



Together From The Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families

Executive summary

This is guidance issued jointly by the Department for Education and Skills and the Department of Health.

It is concerned with the delivery of services to disabled children in the age range birth to third birthday and their families.

Central themes within the guidance are:

- Initial assessment of need
- Co-ordination of multi-agency support for families
- Better information and access for families
- Improved professional knowledge and skills
- Service review and development
- Partnership across agencies and geographical boundaries

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.

The guidance also informs the Early Support Pilot Programme (ESPP) funded by the DfES.

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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 and help tackle some of the many social and physical barriers families of disabled children face to full participation in society. It is not only disabled children's impairments which determine the quality of life, but also disabling attitudes and a disabling environment, which can result in unequal access to community services and facilities. Effective intervention 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 disabled children (birth to third birthday) 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
- exclusion from some mainstream and community services and facilities

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. He has a combination of disabilities.

Adam has had 315 different service based appointments in the last nine months, in 12 different locations. His family have found it extremely difficult to access information, specialist equipment, financial help, support from local or national groups, or co-ordinated services. They report that the attitude of some professionals is still the most distressing challenge they face.

His family 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 key worker
- recognition from professionals of the emotional trauma they have gone through

Views from parents¹ 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 with 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. It is not easy to apply existing legal definitions of disability to children aged birth to third birthday:

- many people find the language of some existing definitions insensitive, and in particular

¹Throughout this guidance “parent” includes any person with parental or caring responsibility for a child.

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.

Working definition of disability

Where a child's development is impaired, it is not always possible to know whether this represents a delay which can be caught up, or whether development may remain impaired. Nor will it always be possible to determine clearly whether any impairment will be long term, but we are clear that the need for early intervention remains.

The following working definition of disability is used for the purposes of this guidance and the associated Early Support Pilot Programme (ESPP):

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

(i) is experiencing significant developmental impairment or delays, in one or more of the areas of cognitive development, sensory or physical development, communication development, social, behavioural or emotional 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 impairment or 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 having such difficulties, until it becomes clear that such a child is not showing evidence of impairment. Children with severe sensory-neural hearing could be considered as disabled.

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 Children's 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. local 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
- *Disability rights.* 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

- *Children's Trusts pilots*. These will bring together education, social services and health services within one organisation structure locally. The pilots are intended to help with more joined up service planning, commissioning and delivery for children and their families

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. Factors contributing to disability may be evolving and review of secondary impairment in areas such as feeding and sleeping may be needed
- 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
- helping to tackle the disabling social and physical factors which are inhibiting the child's access to a good quality of life

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

NOTTINGHAMSHIRE - in 1997, the Local Education Authority drew up a service level agreement with the Social Services Department to provide educational support to children in need 0-3 (including those with disabilities) and their families attending the County's Family Centres. This on-site provision is delivered by a team of specialist teachers and teaching assistants. Staff provide general advice on educational matters to all staff and parents and individual teaching support and guidance for children with disabilities/SEN. Regular multi-agency planning meetings take place to ensure co-ordinated support and information is readily accessible on-site to all those working with an individual child. Parents benefit from having access to additional support and advice without the need for another appointment or visit. This method of providing support has proved particularly helpful to some families who have traditionally proved hard to reach.

1.8 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 local Sure Start programmes, Neighbourhood Nurseries, the Early Excellence Centres Programme and the development of Early Years Development and Childcare Partnerships (EYDCPs).

Local authorities are currently required to establish a network of early years area special educational 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 their third birthday 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.

Further guidance entitled *Sure Start - supporting families who have children with special needs and disabilities* was produced by Contact a Family for staff involved with local Sure Start programmes in November 2002. It incorporates many of the topics covered in *Together from The Start*, and focuses on providing support and advice for staff and volunteers - as well as families - within the 522 Sure Start catchment areas in England. It aims to help programmes develop an awareness of, and respond appropriately to, the needs of families who have children with special needs and disabilities and encourages them to design their services to be inclusive of the whole community. The guidance underlines the key Sure Start principle of effective inter-agency working to ensure that well integrated services are provided for families. In addition, it covers the provision of support in the early stages following diagnosis, getting financial help, child protection for children with disabilities and it contains a succinct good practice checklist.

The importance of early identification is further reinforced within the new Special Educational Needs Code of Practice (2001), which 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.

The Department of Health is developing a Children's National Service Framework (NSF). This will develop new national standards for children across the NHS, social services and interface with education. The Standards set will provide a coherent and integrated approach to providing services for disabled children. The External Working Group looking at services for disabled children has been considering how best to make recommendations about implementing "Together from the Start" as part of its work. Further details can be found on the Department of Health's website <http://www.doh.gov.uk/nsf/children/externalwgdiseabled.htm>

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 currently 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. Some parents will particularly appreciate being put in touch with other parents whose child has the same condition/impairment.

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 resulting 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 template² are detailed below.

Right From The Start

Sharing the news: key principles

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 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

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Contact: Right From The Start, Scope, 6 Market Road, London, N7 9PW

Tel: 020 7619 7100 E-mail: rfts@scope.org.uk Website: rightfromthestart.org.uk

- When sharing the news of additional needs identified in an older child, consideration should be given as to whether the child should be present

Respect parents and families

- Support and empower parents
- Treat all parents' concerns seriously
- Listen to parents and share information sensitively and honestly
- Use plain and understandable language and give explanations to build parents' confidence
- Acknowledge and respect cultural difference
- Give opportunities to ask questions and check parents' understanding of their situation
- Avoid giving negative non-verbal messages before concerns have been shared with parents

Good practice framework

Preparation

- Allocate time for individual and team preparation prior to specific interviews/consultations
- Families and their circumstances vary enormously so professional teams need to share their knowledge of the family in order that the news is shared sensitively and effectively

Who should be present?

- 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 alone, 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 close 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 the 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 in 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
- 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

- Acknowledge and address personal and professional development needs
- Ensure staff participate in training, clinical supervision and continuous professional development
- Promote inter-professional practice, mutual support and sharing good practice
- 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 and auditing of practice

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 among populations who are 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. Assessment should also identify the disabling social and physical factors which are inhibiting the child's access to a good quality of life and what support agencies can provide to help tackle some of these barriers. 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.³ Assessment 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
- 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, and be delivered in a location appropriate to the child
- 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

³For 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.

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. 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 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

Parents want meaningful, joined-up assessment. 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**. The Plan should be provided in a format which is accessible to parents.

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 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 and often distressing 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. This has 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 seek 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, as 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.

NORFOLK - children are assessed over an 8 day period at the Newberry Clinic. All professionals carry out their assessments within the clinic encouraging joint working, joint assessment and ongoing discussion. Reports are presented in a bound booklet with an agreed action plan discussed with parents. This works well because Great Yarmouth has geographic administrative co-terminosity.

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 them.

3.2 Co-ordinating service provision

Local Sure Start programmes aim 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 of 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. One 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 challenge is to identify the gaps that new Sure Start 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 childcare 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.

The White Lodge Child Development Centre in Chertsey, Surrey, offers a "one-stop shop" service for children with disabilities and their parents. This service provides

- access to information
- medical treatment as necessary including paediatrics
- pre-school speech and language therapy services
- planning and support for education provision
- physiotherapy and occupational therapy
- a range of respite services
- and links to other support services and interest groups

3.4 The Key worker 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 key worker 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 'key worker' in different ways at different times and this has sometimes caused confusion. Key workers 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 key worker 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

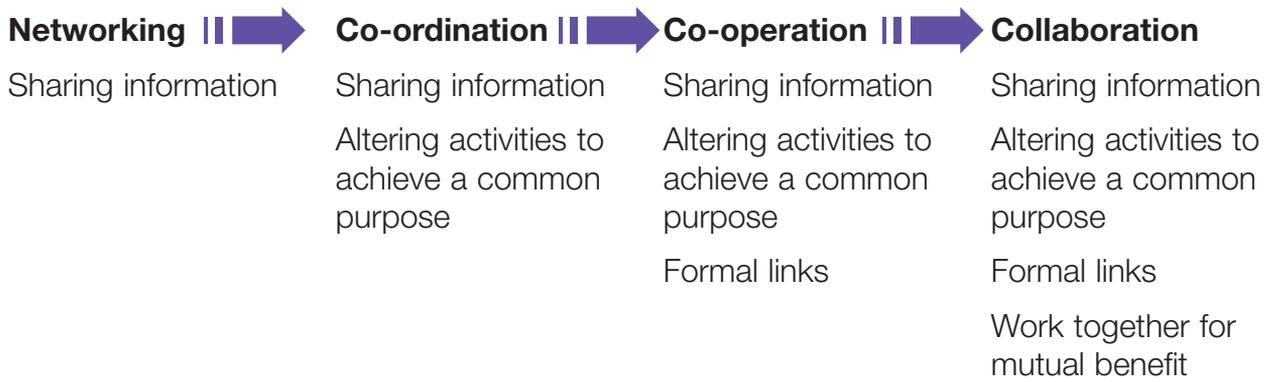


Figure reproduced by kind permission of Social Policy Research Unit, York University, Himmelman (1996).

Key workers 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 for families to look forward to the child's next stage of development and anticipate service needs
- a role in implementing the Family Service Plan (see 2.7)

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 key worker brings to the total package of support must be clearly defined and understood by everyone involved.

In many situations, the key worker will be a professional who already provides some services to the family. The function of key worker 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 key worker for a family, the time requirement of this role should be taken into account in planning workloads. As key worker, 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 key worker 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 key worker roles undertaken by non-statutory agencies are also available, offering independence from the statutory service providers involved.

WOLVERHAMPTON - The Education Department and Health Authority are initiating a Key worker pilot project. The authorities are supportive of the philosophy of Keyworking and recognise many professionals 'work together' but do not co-ordinate through a Key worker and Family Service Plan model. Although an outside consultant is being funded to support this move, all services will be delivered through existing resources. One of the outcomes of the project will be to determine the time management aspects of the individual involved.

3.5 Who should be the Key worker?

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

- is the proposed key worker 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 key worker 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 key worker have sufficient understanding of the different professional roles undertaken by other agencies in order to provide the co-ordination role that the family will need?
- does the proposed key worker possess the necessary competencies and experience for working with families under stress?
- the family is from one particular ethnic group, is there a possibility of identifying a key worker from that same group?

Key worker competencies would include:

- specific training in working with pre-school age disabled children and their families
- knowledge of local and national services for the children they work with and how to access them
- skills in presenting information without bias
- knowledge and understanding of different methods to address the child's needs if appropriate
- the ability to fully support families in their choice of provision

- knowledge of who the key professionals are and how to contact them
- counselling, communication and negotiation skills
- the ability to introduce families to other families with children affected by similar disabilities

The quality of the relationship between the family and the key worker 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 key worker, if the relationship becomes strained. Key workers should receive regular supervision.

Parents should have explanations about:

- whether a key worker system is in place
- who their key worker is and what can be expected of them
- the process for allocating key workers
- 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 key worker 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. It 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 co-ordinator 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 re-telling their child's story.

The development of the Integrated Children's System (Department of Health et al, forthcoming) offers an important opportunity to open up access for families to the records held on their child.

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, to which workers working with the family contribute. 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. 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' requiring 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.

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 the same
- 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 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.⁴

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

⁴ For further discussion see Chapter 2, *Assessing Black Children in Need and their Families in Assessing Children in Need and their Families: Practice Guidance* (Department of Health 2000), and *Sure Start for All: Guidance on Involving Minority Ethnic Children and Families* (Department for Education and Employment 1999).

- 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. 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 and 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 local Sure Start programmes, Early Excellence Centres and local authorities 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.

Section 332 of the Education Act 1996 provides that if a health authority, primary care trust or NHS trust are of the opinion that a particular voluntary organisation is likely to be able to give the parent advice or assistance in connection with any special educational needs that the child may have, they shall inform the parent accordingly. Local authorities have a duty under the Children Act 1989 to publish information about the services they provide to families.

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 give 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

Portage is a well-established and well-evaluated model of service delivery for very young children with additional support needs and their families. 150 services registered with the National Portage Association offer parents regular, usually weekly, opportunities throughout the child's early years to be fully involved with decisions on their child's development. Portage services work in partnership with parents in their own homes and offer a flexible and individual programme that takes into account each family's unique circumstances. Regular supervision and liaison is inherent in the Portage model and this provides an effective way of offering a key worker system linked into local communication networks. Regular written reports on the child's progress and the family's views are provided and shared with others

working with the child.

Portage services have been operating in this country for over 25 years. They have been evaluated at local and national level and found to be valued by parents and other professionals and to offer high quality teaching. Service delivery is backed by a programme of training delivered by accredited trainers. Support to families and professionals is provided by the National Portage Association.

NOTTINGHAM CITY - the Portage team in the City have recently organised some parent groups based on the Hanen 'More than words' principles. This is a Canadian programme which supports parents to develop and extend their communication skills with children who have autistic spectrum disorders. This has involved joint training between a Portage worker and a speech and language therapist. The course consists of 12 evening sessions and also involves video sessions of parents interacting at home, with their child. The feedback from these sessions has been very positive as parents felt that they are receiving practical advice with the added value of meeting other parents who may be experiencing similar circumstances. Parents are also given the opportunity to meet other professionals who may be involved with their child's future education. This gives parents an opportunity to ask questions and thus learn more about the education system.

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 on-going 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 key worker

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 General Medical Council Guidelines on the Withdrawal or Withholding 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 Safeguarding disabled children

The available UK evidence on the extent of abuse among disabled children suggests that they may be especially vulnerable to abuse. It is therefore important that agencies jointly work to implement the recommendations in the Government's inter-agency guide to safeguarding children 'Working Together to Safeguard Children'. In particular, Area Child Protection Committees should ensure that procedures for safeguarding disabled children promote a high level of awareness of their possible vulnerability, and the high standards of practice required when working with them.

4.9 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).

4.10 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 local authority 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.

4.11 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 childcare costs incurred by families of very young disabled children.

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 local Sure Start programme provides specialist crèches for disabled children and their families which offer 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 de-skilled. They should be provided flexibly and reviewed regularly as the family's needs change.

4.12 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.

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 these should underpin both 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.

Agencies should consider making maximum use of Health Act 1999 flexibilities - pooled funds, lead commissioning and integrated provision. Benefits include:

- higher quality and effective services
- multi-skilled workforce and integrated staff training and development
- co-ordination of needs assessment and care planning
- common information systems
- no boundary disputes over funding

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 through 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 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, Monday to Friday).
- opening times/contact times are published and conveniently offered

BIRMINGHAM - a group of parents have been actively involved in developing and delivering training to promote good practice not only at the time of diagnosis of their child's disability, but also in the follow-up care offered by health, education, and other agencies.

The parents came together through the West Birmingham Portage Service. They formed the *Sharing Concerns Portage Parents Project* to work in collaboration with health and education professionals, such as paediatricians, midwives and educational psychologists, on various training initiatives. These have included the development of guidelines for good practice and various multi-disciplinary workshops using the drama 'Moments' devised for the project by Women and Theatre.

The most recent development by the project has been the production of the *Sharing Concerns* video and training handbook with the School of Women's Health Studies, University of Central England.

The *Sharing Concerns* materials have been adopted by SCOPE as part of the training strategy for the 'Right from the Start' template. They are regarded as a notable contribution to an area of practice that increasingly recognises the necessity of genuine dialogue between families and professionals. The materials provide a framework of principles through which professionals can develop and reflect on their own practice in this sensitive and difficult field.

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 workforce plans to ensure the workforce 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 the local authority in the area of early years education and childcare, 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 key worker for each disabled child from birth to third birthday, which takes due account of the wishes of the family. The function of the key worker is agreed by all relevant agencies, and sufficient time is allocated to the key worker 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 key worker, 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 key worker, 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 key worker 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, in a format accessible for parents
- in line with the Department of Health's *Fair Access to Care Services* guidance, agencies ensure that parents with physical or sensory impairments, learning disabilities, or mental health problems, have access to all services. Children and adult services have agreed policies and protocols on supporting these parents
- parents' communication needs are met, for example interpretation support where required

5.6 A competent service

- there is a system to ensure the sensitive sharing of news of disability with families in an 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 a Family Service Plan agreed between the family and the professional agencies providing services
- that a named key worker 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 1999 flexibilities
- a regular cycle of self-evaluation

As part of the work being carried forward under the DfES-sponsored Early Support Pilot Programme (ESPP), a multi-agency service audit tool is being produced. This will serve as a framework against which services can plan for service development and track progress. It will have regard to the principles set out above and will also aim to be accessible to parents.

EARLY SUPPORT PILOT PROGRAMME (ESPP)

A DfES-funded programme has been established to support a range of projects carrying forward the principles set out in this guidance and the parallel guidance on early intervention/support services for deaf children and their families.

Further information on this programme, funded to financial year 2005-2006, is available on line at www.espp.org.uk and from:

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(roles indicated are those at time of membership)

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