



# Together from The Start – Practical guidance for professionals working with disabled children (birth to 2) and their families

## Executive summary

### Overview

This is a consultation document issued jointly by the Department for Education and Skills and the Department of Health.

It is concerned with the delivery of services to children with disabilities in the age range birth to 2 and their families.

Central themes within the guidance are:

- Active partnership with parents, and communicating news of disability in a sensitive way
- Prompt and co-ordinated assessment of needs, leading to a written Family Service Plan
- The importance of keyworkers

This guidance has been produced by a multi-agency working party chaired by Paul Ennals CBE and is being issued in tandem with a separate but related piece of guidance, Developing Early Intervention/Support Services for Deaf Children and their Families.

### Action required

If you wish to comment on any or all of the questions contained within the consultation document, please send your response to John Hall, Special Educational Needs Division, Area 2E, Department for Education and Skills, Sanctuary Buildings, Great Smith Street, London SW1P 3BT or by e-mail to:

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# Chapter 1: Setting the scene

## 1.1 Introduction

All children have a right to the best possible start in life. Where children have special needs and disabilities, it is important that these are identified at an early stage and that identification leads directly to effective early intervention and support for families and children. Early identification and early intervention are key themes in the Framework for the Assessment of Children in Need and their Families (2000) and the Special Educational Needs Code of Practice (2001). They are central to a number of Government initiatives including Quality Protects and Sure Start and they should lie at the heart of care provided by all professionals.

Effective early intervention and support can produce improvements in children's health, social and cognitive development. It strengthens the ability of families to provide effective support to their children, and improves outcomes for the whole family.

This guidance is designed to improve service provision to very young disabled children and their families. It is being issued at the same time as *Developing Early Intervention/Support Services for Deaf Children and their Families*, which considers particular issues for early-identified deaf children and their families in the context of the implementation of Newborn Hearing Screening.

## 1.2 Who is the guidance for?

This guidance has been produced primarily for use by professionals involved with the planning and delivery of services to children with disabilities (birth to 2) and their families. Professionals and other staff working in this field will normally work within health, social care, education, in early years settings, Early Years Development and Childcare Partnerships, and voluntary and independent organisations.

## 1.3 Why is it needed?

The population of children and families requiring services is changing, and new screening procedures are making it possible for some disabilities to be identified earlier than ever before. The aims of this guidance are:

- to promote effective early intervention services for meeting the needs of very young disabled children and their families
- to identify and promote existing good examples of effective partnership working and
- to support the strategic development of services for this population

There are many examples across the country of effective service delivery and partnership working. However, consultations with parents have identified many more examples where needs are not yet effectively being addressed.

Perceived barriers include:

- a lack of sensitivity at the time of diagnosis
- inconsistent patterns of service provision
- lack of co-ordination between multiple service providers

The following case is an example of how services may not effectively deliver care and support to children and families.

## Adam's Story

Adam was born at full term, a healthy baby. At four weeks old he developed meningitis and spent the next three months battling for survival.

Adam is now 13 months old. The effects of his meningitis are that he has cerebral palsy-spastic quadriplegia, he has epilepsy, he is blind and he is fed by naso-gastric tube.

Despite this Adam is a relatively healthy child and is large for his age. It is currently predicted that he will live until adulthood. Adam's family are coming to terms with his disability but their life has been made far more difficult by fragmented and inflexible service provision. He has had 315 different service based appointments in the last nine months in over 12 different locations.

He has no head control and was referred for a specialist buggy seven months ago. The family has yet to receive their first assessment appointment. The family has been told that they will not be formally considered for aids and adaptations until he is three. This is despite the fact that he is now heavy and father and grandmother have already damaged their backs.

He has been referred for a gastrostomy tube as the naso-gastric one is repeatedly being pulled out, he is often sick, the family are not confident at re-inserting the tube and the tape being used to attach the tube to his face is causing irritation and bleeding.

The family is now looking at moving into housing which can be adapted to meet Adam's needs. And require an assessment for aids and adaptations for the home. They have been told that they will not be eligible for a Disabled Facilities Grant as the father works and so there will be no financial support for adaptation.

They have received no comprehensive information or support about their entitlements to benefits, access to counselling, or national and local support groups. They had limited access to a hospice, and support from the children's community nursing team.

The family members report that the attitude of some professionals is still the most distressing thing they face.

They would like:

- information
- access to an assessment for: aids, equipment and adaptations and delivery in a reasonable timeframe
- an appointment system that recognises the complexity of their son's needs and brings some together
- a break from caring
- help at night as Adam's epilepsy means that he does not sleep longer than 15 minutes
- help with future planning both in terms of finance and adaptations
- a keyworker
- recognition from professionals of the emotional trauma they have gone through

Views from parents and professionals alike cite the following factors as having positive impacts on service development and provision:

- earlier diagnosis and a joined up approach to assessment
- effective co-ordination of service provision that incorporates the sharing of information
- parent/family held records
- the existence of a key worker, who can act as a gateway to a multi-disciplinary approach
- effective communication between professionals
- emotional support

## **1.4 Which children are we talking about?**

The needs of children and families will vary along many dimensions:

- for some children, their impairments will be apparent from birth or before; for others, the impairments will develop or become apparent only gradually
- an increasing proportion of children will have complex and multiple disabilities, requiring co-ordinated interventions to the child and family from several professionals
- some children can have high expectations of future development, if appropriate support is available. For other children the prognosis may be one of increasing difficulty and reduced life expectancy
- for some families, their need for support will focus on the provision of practical services and ideas to assist their child. For other families, their greatest need may be for emotional support

Disability and significant developmental delay may be detected immediately at birth or through:

- detection by parents and relatives
- detection by midwives, playgroup leaders, nursery nurses, health visitors and general practitioners in the course of their routine work
- the neonatal and eight week examinations
- follow up of infants and children who have suffered various forms of trauma or illness affecting the nervous system
- close observation of children with a strong family history of a particular disorder

Existing legal definitions of disability vary – these are summarised in Appendix A. It is not easy to apply existing legal definitions of disability to children aged birth to two years:

- many people find the language of some existing definitions insensitive, and in particular they may be off-putting to families with very young children
- existing definitions tend to rely upon the existence of a long-term and substantial disadvantage. In very young children, it is often not possible to determine clearly whether any impairment will be long-term, but the need for early intervention remains

Services will require a clear working definition that enables them to know how many children and families are likely to need their support. At the same time, the process of deciding whether a child fits a definition must not act as a barrier to the receipt of early support. An effective working definition for this age group therefore may be based on the child's developmental needs and the likelihood that a child will benefit from the services that are offered. This approach mirrors that employed within the Children Act 1989 for determining whether a child should be considered to be "in need". See Appendix A for children in need definition.

The following definition of disability is used within this guidance.

**A child under 3 years of age shall be considered disabled if he/she:**

**(i) is experiencing significant developmental delays, in one or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or**

**(ii) has a condition which has a high probability of resulting in developmental delay.**

Services will wish to consider whether particular medical situations suggest a high probability of developmental delay, in order to identify simple pragmatic ways of deciding whether children should be considered as disabled. For example, using the above definition, children born very prematurely may be considered as potentially disabled, until it becomes clear that such a child is not showing evidence of developmental delay. Children with severe sensory-neural hearing loss are potentially disabled unless appropriate services are in place.

## 1.5 How many children might we expect?

It is not easy to anticipate how many children might be expected to fit the above definition in any one area. Factors to consider include:

- among the older child population, estimates of incidence of disability vary between 3 and 5%
- some causes of disability only emerge over the first few years, whilst other children who show developmental delay in early childhood overcome their early difficulties
- incidence of disability is considerably higher in areas of deprivation
- some causes of disability are particularly prevalent in some minority ethnic groups

Incidence levels will show significant variation between areas. Planners might expect on average to be able to identify 3% of children in any one area, subject to local factors.

In recent years there have been advances in the prevention of disabilities in children, and improvements in the healthcare services that support the survival of severely disabled children. Consequently there has been an increase in the proportion of children whose disabilities are severe and multiple, and a corresponding decrease in the proportion of children with mild or moderate disabilities. The total number of disabled children has remained broadly constant.

## 1.6 Current trends in policy

A number of current trends in policy may provide opportunities to review and develop the services for disabled children and their families.

- *Earlier Identification.* It is becoming possible to identify some impairments much earlier in children – for example, hearing impairment or autism. This is likely to result in increases in demand for services at an earlier age.
- *Inspection, regulation and accreditation.* The introduction of new frameworks may provide opportunities to review and change patterns of service delivery.
- *Performance Management, Best Value and self-audit.* New expectations of performance management will require a reassessment of which services are being delivered, taking full account of user perspectives.
- *Service Co-ordination.* Opportunities afforded through the use of Health Act flexibilities for pooling budgets, integrating provision and developing lead commissioning arrangements between health, education and social services should be fully explored.



- *Standards.* The new and emerging National Service Framework should help towards the establishment of a series of national standards that all service planners and providers work towards. Whilst service models across the country may need to be different to reflect local needs it is important that a common framework for delivering services to agreed standards is observed. A consistent approach is needed to ensure people have access to an equitable service across the country.
- *Neighbourhood Initiatives.* Communities of practice that develop a shared approach and culture are reaping significant benefits e.g. Sure Start Programmes.
- *Co-ordinated and participative planning systems.* Through the development of Local Strategic Partnerships for children and young people improvements in the co-ordination of local service developments should be more effectively supported and targeted.
- The rights of disabled people are being enhanced through the Disability Discrimination Act 1995, the SEN and Disability Act 2001 and the establishment of the Disability Rights Commission. The emphasis on rights applies to all age groups and supports the Government's inclusion agenda.

## 1.7 Aims for service provision

The needs of most children will be met within a family setting. This should be reflected in an integrated response to child and family need, which is sensitive to differing family cultures and religions. Early intervention should include support for the child, support for the parents and support for the parent-child relationship.

The Government is committed to delivering better life chances for disadvantaged and potentially vulnerable children through the earlier identification and understanding of their needs. Delivering services to disabled children is a corporate responsibility and improvements in outcomes for children and their families can only be achieved by close collaboration between parents, professionals and agencies working with children and their families. However, it is health services that tend to be the first point of contact for parents of a young child with disability and is often the lead service in organising multi-agency collaboration.

Therefore the aims for service provision should be:

To support the child in all aspects of their development including:

- providing the health care, to include diagnosis, aetiological investigation where appropriate, an assessment of development, impairments and needs, rehabilitation and equipment needed to sustain life, minimise pain and maximise potential development
- providing the educational and therapeutic input needed to maximise social and cognitive development
- providing support to the family needed to maximise emotional development
- providing support which respects the cultural and religious views of the family

To provide families with the support they need in bringing up their child including:

- information they need to understand their child's situation, to make informed choices, and to access sources of help
- emotional and practical support to enable them to adjust to their situation and provide the support their child will need
- advice on practical ways in which they can maximise their child's development
- access to childcare and other appropriate community services
- opportunities for the family to lead an active and "ordinary" life

## 1.8 Duties and powers of statutory bodies

This guidance reflects the principles contained within the United Nations Convention on the Rights of the Child, ratified by the UK Government in 1991 and the Human Rights Act 1998. Many agencies have contact with, and responsibility for, children and young people under a range of legislation. This is summarised within Appendix A.

## 1.9 The Government's policy agenda

The Government is committed to creating an inclusive society, a society where every individual can make a distinctive contribution and has the opportunity to fulfil their own unique potential.

An important element in tackling social exclusion is ensuring that disabled children have their needs recognised and that these needs are addressed promptly and effectively. Families also need support when seeking help for their children from professionals across a range of services. For some parents it may be the first time they have had such contact. Their reasonable expectation is that agencies will work together closely and flexibly to improve the provision made for their children.

A number of initiatives and programmes have been introduced to support families and young children in recent years and these have helped to raise the profile of effective intervention in the early years. Of particular importance for this age group are initiatives such as Sure Start, Neighbourhood Nurseries, Early Excellence Centres Programme and the development of Early Years Development and Childcare Partnerships (EYDCPs).

EYDCPs are currently required to establish a network of Area Special Needs Co-ordinators (SENCOs) by 2004. Area SENCOs will provide day-to-day support for setting based SENCOs in non-maintained early years settings on early identification and appropriate intervention measures. A key part of their role is to build links between settings and services offered by the LEA, Social Services and Health. Although this provision is aimed at children beyond 0–2 as they move into funded early years education, there will need to be an awareness of this guidance and suggestions for joined-up good practice in order to maintain and develop the links already established.

The importance of early identification is further reinforced by the fact that the new Special Educational Needs Code of Practice (2001) devotes a whole chapter to the early years. The Quality Protects programme and Carers Grant are increasing the level of family support services to families with disabled children. The Framework for the Assessment of Children in Need and their Families is designed to identify if a child is in need and ensure that these children and their families are provided with appropriate and timely services. Chapter 2 in the Practice Guidance (Department of Health, 2000) focuses specifically on disabled children and considers how the Assessment Framework can be used to address the needs of disabled children and their families.

The Inquiries into Alder Hey and Bristol have highlighted the importance of placing patients and their families at the centre of the provision of care. Specific recommendations have been made to ensure that patients and their families are enabled to meet healthcare professionals as equals, recognised as the expert in the care of their child, are valued and provided with relevant information tailored to meet their individual needs.

### Consultation questions

- 1.1 Do you agree with the aims for service provision?
- 1.2 Are there any other aims you would like to see services aspire to?
- 1.3 Do you find the proposed definition for this age group helpful?
- 1.4 Can you offer examples to illustrate how senior level commitment and/or a shared vision has made a difference?

# Chapter 2: Assessment and early intervention

## 2.1 Introduction

- The Framework for the Assessment of Children in Need and their Families (2000) provides a comprehensive structure for a full consideration of the developmental needs of the child within their family and wider environmental context.
- National Screening Programmes and new developments such as the introduction of Newborn Hearing Screening are now available.
- The Special Educational Needs Code of Practice (2001) sets out an approach for assessing special educational needs.

The diagnosis and assessment process does not always work effectively for young children and their families, however, despite the policy intentions of Government.

## 2.2 Partnerships with parents

Key principles for working with families include:

### Rights and Responsibilities

Parents have rights and responsibilities in relation to the development and care of their child. Professionals have a duty to acknowledge and understand the unique role and relationship each parent has with their child.

### Respect

Parents have unique knowledge about their child. They have the right to be respected as the primary carers of their child.

### Informed Choice

Parents have the right to be provided with unbiased, accurate and up to date information in order to be able to make informed and appropriate choices for their child.

### Individuality

There are many common issues for parents of disabled children but no two families are the same or have identical needs. Families can be diverse in terms of their experience, resources and expectations as well as their cultural, religious and linguistic influences.

### Equality

Optimum support for a disabled child will only occur when parents are considered to be valued and equal partners alongside the range of professionals working with them and their child.

## 2.3 Communicating the news

The way in which parents are told of their child's disability may significantly affect how they subsequently view and use support services. How well parents are told of their child's disability often influences their capacity to respond positively to their child. News of disability will come as a shock to many parents, particularly where

there is no recent history of disability in the family. It is possible to lessen the potential impact of this event by giving news and information in a way that shows respect for the parents and their child.

Professionals may not find it easy to tell parents that their child has a disability, particularly if there is no clear diagnosis, but there is still a need for professional sensitivity and effective communication skills.

Many disabilities are diagnosed in the neonatal period. This is a sensitive time for parents and particular care should be taken in communicating to parents the facts, as they are known. However, for some children diagnosis will be an evolving process and parents will have to face new information at different stages of their child's development. For other parents, their child's disability will have no known cause.

Parents will react differently according to their own experiences of disability and immediate support should be made available if required. This may be in the form of emotional support, further information about their child's condition, signposting to other support services, or practical guidance.

Many local practitioners have developed guidelines and training to support professionals who may find themselves communicating news of a child's disability. These originated in "Right From the Start", a campaign to promote effective practice. The proposed template is a working document, founded on respect for parents and the value of their children as children first and foremost. It offers a framework for organisations to develop effective policies and procedures that ensure a quality service and to encourage individuals working in this area continuously to reflect on and enhance their practice.

Key components from the draft template are detailed below.

## **Right From the Start:**

### **Valuing the child**

- All children are unique; it is vital that professionals see the child first and their condition/disability second
- The child's name should be used at all times
- Keep your discussions about the child positive and avoid making predictions
- Whenever possible keep the baby or child with the parents when sharing the findings and diagnosis
- If it is not appropriate for the baby or child to be present, remember to communicate in a way that shows respect for the child
- Extra consideration should be given as to whether the child should be present when sharing the news of additional needs identified in an older child

### **Respect parents and families**

Professionals should empower and support parents and acknowledge and respect cultural difference

- Listen to parents and share information sensitively and honestly
- Use plain understandable language and give explanations to build parents' confidence
- Give opportunities to ask questions and check parents' understanding of their situation
- Avoid giving any non-verbal messages through body language and behaviour before you have shared your concern with the parents
- Treat all parents' concerns seriously

## **Who should be there?**

Evidence shows that parents, wherever possible, prefer to hear the news together and always in private

- It may be appropriate for another family member or friend to be there in support of one or both parents
- If it is unavoidable that a parent is unaccompanied, a member of the team should be present to support the parent during and after sharing the news
- When an unaccompanied parent has heard the news alone, arrangements should be made to inform the other parent and family members as soon as possible
- The number of staff involved should be kept to a minimum, ideally the person responsible for sharing the news and one additional team member known to family
- If an interpreter is required, care should be taken in their selection and on no account should a family member be expected to undertake this role

## **Tuning in to parents: effective communication**

- Parents' reactions vary enormously and cannot be predicted
- Professionals need to be well prepared and confident to share the news whilst flexible enough to respond to parents' needs
- Time and space should be available for parents to reflect on the news and meet again with a member of the team if they wish

## **Next steps: practical help and information**

- A record of the initial discussion should be made available to parents and their general practitioner. This could be written or audio formats, but always in the parents' first language
- Contact details should be provided at the initial meeting and parents should be encouraged to ask further questions as they arise
- An early follow up appointment should be arranged at the end of the initial meeting
- Written information should be provided at an early stage about:
  - the child's condition
  - statutory and voluntary services
  - practical and emotional support
  - benefits
- Support should be offered to parents to enable them to share the news with other family members and friends
- Parents should be made aware of their right to seek other professional opinions
- Early contact should be established between hospital based and community services

## **Support for professionals**

- Ensure staff participate in training, clinical supervision and continuous professional development
- Promote inter-professional practice
- Allocate time for team preparation prior to specific interviews/consultations
- Give opportunities for de-briefing for all team members following meetings with parents
- Identify, acknowledge and seek to address inequalities between professionals and parents
- Promote an ethos of continuous quality improvement

## 2.4 Assessment and the identification of individual needs

Disabled children are far more likely than non-disabled children to be subject to multiple assessments by health, education and social services. There are several reasons for this:

- there are more disabled children in groups already socially disadvantaged
- disabled children are more likely to have a number of experiences that may trigger assessment
- assessment has become the route to ordinary entitlements for many disabled children and their families

## 2.5 What is assessment?

The term assessment is used amongst professionals and parents in slightly different contexts, which may result in some confusion. 'Assessment' may refer to the process of arriving at a diagnosis, to the process of identifying needs, or to both. It is therefore important for professionals to be clear what the expectations are for the assessment at the outset.

Assessment is a process of gathering information about the health, education and social care needs of a child. For those children with special needs it is important that the process of assessment is supportive of the child and the family, particularly recognising the needs of siblings. (For further discussion on assessing the needs of disabled children and their families, see Chapter 2 in *Assessing Children in Need: Practice Guidance*. Department of Health, 2000.) Assessments should begin as soon as possible when a developmental delay or disability is suspected; fast track arrangements may be necessary to ensure timely support.

The earlier action is taken, the more responsive the child is likely to be, and the greater the likelihood of preventing some longer-term difficulties. Outcomes for the family as a whole will also be improved: long waits increase anxiety when parents suspect that their child has difficulties.

Assessment should:

- identify the health needs of the child, particularly if medical intervention is needed for life threatening conditions or within 'critical periods' for intervention, for example cataract extraction
- promote understanding and agreement about the potential developmental implications of the condition so that effective educational, behavioural, physical or communication strategies can be put in place to promote development
- address the needs of the child in the family context so that the family is empowered and feels confident to provide for the learning and care needs of their child at the same time as feeling that their own needs and those of their other children are also being addressed

For the paediatrician, effective developmental assessment is a process that starts with information gathering from all who know the child either informally or more formally, using checklists to structure observations. It then encompasses the meeting with parents or carers. This should include a developmental, family and personal/social history, told as the parents' 'own story' and the examination of the child. Sufficient time should be allocated to this meeting in order to allow parents and carers to have an open and honest discussion about their child and to ask any questions or raise issues that concern them.

The process results in a conclusion, if possible a diagnosis with aetiological explanation informed by relevant investigations, and always a plan of action to meet needs. Further assessment, investigations and tests may be needed to inform a medical diagnosis. These should be arranged as expeditiously as possible with services at district (secondary/local) and tertiary services setting waiting time goals.

For most families, a clear diagnosis of their child's condition is an important starting point for being able to move forwards. A diagnosis can help families to readjust to their situation, to understand the nature of the condition and its likely impact and to plan for the future.

However, a clear diagnosis is not always possible. If professionals are unable to provide a child and family with an appropriate diagnosis it is important that steps are taken in response to parental anxiety. It may be that further assessments are required before a firm diagnosis is formed, but the lack of a diagnosis should not be used as a barrier to access services.

## **2.6 Ongoing assessment**

Assessment should not be regarded as a single event but rather as a continuing process. An early assessment of need, in terms of medical, social and educational needs, is essential to secure and define appropriate service provision. However, the needs of the child and the family will change over time as a result of the child's development, family factors and as an outcome of the support provided. The ongoing assessment process must be flexible and responsive to changing needs. A problem-based learning approach by all those involved will provide a collaborative basis for involving different perspectives. A plan should be drawn up with families and relevant professionals which sets out what services are required given an understanding of the child's needs within their family context (Department of Health et al, 2000).

All services should aim to:

- safeguard and promote the child's welfare
- enhance the parents' understanding of their child
- promote the relationship between parent and child
- support families as the most significant caregivers
- identify services to meet needs, provide practical help and emotional support
- use language that is understood by all
- remove barriers to service use by families
- develop understanding of cultural diversity

## **2.7 Assessment outputs – the Family Service Plan**

In the early days, families and professionals, working together, need to

- define the nature of the child's disability and the impact on the family
- assess the level and type of service needed and agree the nature of the equipment, medical care, therapy, information and practical advice required
- agree how, where, when and by whom professional support will be provided
- agree how often the family will be visited in the home and by whom (where a home visiting service is available)
- agree how and when the appropriateness of the care/support package will be reviewed
- agree how, when and by whom the child's development will be monitored
- agree who will undertake the role of key worker

Within a specified period after the early assessment, the family should receive a written summary of the above, in the form of a Family Service Plan.

A number of different types of plans may be required by Statute, Regulation or Government Guidance; for example where the Social Services Department has lead responsibility a children in need plan, a child protection plan, a child protection plan or a care plan for a child looked after may be required [see paragraph 4.33 in the Assessment Framework].

## 2.8 Working towards joint assessment

The way that professionals work together during the assessment process is crucial. A co-ordinated approach to gathering information about a child is key if parents are to avoid the frustrating experience of having to “tell their story” again and again to different people. A co-ordinated approach will also benefit the professionals allowing them to set the information they have gained in the context of the picture that is evolving about the whole child.

CAMBRIDGESHIRE have a long established Visual Assessment Clinic for pre-school children which brings together a range of professionals including a paediatrician, a specialist teacher and an orthoptist in a single location that had improved communication, reduced the need for separate visits and pooled skills in delivering multi-professional assessments.

Local practitioners have a key role to play in supporting children and their parents, but professionals may wish to seek advice from specialist colleagues. This should be done with the full knowledge and understanding of parents. Parents may also wish for a referral to another professional for specialist advice or for a second opinion to gather more information about their child’s condition.

## 2.9 Working with parents

Parents need information about the assessment process. Professionals should explain their role or their service to parents and how these relate to others. It is also helpful for parents with a young baby if clinic waiting times are kept to a minimum and if professionals can come together at a single location. Services should seek to minimise the extent of avoidable stress in parents’ lives, which can be caused by a range of appointments and personnel. Paediatric clinics are more suitable than ‘mixed’ clinics.

Parents know their child better than anyone else, so a parent’s concerns about their child’s health or development should always be taken seriously. Parents should, wherever possible, participate fully in the assessment process, they should be active partners. Time taken over ‘history taking’ will give useful information about their child’s capacities and requirements. Sensitive and expert questioning by the professional can give valuable insight into the child but also reinforce feelings of self worth in the parents as central to an understanding of their child’s development. This will also make certain that the needs of the family are taken into account in any future planning, building on their strengths and resources.

### Consultation questions

- 2.1 What conditions are necessary to place services in the best position to conduct joint assessments that will command the confidence of parents?
- 2.2 What strategies have you found particularly effective in encouraging parents to play an active part in the ongoing assessment process?
- 2.3 Do you agree that families should receive a written Family Service Plan following assessment? How should these fit with statutory requirements for other types of plans, for example children in need, child protection or care plans for children looked after? Do you have examples of such approaches?
- 2.4 Can you offer practice examples to illustrate the principles set out in this chapter?



# Chapter 3: Co-ordinating service provision – ways of working in partnership

## 3.1 Introduction

This chapter outlines the way services should be delivered to meet the needs of disabled children and their families, and considers the nature of service provision designed to achieve good outcomes for children and their families.

## 3.2 Co-ordinating service provision

Sure Start aims to improve the health and well-being of families and children before and from birth, so children flourish at home and when they go to school.

At local level, Sure Start is run by partnerships including voluntary and community organisations, practitioners from health, social services, education, other local government departments and – very importantly – local parents. Working in partnership with different organisations is crucial to improving local services for young children and their families. The challenge is to “join up” the pieces of existing services for young children and their families so they are more effective and easier to use. Another will be to identify the gaps that new services, premises, expertise and funding can fill.

Families with very young children receive help from a number of different agencies. Where disability is identified very early, families may receive support from Health, Education, Social Services and the voluntary sector. They may be required to keep appointments with a number of different departments or clinics.

Where services are **well co-ordinated**, families participate in the development of a cumulative understanding of their child’s needs and receive:

- useful input from professionals meeting the family for the first time
- release from the responsibility of rehearsing their child’s history from the beginning to each new individual they meet
- relevant information from a number of different perspectives
- reassurance that needs are recognised and taken seriously by relevant agencies
- input on particular aspects of their child’s development which takes note of other relevant factors in the situation
- consistent messages
- a focus on their child’s abilities as well as impairments
- well co-ordinated practical help
- continuity of care

Where assessment arrangements are duplicated and service provision **fragmented**, the normal routines of family life with a young child may be severely disrupted by multiple appointments outside the home and a string of unconnected visits to the home by professionals representing different agencies. Families may be left with the feeling that the right hand does not know what the left hand is doing, and may:

- experience additional stress in an already difficult situation

- waste time attending appointments at different times which might have been scheduled for the same day
- develop a negative, or confrontational, attitude towards professionals
- incur unnecessary travel costs
- incur unnecessary child care costs, where there are siblings to consider
- receive conflicting information and advice
- be obliged to re-tell the story of their child's life (including the parts that are particularly painful to them) each time they meet a new professional
- be left to put together for themselves information received from different agencies where one aspect of their child's need has been assessed and considered in isolation

“On first visiting Faye, her mother gave me a plastic counter and explained how I should use it. There were eight professionals trying to offer support. There were mixed and contradictory messages. There was little time in the week for her mother to enjoy Faye and none to shop, wash or do the housework. If she felt I had something positive to offer she would give me a counter to push through the letterbox on my next visit. Those professionals who did not receive another counter were not allowed back in the house. Faye's Mum made all of us think about working together and what it really means to provide joined-up services.”

### **3.3 Different ways of achieving co-ordination**

The potential for families to receive well-integrated, multi-agency support is greatest where different agencies are co-located and can provide a 'one stop shop'. This is equally true of clinics where families can meet a range of health professionals on one occasion and of Child Development Centres where families can meet psychologists, speech and language therapists, occupational therapists and social workers in one place.

Where formal structures are not in place to organise service delivery in this way, informal arrangements for joint appointments and joint assessments by more than one professional at a time can make a big difference.

### **3.4 The Keyworker function**

Effective use of keyworking is one of the key issues for improving standards. All children with complex needs and their families should be allocated a keyworker who works in partnership with them, with the function of co-ordinating service provision and providing a clear point of reference for the family.

Different professional groups can define the term 'keyworker' in different ways at different times and this has sometimes caused confusion. Keyworkers have been variously defined as:

- the person who takes responsibility for sign-posting families to other professionals and services
- the person who takes responsibility for communication, making sure everyone has up-to-date information about the child and any key events impacting on the provision of care and support
- the person who maintains most consistent contact with the family or the child and who assumes the key care role, as case worker
- the person within a specific setting who takes responsibility for a child during a session

For the purposes of this guidance, the following definition has been used:

**‘A keyworker is both a source of support for the families of disabled children and a link by which other services are accessed and used effectively. They have responsibility for working together with the family and with professionals from their own and other services and for ensuring delivery of the plan for the child and family. Workers performing this role may come from a number of different agencies, depending on the particular needs of the child.’**

### The continuum of co-ordination

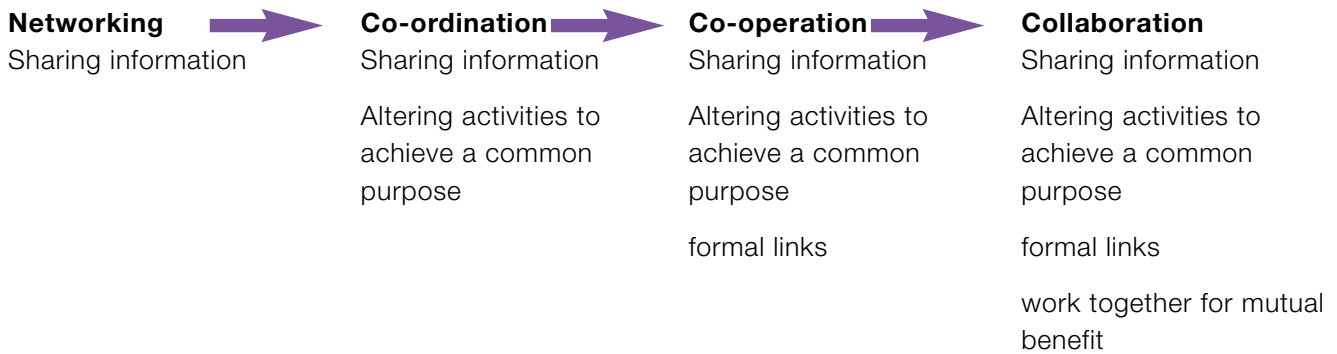


Figure reproduced by kind permission of Social Policy Research Unit, York University, Himmelman (1996).

Keyworkers should provide:

A single point of reference for information –

- co-ordination and help in identifying the needs of the child and family
- regular review of support arrangements in the context of growing understanding of a child's abilities and needs
- regular, long term contact and continuity of support
- a means to co-ordinate support from different agencies
- personal or emotional support, sensitive to needs and family circumstances
- help to enable families to access and receive relevant services.
- help families to look forward to the child's next stage of development and anticipate service needs
- a role in implementing the plan

Where interpretation of the role moves beyond facilitating and improving service delivery, and towards advocacy, individuals may be specifically chosen to act as key worker because they are independent of the professionals and agencies already in contact with the family. Where this is the case, the added value the keyworker brings to the total package of support must be clearly defined and understood by everyone involved.

In many situations, the keyworker will be a professional who already provides some services to the family. The function of keyworker will be additional to their core professional role. In some instances parents themselves may choose to exercise this role. The introduction of direct payments for parent carers under the Carers and Disabled Children Act 2001 is likely to increase the number of parents wishing to operate in this way.

However, where an individual has been identified as the keyworker for a family, the time requirement of this role should be taken into account in planning workloads. As keyworker, they assume a responsibility for co-ordinating and facilitating the total care package, which extends beyond their immediate role as a direct service provider.

The keyworker should be identified during the process of initial assessment of the child, and named within the Family Service Plan. Parents should have an understanding of the role, and should be given the opportunity to suggest which professional they would wish to have undertake this role. Where it is not considered possible or appropriate for the parent's suggestion to be acted upon, the reasons should be made clear to the parent. Examples of keyworker roles undertaken by non-statutory agencies are also available offering independence from the statutory service providers involved.

### **3.5 Who should be the Keyworker?**

The choice of an appropriate professional to undertake the role of keyworker will need to take into account several factors.

- Is the proposed keyworker acceptable to the family?
- Is there one agency, which is likely to have the largest role in supporting the child? A child with multiple disabilities, who will require complex medical interventions, might benefit from having a keyworker from within the health service. A child with a specific impairment such as a sensory impairment might benefit from having a key worker who provides specialist educational advice.
- Does the proposed keyworker have sufficient understanding of the different professional roles undertaken by other agencies in order to provide the coordinative role that the family will need?
- Does the proposed keyworker possess the necessary competencies and experience for working with families under stress?
- If the family is from one particular ethnic group, is there a possibility of identifying a keyworker from that same group?

The quality of the relationship between the family and the keyworker will play an important part in determining the success of the package of support provided to the family. Parents should be given the opportunity to request a change of keyworker, if the relationship becomes strained. Keyworkers should have supervision.

Parents should have explanations about

- whether a keyworker system is in place
- who their keyworker is and what can be expected of them.
- the process for allocating keyworkers and
- how long the worker is likely to undertake the role. Frequent changes are likely to be disconcerting to parents and may undermine the value of the keyworker arrangement

### **3.6 Sharing information about the child and family**

However service delivery is structured, it is essential to have flexible and efficient arrangements to share information about the child and the family between all the professionals and agencies involved. Without this, the opportunity to build a cumulative picture of the child's abilities and needs over time is lost and parents are left with the responsibility of bringing every new professional they meet up to speed and up to date.

The Department of Health is taking forward work with relevant Government Departments and key stakeholders to develop an Integrated Children's System (Department of Health et al, forthcoming). This system will inform the core data requirements for children's services. This will assist agencies to collect information using a common format. It will also enable systems to be developed which retain information over time, and provide a record of the child's developmental progress as well as of services provided and their effectiveness.

Where they do not already exist, efficient systems for sharing paper and electronic information about the child and family between professionals and agencies should be developed as a priority, in compliance with the requirements of the Data Protection Act 1998. Systems of this type should be regulated by clear protocols to protect service users.

### **3.7 Records and registers**

The changing nature of disabled children makes the keeping of a statistical database a necessity. Current health recording systems should identify disabled children, in such a form as to enable shared planning between different statutory agencies. The Children Act registers of disabled children offer an inter agency approach to a database which maps children and acts as a basis for service planning as well as information sharing and consultation with parents. Registers should comply with the following general criteria. They should:

- provide for collaboration and joint planning with other agencies
- have an agreed definition of disability, which is clear to all
- provide an information service to families who use them
- comply with the data review and data protection requirements

Further information on registers can be found in “Registering Effectiveness” (Council for Disabled Children, 2002).

STOCKPORT has a designated link to the register through a health visitor. This facilitates a visit by the register coordinator to families who wish to access it. Families are then provided with information and access to local and national support groups.

### **3.8 Records on individual children and families**

A move towards joint assessments and planning provides an opportunity to look again at individual record keeping and how it can provide parents with a clear record and aid inter-agency assessments.

A number of health agencies are looking at how the current parent held child health record could be adapted to cater for the extra information necessary for disabled children. Parent held records have, for some families, increased confidence in the quality of health/social care that the child is receiving. They also enable parents to avoid the trauma of retelling their child's story.

The development of the Integrated Children's System (Department of Health et al, forthcoming) offers an important opportunity to consider what common information about individual children and families is kept by relevant agencies. Also, how computerised systems for collecting this information and producing relevant reports, for example, an assessment, plan or review report can be developed to allow information to be exchanged between agencies, and between agencies and families, as well as enabling families to have access to their records.

WILTSHIRE – Social Services, Education and Health working together have produced a family file for children with disabilities. The record builds on the existing Personal Child Health Records and provides a centralised record of information. The file comprises of a joint agency record that acts as a multi-agency running record for all workers working with the family to contribute to. There are also separate sections for Health, Education and Social Services with a calendar for appointments and meetings. Families keep the file. One parent commented, “It is nice to have a “whole picture” of what is going on in her life, not just for us, but so professionals are aware of who else is involved and what they are doing.”

### 3.9 Current opportunities for service development

Opportunities are available to planners, commissioners and providers to review how services are currently responding to local needs, taking into account local circumstances and drivers for change. These opportunities may involve reviewing service delivery through local modernisation reviews, by responding to local Health Improvement and Modernisation Programme targets. An example of utilising existing guidance to support change is highlighted in 3.10 below.

### 3.10 Funding and provision of equipment

Babies with complex needs may need equipment provided on discharge from hospital. This may include medical equipment, e.g., for the administration of oxygen or suction, or domestic equipment, which aids daily living. Decisions on the provision of equipment should be made before the child is discharged and any funding issues resolved. However, it is important that such decisions do not impede the child's timely discharge. The discharge and provision of services, including equipment to babies with very complex needs is likely to benefit from a joint approach using Health Act Flexibilities. Recent research shows that families of very young children often have critical gaps in their equipment needs, assumptions that babies are just babies need to be questioned in relation to this group. For example, very premature babies may be tiny but the need to always carry a portable oxygen cylinder adds significantly to weight and may necessitate a specialised buggy.

Once children begin to access community resources equipment needs will have to be considered further. For some families this will mean access to a blue parking badge. For others, portable lifting equipment or specialist changing facilities may be necessary. The Department of Health issued new guidance on community equipment in April 2000. "Integrating community equipment services" requires local authorities and their health partners to establish a consumer focused equipment store by 2004. Children's equipment, including the provision of communication aids, is covered by this guidance and all agencies have a responsibility to ensure children's needs are met too.

Parents should be given information on financial and other assistance with the provision of mobility or other equipment and with the cost of transport (including hospital visiting). Many young families are unaware of the minimum age for application for DLA or of the role of the Family Fund Trust. They are also largely unaware that they may be eligible for a Blue Badge to assist with parking.

#### Consultation questions

- 3.1 What, in your experience, are the factors which facilitate or inhibit co-ordinated service provision? Where there are problems, how have you sought to overcome them?
- 3.2 What specific obstacles do services need to overcome in order to establish effective key worker arrangements?
- 3.3 Most professionals agree with the need to share information but it does not always happen. Why? What prevents it?
- 3.4 Can you offer examples to illustrate the practice set out in this chapter?

# Chapter 4: Working with children and families

## 4.1 Professional attitudes and competencies

Agencies and professionals supporting families with very young disabled children must be able to provide practical help and have relevant knowledge, skills and experience.

Positive attitudes to families, to children and to disability are essential. It is important that:

- the disabled child is seen as a child, first and foremost
- the child's needs are viewed holistically, rather than being defined by a diagnosis of difficulty or disability
- the rights of children and families and the limits on professional involvement are clearly understood
- professionals understand that each family will have its own needs and circumstances. No two families will be alike
- professional interventions should be designed to strengthen families

Professionals working with this group of children need the interpersonal skills to deliver a family-centred approach and the interactional skills required to work with infants. The following attitudes and competencies are all relevant:

- professionals should approach work in this area with the expectation that they must work in partnership with families, with parents fully involved in any decision-making processes affecting the provision of support to their child
- they should respect the right of parents to receive comprehensive, accurate information about their child and service provision options and understand that families deserve continuity of care
- they need to understand that every family is different and to be flexible in the way that they work with the families on their caseload
- they need a positive 'can do' attitude and a professional disposition to 'support', but not to 'rescue'
- they should approach disability with positive attitudes and should themselves have received Disability Equality training
- they should demonstrate commitment towards keeping their professional knowledge and skills up-to-date

They also need to recognise the limitations on their involvement. They are there to help families but they will not be able to solve all of their problems.

## 4.2 Recognising and responding to diversity in families

The general principles of working in partnership with parents set out in the *Framework for the Assessment of Children in Need and their Families* (Department of Health et al, 2000) and the SEN Code of Practice (2001) are of particular relevance for all professionals and agencies working with this population. Sections 2:6 and 2:7 of the Code of Practice state:

*'Positive attitudes to parents, user-friendly information and procedures and awareness of support needs are important. There should be no presumption about what parents can or cannot do to support their children's learning. Stereotypic views of parents are unhelpful and should be challenged. All staff should bear in mind the pressures a parent may be under because of the child's needs.'*

To make communications effective, professionals should:

- acknowledge and draw on parental knowledge and expertise in relation to their child
- focus on the children's strengths as well as areas of additional need
- recognise the personal and emotional investment of parents and be aware of their feelings
- ensure that parents understand procedures, are aware of how to access support in preparing their contributions, and are given documents to be discussed well before meetings
- respect the validity of different perspectives and seek constructive ways of reconciling different viewpoints
- respect the differing needs parents themselves may have, such as disability, or communication and linguistic barriers

Parents are the first and primary educators of their child and the agencies and services supporting them must be able to respond flexibly and positively to the very wide range of families with whom they work.

Stereotyped assumptions about family reactions to disability in a child or about service requirements for any defined population may well be misplaced. Many of the concerns of families from ethnic minorities, for example, will be the same as the concerns of other families. However, it is important that agencies working with the family are aware of, and demonstrate sensitivity to, any cultural and religious differences influencing family response. Services cannot support families effectively without this knowledge and awareness. (For further discussion see Chapter 2, *Assessing Black Children in Need and their Families in Assessing Children in Need and the Families: Practice Guidance* (Department of Health, 2000))

Where a language other than English is used in the home, key service provision issues are:

- the arrangements that are in place to make written and video format information available to families in their own language and to supplement written material with a spoken explanation where parents and others cannot read English
- the availability of professional interpreters to facilitate meetings and discussions between supporting agencies and families. The use of children within the family as interpreters should be regarded as inappropriate

Where families in one locality use many different languages, agencies may find it cost effective to share written information materials across Local Authority boundaries. The Department for Education and Skills' eleven Special Educational Needs Regional Partnerships provide a forum where such co-operation might take place. Telephone-based interpreting services can also help in some circumstances.

Where many families share a common language other than English, it is helpful, where possible, to plan for continuity in interpreting arrangements. Where spoken or British Sign Language interpreters have previous experience of interpreting discussions relating to disability in young children, they are more likely to:

- be aware of the sensitivities involved
- have developed the technical vocabulary they need to do their job well

### **4.3 Providing information for families**

Providing information to families is a key function of service provision for families. Good information enables families to remain in control as they take decisions about what to do. Difficulty accessing relevant information is positively disempowering in a situation that is often already very stressful.

Information provision is central to Government policy in health and social care. Within all agencies there is an increasing emphasis on user involvement in decision-making both at an individual level and service development level.



## 4.4 What kind of information helps?

Families need information about:

- the nature/characteristics of any disability/disabilities relevant to their child's situation
- the severity and range of their own child's disability
- the likely impact of factors identified on their child's development over time
- the full range of services available locally and about how to access different types of support
- the options available, where a range of therapeutic or communication approaches exists & where families must make a choice about what to do
- the rights and responsibilities of families under current legislation
- the range of provision for young children with special educational needs (including the name and contact number for the Parent Partnership Service in the area)
- the support available from local parents groups, and organisations in the voluntary sector
- names, addresses and telephone numbers for all the agencies and professionals with whom they are in regular contact

In all this, it is important that families understand that specialist services and intervention should be seen as additional to the services that all young children and families receive. For children in the first year of life, this means outlining clearly:

- what standard General Practitioner and Health Visitor support to families will provide
- what additional help and services are available and how they can help
- how the two will be co-ordinated

In the same way, as children pass through the second year of life, it is important that families are well-informed about what Sure Start, Early Excellence Centres and Early Years Development and Childcare Partnerships in their area are able to provide. Mainstream service provision should enhance any support of a more specialist nature that the family receives. Children's Information Services are now in place in every local authority and will hold valuable 'mainstream' information. It is important that specialist agencies feed in their information so that these universal Children's Information Services provide information for parents of young disabled children.

Service providers have an obligation under Section 332 of the 1996 Education Act to provide families with relevant information about support groups and organisations in the voluntary sector. Local Authorities have a duty under the Children Act 1989 to provide information for the parents of disabled children.

Many families find it helpful to receive a directory of services, at an appropriate time, outlining the standard range of services available locally, with up-to-date contact details early in the process of responding to the news of disability in their child. Where such a directory of services does not already exist, service providers are encouraged to develop one. Developing inter-agency directories can provide a valuable focus for joint work.

## 4.5 Making information accessible

The previous section defines the 'What?' of information provision, but the 'How?' is equally important. To be useful to families, information has to be accessible, accurate and relevant. Families must have the opportunity to build up a full and unbiased picture of their child's situation and the options that are available to them, over time. However, providing all the information required by families in a sensitive and timely fashion is a skilful process. The ability of families to absorb and use information varies widely; the same family may respond in different ways over time and different families are likely to bring very different levels of understanding to the task of taking on board and using the information being provided.

The ability to take in information is clearly influenced by emotional factors. For example, any information given verbally at the time that disability is identified should always be supported by written material that the family can take away, and perhaps a tape recording of the relevant professional outlining the information. Parents consistently report that their ability to absorb anything that was said to them at this time was compromised by their emotional response to the news of disability in their child. They also report the value of receiving information from a trusted professional in the context of a supportive relationship.

Pacing the provision of information is important. The family should determine the pace at which information is provided, but this assumes professionals will be able to:

- pick up and understand the cues families give about how much information, repetition and pause for reflection they require
- read carefully between the lines for the questions families do not ask, but would like to ask
- deliver a standard battery of information flexibly to meet individual need
- keep track of the information that has been given over time, using a checklist, to make sure that nothing has been missed

Where the family does not share a language or culture with the professional delivering services, there are obvious practical considerations to be considered. Families who use a language other than English will need written materials in their own language and/or flexible access to an interpreting service. Other families will only be able to use information if it is provided in an alternative format (e.g. in Braille). Service providers must be able to demonstrate that they have actively considered issues of this type and have taken reasonable steps to meet the needs of all the families with whom they work.

#### **4.6 Practical support: families and professionals working together. What do families with very young disabled children need from services?**

In general, families will be looking for:

- help applying any general information they have received to the particular situation of their child
- suggestions about what to do to facilitate development
- the skills they need to acquire to meet the physical care needs of the child
- ideas about how to integrate the use of equipment into daily family life
- ideas about how to integrate the routines of physical therapy into the home
- ideas about how to introduce and use new communication strategies and systems into family life
- help and family support services, where a child is severely disabled and requires extensive care
- reassurance drawn from the experience of others
- emotional support as they adjust to the news of disability in their child

For some families a major service provision priority in the early days will be easing the transition from a very high technology clinical environment to life at home. Each child who is discharged from hospital with on-going complex needs will need to have a formal discharge meeting. This will need to involve the family, hospital and community-based professionals, and should consider;

- the need of the child and family for support in the community
- the need for equipment, both clinical and domiciliary
- whether the Consultant or GP remains the key medical professional and whether ongoing support offered through paediatric nursing teams is appropriate and available
- referral to Social Services if this has not already happened

- which community professional will act as keyworker

## **4.7 Practical support for children with the most complex disabilities**

Where children have the most complex needs, services will need to look specifically at the barriers which stop them accessing community life. For many children, one barrier has appeared in the area of risk management and assessment.

A growing number of children will require a service that carries a risk to the child and those administering it. Examples include invasive medication, lifting and handling and the management of physical interventions. It is important that agencies have protocols for these, which are based on how to include the child and manage the risk rather than to exclude the child and eliminate the risk. A number of these protocols are in place and evidence shows that they require multi-agency co-operation at both a practitioner and commissioning level.

In some circumstances difficult decisions may sometimes have to be made in the best interests of the child about the withdrawal or withholding of treatment. The decision not to treat, or continue to treat, children with life limiting conditions will be deeply distressing for parents and the professional team. When the possibility of such action is an option, every effort should be made to convey information and future options to the parents in an appropriate and sensitive manner. The revised GMC Guidelines on the Withdrawal or With-holding of Life-prolonging Treatment (2001) emphasise the importance of working with and supporting families throughout the decision-making process and its consequences. Parents should be offered a strategy for the care of their child, which embraces a continuum of support and which respects the wishes and feelings of parents as key members of the team. Parents may need advice and support from other professionals or family members and must be offered sufficient time in which to reach informed decisions about the care of their child.

Parents should be offered the opportunity to contact relevant parent support groups if they so wish. They and other family members will need reassurance that the child is receiving appropriate care and support. Such support should reflect the preferred culture and lifestyle of the family. If the child returns home, parents and their wider family networks need to be confident that planned support (including the provision of any equipment) is available prior to discharge from the hospital unit.

## **4.8 Families supporting each other**

Families rely on an informal support network provided by friends and extended family and it is important for service providers to adopt a positive and inclusive approach towards family members and 'significant others' other than parents. Friends, grandparents or providers of childcare may all be important elements in the network of support around a child and should be provided with information and included in discussions, wherever parents wish this to be the case.

Parent support groups, where families with young disabled children have the opportunity to meet with each other and exchange experiences, are an important source of mutual support and information. They also provide one means to overcome the isolation that many families feel when disability has been diagnosed. Service providers should actively encourage the development of such groups at local level and do whatever they can to make it possible for all parents to attend. It is important that some of these meetings take place without professionals and that the families decide the nature and format of meetings.

Information about the Contact-a-Family Helpline should be given to every family identified with a disabled child. [Telephone number 0808 808 3555, Monday-Friday]

## 4.9 Accessing childcare

Affordable, accessible childcare for children with special needs or disabilities is critical to enable them to fulfil their potential and meet their needs. It is also critical to enable their parents to access employment and training and help reduce child poverty.

The introduction of the National Childcare Strategy in 1998 has seen an increase in childcare provision being developed to encourage mothers to return to work. Many parents of disabled children would want to return to the workforce but are not always enabled to do so. The General Household Survey (1996) showed that mothers of disabled children who wanted to return to work were seven times less likely than those with non-disabled children to do so. This discrepancy arises partly out of the much higher support needs which many disabled children present, which can make it extremely difficult for parents to feel comfortable about leaving their child. Parents can also be much more tired through the efforts of supporting their child.

In addition, the growth in available childcare provision in recent years has not been matched by a growth in schemes which make childcare available for disabled children. Specialist services for disabled children need to be fully integrated with early years services and Early Years Development and Childcare Partnerships (EYDCPs) so that parents have access to a full range of options. Each EYDCP is expected to develop strategies for ensuring that their childcare provision is accessible to disabled children and their families. Such strategies may include supported childminding, extra staffing in day nurseries, support with training and assisting baby-sitters, or other day services.

In order for work to be a possibility for the child's main carer (and sometimes both carers) there is a need for all services to become more family-friendly e.g. flexible appointment times. There is often a need for services to work together in order to allow parents to work.

### Case Study

Jack has multiple disabilities and his mother, a lone parent, wanted to and needed to return to her job as a nurse working shifts. Her employing Trust offered some flexibility in her working hours but had no crèche. The Children's Information Service provided Jack's mother with detailed information about the tax credits she was entitled to and helped her find a local childminder with the necessary skills. Social Services assessed Jack's family as in need of additional support and a direct payment is now in place that means that Jack's mother can pay for a carer at home that accommodates her shift pattern.

## 4.10 Practical support: families and professionals working together. How are the services delivered?

**Centre based or clinic based services** give families access to a range of services and professionals in one place and should ensure continuity of care is maintained over time. Where families live at a distance from services of this kind, service providers are actively encouraged to consider the impact of attendance on family life and to make provision to support the additional transport and child-care costs families of very young disabled children incur.

**Home visiting services** such as education services and advisory/support services for children with sensory impairments or Portage, provide regular, practical support of the type outlined above to families in the home.

**Centre based family support services** offer children and families group based activities where the child and family can meet others. This may include parents groups, mother and toddler groups and opportunity for mainstream playgroups

**One Sure Start programme** provides specialist crèches for disabled children and their families which provide both high quality childcare and a chance for parents to keep up to date. While the child starts off

in a specialist setting, the third term of the sessions involves child and family being introduced into suitable mainstream services.

**Home based family support services** can provide practical support for families expected to manage significant care needs. These can be provided by a variety of agencies and individual professionals. For the majority of very young children it is important that support services are home based rather than sending the child out of the home to a carer or residential service as in the traditional short break/respite care model. Home services need to develop effective relationships with both the parent and the child and work alongside them to build skills rather than leaving families further deskilled. They should be provided flexibly and reviewed regularly as the family's needs change.

#### **4.11 Welfare benefits and tax credits**

Research by the Joseph Rowntree Foundation has shown that there can be significant additional costs to bringing up a severely disabled child. Parents were only able to spend half of what they felt was required to ensure a reasonable standard of living. The biggest shortfall between actual spending and the budget standards was for children aged up to five years. It is therefore important that families are given clear, relevant information in relation to all the financial benefits available. Services should not unwittingly add to families' financial struggles, by for example failing to explain how the costs of transport to hospital can be met or not ensuring appropriate referral to a nappy service. Families should be offered an opportunity to have their financial situation assessed. This should cover benefits available to them as a family, benefits directly available to the child and financial aid available from other sources such as the Family Fund Trust (telephone number 01904 621115). All financial information needs to be handled sensitively but concern about intruding should not stop the service being offered.

#### **Consultation questions**

- 4.1 What practical steps can services take to ensure that parents feel supported and confident that they have access to all relevant information?
- 4.2 What approaches have services found especially effective when responding to diversity in families?
- 4.3 Where children have complex needs, what additional steps have services found effective?
- 4.4 Can you offer practice examples to illustrate the principles set out in this chapter?

# Chapter 5: Planning a family centred approach to service delivery

## 5.1 Introduction

The Government has already put in place initiatives that promote a more integrated approach to providing services for children and their families. The experience of these initiatives plus a range of other local projects has confirmed that there is much to be gained from bringing services together to meet the needs of disabled children and their families.

The effective planning and commissioning of services requires all agencies to work together in a partnership approach to ensure that the development of local services reflects actual assessed needs and should underpin service development and delivery.

New initiatives should be commissioned as a result of evidence of need and supported by an evaluation framework with child/family feedback and should be flexibly designed especially in terms of meeting the individual child's and their family's needs.

Planning of services to meet future needs should reflect medical and technological advancement. Data for identifying local incidence and prevalence should be used proactively to support service developments.

It is important for services to be commissioned that improve the outcomes for disabled children and their families and connect to wider government policies such as promoting social inclusion and reducing health inequalities.

Local mechanisms for promoting successful service models and good practice exemplars should be established to influence commissioning decisions on future service developments.

The development of services for children with disabilities needs supporting at a senior level throughout all organisations to ensure that decisions are appropriately taken that will make a real difference to improving outcomes. Whilst the role of a children's champion can be advantageous it is important that organisations back this up by recognising the need for senior level support.

It would not be appropriate to describe one service model that could be applied in all parts of the country. Characteristics of an effective service will depend upon a host of local circumstances. However, it is possible to list those features that should be present. Services should audit the service in their area against the following features, and develop an action plan showing how unmet needs will be met.

## 5.2 A family centred service

- the service can demonstrate that it shows respect for parents as the primary care givers for the child; involvement of parents in all relevant decision-making processes, a commitment to maintaining positive relations with families, and a recognition of the differing needs and expectations of families from different backgrounds
- the needs of the families are effectively assessed, and services identified and delivered which support the family's ability to care for and support their child
- there are robust systems in place to provide support for families where spoken English is not used
- families and carers of service users are effectively and appropriately engaged in the planning of service developments where feasible, services are delivered within the home

- families are given support to access childcare facilities, which other families in the area might expect
- families are routinely referred to appropriate support networks – in particular, to Contact-a-Family's Contact line Family support networks (Hotline number 0808 808 3555).
- opening times/contact times are published and conveniently offered

### **5.3 A well planned service**

- mapping of local incidence/need is routinely undertaken
- existing service provision, resource allocation and geographical location is compared with the identified level of need and used to highlight service gaps and overlaps.
- organisations routinely review work force plans to ensure the work force is sufficient to deliver the appropriate level of service.
- the service is aware of the impact of new screening procedures
- specialist services are developed in co-operation with 'mainstream' facilities and services, and co-ordinated with the work of Early Years Development and Childcare Partnerships, Early Years Excellence Centres and leisure services.
- mechanisms are in place to enable joint planning between health, education and social services, involving voluntary and independent providers, resulting in a shared vision and strategy
- all available funding streams are appropriately accessed
- there is a shared understanding of desired service outcomes
- there is a shared commitment to seek new ways of working in partnership
- mechanisms exist for documenting and sharing examples of effective service delivery

### **5.4 A well co-ordinated service**

- there are clear definitions of roles, responsibilities and referral procedures
- there is a common register of the numbers and needs of young disabled children and their families;
- protocols have been established to enable relevant information on the needs of families to be shared between relevant professionals
- a system of family-held records has been introduced
- a system is in place to allocate a keyworker for each disabled child aged 0–2, which takes due account of the wishes of the family. The function of the keyworker is agreed by all relevant agencies, and sufficient time is allocated to the keyworker function to meet the needs of the family;
- there is a central bank of information for parents, which meets the needs of families from diverse backgrounds;
- there is an agreed protocol for making joint appointments, co-ordinated by the keyworker, and an agreed multi-agency protocol for assessment;
- the assessment protocol includes assessment of the needs of the child, siblings and the family;
- there is an agreed time-table for preparing a written Family Service Plan, involving the family, which summarises the needs of the child and the family, outlines the services which will be provided, names the keyworker, and describes when the Plan will be reviewed.
- there is an agreed programme for delivering joint training
- opportunities for co-locating services have been fully explored and implemented



## **5.5 An accessible service**

- services take account of the transport needs of families. The location of services to families is planned taking into account the availability of public transport. Services are delivered to the homes of families where possible and appropriate. There are systems for providing transport support to families who need it
- there is a system for contributing towards extra transport costs that families may face in accessing services, or in carrying out their normal daily activities. There is a system for allocating Disabled Parking badges, where appropriate, for parents of young disabled children who face difficulties
- families know how to make direct contact with their keyworker and with vital services, and face little difficulty in making such contact
- there is a clear local directory listing relevant specialist and mainstream services which families might need

## **5.6 A competent service**

- there is a system to ensure the sensitive sharing of news of disability with families in appropriate setting, through the use of good practice templates and checklists such as those produced by the Right From The Start process
- there is adequate time for discussion at time of diagnosis
- families with very young children have priority for fast track assessments
- there is prompt and competent early assessment of child and family need
- services can demonstrate that they are responsive to diagnosis and changing family need
- there are clear referral pathways following diagnosis, with clear response times
- staff receive appropriate training; their training needs are regularly reviewed, and there is a jointly agreed programme of multi-agency training.
- disability equality training is available for all professionals discussing initial assessment of need
- services can demonstrate that they are responsive to individual differences in a family's race and cultural needs

## **5.7 An accountable service**

- there are clearly defined processes for self audit, planning and review
- performance indicators are jointly agreed, and are regularly reviewed and monitored
- indicators include expectations of outcomes for children and families
- there are measures of consumer satisfaction/client feedback
- there is a system for the longitudinal tracking of children

## **5.8 Recommendations for action**

Where the following are not already in place, the guidance recommends:

- the establishment of an inter-agency working group at senior management level to review current arrangements agree a strategy for development and implement change. A top level commitment and a clear vision for disabled children and their families should be established within organisations
- opportunities and mechanisms for the full engagement of families as consumers of services should be maximised in the review and planning process
- an accurate and up-to-date picture defining local incidence of disability and service provision should be undertaken on a regular basis to ensure services are meeting local needs and responding to changing needs



- service provision and resource allocation should be made through decisions supporting evidence of need
- that early assessment of child and family need leads directly to a statement of the services required to meet those needs and to an action plan agreed between the family and the professional agencies providing services
- that a named keyworker is identified for each family accessing services and particularly where families receive services from more than one agency
- a template for communicating the news such as the one developed by “Right From The Start” should be adopted to ensure parents and families are appropriately treated and supported
- opportunities to pool budgets, to support the development of integrated provision and to develop joint commissioning approaches are fully explored using Health Act Flexibilities
- a regular cycle of self-evaluation using the self-audit tool at Appendix B should be created

### **Consultation questions**

- 5.1 What do you see as the key factors determining a successful family centred approach?
- 5.2 What monitoring and accountability mechanisms have worked best, in terms of securing consistent, high quality support for children and families?
- 5.3 What approaches are you aware of that have been successfully used to integrate services for this group
- 5.4 Can you offer practice examples to illustrate the principles set out in this chapter?

# Appendix A: Definitions of disability under other legislation

***This Appendix sets out definitions of disability in legislation other than the Disability Discrimination Act 1995. The SEN and Disability Act 2001 uses the definition of disability as set out in the Disability Discrimination Act 1995. However, providers of education and responsible bodies should be aware that children and young people may be defined as disabled under other legislation and may be receiving services under that legislation in addition to any other provisions made under this Act.***

## Introduction

References to disability also appear in:

- The Children Act 1989
- The Children (Scotland) Act 1995
- The Education Act 1996
- The Education (Scotland) Act 1980
- The Disabled Persons (Services and Representation) Act 1986
- The Chronically Sick and Disabled Persons Act 1970
- The Chronically Sick and Disabled Persons (Scotland) Act 1972

Although the Disability Discrimination Act 1995 covers Scotland as well as England and Wales, there are important differences within education and children's legislation and hence the legislative and policy context within which the SEN and Disability Act 2001 will be implemented.

## Definitions of disability as used in services for children and young people

The Children Act 1989 (England and Wales) and the Children (Scotland) 1995 do not use the same definition of disability as the Disability Discrimination Act 1995.

The Disability Discrimination Act 1995 defines a disabled person as someone who has:

‘a physical or mental impairment which has a substantial and long-term adverse effects on his ability to carry out normal day to day activities.’

‘*Physical and mental impairments*’ include sensory impairments, such as those affecting sight and hearing. The term ‘*mental impairment*’ includes learning disabilities and mental health problems. However, the DDA definition of disability does not include any impairment resulting from or consisting of a mental illness, unless that illness is a clinically well-recognised condition. A ‘*clinically well recognised illness*’ is one that is recognised by a respected body of medical opinion.

The DDA definition of disability protects disabled people from discrimination *even if they have subsequently recovered*.

The definition also covers people with severe disfigurements. They are not required to demonstrate that the impairment has substantial adverse effects upon their ability to carry out normal day-to-day activities. However, certain specified *disfigurements* which consist of a tattoo (which has not been removed), non-medical body piercing or something attached through such piercing are *not* to be treated as having a substantial adverse effect on the person's ability to carry out normal day-to-day activities.

## What are 'substantial' and 'long term' effects?

A '*substantial*' adverse effect is something which is more than a minor or trivial effect. The requirement that an effect must be 'substantial' reflects a general understanding of disability as a limitation going beyond the normal differences of ability, which might exist among people.

'A long term effect' of an *impairment* is one:

- Which has lasted at least 12 months, or
- Where the total period for which it last is likely to be at least 12 months, or
- Which is likely to last for the rest of the life of the person concerned

Effects which are *not* long-term would therefore include loss of temporary mobility due to a broken limb which would be likely to heal within 12 months or the effects of temporary infections from which a person would be likely to recover within 12 months.

*Progressive* conditions are covered by the Act. They are defined as conditions which are likely to change and develop over time. Examples given in the Act include cancer, multiple sclerosis, muscular dystrophy and HIV. Where somebody has a progressive condition, he is covered by the Act from the time when the condition leads to an impairment which has some effect on ability to carry out normal day-to-day activities, even though it is not necessarily a *substantial* effect at that time. However, the impairment in question should be likely to *eventually* have a substantial adverse effect on such ability.

*Genetic conditions* may also be covered by the Act. The diagnosis of a genetic condition does not automatically bring the person within the definition of disability. If the genetic condition has no effect on the ability to carry out normal day-to-day activities, then the person concerned is not covered. However, if the condition is progressive, then the rule about progressive conditions will apply.

## What are normal day-to-day activities?

'*Normal day-to-day activities*' are those which are carried out by most people on a fairly regular or frequent basis. The term is not intended to include activities which are normal only for particular groups of people or a particular person (such as playing a musical instrument or a sport to a professional standard). However, if someone who is affected in such a specialised way is also affected in normal day-to-day activities, he would be covered by this part of the definition. The test of whether an impairment affects normal day-to-day activities is whether it also affects one of the broad categories of capacity listed in Schedule 1 of the DDA.

These categories are:

- mobility
- manual dexterity
- physical co-ordination
- continence
- ability to lift, carry or otherwise move everyday objects
- speech, hearing or eyesight
- memory or ability to concentrate, learn or understand or
- perception of the risk of physical danger

## How does treatment affect the definition of disability?

Someone with an impairment may be receiving medical or other treatment which alleviates or removes the effects (although not the impairment). In such cases, the treatment is ignored and the impairment is taken to have the effect it would have had without such treatment. This does not apply if substantial adverse effects are *not likely to recur even if the treatment stops* (i.e. if the treatment has been cured).

The sole exception to ignoring the effects of treatment relates to the wearing of spectacles or contact lenses. In this case, the effect while the person concerned is wearing spectacles or contact lenses should be considered.

## Are any conditions specifically excluded from the coverage of the DDA?

Certain conditions are specifically excluded from the definition of impairments within the Act. These are:

- addiction to or the dependence on alcohol, nicotine or other substances (other than as a result of that substance being medically prescribed)
- seasonal allergic rhinitis (e.g. hay fever) except where it aggravates the effect of another condition (e.g. severe asthma)
- a tendency to set fires (arson)
- a tendency to steal
- a tendency to physical or sexual abuse of another person
- exhibitionism
- voyeurism

However, in looking at the above exclusions, it is important to note that people who otherwise meet the definition of impairment within the DDA, but who *also* have difficulties as set out above *could* be covered.

## Children Act 1989 – definition of disability

The Children Act 1989 brings together most public and private law relating to children in England and Wales. Section 17 clarifies the position of ‘*children with disabilities*’ as ‘*children in need*’ and therefore eligible for a range of services and support from the local authority. Schedule 2 of the Children Act 1989 permits a local authority to assess a child’s needs at the same time as other assessments under different legislation (for example under the Education Act 1996). Further information is provided in:

- *The Children Act 1989 Guidance and Regulations, Volume 6, Children with Disabilities (1991), Department of Health and HMSO*
- *Framework for the Assessment of Children in Need and their Families (2000), Department of Health, Department of Education and Employment and Home Office, Stationery Office*

Local authorities, as providers of services, are already covered by Part III of the DDA with regard to provisions made for disabled children under Section 17 of the Children Act 1989.

In Section 17 of the Children Act 1989, a child is defined as being ‘in need’ if:

- a) *he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining a reasonable standard of health or development without the provision for him of services by a local authority under this [Part] of the Act*
- b) *his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services or*
- c) *he is disabled*

'Development' is defined as physical, intellectual, emotional, social or behavioural development. 'Health' means physical or mental health.

The Children Act 1989 definition of disability mirrors the National Assistance Act 1948 definition, which states that:

'A child is disabled if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed.'

## **Education Act 1996 – definition of disability**

The Education Act 1996 specifies the procedures to be followed by Local Education Authorities (LEAs) with regard to the identification and assessment of children with special educational needs and any special educational provision arising from such assessment. The Act is accompanied by a Code of Practice (*Code of Practice on the Identification and Assessment of Special Educational Needs, 2001*).

The majority although not all disabled children will also have special educational needs. Section 312 of the Education Act 1996 defines disability in the context of special educational needs as follows:

*'A child has 'special educational needs' for the purposes of this Act if he has a learning difficulty which calls for special education provision to be made for him.'*

*A child has a learning difficulty if he:*

- a) has a significantly greater difficulty in learning than the majority of children of the same age or*
- b) has a disability which prevents or hinders the child from making use of educational facilities of a kind generally provided for children of the same age in schools within the area of the local education authority*

*is currently under compulsory school age, but who is or would have been likely (without special provision) to fall within the preceding paragraphs when he reaches that age*

*A child must not be regarded as having a learning difficulty solely because the language or medium of communication of the home is different from the language in which he is she will be taught.'*

The majority of disabled children will also have special educational needs. However, a minority may not, because:

- their disability does not prevent or hinder the child from using educational facilities generally provided in the area, and
- they do not otherwise have a learning difficulty as defined out in Section 312 of the Education Act 1996

A disabled child does not need to be assessed as having a special educational need in order to be protected from discrimination under the SEN and Disability Act.

The SEN and Disability Act does not require education services to provide auxiliary aids and equipment. These would usually be provided following assessment under Part IV of the Education Act or Sections 60–65G of the Education (Scotland) Act.

# Appendix B: How good is our service?

## Self-audit to support planning for service development

Aspects of service provision	How are we doing?				
	1	2	3	4	5
<b>How well planned is our service?</b>					
Local incidence of disability 0–2 and range of service need has been mapped?					
Existing database arrangements supporting service provision have been mapped?					
Awareness of likely impact of new/emerging new-born screening procedures including Newborn Hearing Screening					
Education, Health and Social Services have agreed a joint vision for service delivery to families with disabled children under 2?					
Education, Health and Social Services have agreed a joint statement of the outcomes for children and families they expect effective service provision to deliver?					
Joint planning for service delivery?					
Joint planning for service development?					
Effective communication and co-operation with services provided for all children by Health Visitors, General Practitioners, Early Years Development Partnerships, Sure Start and Early Excellence Centre initiatives?					
Mechanisms/opportunities to share/learn from examples of effective service delivery?					
Awareness of broader agenda of social inclusion as demonstrated by the SEN Code of Practice (2001) and the Special educational needs and Disability Act (2001)?					
Consumers of service delivery participate in the planning process for service development?					
<b>How well co-ordinated is our service?</b>					
Clear definition of roles and responsibilities of different agencies?					
Clearly defined mechanisms to ensure prompt referral on?					
Shared register of families/database between Health, Education and Social Services?					
Effective arrangements to share information about the families between all service providers working with a family?					
Unified record keeping and reporting?					
Central bank of information for parents?					
Co-location of assessment, information and treatment services?					

Aspects of service provision	How are we doing?				
	1	2	3	4	5
Opportunities for families to make appointments with professionals from more than one agency at a time?					
Opportunities for joint assessment by more than one agency at a time?					
Agreed common terminology used by Health, Education and Social Services					
Arrangements in place to identify a named Key Worker for each family receiving services?					
Clear definition of the role and responsibilities of Keyworkers?					
<b>How accessible is our service?</b>					
Families receive service directory when first referred to service?					
Families have telephone numbers and contact details for all the professionals in contact with them?					
Key facilities are easily accessible by public transport?					
Help with additional travel costs available to families?					
Service providers available to families outside normal office hours when necessary?					
<b>How family centred is our service?</b>					
Services address the needs of the child and the needs of the family?					
Initial assessment of need leads to agreement of a clear plan with families?					
Services are organised to be delivered in the home where this is appropriate?					
Arrangements in place to identify families who require help in the home and respite care and to deliver this support when it is needed?					
Family held records?					
Service recognises and is able to respond to a wide range of families and family circumstances?					
Service recognises and is able to respond to a range of cultural assumptions about disability and parenting?					
Service identifies and is able to respond to families using a language other than spoken English?					
Families as consumers of services are involved in the planning and review of services?					
Service actively involves families in initial identification of need and on-going monitoring of progress in the child?					

Aspects of service provision	How are we doing?				
	1	2	3	4	5
<b>How competent is our service?</b>					
An agreed protocol exists to ensure initial news of disability is shared with families sensitively and in an appropriate setting?					
Families have sufficient time to discuss child's situation at time of diagnosis?					
Diagnosis leads quickly to initial assessment of need and agreement of a plan with families?					
There are service standards for response times once family/child need has been established?					
Service standards for response times are met?					
All professionals delivering services to families have the knowledge, understanding and skills required to do their job?					
Where accredited training is a requirement, all staff have appropriate training and qualifications?					
There is a staff development/training plan and funding to support professional development?					
Up-take of opportunities for professional development is monitored?					
There are opportunities for professionals from different agencies/professional backgrounds to train together?					
The information families need is defined and provided?					
Information can be provided in a range of languages and formats?					
Arrangements in place for regular review of progress in the child?					
Arrangements in place for regular review of appropriateness of service package?					
<b>How accountable is our service?</b>					
Service has clearly defined processes for self-audit, planning and review?					
Outcomes for children and families are documented as one important measure of the impact of the services provided?					
Service has an agreed set of performance indicators and uses them?					
Service has a set of minimum service delivery standards and uses them to monitor service delivery?					
Arrangements in place to track the achievements of children longitudinally to 3 and beyond?					
Arrangements in place to measure consumer/client feedback on services provided?					

### Key

- |   |                |   |
|---|----------------|---|
| 1 | Very good      | There are major strengths and no obvious gaps in service provision.                                   |
| 2 | Good           | Some strengths. Strengths clearly outweigh weaknesses.  |
| 3 | Satisfactory   | Services meet agreed minimum standards but obvious areas in which service delivery could be improved. |
| 4 | Fair           | Some strengths, but there are important and obvious weaknesses/gaps.                                  |
| 5 | Unsatisfactory | Major weaknesses.   |



**What evidence is available to support self-audit rating?**

**What do we need to improve on?**

**What are we going to do about it?**

# Appendix C: Working party membership

## **Chair**

Paul Ennals, CBE

Chief Executive  
National Children's Bureau

## **Secretariat**

Kathryn Blackshaw

Department for Education and Skills  
(seconded)

Diane Emm

Department for Education and Skills

Julia Rich

Department for Education and Skills

## **Members**

Brian Lamb

Special Educational Consortium

Virginia Bovell

PACE

Dr Gillian Baird

National Autistic Society and  
Royal College of Paediatrics and Child Health

Elizabeth Andrews

RNID

Lesley Campbell

MENCAP

Gill Bishop

Bournemouth Social Services

Claire Lazarus

Regional Co-ordinator  
Eastern SEN Project

Helen Norris

Phoenix Pre-School Assessment Centre  
Bromley

Anne-Marie Hall

National Deaf Children's Society

Toni Russell

London Borough of Newham

Janice Funnell

Barnardo's

Christine Lenehan

Council for Disabled Children

Julie Jennings

RNIB

Jan Sharpe

Scope

Prof. Lesley Abbott

Manchester Metropolitan University

Simon Boulton

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Jane Scott

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Peter Smith

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Kevin Woods

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Sophie Rees

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Ann Gross

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Stephen Dance

SEN Division  
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Alison Thompson

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Caroline O'Shea

Sure Start Unit  
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Michael Collins

Early Years & Childcare Unit  
Department for Education and Skills

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