme organiser

Time scale:
Data from 5 years of training courses

Each course 5 days
Integrity: Programme run by TEACCH accredited personnel
Ethical concerns:
Training based on an understanding of the difficulties in autism in communication, social interaction and flexibility and recognises them as visual learners.
Emphasises enabling development towards independence.
Involves family, but assesses for stress
Results:
Virtually all reported the training to be useful and satisfying
70% found it excellent in helping them work with people with autism up to 4 years after training.
Training implications: Need accredited staff to run training programme

8.1.7 Study 7: on TEACCH

The TEACCH strategy in mentally retarded children with autism: a multi-dimensional assessment pilot study (Panerai, Ferrante and Caputo, 1996)

Programme:
Based on TEACCH programmes
Sample:
Age: 6 to 18 years
Diagnosis: Autism
IQ: Mean MA 16 months
Language level: Mute, gestures, vocalisations, crying
Additional difficulties: all with profound and multiple learning difficulties
Number: 18
Control: No control group
Dependent variable: Cognitive and social development
Measures for dependent variable:
Direct observation
VABS Adaptive Behaviour Scales
Psycho-Educational Profile-Revised
Time scale: 12 months
Intensity: Various
Integrity: Programme part of university research, supervised by TEACCH personnel
Ethical concerns:
Based on an understanding of the difficulties in autism in communication, social interaction and flexibility and recognises them as visual learners
Enables development towards independence but adult in control and sets goals
Involves family, but assesses for stress
Results:
Statistically significant progress made in communication, socialisation, and self care.
Statistically significant differences in perception, motor activities, cognitive performance.
Statistically significant reduction in stereotypes, but not SIB nor aggression.
Training implications: Training needed in TEACCH methods - 3 day minimum

8.1.8 Study 8: on TEACCH

Effectiveness of a home program intervention for young children with autism
(Ozonoff and Cathcart, 1998)

Programme: Based on TEACCH pre-school and home based programme.
Sample:
Age: 2.3 to 7.5 years, mean 4.7 years
Diagnosis: Autism: DSM-IIIR; CARS
Exclusion: More than 9 years old, more than 2 hours travel from the clinic
Language level: Information not available
Additional difficulties: Most with severe learning difficulties
Number: 11
Control:
Not random, designated by time of arrival into the programme
11 in control group for home treatment effects matched on age and severity of autism, initial PEP-R and time interval between pre and post testing
Additional treatment:_
All children were in preschool, most receiving discrete trial learning in school
Dependent variable: Cognitive, motor and social measures:
Evaluator: Not independent of programme, nor blind to design
Measures for dependent variable:
PEP-R - repeated measures MANOVA on pre and post PEP-R scores
Context: Parents trained in clinic and at home
Time scale: Duration of programme, 6 to 8 sessions over 4 months
Intensity: 1 hour a week training parent in clinic/ home based treatment (3.5 hours a week)
Integrity: Programme part of university research, supervised by TEACCH personnel
Ethical concerns:
Based on an understanding of the difficulties in autism in communication, social interaction and flexibility and recognises them as visual learners
Enables development towards independence but adult in control and sets goals
Involves family, but assesses for stress
Results:
Experimental group improved significantly more than the control group on scores of imitation, fine motor skills, gross motor skills and non-verbal conceptual skills.
Progress of treated group 3 to 4 times greater than discrete trial only group, on all outcome measures
Treatment group made 9.6 months developmental gain in 4 months.
Training implications: Training needed in TEACCH methods - 3 day minimum
Identified precursors for success:_
Higher initial abilities led to more improvement.
Cognitive verbal scores related to positive outcome in terms of change scores.
Age not correlated with change scores.
No significant correlations between independent and dependent scores in the control group.

8.2 Research planned or in progress on TEACCH

8.2.1 Study 1 in progress: TEACCH

An international study of parental views of TEACCH programmes
(Haeussler, in progress)

Programme:
Comparison of two TEACCH programmes (N. Carolina; Denmark) with non-TEACCH approach (Germany).
Sample:
Age: 5-18 years
Diagnosis: Autism/PDD (17% unconfirmed): ICD-10/ DSM IV
IQ: Information not available
Exclusion: No children with Retts syndrome or in residential settings
Language level: Information not available
Additional difficulties: Two with tuberose sclerosis
Number: 108 (including control)
Control:
3 settings
1 non-TEACCH programme
Dependent variable:
Parental knowledge of, and attitudes to: autism; involvement in TEACCH;
Parental knowledge and evaluation of programmes
Parental attitude to treatment goals of programmes
Satisfaction rating by parents
Measures for dependent variable:
Parent questionnaire
Interview with practitioners who worked with the child
Context:
Time scale: 12 months study
Intensity: 40 hours per week
Integrity:
Programme part of university research - supervised by TEACCH personnel
Ethical concerns:
Based on an understanding of the difficulties in autism in communication, social interaction and flexibility and recognises them as visual learners
Enables development towards independence but adult in control and sets goals
Involves family, but assesses for stress
Programme part of local provision in different settings
Training implications:
Training needed in TEACCH methods - 3 day minimum

8.3 Evaluation of the research on TEACCH

Although TEACCH is one of the longest-established programmes, with an international influence, there has been surprisingly little done to evaluate the programme in terms of outcomes. Some of the outcome measures given are not systematically researched and all the details needed to fully evaluate them are not present. Mesibov's (1997) review of formal and informal evaluative measures showed that there is research evidence for the rationale of the approach and evidence of parental reports of satisfaction, but that does not constitute scientific evidence. The major weakness of follow-up studies that have no control groups is that there is no control for history effects such as changes in national policy that may have made institutionalisation less likely, regardless of behaviour, treatment or ability.

An early study, that did attempt a more systematic evaluation, was that of Short (1984) who used the children as their own control (in a baseline design) and included an unspecified comparison group who had not received TEACCH treatment. He reported significant differential improvement in appropriate behaviour and communication in the group who had undergone the TEACCH programme. Lord and Schopler (1989) report a follow up of 50 children on the TEACCH programme, based on pre and post non-verbal intelligence test scores. They found substantial changes in IQ scores over a period of four or five years, with the three year olds increasing their scores by 22 to 24 points over a four year period and the four year olds doing so by 15-19 points over a five year period. Even these large gains, however, were not sufficient to remove them from the category of mild learning difficulty. This shows that IQ scores can change by substantial amounts over time, at least in this group, but it is not evidence that it was the TEACCH programme that produced those gains.

Venter, Lord and Schopler (1992) conducted a further follow-up study of children who had been in the TEACCH programme some 8 years ago and who had then had an IQ of more than 60. In spite of the inclusion of at least three children with a degenerative disease, 66% of the sample used speech as their main mode of communication and their academic skills were higher than expected from earlier studies. Again, there was no control group and the evaluation was not done by an outsider, so it is not possible to draw any conclusions from this study. More recently, however, there have been attempts to provide more systematic evaluations of the work.

Ozonoff and Cathcart (1998) provide a well matched control study of 22 children, 11 of whom had parents giving them a TEACCH programme at home and the other 11 served as no-treatment controls. However, all 22 children were also in day school or preschool programmes which used behavioural discrete trial learning (as advocated by Lovaas). Thus, although the study makes no direct comparison of Lovaas style ABA and TEACCH, the ABA programme is acting as a baseline to the performance of both groups. The results showed significant differences in favour of the TEACCH group in four skill areas (imitation, fine and gross motor skills and non-verbal communication, with the experimental group scoring 3 or 4 times the rate of development (using gains in PEP-R scores) of the control group. Although there was no independent person to make these assessments, these figures do appear to show that a short (4 months only) TEACCH programme can be effective in improving scores (in conjunction with some ABA schooling) over and above that of a group doing ABA alone. Unfortunately, there is no control for intensity or parent involvement and so it is possible that it is any double programme or any programme using parents (rather than TEACCH in particular) that is effective.

The proposed Haeussler study is interesting in that it looks at the TEACCH programme in two different countries with a view to analysing what might be imported (and how) to a third. However, its dependent measures of parental report miss opportunities to do anything other than provide a descriptive, rather than a truly evaluative account.

8.4 Research needed on TEACCH

There need to be other larger controlled studies that directly compare children's performance (short, medium and long-term) in a TEACCH programme as against another programme, and involve evaluators blind to the purpose of the study and the status of individuals with respect to prior or current treatments. A comparative UK based study is needed.

Further research recommended by Short (1984) was to look at the treatment effects on family adaptation, especially re the parents' emotional state and capacity to cope and re the siblings, to study the role of fathers and siblings in treatment and to consider which specific aspects of treatment contribute to therapeutic change. All of these would be valuable aspects to study across a range of approaches, especially those involving parents. Again, there is little to be gained from a study by the people carrying out the approach since the results would be contaminated by the relationship of the parents to the providers of the service. It is also important to obtain data on immediate and long-term effects on the educational profile of the children and the health of the family. Parental reports can only provide weak evidence of effectiveness and measures should aim to be as objective as possible, while still being a valid reflection of the complex effects that are likely both in the treated children and other family members. It will also be important to collect data on those families who reject or are excluded from programmes (not just TEACCH) and those who abandon programmes.

Chapter 9: Daily Life Therapy at the Boston Higashi School, USA

The Boston Higashi school was opened in 1987 by Dr Kiyo Kitahara and was run along the lines of the school she founded in Tokyo in 1964 (Kitahara, 1984). The term Daily Life Therapy (DLT) was given to the educational model that Dr Kiyo Kitahara developed over a 20 year period. She was convinced that this model could be successfully implemented in other cultural settings (Quill et al., 1989). A major difference between the original school in Tokyo and the Boston school is that the latter has only children with autism on roll, whereas the former had normally developing children as well.

The practice of DLT

> *'...appears to be founded in Eastern philosophy, which accepts a relationship between an individual's mind, body and spirit, and Japanese pedagogy, which focuses on group education and group performance..'* (Quill et al., 1989, p 626).

The emphasis is on teaching and learning within a group, with little teaching on an individual basis. In some classes there may be just one teacher and 6 children and the teacher will prompt and facilitate the children individually to help them complete tasks within the group. Initially, many of the teachers were Japanese, but now almost half the staff are American, including the Principal. The school has been developed from a former school for the hearing impaired and is on a large site in Randolph, a small town near Boston, USA. In February 1998, the school had 113 pupils on roll aged between 3 and 22 years, 73% of whom were residential. There were 26 children on roll from the UK. The school does not differentiate between education facilities and residential facilities in terms of the programme. DLT is seen as essentially an educational process which permeates the whole of the child's life. The residential accommodation is 45 minutes drive from the school, although this is to move onto the school site in the near future. The children are bussed to the school with escorts who also work in the school or the residential setting.

All children are regarded as having autism or a pervasive developmental disorder. An assessment is made of the child prior to admission based on reports from other professionals and by observing the child. A video of the child taken in various settings is requested for this purpose. Children who have an additional physical condition or severe epilepsy may not be taken on at the school because parts of the DLT programme involve vigorous exercise which may be too demanding for these children.

A questionnaire was completed and returned by a member of staff who has worked at the Boston Higashi school for seven years. The details marked with an asterisk below are taken from this questionnaire.

Aims: To stabilise the emotions, establish a rhythm of life and stimulate the intellect
Target population: Autism; PDD (APA, 1987)
Ratio of adult to child in class: * 1:6 for class-based subjects; 1:3 for music, physical education (PE) and art
Cost per child per year:* $86,000 a year for 44 week boarding/ $30,000 for a day pupil
Funded by: The state, LEAs or the parents themselves
Setting: School and residential hostel for two thirds of the children on roll

Hours per week: * It is a 24 hour a day approach, taking into account all areas of daily life
Who carries out the approach? Staff at the school and residence and/or parents
Assessments used: 14 point rating scale devised by Dr Kitahara
Motor scale checklist (using sections of the VABS and the McCarthy Scales and Higashi curriculum goals)
Staff qualifications and training:* Teachers/instructors have college degrees. Most day school teachers have MEd degrees in special education. High academic standards are expected, including qualifications in teaching children with special needs and staff have to manage the high physical demands of the programme. There is a detailed induction pack and programme.
Parent involvement:* This is necessary for the child to generalise their skills to all environments. Staff make regular home visits, where possible, and there are meetings and concerts at the school for parents to attend. Children are given homework which parents are expected to support and they contribute to the IEPs. Staff aim to increase parents' confidence with their child and to acquire skills and an understanding of autism.
Staff training*: In-house orientation for teachers, parent training is ongoing. Staff in-service training monthly in addition to monthly parent-staff study meetings.
Compatibility*: DLT is a group centred approach and very strict 1:1 approaches would not be compatible. The progress of the children will be maintained if they enter a setting where the structures and patterns of life acquired through DLT are maintained - but if follow-up programmes differ from the basic principles of DLT, then regression could occur. DLT can transfer to any setting that can accommodate the students' needs for structure and continuity. The school does not see the individual components (eg music and PE) as effective in isolation - only as part of the overall school approach.

The ethos of the school is that children should be exposed to age-appropriate 'normalising' experiences. In 1995, 12 pupils at the school were spending some time in mainstream schools. They also set up reverse mainstreaming experiences for all the children on roll. Within the context of DLT, the intention is to make the school function along the lines of a mainstream school. Special subjects including art and music are taught on the premise that children with autism can develop creativity and are able to express their artistic abilities through painting, drawing and musical performance.

There is a very positive ethos - the children are given the strong message - 'you can do it'. Grand festivals and displays are included as part of the curriculum which give a feeling of corporateness and offer opportunities for PE, music, drama and art. The school is very well resourced in terms of space and certain equipment (eg trampolines; unicycles; roller skates; musical instruments; computer and audio-visual materials). PE is an impressively taught subject and all the children (and staff) engage in aerobic exercise for at least 20 minutes every day.

There have been several visitors to the Boston Higashi school from the UK either to observe the school and its practice as a whole or to review individual children. Two reports have been written by representatives of the NAS who visited in 1991 (Gould et al., 1991) and 1995 (Collins et al., 1995). Similarly, staff from the Boston school have visited several UK schools and practice and ideas have been shared both ways. Some schools and units in the UK follow aspects of DLT, but there is nowhere, as yet that has adopted the full approach. However, an independent school in the UK is currently in discussions with the Boston Higashi school with a view to following the approach in its entirety and another independent body has been established with the specific goal of setting up a UK school based on the principles of Daily Life Therapy. The intention of this latter group is to incorporate evaluative research into the development of the project.

9.1 Research on Daily Life Therapy

There have been three studies to date on the efficacy of Daily Life Therapy as practised at the Boston Higashi school.

9.1.1 Study 1: on Daily Life Therapy

The efficacy of four months of Daily Life Therapy at the Boston Higashi School
(Hardy, Henrichs and Edwards, 1991)

Programme:
Daily Life Therapy at the Boston Higashi School
Sample:
Age: Pre-school /primary (3:2 - 7.0 years; mean 6.5 years)
Diagnosis: Severe autism, DSM-IIIR; CARS 28+
IQ: Merrill-Palmer, Bayley - details not published
Language level: Speech level: 2 no speech, 2 one or two word speech, 2 bizarre speech with some meaningful phrases
Exclusion: Uncontrolled epilepsy and physical difficulties or degenerative disease excluded from the programme
Number: 6
Control: None
Additional treatment: Not available
Dependent variable:
Level of communication, daily living skills, socialisation and maladaptive behaviour
Measures for dependent variable:
VABS from parent interview, teacher reports and observations
Sequenced inventory for communication development
Evaluator:
Not independent of programme, nor blind to design
Context:
Children attending Boston Higashi school from the UK
Time scale
4 months
Intensity: Full day and residential programme
Integrity:
Staff at Boston Higashi school in dialogue with staff from original Higashi school in Tokyo
Ethical concerns:
Based on assumption that normal functioning and age appropriate behaviour can be trained
Assumes that autism leads to the appearance of severe learning difficulties rather than recognising a dual disability
Part of Japanese cultural values with the importance of the group taking precedence over that of the individual
Early residential treatment seen as beneficial and staff work towards integration from a segregated start
Results:

Increases (unspecified) in adaptive behaviour
Most gain in daily living skills - age equivalency gain of 6.5 months in 4 month period
Age equivalency gains of 2.5 months in communication and socialisation domains of VABS

Training implications:
Only qualified teachers employed in daily class activities at school; some other residential staff, but no therapists.
In-service training conducted at the school

Identified precursors for success : Not available

9.1.2 Study 2: on Daily Life Therapy

The potential benefits of Daily Life Therapy for children with autism
(Richardson and Langley, 1997)

Programme:
Daily Life Therapy at the Boston Higashi School

Sample:
Age: i) (UK schools) 4 to 16 years ii) (DLT group) 3 to 18 years
Diagnosis: Information not available
Language level: Information not available
Number: 71 (in UK special schools); 18 (at the Boston Higashi school)

Control:
Children attending one of 7 special schools in the UK
No matching data given. Report from retrospective data that they were similar on measured features at age 5 years

Additional treatment:
No details of programme being received by control children

Dependent variable:
25 features of behaviour including toilet training, normal eating, normal sleeping, playing with other children, imaginative play, 4 cognitive skills, at time of study and retrospectively at 5 years (school entry)

Measures for dependent variable:
Questionnaires from parents and teachers, assessed on a 4 point scale

Evaluator:
Not independent of programme, nor blind to design

Context:
Children attending Boston Higashi school from the UK plus a control group of children with autism attending one of 7 special schools in the UK

Time scale:
One school year

Intensity: Full day and residential programme for DLT group, unspecified for controls

Integrity:
Staff at Boston Higashi school in dialogue with staff from original Higashi school in Tokyo

Ethical concerns:
Based on assumption that normal functioning and age appropriate behaviour can be trained
Assumes that autism leads to appearance of severe learning difficulties rather than recognising a dual disability
Part of Japanese cultural values with the importance of the group taking precedence over that of the individual

Early residential treatment seen as beneficial, staff work towards integration from a segregated start

Results:

19 features (including 4 cognitive skills) the same for all children, showing increasing development with age

10 features were better developed in the group with DLT - including toilet training, eating behaviour, reduction in self harm, and reduction in physical aggression to others.

Training implications:

Only qualified teachers employed in daily class activities at school; some other residential staff, but no therapists

In-service training conducted at the school

Identified precursors for success : none given

9.2 Research planned or in progress

9.2.1 Study 1 in progress: Daily Life Therapy

(Hardy, Henrichs and Edwards, 1991)

Programme:

Daily Life Therapy at the Boston Higashi school

Sample:

Age: Preschool /primary (I: 3:2 to 12 years; mean 7.4 years) (II: 5.3 to 12 years, mean 7.11 years) (III: 6. 9 to 12. 8 ; mean 8 years)

Diagnosis: severe autism, DSM-IIIR; CARS score of 28+

IQ: Merrill-Palmer; Bayley Scales - details not published

Exclusion: No parental agreement for research; uncontrolled epilepsy and physical difficulties or degenerative disease excluded from the programme

Language level: Speech level: 33% no speech; 50% two word or phrase speech; 17% bizarre speech with some meaningful phrases

Number: 25

Control:

Three lengths of treatment groups: I) 10 months (16), II) 20 months (4) and III)30 months (5)

Additional treatment: None

Dependent variable:

Level of communication, daily living skills, socialisation and maladaptive behaviour

Evaluator:

Not independent of programme, nor blind to design

Measures for dependent variable:

VABS from parent interview, teacher reports and observations

Sequenced inventory for communication development

PPVT

Expressive one word vocabulary test

Time Scale:

10 to 30 months

Integrity:

Staff at Boston Higashi school in dialogue with staff from original Higashi school in Tokyo

Ethical concerns:

Based on assumption that normal functioning and age appropriate behaviour can be trained

Assumes that autism leads to appearance of severe learning difficulties rather than recognising a dual disability

Part of Japanese cultural values with the importance of the group taking precedence over that of the individual

Early residential treatment seen as beneficial, staff work towards integration from a segregated start

Training implications:

Only qualified teachers employed in daily class activities at school; some other residential staff, but no therapists

In-service training conducted at the school

9.3 Evaluation of research on Daily Life Therapy

There appears to have been no adequate evaluation of Daily Life Therapy as practised at the Boston Higashi School. The Hardy et al. study (1991) uses no control group and the results and child characteristics are not reported in detail; nor has the research been published for peer review. The larger research project by the same authors, reported in 1991 to be in progress, has still not produced published results and may now be defunct. The Richardson and Langley study (1997) does have a control group, but insufficient details are given to assess how well matched it is and exactly which aspects of DLT are being controlled. The data from this study is inadequate in that it is derived from parental and teacher questionnaire and (in many cases) asks for retrospective information. The opportunities for bias are clear. This paper also was only published as a 'research in brief' section in a peer reviewed journal, so does not give full information.

9.4 Research needed on Daily Life Therapy

There is a need for a controlled longitudinal study to evaluate the effects (in the short, medium and long-term) of Daily Life Therapy. Since an independent UK group of residential schools is to establish DLT classrooms on one of its sites, under the auspices of the Boston Higashi School, and a further group is to establish another school based on Daily Life Therapy, this would present the ideal opportunity to conduct such a study without having to control for the effects of long-distance residential provision and the effects of a third cultural perspective (ie the USA). The research design could not involve random allocation of children to groups since parents and authorities selecting places here will be a particular sample. Thus, it will need to employ a matched subject design. However, it will be difficult to find adequate controls for the residential component at such an early age in other UK schools. It may be necessary to have different control groups for separate aspects of the DLT programme and early residential placement could be contrasted to schools that offer only day treatment allied to parental guidance and support. It will be important to research the effects on families and to look at long term outcomes for the children.

There would also be fascinating opportunities for social anthropologists to research the importation of a different cultural model of education into the UK, but although that would provide useful information about the replication of the model in the UK, it would not be direct evaluative evidence of DLT.

Chapter 10: Behavioural approaches

Behavioural methods have been used in the education of children with autism and children with severe learning difficulties in the UK from the time such children were included in educational provision (Howlin and Rutter, 1987; Kiernan, Jordan and Saunders, 1978; Kiernan and Woodford, 1975; Wing, 1997). In most cases they have evolved and been modified to fit a broader curriculum focus (Jordan, 1991) and other approaches (Christie, Newson and Prevezer, 1992; Nind and Hewett, 1994; Powell and Jordan, 1997) have been incorporated. Lovaas and his colleagues, however, have continued to research and apply early forms of behavioural treatment, including the particular methodology of applied behaviour analysis and discrete trial learning (Lovaas, 1981). 'Applied behaviour analysis' is where a skill is analysed into steps which are then used as a teaching programme for the child. 'Discrete trial learning' is where each of these steps is presented with a clear goal, in a single trial, with successful completion followed by a reward. Ainscow and Tweddle (1984) or Kiernan, Jordan and Saunders (1978) give a simple guide to these procedures.

The aims and rationale given for Lovaas' version of ABA are set out below and these would be similar for all approaches that described themselves as 'behavioural' in orientation. The main difference is that some behavioural approaches have incorporated developments in behavioural methodology (such as 'general case programming' instead of 'errorless discrimination learning' and 'ecologically valid task units' instead of 'discrete trial learning'), whereas Lovaas has maintained the methods used in the 1960s and 1970s. 'General case programming' essentially gives the child experience of many different exemplars of the concept to be taught (usually in the form of a sorting task) whereas 'errorless discrimination learning', as its name suggests, only uses one 'correct' exemplar at a time and structures the task to maximise the child's chance of success. 'Ecologically valid task units' is behavioural jargon for functional strings of behaviour, rather than breaking the behaviour into small (and thus, often in themselves, meaningless) steps as in discrete trial learning. The most obvious differences are in the area of language teaching. Behaviourists came under most criticism for this aspect of the curriculum, as knowledge of pragmatics and language acquisition grew in the 1970s, and even those who were applying behavioural approaches to all other aspects of the curriculum were incorporating some of the new knowledge about pragmatics and the importance of functional contexts and communicative intent into their language teaching (Kiernan, Reid and Goldbart, 1987). Lovaas (1993) also makes clear that a behavioural approach is not just about behaviour modification but also about skills analysis and the use of shaping procedures to teach new skills. In this way, he is claiming that behavioural techniques can be used not just to effect performance (ie to get the child to perform already acquired skills) but also in skill acquisition.

Such skills based curricula were common in all kinds of UK schools in the 1970s and 1980s (Ainscow and Tweddle, 1984; Gardner, Murphy and Crawford, 1983) and are still a feature of some parts of the teaching approach in many special schools, including those for pupils with an asd. The TEACCH programme, for example, would include a behavioural approach to skill acquisition in the teaching of new skills while devoting more time than some other behavioural approaches to teaching the child to practise those skills independently through visual cueing. However, behavioural approaches have been criticised for their inappropriate and narrow focus (Wood and Shears, 1986) and Sebba, Byers and Rose (1993) chart the move in UK special schools from strict behavioural approaches to more interactive approaches (Collis and Lacey, 1996; Hewett and Nind, 1998). This change is also reflected in schools for children with autism, although positive behavioural approaches remain a part of the curriculum and often underpin the 'structure' that is seen as essential (NAS, 1997). It would be more unusual to find a behavioural approach being used in language teaching in UK schools, where the emphasis is much more likely to be on communication and the pragmatic aspects of language than on building up words from imitated sounds as a separate activity. Against this trend away from behavioural approaches, Greer (1996) has introduced a very strict behavioural model into a school which has been established for children with an asd in London. Greer aims to re-introduce behavioural approaches to a variety of teaching situations in the UK, including mainstream, based on his experience in the USA with strict ABA teaching approaches (Comprehensive Application of Behavior Analysis to Schooling (CABAS)).

As indicated above, behavioural approaches form a part of many other approaches (such as TEACCH, and even Option) but we are only using the term here where behavioural methodology is the predominant aspect of the approach. We have grouped the research together, but we do indicate where the method followed would fall in or outside of Lovaas' method of application of behaviourism, although this is not necessarily the view taken by the authors of the approach themselves or Lovaas; we have based our decision on reading the material available about the approach.

10.1 Lovaas: Applied behaviour analysis (ABA) through discrete trial methodology

Lovaas and Smith (1989) maintain that behavioural work is distinguished from 'traditional' work with children with autism in three ways, although it is not clear which approaches would fit this definition of 'traditional'. The ways are:

- it focuses on specific behaviours rather than on the diagnostic entity of autism
- it emphasises the immediate environment rather than aetiology or early history
- research is inductive rather than hypothetico-deductive

Applied behaviour analysis and the discrete trial approach are based on the idea that human behaviour is learned and that it is governed by its antecedents and its consequences. So children can learn new skills by skilful modification of stimuli and the presentation of immediate reinforcement. This is based on Skinnerian operant conditioning from the 1960's, based in turn on the notion that learning can be reduced to the repetition of responses that in the past have led to reward and the elimination of responses that have led to punishment. Skills can be built up by the rewarding of successive approximations through a 'shaping' procedure.

Lovaas and Smith (1989) describe the method as follows,

> *'Behavioral treatment centers on reinforcement control, effecting behavior change by manipulating the consequences of behavior. The goal of treatment is to shape a large number of adaptive behaviors (affective, linguistic, social etc.) by reinforcing increasingly closer approximations of the target behaviours and increasingly complex discriminations among situations. In contrast, traditional treatment centers on stimulus control, in which the major manipulations consist of changes in the*

> *variables which precede behavior. The showing of love and acceptance, the holding, the efforts to arrange a situation in which children will speak....... are all attempts at stimulus control. In short, behavioral treatments aim to build behaviour, and traditional treatments aim to cue behaviour. Certainly, cueing behavior is likely to be more rapid than building behavior. From a behavioral standpoint, however, the main problem with cueing behaviours through stimulus control procedures is that it does not result in the acquisition of new behaviours. Stimulus control can only change behaviour if there is already behaviour to control, and this does not seem to be the case for autistic children. Indeed, autistic children are selected on the basis of having little or no social behavior, language, self-help skill etc. Thus behaviorists would expect stimulus control procedures to be ineffective for most autistic children.'* (p. 25)

Lovaas uses tangible rewards (mostly edible) but now refrains from punishment, beyond a shouted 'No!' for an incorrect response. The programme emphasises teaching in small steps, rewarding, giving clear instructions, prompting and fading and teaching all the steps needed to enable participation in a normal nursery school, where taught social skills are generalised. Lovaas retains the original features of the Skinnerian approach in his programme so that, for example, concepts are taught through errorless discrimination trials rather than through general case programming techniques. Skills are built up in small steps, often through a process of backward chaining or shaping (Ainscow and Tweddle, 1984), rather than in larger units.

> *'Because autistic children have so many difficulties that need to be addressed separately, they need to be taught virtually everything, and the teaching needs to proceed piece by piece instead of in major steps.'* (Lovaas and Smith, 1989, p21).

The sequence of skills being taught is within a hierarchy of difficulty and in a logical sequence.

The child is taught new skills or behaviours during a number of 'drills'. These drills may be carried out for 10 to 15 minutes and then the child is given a period of play, followed by another 10-15 minute work session. In a drill, a short sequence is presented to teach a new target behaviour (such as sitting on a chair; looking at the adult; or saying a word). A command such as, "Sit down" might be given and a correct response followed by a positive reinforcer such as a piece of popcorn or a favourite activity. Verbal praise accompanies all reinforcers so that other reinforcers can be faded out over time. If children engage in inappropriate behaviour (eg making noises; rocking; hitting), they would be ignored, lose privileges or have time out. Physical or verbal prompts are used and these are gradually reduced. Once the child can respond correctly without prompting, then work towards achieving mastery is done. The child will be given the same command ten times for example, and has to respond correctly to a preset criterion (usually 90%) on a preset number of occasions. Generalisation is said to have been achieved when skills are performed in a new situation (eg with different staff members on a preset number of occasions, across a preset number of different staff members).

In the Young Autism Project (Lovaas, 1987), Lovaas and his colleagues taught these techniques to parents in an intensive home-treatment programme. The features of that programme were that children were very young, the programmes for the experimental group occupied 40 hours a week and there was planned integration experiences in the second and third year of treatment.

Aims: To teach skills and reduce inappropriate behaviours by shaping and rewarding correct responses
Target population: Children with special needs, with or without an asd
Ratio of adult to child: 1:1
Cost per child: £17,000 per year approx. (based on 36 hours a week for 50 weeks of the year and including the costs of initial training and supervision by a programme supervisor)
Funded by: Parents or education or health
Setting: Home, school or centre
Hours per week:
40 hours a week
Who carries out the approach? Parents and trained volunteers and/or school staff
Assessments: IQ, VABS
Staff qualifications and training:
Parents and other adults who have been trained in the approach.
Parent involvement:
Parents are central to the approach as they often spend the greatest amount of time teaching their child. For home-based programmes they are often responsible for recruiting the volunteers.
Compatibility with other approaches:
Given that the presentation of drills is interspersed with 'play' periods, it could be conceived that this programme could mesh with most others, but Lovaas believes that it should stand alone and can be applied to all aspects of development - negating the need for other programmes. There are no augmentative systems of communication used, on the advice that they may interfere with the speech programme. It represents the opposite of DLT in that it is individual rather than group focused, and the opposite of interaction approaches, in that it is highly adult rather than child directed.

It is not known which children on the autistic spectrum are most successful but Lovaas and Smith (1988) state that children vary markedly in their response to treatment and this response can only partially be predicted on the basis of their intellectual functioning. Connor (1997) cites some undated notes of Eikeseth who says that the children most likely to benefit from intensive behavioural intervention modelled on the Lovaas principles are those diagnosed as having mild to moderate autism and who begin the programme before they are 3.5 years old.

10.2 Research on behavioural approaches

10.2.1 Study 1: on the Lovaas approach

Behavioural treatment and normal educational and intellectual functioning in young autistic children ('*The Young Autism Project*',' Lovaas, 1987)

Programme: Intensive pre-school ABA discrete trial programme with aversives, plus integration experience
Sample:
Age: Less than 46 months (if echolalic) or less than 40 months

Diagnosis: Autism (DSM III) 2 diagnoses agreed
IQ: At start 30-82; pro-rated mental age Experimental group mean: 18.8, Control group 1 mean: 17.1 Control Group 2 mean: 17.6 Tests: Pre: Bayley Developmental/ Cattell infant/

Stanford Binet/ Gesell infant/ VABS for 'untestable'
Language level: E Group: 42 % had words, 24 % had abnormal speech.
C1 Group: 58% words, 22% abnormal speech
Exclusion: more than 40 months or more than 46 months if echolalic, less than 11 months prorated MA at CA of 30 months
Number: 19
Control: 40 (19, Control Group 1, 21 Control group 2)
Group 1 - up to 10 hours a week of ABA without aversives, and local services
Group 2 - no specified treatment / local pre-school services
Additional treatment:
Integration experiences
Possible play intervals
Dependent variable:
IQ scores and school placement at age 7 years
'Pathology' measure based on IQ and placement
Measures for dependent variable:
WISC-R/ Stanford Binet/ Merrill-Palmer/ WPPSI /PPVT / Bayley/ Cattell/ Leiter
Observation and school records
Evaluator: Independent of programme and blind to treatment status
Context: Home based involving parents with graduate student support
Time scale: 2 years +
Intensity:
Experimental group: 40 hours/ week, 365 days a year
Control Group 1: up to 10 hours/ week
Control Group 2: -
Integrity: Treatment team trained and closely monitored by university based staff

Ethical concerns:
Experimental group received contingent aversives for non-compliance or unwanted behaviours
Based on application of operant conditioning theory (Skinner, 1957) which is assumed to be universally applicable (ie no account of autism other than in content of programmes).
Parent involvement essential to maintain intensity
Results:
At follow-up,
E group : 9 children (47%) passed through 1st grade mainstream and normal IQ (mean 107; 94 to 120).
8 (42%) 1st grade in aphasia class, mildly retarded IQ (mean 70; 56 to 95);
2 (10%) class for autistic/ retarded, IQ profoundly retarded (IQ less than 30)
C groups: No significant difference between the 2 control groups. MA and IQ scores remained virtually unchanged
1 child (2%) normal 1st grade placement and IQ of 99;

18 (45%) in aphasia classes with mean IQ 70 (30 to 101);
21 (53%) classes for autistic and/or retarded, mean IQ 40
(20 to 73)

Training implications:
Staff trained and monitored by university project directors - 'extensive theoretical and practical knowledge' seen as essential for effective programme
Identified precursors for success : Not available

10.2.2 Study 2: on the Lovaas approach

Long-term outcome for children with autism who received early intensive behavioral treatment (McEachin, Smith and Lovaas, 1993)

Programme: Intensive pre-school ABA discrete trial programme with aversives, plus integration experience, 4 to 7 year follow-up
Sample:
Age: Mean 11.5 years (9 to 19 years)
Diagnosis: Autism (DSM III) 2 diagnoses agreed from 1987 study
IQ: At start 30 to 82; pro-rated mental age Experimental group mean: 18.8; Control group 1 mean: 17.1 Control Group 2 mean: 17.6. Tests: Pre: Bayley Developmental/ Cattell infant/ Stanford Binet/ Gesell infant/ VABS for 'untestable'
Language level: E Group: 42 % had words, 24 % had abnormal speech.
C1 Group: 58% words, 22% abnormal speech
Exclusion: More than 40 months or more than 46 months if echolalic, less than 11 months prorated MA at CA of 30 months
Number: 19 for basic follow up, 9 for in-depth
Control: 19 - Control Group 1, Group 1 - up to 10 hours a week of ABA without aversives, and local services
Control Group 3 for in depth study - normally developing, age matched
Additional treatment:
Integration experiences
Possible play intervals
Dependent variable:
i) All 38 - standardised tests of intellectual and adaptive function and school placement (defined by parents) at follow up
ii) 9 'best cases' - test for autistic 'pathology'
Measures for dependent variable:
i) WISC-R/ PPVT / Leiter for IQ, VABS for adaptive functioning, Personality Inventory for Children to assess emotional functioning
ii) Additional clinical rating scale
Evaluator:
Some of i) carried out by project personnel
ii) carried out by people independent of programme and blind to treatment status
Context:
Home based involving parents with graduate student support, followed up an average of 7 years later

Time scale: 2 years + project
Intensity:
Experimental group: 40 hours per week, 365 days a year
Control Group 1: up to 10 hours per week
Integrity: Treatment team trained and closely monitored by university based staff

Ethical concerns:
Experimental group received contingent aversives for non-compliance or unwanted behaviours
Based on application of operant conditioning theory (Skinner, 1957) which is assumed to be universally applicable (ie no account of autism other than in content of programmes).
Parent involvement essential to maintain intensity
Results:
At long-term follow-up:
E group : 1 previously mainstreamed child now in special education, 1 previously in special education now in junior college, 17 maintained former placement. C group: As before, none in mainstream (details unreported). Significant difference between the two groups maintained.
E group: 11(58%) with IQs 80+ (mean IQ of 83)
VABS score 72 (below 'normal' adaptive score of 100±15)
Maladaptive behaviour not clinically significant
Personality Index score: 62
C1 group: 3 (17%) with IQs 80+. (mean IQ of 52) (significant difference between 2 groups)
VABS score 48
Maladaptive behaviour clinically significant
Personality Index Score: 65 (not significantly different from experimental group except on psychosis scale -favouring E - and somatic complaints - favouring C)
C3 group: 119 IQ on WISC-R (116 verbal; 118 performance)
VABS: 102 communication, 100 daily living skills, 102 socialisation, 101 composite
Personality Index score: 49
9 best outcome children from E group had WISC-R scores from 99 to 136. All 9 had composite scores within the normal range on VABS. On Maladaptive Behaviour Scale 3 scored in clinically significant range. Normal range scores for all 9 on the Personality Index.
On the Clinical Rating Scale, 8/9 best outcome scored 0-10 and the ninth child scored 42 (Mean 8.8); Of the Control group, three children scored 0-5 (Mean 1.7). Thus, there was a significant difference between the two groups on this scale.
Training implications:
Staff trained and monitored by university project directors - 'extensive theoretical and practical knowledge' seen as essential for effective programme
Identified precursors for success : Not available

10.2.3 Study 3: on the Lovaas approach

Intensive behavioural treatment for autistic-like pre-schoolers with severe mental retardation (Smith, Eikeseth, Klevstrand and Lovaas (in press))

Programme: Intensive pre-school ABA discrete trial programme

Sample:
Age: Pre-school less than 46 months, mean CA 3.1
(E group mean 3.0; C group mean 3.2)
Diagnosis: PDD (DSM III) and mental retardation
IQ: Bayley score less than 35 (E group mean 28; C group mean 27)
Language level: no speech
Exclusion: Major medical limitations, too distant from site, unwillingness of parents to participate
Additional difficulties: Severe learning difficulties. Control group only - sensory deficits
Number: 11
Control: Assigned on therapist availability. Matched by CA and IQ and diagnosis. All at one site. Control group: 10 children, up to 10 hours a week of ABA, and local services
Dependent variable:
Intellectual functioning
Behaviour ratings
Measures for dependent variable:
Bayley
Treatment logs and parent interviews
Evaluator:
Mix of project staff and staff independent of programme and blind to treatment status
Context: Home based involving parents with graduate student support
Time scale: 2 years + follow -up end of treatment or 3-4 years later (for 2 in each group)
Intensity:
Experimental group: 30 hours per week, 365 days a year
Control Group : up to 10 hours per week
Integrity:_Treatment team trained and closely monitored by university based staff or staff from approved replication sites for Young Autism Project
Ethical concerns:
Based on application of operant conditioning theory (Skinner, 1957) which is assumed to be universally applicable (ie no account of autism other than in content of programmes).
Parents required to participate for 5 to 10 hours a week
Results:
At follow-up,
E group : mean IQ increased from 28 to 36
10/11 developed some spoken words, 2 phrases
large individual differences
C groups: mean IQ decreased from 27 to 24 (difference between 2 groups significant)
2/10 developed speech
no significant difference between 2 groups in behaviour problems
Training implications:
Staff trained and monitored by university project directors and staff at replication sites also trained at central site - 'extensive theoretical and practical knowledge' seen as essential for effective programme
Identified precursors for success : Not available

10.2.4 Study 4: on the Lovaas approach

The Murdoch Early Intervention Programme after two years
(Birnbrauer and Leach, 1993)

Programme: Intensive pre-school ABA discrete trial programme without aversives, plus integration experience

Sample:

Age: 24 to 48 months

Diagnosis: Autism or PDD (DSM III)

IQ: Less than average IQ and adaptive level

Language level: Information not available

Exclusion: Sensory abnormalities, physical impairments

Additional difficulties: Learning difficulties

Number: 9

Control: 5 closely matched for MA, CA and adaptive level, no treatment

Dependent variable:

Intellectual, language and adaptive functioning
Sociability levels
Parental stress

Measures for dependent variable:

IQ tests
Observation checklists
Personality index
Stress rating schedule

Evaluator: Not independent of programme nor blind to treatment status

Context: Home-based involving parents with project director and volunteers

Time scale: mean 21.5 months (17 to 24 months)

Intensity:

Experimental group: 18+ hours per week, 365 days a year
Control Group 1: No treatment

Integrity: Treatment team trained and closely monitored by project staff

Ethical concerns:

Emphasis on compliance but programmes individualised

Based on application of operant conditioning theory (Skinner, 1957) which is assumed to be universally applicable (ie no account of autism other than in content of programmes).

Parent involvement essential to maintain intensity

Results:

E group : 4/9 children marked improvement in IQ and large gains in language and adaptive behaviour (but still below the norm). 5/9 made moderate or low levels of improvement.

More sociable and socially competent

Parents' stress reduced

C group: Minimal change over time period

Parents' stress increased or remained the same

Training implications:

Staff trained and monitored by university project directors - 'extensive theoretical and practical knowledge' seen as essential for effective programme

Identified precursors for success: Initial speech predicted good outcome

10.2.5 Study 5: on other behavioural approaches

Age at intervention and treatment outcome for autistic children in a comprehensive intervention program (Fenske, Zalenski, Krantz and McClannahan, 1985)

Programme: intensive pre-school and school ABA behavioural programme with visual mediation and later parent training
Sample:
Age: Mean 36 months
Diagnosis: Autism (DSM III-R)
IQ: mean 57 (36 to 83) Stanford-Binet
Language level: Non-verbal
Exclusion:
Additional difficulties: Some learning difficulties
Number: 32
Control: None
Dependent variable:
Placement outcomes
Developmental gains
Measures for dependent variable:
IQ tests
Parent interview
Evaluator: Not independent of programme nor blind to treatment status
Context: School-based but involving training parents
Time scale: 2+ years
Intensity: Experimental group: 25+ hours per week at school. 15 hours per week at home, 365 days a year
Integrity: Treatment team trained and closely monitored by project staff
Ethical concerns:
Emphasis on compliance but programmes individualised
Based on application of operant conditioning theory (Skinner, 1957) which is assumed to be universally applicable (ie no account of autism other than in content of programmes).
Parent involvement essential to maintain intensity
Results: Mean gain of 22 to 24 points in IQ by 7 years (ie after 4 years).
Training implications: Staff trained and monitored by university project directors
Identified precursors for success: Initial speech predicted good outcome

10.2.6 Study 6 : on other behavioural approaches
The Princeton Child Development Institute (McClannahan and Krantz, 1994)

Programme: Intensive pre-school behavioural programme without aversives, plus functional curriculum
Sample:
Age: Mean 43 months (30 to 58)
Diagnosis: Autism (DSM III-R plus observations)
IQ: Stanford Binet mean 57, (less than 36 to 83) VABS
Language level: PPVT -R
Additional difficulties: Learning difficulties
Number: 32
Control: No control group
Additional treatment:_
Lots of access to computer assisted learning
Photographic work schedules - similar to TEACCH
Augmentative communication systems but not sign

Dependent variable:
Intellectual, language and adaptive functioning
Sociability levels
Parental stress
Measures for dependent variable:
IQ tests
Observation checklists
Personality Index
Stress rating schedule
Evaluator: Not independent of programme nor blind to treatment status
Context: Teaches key ecologically valid behaviour to assist later integration
Time scale: Mean 21.5 months (17 to 24 months)
Integrity: Treatment team trained and closely monitored by project staff
Ethical concerns:
Emphasis on cued behavioural approach, with individually tailored programme
Parent involvement essential to maintain intensity
Child initiating periods
Results: 80 to 90% interventions scored as achieving objective in desired direction.
Training implications:
Theoretical training and hands-on practical training of staff
Generalist staff model so all staff teach everything, or anything
Identified precursors for success: IQ scores not a good predictor of outcome

10.3 Research in progress or planned

10.3.1 Study 1 in progress: on the Lovaas approach

Intensive and long-term behavioral treatment for four to seven year old children with autism: a one year follow-up
(Eikeseth and Center, in progress)

Programme: Intensive pre-school ABA discrete trial programme plus mainstreaming
Sample:
Age: 4 to 7 years
Diagnosis: Autism (ICD-10) ADI, CARS and/or ABC
IQ: Deviation IQ of 50+ (WPPSI-R) or ratio IQ 50+ (Bayley Scales), and/or Leiter/ Merrill-Palmer. VABS
Language level: Reynell
Exclusion:
Additional difficulties:
Number: (9 to date)
Control: (3 to date) selected by treatment availability
Controlled for treatment by alternative treatment with same intensity
Additional treatment :
Integration experiences
Dependent variable:
IQ, Language and adaptive scores
Measures for dependent variable:
WISC-R/ Merrill-Palmer/ WPPSI-R / Leiter
Observation and school records

Evaluator:
Independent of programme and blind to treatment status
Context:
School based involving parents and teachers
Time scale:
1 year
Intensity:
Experimental group: 30 hours ABA per week, 365 days a year
Control Group: 30 hours eclectic pre-school per week
Integrity:
Treatment team trained and closely monitored by university based staff
Ethical concerns:
Based on application of operant conditioning theory (Skinner, 1957) which is assumed to be universally applicable (ie no account of autism other than in content of programmes).
Parent involvement essential to maintain intensity
Training implications:
Staff trained and monitored by university project directors - 'extensive theoretical and practical knowledge' seen as essential for effective programme

10.3.2 Study 2 in progress: on Lovaas

A replication study on Lovaas in the UK
(Mudford et al., in progress)

Programme: Intensive pre-school ABA discrete trial programme
Sample: Children with an asd following the Lovaas approach for varying lengths of time in the UK, so not randomly selected; a second group to start the Lovaas approach shortly
Age: Pre-school to primary
Diagnosis: asd, diagnosed by a number of different professionals
Baseline data: Taken from the children's statement reports, so this varies
IQ: information not available
Language level: Information not available
Number: 85
Control: Would like to have a comparison group whose members are following other interventions
Additional treatment: May also attend school or pre-school group
Dependent variable:
IQ, language and adaptive scores
Educational placement
Evaluator: Not independent of the programme
Measures for dependent variable:
WISC-R/ Merrill-Palmer/ Reynell / Leiter/VABS/parent and practitioner interviews/attainment tests/child observations
Context: Home-based, but as children become older, this may be done in school
Time Scale: Information not available
Intensity: 40 hours per week
Integrity: Treatment team trained and closely monitored by university based staff
Ethical concerns:
Based on application of operant conditioning theory (Skinner, 1957) which is assumed to be universally applicable (ie no account of autism other than in content of programmes).

Parent involvement essential to maintain intensity
Training implications:
Staff trained and monitored by Lovaas therapists.

The researchers intend to go on to investigate the validity of the claims of 'recovery' made by the original Lovaas studies. They stated on their questionnaire return that:

> *'Once the children reach a level that appears to make them indistinguishable from other children with no history of developmental disorders (recovered), a further assessment using a different methodology will be used to verify that.'*

10.3.3 Study 3 in progress: on Lovaas

A comparative study on Lovaas in the UK
(Howlin and Gould, in progress)

Programme: Intensive pre-school ABA discrete trial programme
Sample: Children with an asd following the Lovaas approach for varying lengths of time in the UK, so not randomly selected
Age: 2-5
Diagnosis: asd, DSM IV or ICD 10 plus ADI to confirm
Baseline data: IQ (WPPSI; Merrill Palmer) Language Tests
IQ: No exclusion on IQ basis
Language level: Information not available
Number: 25
Control: 25 following early educational pre-school programme, matched on IQ, CA, and language age
Additional treatment: May also attend school or pre-school group
Dependent variable:
IQ, language and adaptive scores
Educational placement
Evaluator: Independent of the programme, but not blind to the design
Measures for dependent variable:
WPPSI/ Merrill-Palmer/ Reynell / parent and practitioner interviews/attainment tests/child observations
Context: Home-based,
Time Scale: 2 years
Intensity: 40 hours a week
Integrity: Treatment team trained and closely monitored by research team

Ethical concerns:
Based on application of operant conditioning theory (Skinner, 1957) which is assumed to be universally applicable (ie no account of autism other than in content of programmes), but already chosen programme
Parent involvement essential to maintain intensity
Training implications:

Staff trained and monitored by Lovaas therapists.

10.4 Evaluation of the research on behavioural approaches

Greer (1996) provides a review of some of his own and others' research demonstrating the efficacy of ABA approaches over a range of educational contexts. However, since none of these studies relate to children with an asd, they are not given here. There is little that is specific to say about the two studies outside the strict Lovaas style of intervention, so the comments mainly concern the latter approach. The Fenske et al. (1985) study does show a successful outcome after the age of 4 years, but with speech as a good predictor of outcome. That study was not controlled and nor was the Princeton study, also showing good results from a modified behavioural approach, so they do not provide evidence comparable to that offered in the Lovaas studies. The comments on these latter studies are extensive, mostly reflecting the nature of the claims made by the proponents of the approach and in particular the claim that *'studies have shown the approach to be more effective than other methods'* (Bibby, cited McCurry, 1998, page 21).

Gresham and MacMillan (1997a) point out some key problems with the methodology of the Young Autism Project (Lovaas, 1987) which, in turn, also affect the follow-up study (McEachin et al., 1993). The treatment for Control Group 1 was delayed so that they were 6 months on average older when their treatment started. The two outcome measures used (IQ and educational placement) are gross measures and do not reflect improvements in the key areas of difficulty in autism that one would expect when claims are made of 'recovery' from autism. The educational policy of the district, for example, will have a considerable (uncontrolled) effect on placement decisions. The IQ of the children is assessed with 7 different tests with publication dates and norms from 1948-1974. Even more crucially, the same test is not necessarily used with the same child at follow up (either at 7 years old or at later follow-up). The children are pretested with 4 measures of cognitive functioning or mental development at the pre-test level and 5 other measures at post test. Given that many of the developmental tests which are used at the pre-school stage to assess IQ have a low correlation with later IQ scores in normal development (Correlation 0.40 at 6 years: McCall, 1979), 'increases' using two different instruments have little meaning. When it comes to the long-term follow-up data, there is once more a discrepancy in the time period considered for the two groups; Control group 1 is followed up at 6-14 years of age, whereas the experimental group ages at follow up are 9-19 years. Thus, there may be 3 to 5 years of additional development and education to account for the differences between the two groups in the long term follow-up study.

The way the findings are presented are also confused and could lead to misunderstandings about the extent of the difference between the experimental and control groups. This occurs because the measures used to define the category of outcome ('recovered' versus 'aphasic' versus 'autistic/retarded') in terms of placement, differs between the groups with respect to the IQ scores within each category. For example, the IQ scores of the experimental group who are 'recovered' range from 94-120, those that are 'aphasic' from 56 to 95 and the 'autistic/retarded' under 30. Yet when we look at the range of IQ scores of the two control groups in those same categories, the 'aphasic' range is from 30 to 102, and the 'autistic/retarded' range from 20 to 73. This emphasises that placement may not be the most appropriate measure of within-child change, and it also shows that on IQ scores alone, more of the control group may have achieved comparable gains to the experimental group than

Lovaas is indicating. The overall group scores (as seen by means) may still be significantly different, but it would be helpful to have a more accurate picture of the number of children who made substantive IQ gains in all groups.

There are doubts about the matching of the experimental and control groups. At a gross level, there are many more girls in the control group and this may introduce bias. Greater problems with the validity of the studies of the Young Autism Project are made by Gresham and MacMillan (1997a). One is to do with the measures of IQ and mental age that are used. Lovaas' use of the 'prorated mental age' (PMA) measure for matching is described as psychometrically dubious. PMA assumes a chronological age (CA) of 30 months and is calculated by the formula: PMA = MA/CA x 30. The effect of this is to reduce the MA score at the pre-test, thus biasing the likelihood of gain on later testing. There is also a problem in the way the tests are administered at the two periods. At the pre intervention testing, IQ scores are 'optimised' by reinforcing compliant behaviour during the testing. This violates standard test procedure but would be less important (given that it applies to the testing of the experimental group and Control group 1) were it not for the fact that standard procedures are used at follow-up. This means there are very different testing conditions at the two points, once more making any changes uninterpretable.

Gresham and MacMillan (1997a) also point to the likely effects of statistical regression (the tendency for scores at one point to regress to the mean at a second time point) and explore the possibility of differential regression across the groups. As they point out, the three groups in the study had children with IQs 40 points below the mean and so regression is a real danger, that has not been addressed in the design, nor in the interpretation of the results.

A problem in the way the children were allocated to different groups for treatment has also been criticised; most criticisms point to the unsatisfactory nature of anything less than random assignment (Gresham and MacMillan, 1997b; Rutter, 1996; Schopler, Short and Mesibov, 1989). The assignment to the experimental and Control Group 1 in the Lovaas (1987) study was on the basis of whether staff were available and the distance from the treatment centre. Control Group 2 was an opportunistic sample. Lovaas shows that there was no significant difference in terms of several child characteristics, but there remains the possibility of bias in terms of parental characteristics, and staff availability and motivation. Lovaas (1987), for example, comments that not all parents can be trained to work effectively on ABA programmes and suggests such negatively indicating factors as mother working, personal problems, lack of interest and severe difficulties in the child; such parental situations triggered the offer of group home treatment rather than inclusion in the then ongoing Young Autism project. However, we accept Lovaas' (1989) rejoinder that random assignment is seldom appropriate (in terms of practicality and ethics) in educational research and would find a well matched (for crucial variables) study acceptable. After all, Rutter (1996) is happy to accept psychological research on determining key difficulties in autistic cognition on the basis of matched group designs, and only insists that random assignment is necessary for treatment research. The problem is that the groups used in the Lovaas study are only matched on gross (and somewhat inadequate) measures, so that systematic bias remains a possibility.

Gresham and MacMillan (1997a; 1997b) also detail some of the factors in the Lovaas (1987) study that would affect its interpretation and generalisation to other children with an asd. Fifteen per cent of the referred children were excluded on the basis of their prorated mental age (PMA) being less than 11 months at a CA of 30 months, and having a CA of more than 40 months if mute, or more than 46 months if echolalic. Children in the experimental group and in Control Group 1 each had 7 children who were echolalic and 11 who were mute. Schopler, Short and Mesibov (1989) estimate that if those same intellectual criteria were applied to the TEACCH programme, 57% would be excluded. Thus, the findings are not representative of *all* children with autism. Even in the experimental group that excluded 16%, less than half showed 'recovery' and there are no indications of the child variables that affected this outcome. Strictures about the heterogeneity of children with autism are made by Schreibman (1996), highlighting the danger of unwarranted extrapolation of the results and the need for more research detailing the features that are associated with positive outcomes.

There are further problems in maintaining the integrity of the programme over time (Jordan and Powell, 1996) and in determining the boundaries of variation in provision that affect outcome measures. As has been shown by Jordan and Powell (1996), the child's experience in the programme does not include a strict and consistent application of ABA principled treatment alone and even the manual for the implementation of ABA (Lovaas, 1981) suggests periods of play alternating with discrete trial learning. This was not controlled for in the Lovaas study and it could, therefore, (albeit somewhat perversely) be interpreted as supporting the beneficial outcomes from play therapy as much as from discrete trial learning. There is no evidence presented of the relative time spent by each child on the two contrasting experiences of playing and being 'drilled'.

Smith et al. (1993) emphasise the importance of prolonged and expert training for the therapists and this may not be generally available. There are issues of expertise, training and close supervision to maintain treatment integrity and, once again, the amount of variation in this that can be tolerated before affecting outcomes. Many professionals (notably professional psychologists) will receive training in ABA as part of their training. Organisation of interventions using such students in training (as part of their clinical experience) might provide a more cost-effective way of 'delivering' an ABA based programme (should an LEA consider it desirable) but the research offers no evidence for the efficacy of the particular methodology used in the Lovaas study nor for the level of integrity to that methodology.

There are some further points to make. In Lovaas' 1987 paper, Control group 1 did not just differ in the amount of hours of the programme (10 versus 40) but also in the fact that they did not receive contingent punishment (shouted 'No!' and a thigh slap) as the experimental group did. This is hardly something one would wish to associate with the difference in outcome but it cannot be ignored as a factor. In fact, Lovaas (1987) reports a further experimental manipulation with respect to this feature. During baseline conditions for the experimental group, when aversives were not being used, they were introduced (from 3 weeks to 2 years after treatment had started) with 4 children in the experimental group and 4 children in the control group. Lovaas reports that when the aversives were being withheld, there were only small and unstable reductions in inappropriate behaviours and only small and unstable increases in appropriate play, for both groups. The changes at this stage would not have allowed for successful mainstreaming.

> '*Introduction of contingent aversives resulted in a sudden and stable reduction in the inappropriate behaviors and a sudden and stable increase in appropriate behaviors.*' (Lovaas, 1987, p7)

Lovaas uses this to bolster claims that the two groups were similar in composition but it adds a further indication that the difference in procedure between the two groups in relation to aversives may not have been a trivial one as far as outcomes are concerned.

Lovaas himself recognises this fact and states:

> '*...the within-subjects study showed that at least one treatment component contributed to the favorable outcome in the intensive treatment (experimental) group.'* (p. 8)

The 'within-subjects study' referred to is the use of contingent aversives. Lovaas makes an even stronger assertion later on the same page,

> ' *...In the within-subjects studies that were reported, contingent aversives were isolated as one significant variable. It is therefore unlikely that treatment effects could be replicated without this component'.* (p.8)

Later papers (such as McEachin et al., 1993) do not mention this difference in the treatment of the two groups and simply refer to them respectively as receiving *'intensive behavioral treatment'* versus '*minimal behavioral treatment'* (p. 367) as if the only difference were that of intensity. Yet in the Lovaas, Smith and McEachin (1989) response to the Schopler, Short and Mesibov (1989) criticisms, the authors specifically claim the use of contingent aversives as one of the distinguishing factors that can account for the success of this programme over others.

Current statements about Lovaas style ABA programmes emphasise that aversives are no longer used (Eikeseth, undated; Schopler, 1998). This is to be welcomed on ethical and legal grounds, but it does mean that current interventions do not have the treatment integrity of the original study and this in turn undermines the claimed scientific basis of the treatment. It is not clear whether other reported studies (eg Smith, et al. 1997) also shared this same difference in procedure between the experimental and control groups since no direct mention is made; the only comments suggesting this difference remains, is that the methods used were the same as reported in the Lovaas (1987) study (p. 7 of pre-publication copy) and that the experimental group was subject to '*contingency management'* (p. 8 of pre-publication copy). This is also commented on by Schopler (1998). The two broader based behavioural approaches (studies 5 and 6) show considerable success without the use of aversives, so it is likely that Lovaas is incorrect in his assumption that they are a crucial factor in determining success. However, they also use aspects other than a strict ABA intervention, so the question remains unanswered with respect to strict Lovaas replications.

Also, Lovaas admits that subjects attended mainstream nurseries and were moved to others if it became known that they had autism. This was true of both groups so does not affect the judgement on the comparative data, but it does affect the generalisability of the findings since it increases the likelihood of mainstream placement after 1st. grade.

It is the claims for 'recovery', however, rather than treatment gains themselves, that have led to the most controversy. Mesibov (1993) believes that it is not surprising that such intensive intervention should result in positive and lasting results as behavioural approaches have been used effectively with children for many years. But he queries the magnitude of the changes reported by Lovaas (1987) and McEachin et al. (1993) and what they mean. He says that there are concerns about the representativeness and comparability of the sample group, as given above.

Mundy (1993) argues, for example, that the claims of the Lovaas group for marked intervention effects in IQ for some children appear increasingly valid. He cites work by Lord and Schopler (1989) which indicates that there is considerable plasticity in the cognitive test performance of young children with autism and the work of Harris et al. (1991) which suggests that early pre-school intervention can lead to dramatic changes in performance on IQ measures (although this is far from evidence that the particular ABA method used by Lovaas is the crucial variable). However, Mundy takes issue with the fact that McEachin et al. (1993) describe their best outcome group as having normal functioning. He cites the work of Dykens, Volkmar and Glick (1991) and of Szatmari et al. (1989) which shows that high-functioning people with autism may display relatively good adaptive skills and social outcome, yet still be significantly disabled by odd thought processes and obsessive thoughts and concerns. Lovaas (1987) in the first follow-up did say,

> *'Certain residual deficits may remain in the normal-functioning group that cannot be detected by teachers and parents and can only be isolated on closer psychological assessment, particularly as these children grow older'* (p.8).

Mundy (1993) concludes by saying that the data of the McEachin et al. (1993) study should be interpreted with caution and be constrained by the limits of the outcome measures. However, in reply, Smith, McEachin and Lovaas (1993) maintain that high functioning people with autism would be easily distinguishable from their best outcome group and that these differences would be easily detected without turning to specialised measures.

The control in the Lovaas (1987) study is for intensity and use of contingent aversives, not for the treatment itself. The outcomes support this interpretation. Thus, if Control Group 1, who received up to 10 hours a week of ABA treatment (albeit without aversives), had scored some way between the experimental group and Control Group 2, then this would have provided some evidence for the efficacy of the particular programme used. However, Control Group 1 scored no better than Control group 2 (who received indeterminate or no treatment). In fact the one child in the control groups who was judged to have 'recovered' was from Control Group 2. The evidence for the efficacy of the programme, therefore, is based on its intensity alone (plus its use of aversives).

10.5 Research needed on behavioural approaches

Lovaas' approach, reported results, and subsequent claims, clearly invite further study and research on behavioural approaches needs to be directed not just to replication of those results (and those of other reported success through behavioural methods) but also to an analysis of the critical features of the programmes that lead to any success shown. Previous intensive behavioural methods, even those by Lovaas himself (Lovaas, Koegel, Simmons and Long, 1973) have shown limitations in treatment gains (especially with respect to generalisation) and regression in the long term. There is a need to identify the crucial differences in the Young Autism Project. Is it the age of the participants or the use of key ecologically determined goals to permit integration? Jordan (1991) makes these and additional suggestions for some of the variables that may lead to success. There is a need, therefore, for research on the characteristics of children who succeed and those who do not (using retrospective data, if necessary, on past participants of the programme). It is always difficult to trace children who fail at approaches since case study reports are unlikely to be published on negative findings and larger longitudinal studies are difficult to fund. However, there is information (from the research for this review) of a number of children who are being funded on Lovaas programmes within the UK, and follow-up data on those should begin to determine some of the factors within children (or their family circumstances) that lead to positive outcomes.

There also needs to be research on the actual features of the programme that contribute to any success. As has been indicated, the experience of the programme for the child may not be one of the drills alone. Apart from the fact that many parents on such programmes will also have pursued (or be following concurrently) other approaches such as auditory integration therapy, dietary interventions, vitamin supplements and so forth, the manual for Lovaas therapy suggests 'breaks' from the discrete child format when generalisation may be fostered through play. As Rogers and her colleagues (Rogers and Lewis, 1989) have shown, play itself may offer an effective teaching milieu for children with an asd, so it is important to have research on the relative time spent on different types of 'treatment' within the operation of ABA, the kinds of activity that occur in play periods and an independent qualitative analysis (from videotapes) of the quality of teaching and learning in such periods as against discrete trials. Our inspection for quality within schools is not just based on outcome measures, but also on professional judgements of the process. There is no reason why this educational (as opposed to psychological) evaluation should not be applied to these programmes. There are also techniques for evaluating the quality of interaction during teaching sessions and this would be a further guide as to the value of different components of the Lovaas approach.

In spite of the work that has been done, and that that has been planned, there is still no compelling evidence that ABA through discrete trial methodology is more effective than other approaches in autism. There is a need for a good controlled study of outcomes, based on random (or pseudo-random - see below) assignment of participants and controlling for intensity, parent involvement and the 'halo' effect (in this case, the attribution of positive feelings about being engaged in helping their child to the specific programme being followed) by comparing other equally intensive home programmes such as Option. Clearly it would not be ethical to assign children randomly to either of these approaches in our current state of knowledge, but we could use a nationally co-ordinated study to monitor the progress of the 'natural' experiment of children currently being funded to do these approaches. It might even be that authorities could be specially funded to respond positively to requests from parents in these two areas (especially Option, where numbers are liable to be less) to provide participants for the study.

Failing that, or in addition to it, there might be a multiple baseline study using a waiting list approach. This would mean that (in a nationally co-ordinated plan) parents would be guaranteed funding to follow an approach such as Lovaas, but only if they would agree to be part of the study which might mean (by random assignment) that they may have to be in the group where treatment was delayed for a year (or 6 months, if that does not seem feasible). This might be acceptable ethically and practically, given that parents often wait that long while funding is being pursued. Baseline measures would be taken on all the children and the ones on the waiting list could be offered the eclectic mix that might be generally available in the area. It would also be important to have impartial evaluators of progress and at least some check by coding of videos wherein the coder would be unaware of the treatment status of the child and the chronological order of the video material. This is the nearest we are likely to get to a 'double-blind' trial in education.

Foxx (1993) maintains that,

> *'Until their dramatic effects are replicated by others, the McEachin, Smith and Lovaas (1993) and Lovaas (1987) papers will occupy some scientific limbo, and the polarisation and controversy associated with them will continue'* (p375).

Kazdin (1993) also advises that replication of the studies is urgently needed and that such a replication should assign children randomly to groups, have larger samples to look effectively at within group differences, use standardised diagnostic instruments and use a broad assessment battery. Foxx (1993) would also like Lovaas and his colleagues to provide more information on the eight children who were the most successful to ascertain whether degree of parental or sibling support or other family factors seemed important, but given the overall small sample size, such an analysis is unlikely to produce conclusive evidence (Kazdin, 1993).

Smith et al. (1993) began collaborating on potential replication studies in 1988. They report major logistical difficulties in replicating the treatment and assessments they made.

> *'To provide competent treatment, one must acquire extensive, hands-on, supervised training '* (p. 385).

The studies also need to be long-term which presents a different set of issues in terms of funding and research contracts. They conclude by writing,

> '*Although we disagree with the specific criticisms that have been raised, we concur with the general point that we should strive to improve our methodology.'* (p. 390).

In identifying areas themselves for further research, Lovaas and Smith (1989) suggest that research is needed into links between behavioural treatment and neurology and state that,

> '*Intensive behavioral interventions may act to reverse whatever neurological difficulties are involved in autistic children's problems. If so, they may come close to providing a 'cure' for the problems. Such interventions may also prevent difficulties that have been found to emerge in autistic children later in life, such as seizures and high serotonin levels' (p.27).*

Chapter 11: Comparative research of different approaches

There have been few studies which have set out directly to compare the effects of several interventions. Bartak and Rutter (1973) studied the effects of three different educational settings on the progress of young children with autism. Many of the studies described in this review have had comparison groups, but these studies have generally been concerned to assess the effect of one specific treatment approach as measured against what a child might receive during their usual school programme, for example. There are serious logistical difficulties in finding similar samples of children engaged within particular approaches to enable effective comparisons to be made as the numbers engaged in an approach at any one time are relatively small and often geographically widespread. These children are also likely to be engaged in more than one approach and to be attending a school. The research described below, however, set out to investigate the rationale, practice and effects of different interventions on similar children with autism who were attending different educational settings.

11.1 A comparative and descriptive study of interventions for children with autism (Jones, Meldrum and Newson, 1995)

Programme: The children attended a variety of schools and were following one or more of several approaches including, drama therapy; Holding therapy ; musical interaction; music therapy; the Geoffrey Waldon approach; plus other activities offered as part of their school timetable. Some of the children following the Geoffrey Waldon approach or Holding therapy attended a private Centre and/or did this work within their school.

Sample:

Age: 4 to 7 years old at the start

Diagnosis: Autism

IQ: From those with severe learning difficulties to those within the average range

Exclusion: Not selected if they attended school residentially or if English was their second language

Language level: Ranged from those whose communication was limited to sounds or physical means to those who spoke functionally in words or phrases.

Additional difficulties: Learning difficulties

Number: 31

Comparison groups: Each 'treatment' group served as a 'control' for the others. Similar children (in terms of age, expressive skills and time in the setting) were selected from 6 different settings which were: the Geoffrey Waldon Centre; a Mothering Centre (for Holding therapy); an NAS school; an LAS school; LEA unit specific to autism; and from schools for children with severe learning difficulties. During the research some children changed setting or approach.

Additional treatments: Several (see under programme above)

Dependent variable: Self help, motor, academic and communication skills

Measures for dependent variable:

Video recordings analysed

Checklist developed by the research team completed by staff and parents

Interviews with staff and parents

Evaluator: Independent of the settings but not blind to the conditions, although some of the videos were rated 'blind'.

Context: Interventions used within specialist, special and mainstream school settings and at home for some children
Time scale: 16 months
Intensity: Varied with the intervention or the ability of the family to access this
Integrity: Evaluated by the research team
Ethical concerns: Parent chosen interventions contrasted with school placements - not directly comparable
Results: The small sample in each setting did not allow statistical testing of the data to check whether there were significant differences in the performance of the children in the different settings and approaches, so conclusions about the effects of these could not be drawn. In terms of communication skills, just under half the children overall improved their clarity of intent over the 16 month period. The number of contacts that the children initiated with adults at home and school at the start and end of the research, 16 months later, was fairly low - even from those children who were able to speak in phrases. Situations where there was a particularly high number of child-initiated contacts were usually where the child was motivated to communicate (eg for food and drink, during their favourite activity with an adult or when they appeared to need reassurance).

Twenty-one children improved on the undressing scale (21); followed by eating (18); dressing (17);washing (16); drinking (14); and toileting (12). Twenty-one children showed improvement on the picking up and placing scale, followed by pencil skills (20); pulling, turning and cutting (18); writing skills (16) and drawing a person (13). Nineteen of the children improved in their ability to understand time (19), followed by the 'puzzles, sorting, matching' scale (17) and reading readiness scale (17), and the prewriting scale (16). At the start, the average percentage time spent 'on task ' for each setting ranged from 63% to 84% with large individual variation within the groups. Sixteen months later, the average time on task for each setting had increased for three of the settings.
Training implications: Staff appropriately trained for each approach or setting
Identified precursors for success: Not available

11.2 Evaluation of the comparative research study

Evaluative research conducted in natural settings, such as schools, is potentially problematic for a variety of reasons. Many difficulties stem from the inability of researchers to select children for different conditions and then to request that they remain within these. The baseline data in the study above were dependent on the skills of staff and parents in observation and assessment and also on the analysis of the video records. As staff and parents varied in their knowledge and skills, it was of course possible that the data collected were more dependent on these abilities than the characteristics of the child. Because of the small population within the schools in the relevant age group, it was not possible to closely match the children in each approach. Aggregate matching was attempted between the groups in terms of their age, length of time in the approach and expressive skills. Much was learned from this study in terms of the differences in practice within different types of school having similar populations and in developing ways of measuring progress using checklists and video records. A framework within which to describe practice and rationale was developed to enable comparisons to be made.

Chapter 12: Discussion of research findings

At the end of each chapter on the approaches, we have made some suggestions for the kinds of further research that is needed. In this chapter, we draw together the findings from this review and comment on the suggestions that others have made for future research needs when it comes to evaluating approaches. In the final chapter we consider some further research needs based on comparison across different approaches, with a particular focus on the research questions that the questionnaire respondents from the LEAs were interested in, and small scale research investigating different aspects of process, rather than global outcome.

12.1 The overall findings from the evaluative review

Most approaches had some evidence of the effectiveness of what they did in terms of outcome, but this was extremely variable in quality in scientific terms. Some approaches seemed happy to rely on case studies of a few children, reported by the proponents of the approach, and this is clearly the weakest form of evidence. Other approaches have attempted, with variable degrees of success, to produce controlled studies with long-term, objective, follow-up measures. No approach has yet been entirely successful in producing a methodologically sound evaluation of its work.

That is not, it must be emphasised, to make any judgement about the actual approach itself (which was not the purpose of this research review). Some approaches may prefer (along with most other kinds of educational approach) to rely predominantly on research evidence of the rationale for the approach (Mesibov, 1997, for example) and leave outcome evaluations such as parental satisfaction measures and educational assessment of the progress of the child within the programme. Certainly, we were inundated with unsolicited accounts of heart-warming success from parents with children on all kinds of programmes, both home-based and in school settings. We are sorry that time constraints has meant we have not been able to give at least some flavour of those reports. They cannot stand as scientific evidence of the effectiveness of an approach, for obvious reasons, but they do illustrate an important point. A review like this can only make overall judgements based on the evidence over a number of children and situations. Science has little to say about the individual case. Autism is so variable and individuals with an asd so different, that a particular child may benefit from a particular approach at a particular time, regardless of what overall conclusions can be drawn from the research evidence. Teaching is more of an art than a technology (at least, within most educational approaches in the UK) and an inspired and dedicated teacher (whether this is a professional or a parent) can often succeed against the odds, with whatever approach he or she believes in.

12.1.1 Interactive approaches

We did not find any good methodological studies of interactive approaches and those that were underway or planned had methodological weaknesses which will make the results difficult to interpret. The Playschool approach (Rogers et al., 1986; Rogers and Lewis, 1989) offered the best evidence for effectiveness in terms of outcome measures, but there was no control group and the results remain tentative. It provides a model that would fit well with much early years educational practice in the UK, so it is important that more rigorous methods of evaluation are undertaken.

The study under way on musical interaction could be extended to include a more useful comparison group and that would then provide the possibility of more objective evidence of effectiveness. The problem with interactive approaches and research evidence on outcomes seems to be that these approaches are more interested in evaluations of process on an individual basis. This is certainly a justifiable stance in educational terms, but it makes it difficult to make any objective evaluation of the approach overall. In situations where cost-effective approaches are sought and parents and authorities are uncertain about the best approach to adopt, this may mean that such approaches are not endorsed. If they fail to be endorsed because they are not effective, that will not matter, but it is important that their potential benefits are researched fully so that there is no premature dismissal of a possibly beneficial approach simply because the evidence is missing.

12.1.2 Approaches to communication

This category was a problematic one, including as it does some systems that are really part of an overall 'package' (eg PECS and the Delaware programme) while others are based on the premise that a communication aid is the sole educational need (ie Facilitated Communication). Thus, there was some reasonable evidence of the effectiveness of the Delaware programme as a whole, with some indication of the role of PECS in achieving that, but no specific evaluation of PECS itself. But, again, the studies had methodological weaknesses and so the findings can only be suggestive. Given the potential ease with which a PECS system could be incorporated into the educational system in the UK, it certainly merits further study.

The other main finding in this section was a further confirmation that Facilitated Communication cannot be shown to enable independent communication in people with autism. It may have value in leading to computer use for communication, although the evidence for increasing (rather than lessening) dependency on the facilitator as training progressed would suggest that it may not be the best training for independent keyboard skills. As mentioned above, this does not mean that no individuals with autism can benefit from this technique, but it does suggest that its wholesale adoption should be questioned, and the results of individual facilitating dyads interpreted with caution.

12.1.3 Integration approaches

The results here are encouraging but methodological weaknesses mean they must be interpreted with caution. The LEAP approach was compared to a comparison group, but without adequate control criteria. The Walden study also showed impressive treatment gains but once more these are difficult to interpret without a control group. In the third study in this section, the control group was well matched but was of normally developing children, so cannot be considered as a control for the effect of this particular form of integrated experience. What they do show, is that both children with autism and normally developing peers can gain from a well managed integration approach. This is an important finding, given the current emphasis on inclusive practices in the UK, although it does not say anything about whether the children would have done as well or even better under some other approach. Research is needed urgently to resolve this issue and to determine the processes needed to make an integrated setting effective for a child with an asd.

12.1.4 Division TEACCH

In spite of its widespread use in the education of children with autism both in the UK and elsewhere, there was little evaluative research on outcome measures for TEACCH. Most studies reported did not have adequate controls and so the positive results found cannot be unequivocally attributed to the effects of the programme. A more recent small scale study by Ozonoff and Cathcart (1998) did have a control group who were not receiving TEACCH in a home-based programme (although both groups were receiving an ABA approach at school) but they did not receive any home-based programme at all. This means that the positive results might be simply due to parental involvement or to the intensity of the educational intervention, rather than to the TEACCH programme itself. Given the high profile of this approach in the UK, it is important that better methodological studies are conducted to determine its relative effectiveness compared to other approaches.

12.1.5 Daily Life Therapy at the Boston Higashi School

There was some confusion in finding the research on this approach. Some research reported at a conference in 1991 did not appear to have been published and so there is some doubt about the results, which have not been subject to peer review. A further research study had serious methodological flaws and the report of the study did not give sufficient details of the findings nor of the 'comparison' group. There is a great need for a well controlled study of this approach, although there are difficulties in finding adequate controls in the UK. The prospect of some programmes being developed within the UK in the near future offers opportunities to remedy this.

12.1.6 Behavioural approaches

Two approaches independent of the Lovaas approach were found; they reported impressive gains in the children's development but used no control groups. The Lovaas studies all depend on the original Young Autism Project (being replications, extensions or follow-ups of it). The Young Autism project was ambitious in its design, but its results cannot be interpreted as unequivocally, as it is by Lovaas and his colleagues. It is a controlled study, but the controls are for intensity of the programme (10 versus 40 hours versus no specified treatment) and use or non-use of contingent aversives. Moreover, the two control variables are confounded. There is no control for the programme itself. Lovaas interprets the impressive gains as resulting (at least in part) from the use of aversives with the experimental group, although later interpretations refer solely to the variable of intensity. There is no evidence presented to distinguish between these two interpretations and both have been varied in replications of the Young Autism project. Current legal and ethical views in the UK would not permit the use of aversives, so it is important that a methodologically adequate study is performed that explores the issue of intensity and specificity of programme effects through comparison with other approaches of comparable intensity. It is not possible (nor desirable) to test the aversives hypothesis in the UK and we would not like to see this done elsewhere. One of the proposed studies has a control for approach, but it does not appear, at this stage, to have adequate control for intensity.

12.1.7 Comparison of approaches

Only one study was found that compared different approaches, although some have been found that are planned to compare one approach with a single alternative. The study found compared children undergoing a variety of approaches in six different educational settings in the UK (although these were not all now found among the current approaches being researched in the UK). There were methodological problems with the study, which are raised in the relevant section, and as yet the study has not been published for peer review, although the results are available in report form. Such studies are potentially very valuable, but also very difficult and expensive to conduct; nor are the results of such complex studies always easy to interpret. A more fruitful way forward may be to adopt standard methods of evaluation across smaller scale studies, to allow later meta-comparison of results across studies.

12.2 Roger's (1996) meta-analysis

Roger's (1996) examined six published studies showing positive outcomes with children with autism, but found that none used rigorous scientific methods with random assignment of children to groups and evaluators blind to all aspects of the study.

The differences she found between the studies were in:

- curricula
- settings and ratios of staff to children
- ages and functioning levels of the children
- the ways of measuring progress
- the kinds of comparison groups and
- the strategies for looking at change.

She also found common features within the studies. These were:

- significant acceleration of the developmental rate (often IQ enhancement)
- significant language gains (73% overall with useful speech by age 5)
- improved social behaviour and decreased symptoms of autism.

In addition, for most programmes, she found gains within 1-2 years of intensive pre-school education and two long-term follow up studies that suggested treatment gains were maintained.

12.3 Dawson and Osterling's (1997) meta-analysis

Dawson and Osterling (1997) have analysed some of the early interventions in autism and have selected features that appear to be common to the eight programmes showing successful outcomes. This work was completed before the Ozonoff and Cathcart (1998) study was published, but does cover studies from most approaches (other than communication and Daily Life Therapy) covered in this review. Some of the studies quoted (which are also given in this review) have methodological weaknesses, as has been discussed in each case above, but they all provide some evidence of success. The approaches included are the Douglass (Integration study 3), Health Sciences (Interactive study 2), LEAP (Integration study 1), May (Behavioral ABA programme), TEACCH , Walden (Integration Study 2), and the Young Autism Project (Lovaas). Dawson and Osterling select the common features from these (in their judgement) successful programmes.

12.3.1 Common elements of eight 'successful' programmes reviewed by Dawson and Osterling (1997)

Curriculum content

selective attention to task demands and the imitation of others
comprehension and use of language

ability to play with toys
social interaction

Need for highly supportive teaching environments and generalisation strategies
for the first teaching of core skills
as an intensive specialised environment
supported by adult
staff/child ratio 1:1 or 1:2
providing augmented scaffolding
optimal performance trained before functional training
specific generalisation strategies

Need for predictability and routine
most are highly structured and routine with someone prompting to support and guide
use of visual cueing
specific strategies for transitions and change

Functional approach to problem behaviours
prevention through engaging in alternatives
functional assessment and teaching
alternatives for function
change environment to support appropriate behaviour
emphasis on teaching communication

Transition from pre-school classroom
teaching 'survival skills' for school placement
assisting in finding suitable placements
ecological inventory of future placement
staged transition training of placement staff

Family involvement
parents role recognised as critical
variation in how far parental role is prescribed
variation of parent training at home/school or both

Intensity and other common elements
all but 1, 20+ hours per week
all involved parents to extend programme
range of augmentative methods used
emphasis on trusting positive social relations
many used normal peers as models
most identified independence, initiative and ability to choose as goals initiative and ability to choose as goals

Dawson and Osterling (1997) suggest the following requirements of further research:

- standardised measures of cognitive, language, social, and adaptive abilities of participants
- standardised measures of developmental change across programmes
- information on support services needed to sustain mainstream placement
- standard ways of characterising post pre-school placements
- a need for a careful cost-benefit analysis

12.4 Guralnick's review of research into early interventions

Guralnick (1997) produced an overview of all early intervention studies (not just for autism) and reached similar conclusions. He also analysed some of the difficulties that research had highlighted that prevented many approaches from being effective. These were not specific to autism, but nevertheless could suggest issues that need to be researched. One barrier to a programme's success appeared to be the interpersonal difficulties of parents (eg depression) and this might well be an important factor in autism. So also were the effects of poverty and disadvantage and the cultural values of certain groups. We have some information from the research studies of the ethnic and socio-economic status of the parents involved, but this has not been investigated in a systematic way and clearly needs to be if the service is to be inclusive.

As with the studies on autism, Guralnick (1997) concludes that there is a consensus from the research that early intervention makes a difference. He also notes, however, that there is less secure evidence of which approach is best, given that comparisons are often with no service, so that relative benefits are not assessed. He suggests the following research questions, which we would endorse from this review.

Unresolved issues
which curriculum?
when and for how long?
with what intensity?
what methods? (eg didactic or facilitatory?)
with what degree of structure?
how should families be involved
how do social support systems affect outcomes?

Future tasks
identify specific programme features associated with optimal outcomes for children and families
longitudinal studies with prospective randomised designs
appropriate controls
comprehensive and intensive follow-up of carefully chosen samples
examine child characteristics (eg severity of condition, associated problems etc)
severity of family risk as a factor in outcome
aetiological specificity of programme
domain developmental constraints on outcomes (physical disabilities, for example being less amenable to change than cognitive ones)
range of outcome measures to reflect characteristics of children, nature of the intervention, expectations of the extent and nature of change
integrative (eg social competence) outcome measures needed.
effects on families - in own right and as mediators of child's development.

12.5 Bristol et al's (1996) meta-analysis

Bristol et al. (1996) have submitted a report to the NIH in the USA on treatment approaches in autism. Within this report, they give the methodological requirements for a scientific study:

- experimental designs comparing various treatment approaches
- random assignment to treatment and control conditions
- standard treatment protocols in which the range of behaviours and skills in both laboratory and naturalistic settings are assessed.
- outside evaluators
- treatment integrity assessed
- longitudinal research designs for assessing immediate, intermediate and long-term effects

These are by now familiar, but nonetheless important, criteria. Some of them can be accomplished with comparative ease. Some will require ingenuity and we have suggested some alternative and creative ways of meeting such criteria as we have commented in the different sections on research needed. To provide research studies that meet all these criteria is somewhat Utopian, but we should have them as a standard against which to judge all research, so we can be appropriately cautious in our interpretation of research findings and their implementation in practice.

Chapter 13: Implications for future research

This chapter will consider topics on which research is needed, discuss some of the difficulties inherent in research in this area and then suggest some possible research designs and methodologies.

13.1 Research needed

The suggestions made by other researchers in the preceding chapter would largely accord with our analysis. In spite of claims to the contrary, there was no one approach where research had clearly demonstrated either its superiority to other approaches or its own unequivocal success. The Lovaas approach had set standards in evaluation by the attempt at a controlled study and some other approaches had since followed suit. None of these attempts had been entirely successful and most research had methodological weaknesses which would allow it to be interpreted in different ways. Below, we consider some of the issues which make research in education problematic. That is not to say that it should not be attempted, nor that we have learnt nothing from the research to date. Each study has at the very least offered further refinements on the research needed and, by studying the range of approaches in the light of documented evaluative attempts, we can select variables that are likely to lead to successful outcomes. Each of the common elements identified by Dawson and Osterling (1997) could be the basis of controlled studies in the future, to determine which are necessary and sufficient features for a successful outcome.
When Lovaas and his colleagues started the Young Autism project in the 1970's little was known of the special educational needs of children with an asd and there was little experience of making specific educational provision. The problem with longitudinal research is that by the time the research is published and available to influence practice, that practice has itself changed and theoretical understandings have developed. What Lovaas has been successful in demonstrating (backed up by many of the other approaches mentioned in this review) is that early intensive intervention in autism can be very effective, at least for a substantial minority of children. We do not yet know how early that intervention needs to be, how intensive, nor with which children. Still less do we know what kind of intervention it needs to be, although we have some idea of likely characteristics from the list of common features selected by Dawson and Osterling.

What is now needed is what Dawson and Osterling (1997) call 'second generation research'. This builds on the findings of the research that has gone before but also takes into account our current understandings of autism and the experience gained from decades of educational provision (albeit of variable quality and availability). In the UK, also, we must consider the cultural context and remember that children with autism also have rights to a broad and balanced curriculum that meets academic as well as personal and developmental needs.

Some approaches (behavioural ones, for example) will not consider it necessary to consider growth in understanding about autism, since such approaches are not concerned with 'within child' factors, being based on principles of learning theory. Others may wish to ignore general educational contexts on the assumption that the child needs to relate or to develop certain key skills before entry to such a system.

Parents will have very different views on what is a priority for a child to learn at any one time, although almost all will want to do what they see as providing the best opportunity for their child. It is important to remember, however, that children are the ultimate clients of the education provided by LEAs and that provision must meet children's special educational needs. It is always better if parents are involved in, and supportive of, decisions LEAs make about provision but there will be occasions where those decisions do not meet the wishes of parents of children with autism for a particular approach to be adopted, no matter how strongly parents support that approach or how able they are to participate in its provision. Research is needed into the different approaches so that LEAs can more successfully match provision to the needs of the individual child and provide better information to parents on what could be provided and how best parents can be involved in the education of their children.

But the choice of a method is never made on research evidence alone, and other factors should be made explicit so they can be weighed against the evidence for effectiveness in each case.

Throughout this review, in each section on a kind of approach, we have indicated what research needs to be done in that area. It is often difficult to establish and fund comparative studies of approaches and many studies are underway which just seem to repeat the methodological limitations of their predecessors. At the moment, the research that has been done on different approaches is difficult to compare, since they have all used different methods to note individual differences in the participants and different outcome measures. The most useful first step, if different research interests could agree to participate, would be to agree common ways of characterising the children in the studies and common ways of measuring outcomes. An even greater step would be to ensure the objectivity of those collecting the data.

Unfortunately, the existing empirical evidence of different approaches does not provide a resolution. Based on Rutter's (1996) views, we conclude that there is a need for research on:

- Comparison of effects of different treatment approaches to children with an asd, controlled for intensity and age of onset of treatment
- Comparison of effects in different sub-groups of children with autism (eg verbal versus non-verbal, different IQ groups, Wing's different social groups).
- Isolation of treatment variables responsible for success, ie those leading to the most economical, effective programmes (teaching approach, parent intervention, curriculum, one-to-one versus groups, use of allied health therapies, needed intensity, role of normally developing peers, language training strategies, techniques for dealing with unwanted behaviour, techniques for improving sociability etc.)
- Use of rigorous methodologies including: random assignment to different conditions, standard protocols that capture a wide range of skills and symptoms at specific points in laboratory and real-life situations, treatment-blind outside evaluators, treatments that adhere strictly to specific models, longitudinal designs with evaluation at set points.
- Designation of a Standard Programme Evaluation database, nationally, to allow better comparisons across programmes.

Rutter (1986) also makes the point that not all approaches will require such careful evaluation. He suggests that a balance needs to be struck between the need to evaluate new therapeutic claims and the need ' to avoid wasting time and money on the systematic investigation of therapeutic methods that seem unlikely to carry significant benefits ' (p269).

13.2 Possible research designs and methodologies related to process

As mentioned in the section on Facilitated Communication, one reason that that approach has been so well researched is that it offers opportunities for short economical and rigorous research designs, free from many of the restrictions that are associated with longitudinal naturalistic research. This section, therefore, selects some of the issues derived from the other sections, that could also be studied in small scale rigorously designed studies. In addition, these studies offer the opportunity to test out some of the crucial procedural differences between the programmes, without relying on overall outcome measures alone. It may well be the case, for example, that individual aspects of some approaches may have value, while the overall results of the programme are not impressive. Equally, an apparently successful programme may contain inefficient elements which might be eliminated or changed. It may also be the case that some aspects of some approaches will suit some children (or some situations) and not others. This kind of valuable information can be obscured by simple comparisons of outcomes and so there is also a need for research that focuses on the processes involved in the different approaches.

One test which would be short-term and experimental would be an examination of the kind of structure that is facilitatory. For example, a teaching design (even a crossover design using the same children as their own controls with different tasks - task by order by method) could determine the relative value of discrete trial prompted performance, versus visually-mediated facilitatory methods. The findings of an 'abdication' effect (prompt dependency: Bebko, Perry and Bryson, 1996) in Facilitated Communication studies would suggest that this would also feature in prompted methodologies, but this remains to be demonstrated empirically.

There should be similar studies in relation to spontaneity and independently generated communication versus increased compliance and responsiveness. Both increases may be beneficial but it is important to know for an individual which methods lead to which kinds of performance enhancement. The hypothesis, from the theoretical underpinning and methodology of the approaches, would be that PECS (Bondy and Frost, 1994) would lead to greater spontaneity and independence in communication, but perhaps slower acquisition of speech, whereas a Lovaas style training would be expected to lead to less, and later, spontaneity of communication, more responsive speech and earlier vocalisations. This hypothesis also needs to be tested.

Studies should take account of effects of the Hawthorne type, the confusion of treatment with non-treatment variables such as the enthusiasm and dedication of those carrying out the programme and the support given by those training the parents or staff. This may be an important factor in the operation of a programme and then the question of how such effects can be maintained beyond a pioneering project become important (Spitz, 1986). Also FC studies have shown how proponents may be unaware of the way they are affecting the results and these effects may increase over time (Bebko et al., 1996). On the other hand, realisation of the failure of an approach may bring depression and it may be difficult to return to the fold of LEA provision. Doors should always be left open, but there is a need for research to examine reactions of parents to unsuccessful interventions. Reported and planned research of effects on parents have concerned reportedly 'successful' interventions; what of the effects on the families of those who, by their own standards, do not achieve 'recovery' for their children? Does the philosophy of Option that 'to love is to be happy with' mitigate such effects, or is the implied promise of a 'miracle' more influential? A comparative study of the lengths of time children spend within an approach and the reasons for stopping or changing a prgramme would be useful as would be a study of the effects on the family before, during and after intervention for both successful and unsuccessful interventions.

Lovaas programmes do not teach augmentative communication systems until spoken language acquisition has failed to emerge (following intensive speech training). This is contrary to evidence showing that such systems can and do aid spoken language acquisition (especially when supported by verbal imitation training: Kiernan et al., 1987). Such advice is potentially damaging - especially to the group of children on whom Lovaas is now being used, who may not develop speech. It would be useful, therefore, to do a study comparing 'speech' versus 'augmentation plus speech' training (or different combinations). Whether this would need closely matched groups or could be done through a cross-over design is open to debate. The problem with the former is an ethical one, with the latter it is one of contamination, but order effects would help to eliminate this.

Then there is the question of concept formation. There is a personal report (Grandin, 1992) and some experimental evidence that people with autism have difficulty pattern detecting and thus have problems acquiring our normal 'fuzzy' concepts. They try instead to learn by categorical features, for abstract concepts, or by developing rigid concepts tied to an experienced event (eg a particular 'chair' is identified with the concept of 'chair', an old man with the concept 'old'). Lovaas style programmes use discrete trial discrimination learning for concepts and this would be expected to further reinforce this learning style. A short teaching programme for new concepts could be used (using a balanced cross over design once more), although outcomes may not be definitive. It may be, for instance, that children with autism would learn concepts faster through a discrimination method that suited their style and that the benefits of a method of general case programming for concept development might not be apparent except through later cognitive growth. Some tests of concept generalisation, however, might show the difference.

Parents engaged in programmes already mix components of different approaches, although additional treatments were seldom acknowledged in the research. Schools in the UK also use a mixture of approaches. It is important that comparative outcome research takes account of these differences, but there is also a case for process research that looks at how features of different approaches might be merged, or which combinations are counterproductive. A study of the ways different approaches are used within school and nursery settings would also be illuminating. Given the prevalence of TEACCH training for school staff, for example, a comparison of how TEACCH is used in different settings would help establish how far the practice matches the principles of TEACCH and this could influence the interpretation of any outcome research.

13.3 Some topics for future research based on survey findings

13.3.1 The implications of early diagnosis: which models of practice effectively link diagnosis with advice and support to parents?

Diagnosis is occurring earlier (Howlin and Moore, 1997) and many children are being diagnosed before or by the age of 5 years. Parents often express dissatisfaction with the situation where there is a gap between diagnosis and educational advice and treatment for the child. There is a need for research into models of practice which seek to link diagnosis with advice and support to parents, including multi-disciplinary team working, keyworker systems, parent support groups and workshops.

13.3.2 How can LEAs best identify children with an asd and special educational needs ?

Research by Newson and Jones (1992) and Jordan and Jones (1996) indicated great variation between LEAs in the number of children with an asd identified, compared to expected prevalence rates. Some LEAs reached identification rates compatible with prevalence rates of 5 per 10,000, but none reached numbers equivalent to a prevalence rate of 22 per 10,000, let alone the 58 per 10,000 that Wing (1996) has suggested. Although prevalence rates should not be used as some kind of 'target' figure for identification, these data do suggest that many children with an asd and special educational needs are not recognised as such. It is of concern that large numbers of children in schools may not be having their needs identified and addressed, accepting that autism is a signpost to, although not the sole determiner of, those needs.

Some LEAs have conducted their own audits within mainstream and special schools to improve their rate of identification. There is a need to conduct research into ways in which LEAs have attempted to identify children with an asd in order to refine and improve on these and make them available to other LEAs.

13.3.3 Does an intervention work for all children within the autistic spectrum?

Evidence presented in this review suggests that some children following a particular approach are likely to make greater progress than other children with an asd engaged in the same intervention. There is a need for practitioners to establish criteria to suggest which children on the spectrum a particular intervention is likely to be appropriate for and at which age or developmental stage they should start the intervention. To do this, one needs good data on the outcomes for children with asd following particular interventions. There are difficulties in doing the research as some children will follow more than one approach either simultaneously or consecutively.

13.3.4 How important is the nature and intensity of parental involvement to the success of a particular intervention and how feasible is this for parents?

Some approaches require a great deal of commitment and participation from parents and others require far less. What are the relative effects in terms of outcome and how feasible is it in practice for parents to be heavily involved in an intervention? It would be useful, in terms of planning for an effective educational service for children and their families to survey a scientifically sampled population to determine the willingness and ability of parents to be directly involved in teaching. It is important that some children are not further disadvantaged because of the inability or reluctance of parents to carry out home-based programmes and there must be a system of early intervention that allows for all degrees of parental involvement from minimal to total.

13.3.5 What is the cost-effectiveness of different interventions?

The financial costs of interventions to the family and/or the LEA can vary widely. It is necessary to collect good information on the actual costs involved in following particular interventions. Of course, it is not just about looking at the cost per se - but at the outcomes. It may be that an expensive treatment in the early years can reduce expenditure later in the child's life and therefore be deemed cost-effective relative to cheaper, alternative preschool provision.

13.3.6 What are the views of families that have been engaged in different interventions and the professionals involved?

In order to make an analysis of the financial and other costs and the benefits of following particular interventions for the child and for other family members, it would be extremely useful to interview families who have engaged in these - selecting families who have had different lengths of time within an approach and whose children have been engaged recently, or 6 months ago, 12 months ago or longer. Data collected by professionals who have been involved in reviewing the child's progress and have data on the child prior to starting an intervention and after the intervention has stopped should also be reviewed.

13.3.7 What are the long-term and short-term effects of an intervention , including the maintenance of skills when the intervention stops or the child moves to a different environment?

It is well established that the majority of children will make some progress in the early weeks or months of an approach, almost irrespective of the nature of the approach. What is needed is research to compare the relative effects of different interventions on similar children and for research which investigates the long term effects of these interventions.

13.3.8 To what extent can an intervention be transferred for use in other settings?

Some of the approaches reviewed can be used within a variety of settings, but for others the organisation and ethos of the setting is said to be important for its success. There is a need then to collect evidence on the extent to which an intervention can be used in other contexts and with what result. In particular there is a need to consider its use within the current range of schools and units in the UK and to monitor how the children adjust when they move into another setting.

13.39 How are practitioners of an intervention trained and supervised and to what extent is the nature of these important for the success of an intervention?

Many of the approaches require parents and practitioners to be trained in the use of the methods. Some offer continued monitoring and supervision. Clearly the competence of the person working with the child is likely to be a key factor to its success - yet how much do we know and understand of the nature of training required and the impact on practitioners? Courses that offer one single approach to be adopted uncritically may be de-skilling. The initial effect may be positive in that the techniques may offer a framework that appears to work, but, unless the practitioner understands the principles underlying the approach, it may be misapplied or the practitioner may not know how to adapt it to meet individual or changing needs. If the interventions are to be used within a school setting, one needs to consider the training and supervision implications for staff.

13.3.10 How do LEAs 'market' their own provision and provide information to parents of children with an asd?

It is often reported anecdotally that professionals in the UK do not have a tradition of promoting the work they do and advertising good models of practice or the positive effects they produce. Increasingly, schools in the UK are having to consider their public image and how they 'market' what they have to offer to parents. It is likely that some LEAs are more successful than others in this respect. There is a need to identify effective models of providing information on provision to parents and others.

13.3.11 What are the relative effects of different types of school or unit settings in terms of outcome?

The majority of children with autism in the UK attend schools which have a mixed special needs population or they attend mainstream schools. A minority attend schools and units which are autism-specific. To what extent is practice similar within each type of setting and what are the main issues for staff in teaching within these settings? What are the short and long-term benefits to children with an asd in each setting? Is it possible to identify which children on the autistic spectrum are likely to gain most from the different placements, and at which age or developmental stage?

13.312 What are the benefits to the child and their family of residential attendance at a school ?

There is a need for research to establish the benefits of residential attendance to the child and their family and to identify factors which lead to residential placement. There is debate as to whether residential provision is useful to the child - some professionals claiming that the child makes more progress because of the continuity and consistency of approach, and others believing that if the main reason for the placement is the needs of the family, then alternative ways of providing family support should be sought to allow the child to remain within the family.

13.313 What is the relative effectiveness residential schools and other support systems, where families are experiencing significant difficulties in supporting their child within the family?

Given the difficulties that the parents of some children with an asd encounter, more creative and flexible ways of providing support for families to enable their child to continue living at home, should be explored in the future (eg extension of befriending and shared care schemes; extension of school staff's contracts to enable work at home; development of local residential hostels which offer more time to families than traditional respite care facilities). Innovative ways of supporting families beyond the usual school hours should be investigated and evaluated.

13.3.14 Which interventions support the transition from childhood to adulthood?

As a result of the current structure and funding of services in the UK, links between child and adult services are often weak. How can the transition to adult services be organised so that appropriate decisions are made and actions well planned in advance? Can models of practice be identified which enhance this process?

13.4 Difficulties inherent in research into interventions

13.4.1 Diagnostic issues

Autism can be diagnosed in young children but how often is the diagnosis of autism mistaken? This issue is of considerable practical importance given the claims of the benefits

of early intervention. Rutter (1996) suggests that uncertainties remain about the validity of the diagnosis of autism in very young children (under the age of 2 or 3 years).
In addition, Lord and Rutter (1994) maintain that to a large extent agreement has been reached on the key standardised interview and observational measures to be used in research, but there was great variety within the research studied for this review in terms of the basis for diagnosis and its confirmation. Comparing data across projects is therefore problematic.

13.4.2 Issues of assessment

The assessment of children with autism has long been recognised as difficult (Browder, 1991), yet formal testing plays a key role in many of the studies in this review both for matching samples and measuring outcome. A variety of psychometric tests are used including intelligence tests, tests of developmental abilities and speech and language assessments. McConachie(1996) argues that there still

> *'...remains an aura that tests of early development or intelligence measure something relatively precisely and scientifically.' (p.111)*

but that we should be cautious in our use of these and in interpreting the results obtained. In longitudinal studies, it is often the case that two different tests of IQ are employed as the test that was used when the child was of preschool age is no longer appropriate when s/he is older. Often when data are presented on matching and outcomes, reservations about the reliability of these scores are not discussed.

For children with an asd, their performance on the tests can be affected for several reasons and so their scores may not actually represent their ability on the dimension being assessed. Their performance may be affected by:

- their prior experience of 'formal' teaching/work situations - so, for example, a preschool child who has been following interventions which prioritise play and interaction may not have spent much time formally attending to materials presented on a table top, the situation in which the child is expected to perform for many IQ and language tests.
- their difficulties in attending to the relevant parts of a task or instruction
- being assessed by a person (eg research psychologist) who is unfamiliar with their specific needs and learning style

13.4.3 Consistent diagnostic and baseline data to allow comparisons between research samples

Linked to the issues discussed in the two sections above, there is a need for consistent baseline and diagnostic data to be collected.

13.4.4 Defining an intervention/approach

Defining the rationale and practice in relation to the practice of the staff and expected outcomes for the child can be difficult and the information does not always exist in a form which lends itself to the research process.

13.4.5 Outcomes

Deciding on what might be a favourable or impressive or positive outcome for a child is not simple and parents and teachers views on these will vary depending on what they value.

13.4.6 Measuring change

There are a number of areas of difficulty when measuring change in children with autism. Potential difficulties are as follows:

- the heterogeneity of the population
- lack of appropriate standardised tests
- identifying discrete boundaries around an approach - where and when does it start and finish?
- the problem of therapist drift (Jordan and Powell, 1996)
- that professionals and parents may try more than one approach simultaneously and move in and out of approaches over time
- there are likely to be changes in personnel over time with varying levels of training and skill in using the approach
- obtaining a sample which stays in the same research category (intervention; school type; geographical area; family status)

Adequate and effective research methods to evaluate outcomes and the process of interventions need to be developed.

13.5 Conclusions

The need is to ensure that the right kind of education is available to all children with an asd from diagnosis onwards. The areas of social interaction and communication will always be difficult for a child with autism to master. Any good educational programme should address these, but it should also be remembered that the child has a right to access a more conventional academic curriculum, adapted to meet his or her needs. It is important that education gives other skills and aptitudes a chance to flourish, building on the child's interests and strengths. Many successful adults with an asd are living independently and that is usually possible because their skills and abilities have been built upon; it does not come from a sole concentration on their difficulties (Jordan, 1997).

Most of the research reviewed in this report has not had this broad educational focus, but has been concerned with particular approaches within that context. It is important that vital resources are not wasted and, even more importantly, that we do not squander the child's time and energy when it is so needed to enable the child to make sense of, and gain acceptance in, a very confusing world. Thus, research on the efficacy of different educational approaches is very necessary. However, the value of the research will depend at least in part on the questions that are asked. We need to think about how we value difference and how far we are serious in wanting an inclusive education system and eventually an inclusive society. That road to inclusion might include paths of specialist approaches to teach particular skills, but we cannot ask a sensible research question about which approach is the most effective until we first determine what we want it to achieve.

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