

Sure Start



Supporting families who have children with
special needs and disabilities



*Investing in
our future*

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contact a family
for families with disabled children



The Government is committed to creating an inclusive society where every individual has the opportunity and support to achieve their full potential. It is recognised that for this to happen successfully that the agencies and professionals responsible for providing support to children with special needs and disabilities need to work together effectively. This guidance reflects a number of issues discussed in the consultation document *Together from The Start – Practical guidance for professionals working with disabled children (birth to 2) and their families* issued by the Department for Education and Skills and the Department of Health in May 2002. More details of *Together from the Start* and the consultation process maybe found on page 13.

1 Introduction

- 1.1 Sure Start aims to transform the life chances of young children, particularly those with special needs and disabilities who live in areas of disadvantage. Programmes are specifically concerned with reaching *all* families within the catchment area. To achieve Sure Start targets, efforts must be made to ensure that services are designed to meet the particular needs of individual families so that they feel welcomed and supported.

Sure Start operates to a set of core principles that includes the requirement that services be non-stigmatising, culturally appropriate and sensitive to particular families' needs. Working to the core principles as well as the targets is vital to the overall success of Sure Start.

Purpose of this guidance

- 1.2 The purpose of this guidance is to:
- ensure that all families who have children with special needs or a disability have access to and get a good quality service from Sure Start programmes
 - ensure that all the partners in Sure Start programmes consider access and quality issues when designing Sure Start programmes
 - help programmes develop an awareness of and respond appropriately to the needs of families who have children with special needs or a disability
 - help programmes to build and share knowledge about existing information and support available to parents and carers of children with special needs or a disability.

This guidance can be adapted or tailored to suit the needs of individual programmes. It gives some suggestions to help programmes provide services that are appropriate and sensitive to the needs of each family.

The guidance is intended for programme managers, staff and volunteers who work within Sure Start programmes. Parents may also find it useful.

Key questions for Sure Start programmes

1.3 Staff in Sure Start programmes might wish to consider the following questions when reading the guidance.

Sure Start Services

- **How do we welcome families that have a child with special needs or a disability?**
- **Are our services and buildings inclusive and accessible to parents and children with special needs and disabilities?**
- **What play materials, books and displays do we have that support positive images of parents and children with special needs or a disability?**
- **What actions do we take when we think a child we are working with may have special needs or a disability?**
- **Do we have special needs expertise on our partnership board and if not, do we know where to access specialist advice?**
- **Do we have an action plan or policy for working with families who have children with special needs or a disability?**

Links with other professionals and voluntary/community services

- **Who provides special needs and disability training?**
- **Who is the lead on child protection issues for children with special needs or a disability?**
- **How do parents contact the local parent partnership service for advice and information about special educational needs?**
- **Where are the local paediatric services?**
- **How do we contact speech therapists?**
- **How do we get help from the local social services department?**
- **How do we find parent support groups for the families of children with special needs or a disability?**

Definitions of special needs and disability

- 1.4 The term special needs is often used as an alternative to 'disability' and 'special educational needs'. It is used within Sure Start to reflect the wide range of needs that children may have.

It is not easy to apply existing *legal* definitions of special needs to children aged under four years. The following definition (taken from the *Together from The Start* consultation paper) is therefore used within this guidance.

A child under four years of age has a disability or special needs if she or he:

- **is experiencing significant developmental delays, in one or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or**
- **has a condition which has a high probability of resulting in developmental delay.**

A note on language

- 1.5 The words commonly used to describe children with special needs or disabilities have changed. Terms such as "epileptics", "handicapped", "wheelchair bound" can be perceived as negative. More positive and acceptable terms are children with epilepsy, children with special needs and disabilities, and children who use a wheelchair.

The parents of children with special needs or a disability come across more jargon than most. When professionals use abbreviations and shorthand, it can be helpful if Sure Start staff check that all present, particularly parents, understand what is meant (see Glossary in Annex A).

Inclusion

- 1.6 Sure Start is committed to promoting the inclusion of children with special needs or disabilities within all of its services. Programmes must ensure that all Sure Start buildings allow easy access to families who have members with disabilities.

How many children have special needs, or disabilities?

- 1.7 It is not easy to decide how many children under 4 years have special needs or a disability in any one geographical area. Some needs will be apparent from birth or before and some will emerge during the first few years, whilst others are resolved or reduced over time.

The increasing survival rates of low birth weight babies has tended to increase the number of children surviving with severe and multiple needs, while improved health care and preventative programmes have led to a corresponding decrease in the numbers of children with mild or moderate disabilities. This has meant that over all, the total numbers of children with special needs and disabilities has remained broadly constant.

There are other factors too that can affect the incidence of children with special needs and disabilities: numbers increase considerably in areas of deprivation and some causes of special needs and disability, such as sickle cell disease and thalassaemia, particularly affect minority ethnic groups.

This means that estimating the number of children with special needs and disabilities within a Sure Start programme area can be complex. It is important that programme managers liaise with all those responsible for supporting children with special needs and disabilities within their area so that they can make informed judgements about the number of children that they may need to support and the nature of the support they may need to provide to both children and their families.

Early identification¹

- 1.8 The needs of children and families are varied:
- 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 from several professionals
 - some children can have high expectations for their 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 to assist their child. For other families, their greatest need may be emotional support.

1 This paragraph is taken from the *Together from The Start* consultation paper

Disability and significant developmental delay related to such disabilities may be detected immediately at birth or later:

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

1.9 The needs of some children in Sure Start areas will not have been identified because they have not been in touch with a relevant service provider.

Local education authorities have a responsibility to identify and assess young children with special needs and may make assessments and provide services from birth. However, they can only provide services if they are aware of the child's needs. Usually the Primary Care Trust, social services department or a parent informs them that a child might have a special need or disability and requests help. In most cases a child with special needs will be identified through assessments in child development centres or in early education settings. But in some cases, a child's special needs or disability may be identified at a later stage. Some children may not be diagnosed until much later, particularly where difficulties are not apparent until the child gets older.

What are special needs?

1.10 In any Sure Start catchment area there is likely to be a wide range of conditions and needs. Some of the most common types children may experience are:

- mild or moderate learning difficulties and/or developmental delays
- severe, profound and multiple difficulties
- physical and motor restrictions
- sensory impairments such as hearing or visual
- neurological impairments
- mental health problems
- behavioural difficulties, including those caused by stress or trauma

- long-term health conditions, including HIV/AIDS, Cystic Fibrosis, Diabetes, Asthma and Epilepsy
- rare disorders including genetically inherited conditions
- communication difficulties
- technology-dependent conditions that require parents and others to administer medical procedures and therapies
- life-limiting conditions
- undiagnosed conditions.

Case Study

Louis and his mum Nikki have been using Sure Start Newcastle East services at Byker Sands Family Centre for several months now. Louis is three years old and has global developmental delay. Nikki and Louis registered with the Sure Start Toy Library service; it provides parents and children with free access to toy loans. Parents and children are encouraged to explore the toys available before taking them away. The toys are of good quality and provide stimulation for different age groups. The toy library has a number of toys suitable for Louis, which Nikki borrows on a regular basis. This facility allows Nikki to vary the toys Louis plays with at no cost to the family. As a result, Louis' development is encouraged and the toys can be exchanged frequently to prevent him becoming bored. Nikki was so impressed with this facility that she became a volunteer for Byker Equipment Loan Centre who support Sure Start with the Toy Library service and she now regularly helps with the running of the Toy Library.

As Nikki admits, caring for Louis can be very challenging. Sure Start recognises that caring for children is not always an easy task. In response to a request by parents, a course entitled "Managing challenging behaviour" is to be run at Byker Family Centre and Nikki is keen to attend. The course will provide parents with the opportunity to explore different styles of parenting in a safe and supportive group.

Nikki feels that she and Louis have benefited greatly from Sure Start activities in the area as the services are easily accessed and are flexible to the needs of parents and children.

What is assessment?

1.11 The term assessment means different things to parents and professionals when used in slightly different contexts, which can sometimes result in confusion. Assessment may refer to the process of arriving at a diagnosis by an individual professional or a process of collating advice. It is therefore important for Sure Start programmes and families to be clear at the outset about their expectations of any assessment.

Local education authorities (LEAs) are responsible for making statutory assessments of special educational needs. The assessment process is carried out by a child's home LEA and gathers information from parents, education, health and social services about their special educational needs and determines how those needs are to be met.

Statutory assessment of children under two

If an LEA believes that a child in their area who is under the age of two may have special educational needs for which the LEA should determine special educational provision, the LEA may make an assessment of their special educational needs if the parent consents to it, and must make such an assessment if the parent requests it. Such an assessment shall be made in such a manner as the authority considers appropriate. Following such an assessment, the LEA may make and maintain a statement of the child's special educational needs in such a manner as they consider appropriate. (See Section 331, Education Act 1996)

An assessment of a child in need and his or her family gathers information from social services, health and education in order to decide whether support is necessary to ensure that the child reaches and maintains a satisfactory level of health and development, what action must be taken and which services would best meet the needs of that particular child and family. The *Framework for the Assessment of Children in Need and their Families* (Department of Health 2000) gives guidance on how to holistically assess the particular needs of disabled children. It looks at the child's developmental needs, parenting capacity and family and environmental factors.

For those children with special needs and disabilities it is important that the process of assessment is supportive of the child and family, recognising in particular the needs of siblings. The earlier action is taken, the more responsive the child is likely to be, and the greater the likelihood of reducing the severity of any impairment and preventing longer-term difficulties. Outcomes for the family as a whole will also be improved – long waits may increase anxiety when parents suspect that their child has difficulties.

Working with *all* the community

1.12 There may be a number of families whose children's special needs or disabilities have not been identified. Some additional and skilled outreach work by Sure Start programmes may be needed to find out about the needs of children in:

- minority ethnic groups
- families of refugees and asylum seekers
- prisoners' families
- travelling families
- families where the parents have special needs, a disability or health needs
- families where the child's care needs are considerable, for example, those with long-term medical conditions, life-limiting conditions and/or dependence on technology and therapies based in the home, or any other complex needs
- families who are particularly isolated, for example, single parent families, those living in high rise flats, or living far away from shops and services with no access to transport.

Sure Start Berwick

Sure Start Berwick works with a lone carer who has a toddler with significant developmental delay, exacerbated by the family's social isolation. The parent wants to establish a bedtime routine for her child. This, for her, is the most pressing of a number of identified needs. The programme visits the family home twice a week to work with them to establish a bedtime routine. The situation was reviewed and the parent was pleased with the progress to date but felt she needed the work to continue for a further few weeks as she was feeling depressed and needed some more short term support. The work continues.



Parents with special needs and disabilities

1.13 Parents who have physical or sensory impairments, long-term illnesses, learning difficulties, mental health problems, or a combination of these, make up a considerable proportion of the parents involved in programmes run by Sure Start. Sure Start's activities and services should be accessible, welcoming and appropriate to parents with a wide range of special needs and disabilities.

Programmes should ensure that parents with special needs or disabilities are actively encouraged to take part in consultation exercises throughout the life of the programme, so that their experience of using existing services can be taken into account when the programme considers reshaping services to meet the needs of all local families. In addition, they might be encouraged to join the Partnership as parent representatives, where their experiences and input may be of great value to others.

Contact details for the Disabled Parents Network can be found in Annex B.

2 Providing support in the early stages

2.1 Where children have special needs or a disability 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 their children. Early identification and early intervention are key themes in the *Special Educational Needs Code of Practice (2001)*, they are central to a number of Government initiatives including Quality Protects and Sure Start, and they should lie at the heart of care provided by all professionals.

Effective early intervention and support can produce improvements in children's health, social and cognitive development. It strengthens the ability of families to provide effective support for their children, and improves outcomes for the whole family.²

To achieve this there must be:

- recognition of the critical importance of the early years of a child's life and their potential impact on future development
- recognition of the importance of consulting with parents and working in genuine partnership with them
- equality of opportunity and of access to services
- promotion of inter-agency and inter-professional working.

Right From the Start

2.2 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. Guidance, founded on respect for parents and the value of their children as children first and foremost, was produced and is available from Scope at a small cost (telephone: 020 7619 7341). It offers a framework for organisations to develop effective policies and procedures that ensure a high quality service is provided for families and children. It encourages individuals working in this area to continually reflect on and enhance their practice.

2 *Together from The Start* consultation paper.

SEN Guide for Parents and Carers sets out the main points of the SEN Code of Practice, explains procedures and tells parents about their rights.

Special Educational Needs Code of Practice (SEN) plus the related SEN Toolkit 2001. The Code and supporting material provide practical advice on the identification, assessment and making of any special educational provision for children and young people with special educational needs and include sections on early years education. Providers of government funded early education must have regard to the Code. If they do not reflect its guidance in their provision and response to children with special educational needs, they must prove that what they do is equally in the best interest of the child.

Available from DfES Publications, PO Box 5050, Sherwood Park, Annesley, Notts. NG15 0DJ (Tel 0845 60 222 60) and from DfES website: www.dfes.gov.uk/sen

Together from The Start

2.3 Draft guidance *Together from The Start – Practical guidance for professionals working with disabled children (birth to 2) and their families* was issued by the Department for Education and Skills (DfES) and the Department of Health for consultation in May 2002. It is concerned with the delivery of services to children with disabilities and their families. Central themes within the guidance have been reflected within this Sure Start publication and include:

- listening to parents and sharing information sensitively and honestly
- active partnership with parents, and communicating news of disability in a sensitive way
- prompt and co-ordinated assessment of needs, leading to a written family service plan
- the importance of keyworkers.

DfES also announced in May 2002 The Early Support Pilot Programme (ESPP) to help young children with disabilities up to the age of 2 years. It offers them and their parents practical help and will serve as a test bed for the principles laid down in the *Together from The Start* guidance and *Developing Early Intervention/Support services for Deaf Children and their families* produced in

association with the RNID and issued for consultation at the same time. One of the expected outcomes of ESPP is the development of a Toolkit for practitioners to use in association with the guidance when published.

The guidance and results from the scheme will also help inform the development of the National Service Framework for children, which will raise national standards for children's services.

Please note that the final version of *Together from The Start* may differ in some respects from the May 2002 consultation version. Copies of *Together from The Start* consultation document can be obtained by e-mail: dfes@prolog.uk.com or telephone: 0845 60 222 60 quoting reference DfES 0184/2002.

Supporting parents when they are first told their child has a disability

2.4 *How* a parent is told of their child's special needs or disability can significantly affect their subsequent view of support services and have a positive or negative influence on their willingness to use them. News of disability will come as a shock to many parents, but it is possible to lessen the potential impact of this event by giving 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 special need or disability, particularly if they do not have a diagnosis. Effective communication at this sensitive time is central to establishing positive relationships between parents, professionals and the child.

Many disabilities are diagnosed in the neonatal period. This is a sensitive time for new parents and particular care should be taken in communicating the facts to parents, as they are known. Immediate support should be made available if required; Sure Start programmes can offer parents emotional support, further information about their child's condition, signposting to other support services or practical guidance.

"The news that a child has, or is at risk from, a developmental disability is often among the most frightening and confusing pieces of information that parent will ever receive."
(Beckman & Beckman-Boyes 1993).

Having respect for parents and families

2.5 As outlined in Right From the Start (see page 12), Sure Start programmes can help to empower and support families by:

- listening to parents and sharing information sensitively and honestly
- using plain, understandable language and giving explanations to build parents' confidence
- acknowledging and respecting cultural difference
- providing opportunities for parents to ask questions and check their understanding of things
- avoiding any non-verbal messages given through body language and behaviour
- treating all parents' concerns seriously
- ensuring that if an interpreter is required, care is taken in their selection. Unless there is no alternative, family members should not be expected to undertake this role.

Families and their circumstances vary enormously and parents' reactions to the news cannot be predicted. Sure Start teams need to share their knowledge of the family sensitively, effectively and confidentially. They need to be well-prepared and confident to talk about the issues, whilst remaining flexible enough to respond to differing needs. Time and space should be available for parents to reflect on the news and meet again with a member of the Sure Start team in due course should they wish to do so. 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.

Impact on parents and siblings

2.6 Families caring for children with special needs or a disability have the same range of feelings and hopes for their children as all other families. A child's special need or disability may impact differently on each parent and Sure Start programmes will need to consider ways of meeting the needs of both mothers and fathers when developing their services.

Special needs and disabilities in childhood can put extra strain on families and may create additional needs such as:

- additional costs of supporting a child with special needs or a disability
- suitable housing and housing adaptations
- suitable, affordable childcare so that parents who want to work or study can do so
- isolation – there may be difficulties keeping in touch with family and friends
- emotional strain, including the management of children’s behaviour and sleeping patterns and concern about siblings
- prejudice and lack of public understanding
- lack of information about what support, such as short-term breaks, might be available locally
- accessing local community facilities such as transport, childcare and leisure services.

Sure Start programmes are well placed to refer families to appropriate help where these additional needs arise. They may also be able to offer childcare for siblings or a child with disabilities, so that parents can spend time with the other child or attend to their own needs, appointments, and so on.

Next steps: practical help and information for families

2.7 Programmes should ensure information given to parents is accurate, up-to-date and user-friendly; is given to families when they need it; and is based on discussions held with parents about their information needs.

Possible first steps include:

- providing contact details for the Sure Start team at the first meeting and encouraging parents to ask further questions as they arise
- arranging an early follow-up appointment at the end of the first meeting
- providing written information to parents at an early stage about
 - statutory and voluntary services
 - practical help and emotional support and
 - financial benefits
- offering support to parents to enable them to share the news with other family members and friends.

Sure Start PlusBus

At South Northolt in the London Borough of Ealing, the Sure Start PlusBus provides a low-cost door-to-door minibus service for families who have at least one child under 4 years old (health related and journeys to Sure Start services are free). Recently, a mother with her three-year-old son who has an autistic spectrum disorder and one-year-old daughter used the service for an outing to an adventure playground. Travelling by public transport is very difficult because of her son's challenging behaviour; such journeys often prove physically and mentally exhausting. The PlusBus was able to take her and her children in comfort and safety to the play centre and return them home afterwards. This allowed her the breathing space to attend to her children without worrying about getting to the bus stop, queuing, struggling with a buggy and coping with disapproving stares from strangers, let alone the cost.

More families are using this innovative service every week. The PlusBus operates on weekdays between 9-5 and includes a friendly driver who helps with shopping, buggies and equipment.

Parent partnership services

2.8 Parent partnership services are a useful source of information and support to Sure Start programmes and parents. They provide support and advice to parents whose children have special educational needs and can help parents to make informed decisions about their child's education. The parent partnership should be able to provide an independent parental supporter (IPS) to those parents who want one. Contact your local education authority for details. A list of contact numbers for parent partnership services can also be found in the *Special Educational Needs guide for parents and carers* (copies available from DfES Publications e-mail: dfes@prolog.uk.com or telephone: 0845 60 222 60, quoting reference DfES 0800/2001).

For most families, a clear diagnosis of their child's problem is the starting point for being able to move forwards, both to readjust to their situation and to feel in control through understanding the nature of the problem and its likely impact and to plan for the future. Some parents may feel the need for professional advice and counselling at the time of diagnosis. Many will welcome being put in touch with a parent support group or independent parental supporter.

Sure Start Berwick

Sure Start Berwick has introduced a laminated sheet of helpful local information for parents that they can keep for their own personal use. It can be inserted into the Child Health Record or can easily be kept next to the telephone.

When there is no diagnosis

2.9 The diagnosis stage can act as a barrier if the need for a formal diagnosis means that parents are denied access to key services, albeit on a temporary basis. If professionals are unable to provide a child and family with an appropriate diagnosis it is important that steps are taken to support parents at this stressful time. 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 accessing services and professionals should work together to ensure that services respond to meet the child and family's needs.

A Parent's Comment

"I felt that getting a name for our daughter's condition would help us in explaining to others what was wrong, but in the end it didn't really matter. All the professionals involved with Helen only needed to know what her immediate difficulties were so that the right care could be arranged."

Help from voluntary and community organisations

2.10 There are many specialist and generalist sources of information and advice available within Sure Start programmes and wider. There is also a substantial number of voluntary organisations, operating on a local, regional or national basis, that can be of direct help to families caring for children with special needs or a disability. Their services include:

- national helplines
- one-to-one contact with other families

- parent support groups, usually with a UK-wide membership
- information on particular conditions affecting children
- specialist knowledge of and contacts with minority ethnic communities and other minority groups.

A number of voluntary organisations are listed in Annex B and further specialist groups are listed in the *Special Educational Needs Guide for Parents and Carers* or can be accessed via Contact a Family.

The National Deaf Children's Society Language Aide Schemes

The NDCS is an organisation of families, parents and carers that exists to enable deaf children and young people to make the most of their skills and abilities. It provides practical support, advice, information and technology services directly to the families and children that need it, helping them see beyond the challenges of deafness and enabling them to maximise their skills and abilities.

The Essex Language Aide Scheme (including Thurrock and Southend) and the Hampshire Family Communication Service (including Portsmouth and Southampton) exist to provide communication support to families with a deaf child/children.

Through a series of weekly home visits from a local deaf adult, families can benefit from:

- communication support, including basic signing skills
- insight into deafness and deaf awareness
- regular contact at home from a skilled deaf adult role model
- access to local and national advice and support
- support complementary to that already received from local services
- emphasis on support during evenings and weekends to involve all the family.

Families supporting each other

2.11 Families rely on an informal support network provided by friends and extended family and it is important for Sure Start programmes to adopt a positive and inclusive approach towards family members and 'significant others'. 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. Sure Start programmes 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 (0808 808 3555, Monday-Friday, 10am-4pm) should be given to every family identified with a child who has a special need or disability.



Case Study

Caring for young children, although at times very rewarding, can also be very stressful and these stresses increase when caring for a child with special needs. Nikki identifies some of those stresses when she talks about the isolation she felt when she first gave up her job to become a full time mother to Louis. Friends that she relied upon in the past visited initially but soon reduced their visits due to their own work and family commitments. Nikki knew that she had to change her way of life and so she made contact with other parents at Byker Sands Family Centre where she was able to participate in Sure Start activities.

Nikki began by joining the Baby Social Group which meets once each week on a Thursday afternoon. This activity allows parents with children under one year old to meet for social opportunities. Parents and children are provided with stimulating age appropriate toys and parents are encouraged to play with their children whilst socialising and offering support. Parents also have access to a Health Visitor drop in session alongside the Baby Social Group where they can have their babies weighed and seek appropriate health care advice. Nikki found this group a valuable resource which provided Louis with the opportunity to be with other children and offered Nikki the support of their mothers.

3 Working together

3.1 Families with very young children receive help from a number of different agencies. Where special needs or disability are 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 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 that 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 isolation³

3 *Together from The Start* consultation paper.

Different ways of achieving co-ordination

- 3.2 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.

Promoting Speech and Language Development

There are many models of practice for joint working between childcare providers and speech and language therapists. *Sure Start's Promoting Speech and Language Development* guidance sets out a framework for encouraging children's language development within Sure Start programmes. The issues discussed in this guidance will be helpful to those planning and delivering services within Sure Start communities.

Copies can be obtained by e-mail: dfes@prolog.uk.com or telephone: 0845 60 222 60.

A Parent's Comment

"Parents still spend a good deal of their already busy lives just fighting for services, filling in endless forms, waiting for appointments, fundraising for equipment and struggling for their children's rights. As well as being parents, we also have to be unpaid project managers."

Sure Start is committed to creating an inclusive society, a society where every individual has a chance to give and receive support.

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

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

Sure Start Euston working together

The local agencies seconding staff to the Euston Home Visiting Team are:

- Camden Family Service Unit (Somali cultural expertise)
- Hopscotch Asian Women's Centre (Bangladeshi cultural expertise)
- KIDS (disability and special needs)
- Parents & Co (home visiting and group work)
- Camden and Islington Community Health Services NHS Trust (co-ordination with health visiting)
- Camden Council Housing Department (links to repairs, re-housing service and the homeless person's unit)
- Camden Social Services (social needs and child protection, links to services for children in need)
- Camden Local Education Authority (early learning and preparation for education).

Camden LEA holds the budget, employs the office staff and supports the programme in other practical ways. The Sure Start Euston Partnership leads the programme, bringing together representatives from the voluntary and statutory sectors as well as parents.

EYDCPs are currently required to establish a network of Area Special Educational Needs Co-ordinators (SENCOs) by 2004. Area SENCOs will provide day-to-day support for SENCOs based 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 PCT. Although this provision is aimed at children over 2 as they move into funded early education, Sure Start programmes should be aware of this guidance and its suggestions for joined-up good practice in order to maintain and develop the links already established.

The importance of early identification is further reinforced by the *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 support to families who have children with special needs or disabilities. 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 Framework's Practice Guidance (published separately from the Framework, Department of Health, 2000) focuses specifically on children with disabilities and considers how the Assessment Framework can be used to address the needs of children with disabilities and their families.

The keyworker

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

A keyworker is both a source of support for the families of children with special needs or disabilities and a link by which other services are accessed and used effectively. They have responsibility for working together with the family and the 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.

3.4 Effective use of keyworkers in Sure Start programmes and elsewhere is a vitally important means of improving standards. All children with disabilities or special needs and their families should be allocated a keyworker who works in partnership with them, with the function of co-ordinating service provision and providing a clear point of reference for the family.

A keyworker is a named individual whom parents can approach for advice about any problem relating to their child. Sure Start programmes should appoint keyworkers to provide:

- a single point of reference for information
- co-ordination and help in identifying the needs of the child and family
- a regular review of support arrangements so that the child's needs are properly met
- regular, long term contact and continuity of support
- a means of coordinating support from different agencies
- personal support, sensitive to needs and family circumstances.

The keyworker should be identified early. Parents should have an understanding of the keyworker role, and should be given the opportunity to suggest which professional they would like as their keyworker. Where it is not considered possible or appropriate for the parent's suggestion to be acted upon, the reasons should be discussed with the parent. Parents usually welcome the opportunity to build up a relationship with a keyworker over a period of time.

Who should be the keyworker?

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

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

A Parent's Comment

"It's not just a matter of giving information, there needs to be a facilitating process... it needs some human input there... you are in a very delicate area so I think it needs to be one person as far as possible... it'd be some kind of keyworker or facilitator... or advocate."

The quality of the relationship between the family and the keyworker will play an important part in determining the success of the package of support provided to the family. Parents should be given the opportunity to request a change of keyworker if the relationship becomes significantly strained. Arrangements should be put in place to support and supervise the keyworker so that any concerns about relationships or other matters can be promptly addressed.

A Parent's Comment

"The next two years were spent doing the rounds of specialists and doctors; being visited by many people offering help and support; joining various groups to absorb as much information as possible; and becoming familiar with words such as statement, assessment, special needs, ed. psych. and disability. Did my son really fall into that category? It was also a time I did a lot of crying, a time for adjustment and acceptance, not unlike bereavement."

The Family Service Plan⁴

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

- define the nature of the child's special need or 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
- 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 keyworker.

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.

4 *Together from The Start* consultation paper.



Sure Start Battersea

Sure Start Battersea is working with local nurseries to inform and support their work with children who have special needs or disabilities. The Sure Start teacher and special needs worker held an information session about the *SEN Code of Practice* and the role of the nursery SENCO. Nurseries that would like more support are able to call upon the Sure Start teacher who goes out and works with them in the nursery setting.

4 Getting financial help

4.1 Families caring for children with special needs or disabilities may have extra costs to meet as a result. Parents need to be aware of their statutory entitlements and also of discretionary grants that may be made available by charitable trusts. The level of individual benefits available to parents vary with family circumstances. Local Citizens Advice Bureaux, Social Security offices, welfare rights advisers or disability advice service can give advice on these issues, but here are some examples of the financial support available.

Disability Living Allowance (DLA)

4.2 This benefit is divided into two parts – a *Care Component* and a *Mobility Component* – and each of these is payable at different levels according to the child's need for assistance. Parents can apply if the child is over 3 months old and has extra care needs or from birth if they have a life-limiting condition. Children who have difficulty walking can get the mobility component from 3 years or from 5 years if they can walk but need guidance or supervision when outdoors.

For a more detailed description, please see the Contact a Family publication *Benefits for Disabled Children and Their Families* referred to in Annex B.

Income Support

4.3 Income Support may be available to parents who are working fewer than 16 hours per week, are on low incomes and have few savings. Parents receiving Income Support payments may also be eligible for a grant, loan or maternity grant from the Social Fund. Other potential benefits are Housing Benefit and Council Tax Benefit; Council Tax disability reduction; Working Families Tax Credit; and Invalid Care Allowance and Carer Premium. Several of these benefits work together. Savings are usually taken into account and the application forms can be complex. For these reasons, families often need advice from an independent experienced person or organisation.

For further details, contact your local Social Security office or the advisers listed in paragraph 4.1 above.

Getting Advice

A father of a 3 year old with Cerebral Palsy contacts you for advice. He also has 3 other children and getting around is becoming increasingly difficult because of his son's severe mobility difficulties. They receive Disability Living Allowance Mobility Component at the highest rate and the father has heard that he could use this to buy a car through the Motability Scheme (see Annex B). However, he has not yet learned to drive and needs some financial help with driving lessons but isn't certain where he can look for this help. One suggestion you might make is to contact the Family Fund Trust who can offer grants to families who have severely disabled children for a range of sources of help including driving lessons for parents.

The Family Fund Trust

4.4 The Family Fund Trust is an important provider of grants to parents of children with severe disabilities. The Trust can also help parents access a range of practical assistance such as grants for holidays or household equipment such as washing machines, bedding or floor coverings. The Trust's own family visitors can advise on grant applications and provide a range of advice and information on other helpful services. The Trust publishes a range of leaflets and other printed information that will be useful to Sure Start programmes and to parents. Details of the Trust's grant giving and information services are given in Annex B.

There are a number of other charitable trusts that give financial and other help to families caring for disabled children (Annex B lists these sources).



Disabled Facilities Grants

- 4.5 Parents who are planning to adapt their home to meet the needs of a disabled child should get information from the local authority on how to apply for a Disabled Facilities Grant that can help meet the costs of adaptations. Parents may need independent advice when making an application.

Additional help

- 4.6 Benefit forms and regulations can be difficult to understand and respond to, particularly if English is not a parent's first language. Material may be available in different languages from the local authority, NHS Trusts, Primary Care Trusts or voluntary bodies. A service is also available from Language Line (see Annex B).

A Disability Rights Handbook is published annually by the Disability Alliance. The Handbook contains a helpful chapter on benefits for disabled children.

Advising Parents

Sure Start staff may advise parents, whose applications on behalf of children are being considered by benefits agencies, in the following ways:

- Parents should be advised to provide as much information about their child as possible. The people reading the application form may not have come across this child's condition before and may not be aware of its impact on the child's care and mobility needs.
- If parents have additional information from a doctor, health visitor or other professional, it should be attached to the form. It may give extra support to the parent's claim.
- Parents should be advised to describe their child's condition as clearly as possible. This will give the agency an idea of the level of care, supervision and attention that the child needs.
- If appropriate, Sure Start staff should help parents complete the forms.

5 Protection of children with special needs or disabilities

5.1 All Sure Start programmes must have an appropriate child protection policy. The *Planning and delivering Sure Start* pack contains advice to enable them to develop a code of good practice on protecting children from harm. This covers:

- the legal framework
- principles of child protection
- development of a public Child Protection Statement
- safe recruitment procedures
- safe services that are properly supervised and how to deal with allegations of abuse.

Any Sure Start child protection policy must fully cover children with disabilities or special needs. This section gives pointers to additional guidance on the issues that need to be considered. However, it should be read in conjunction with the existing guidance and discussed with the local Area Child Protection Committee and social services department.

5.2 It is often necessary to strike a balance between the need for some appropriate extra protection for children with disabilities or special needs and their need to explore, experiment and take risks. It is advisable to discuss with a child's parents his or her usual boundaries of risk-taking, favourite activities and any special equipment that can assist his or her full involvement in play and other activities.

5.3 There is evidence that children with special needs or disabilities have in the past been more vulnerable to abuse than other children. Some children with special needs or disabilities may receive intimate care from larger numbers of people; have an impaired capacity to resist abuse; find it difficult to tell others what is happening; or be more likely to be bullied and intimidated.

- 5.4 There is a two-fold approach to be considered. Firstly, programmes should ensure that they have access to appropriate levels of supervision and relevant specialist advice. For example, children with communication difficulties need good levels of supervision and care. This may have implications for staffing and volunteer ratios. The provision of signers and facilitators can also be very helpful. Similarly, it may be necessary to obtain paediatric nursing advice when, for example, children who have one of the brittle bone conditions or conditions such as epilepsy are involved in programme activities.
- 5.5 Secondly, programmes should ensure that they devise a pro-active strategy to give children and parents with special needs or disabilities maximum access to local services and activities in a safe manner. The need for accessible environments should be considered and toys and equipment should be planned with child safety in mind. Consultation with parents, including parents and other adults with disabilities or special needs, can produce valuable insights on safe environments for children with disabilities or special needs.
- 5.6 Sure Start programmes will wish to ensure that staff and volunteers who may be required to lift children have good training in handling techniques and the use of any necessary equipment. By this means, it should be possible to ensure that children who need help are not excluded from communal activities and events.
- 5.7 Sure Start programmes will also wish to ensure that the employer has risk assessment and risk management policies in place and that the control measures required for managing the risk are clearly understood by all staff. These policies will address a range of issues, including behaviour management; the use of appropriate restraint; lifting and handling of children; administration of medicine and therapeutic procedures.
- 5.8 The administration of medicines and therapies or other care procedures require careful attention. If children with complex special needs or disabilities are included in programme activities, then the policy should include specific and clear protocols for the management of any invasive care or treatment. Staff administering medication must receive appropriate training and may wish to consult relevant local health care professionals to clarify best practice and appropriate procedures.



Good practice checklist

for *Sure Start* programmes working with families who have children with special needs and disabilities

- 1** Children with special needs or a disability are children first and need the same opportunities as other children for growth and development.
- 2** Sure Start services and activities should be welcoming to parents and be able to meet the needs of all children including those with special needs or a disability.
- 3** Caring for children with special needs or a disability in partnership with parents is the key to success. Parents are the experts on their child and will have a great deal of information to share.
- 4** Parents may have had difficulty in accessing vital information. Always try to refer parents to other sources of help.
- 5** Disability Equality Training should be provided to enable staff and volunteers to gain skills in working with children with a broad range of abilities.
- 6** Materials and activities should promote equality of opportunity and show positive roles for children of all ethnic and cultural backgrounds, of both sexes and with or without special needs or a disability.
- 7** Information provided for parents should be sensitive to cultural diversities, special needs, disability and life experiences.
- 8** Additional efforts may be needed to reach families caring for children with special needs or a disability in certain situations: for example, in high-rise flats or in isolated rural locations.
- 9** Parents and Sure Start staff must keep each other up-to-date on what is happening with the child and to record any key developments.
- 10** Where possible, a key member of staff should be appointed for each child to provide a co-ordinated service.



- 11** Listen to parents. Some parents feel isolated when they find out their child has special needs or a disability and need to feel that their concerns and worries are heard.
- 12** Targeted consultation with parents who have children with special needs or a disability is vital to find out what they want and need for their children.
- 13** Some services for children with special needs or a disability will be found outside the Sure Start neighbourhood. The development of good local, regional and national information connections is essential. For example, Special Educational Needs Co-ordinators (SENCOs) or SEN Advisory Services may be contacted through your local education authority and a range of specialist organisations can be contacted through the agencies listed in Annex B.
- 14** When a child has special needs or a disability it can have an effect on the whole family. Brothers, sisters, grandparents, aunts and uncles may all have a caring role to play in the child's life.

- 15** Families often have contact with a wide number of professional workers if their child has special needs or a disability. Families need professionals to work closely together and to communicate clearly with each other. Sure Start staff may take on the role of care co-ordination for some families.
- 16** Advice should be sought on the design and equipment of buildings and services (such as play facilities and transport) to ensure that children with special needs or a disability and their families have full access to all Sure Start facilities and services.
- 17** Each Sure Start programme must develop its own child protection policy. Staff training on child protection is recommended where there are children with communication and learning difficulties.
- 18** Health and safety procedures should be regularly reviewed around the needs of children with special needs or a disability. Providers of children's services should have clear policies and procedures for risk assessment and risk management e.g. lifting and handling of children.



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Annex A

Glossary of commonly used terms

- **Antenatal screening:** is undertaken for a number of conditions in the mother and unborn baby. For conditions in the mother, treatment is available during the antenatal period to improve her health and indirectly that of the baby. For conditions in the baby, the screening test gives mothers information about their babies and pregnancy.
- **Child Development Centre (CDC):** a centre housing various professionals such as educational psychologists, speech therapists, occupational therapists and teachers. Children are often referred to these centres when their needs are being assessed. Many of the centres house play groups and nurseries and include some element of parental support.
- **Disability Living Allowance (DLA):** a welfare benefit some families may be entitled to (see page 30 for more information).
- **Inclusion:** a process by which services develop their cultures, policies and practices to include all children i.e. nurseries, playgroups, drop-ins and pre-schools welcome and can meet the needs of all children including those with special needs.
- **Independent parental supporters (IPSS):** offer parents independent information and advice about special needs. Contact your LEA for details.
- **Keyworker:** a named individual whom parents can approach for advice about any problem relating to their child with special needs or a disability.
- **Local Education Authority (LEA):** a local government body responsible for providing education and for making statutory assessments of children with special educational needs and maintaining statements of special educational needs.
- **Parent partnership services:** provide advice and information to parents of children with special educational needs and guide parents through education services.
- **Special educational needs co-ordinator (SENCO):** a member of staff at an early years setting or school who is responsible for co-ordinating the special needs provision within the setting.
- **Statement (of special educational needs):** a document that sets out a child's needs and specifies the extra help she/he should get.

Initiatives and programmes that support families and children with special needs and disabilities.

- **Code of Practice for Schools issued by the Disability Rights Commission** (September 2002). Explains the new duties to prevent disability discrimination in education as set out in Part 4 of the Disability Discrimination Act 1995 and covers all education services in maintained, voluntary and independent schools. This Code of Practice will be accompanied by practical guidance. This Code states that if a parent believes that their child has been discriminated against in any school, including nursery schools, they may make a claim on behalf of the child to the SEN and Disability Tribunal. Conciliation procedures are available through the Disability Rights Commission in advance of Tribunal hearings.

Note: There are many private, voluntary and statutory providers of early years services that are not constituted as schools. The social care of young children in these settings has been covered by Part 3 of the Disability Discrimination Act 1995 since 1996. From September 2002, the education that is offered in these settings is also covered by the duties in Part 3 of the Act. If an early years establishment provides education

and day-care for children, all of these services will be covered by the provision set out in Part 3 of the Disability Discrimination Act 1995. All early years providers will therefore have a duty not to discriminate against disabled pupils in both day-care or other services provided within their provision.

- **Framework for the Assessment of Children in Need and their Families** is a key element of the Quality Protects initiative. It provides guidance on the assessments of the needs of children and families. The multi-dimensional Framework outlines children's developmental needs including health, education, emotional and behavioural development and family and environmental factors.
- **Inclusive Schooling (2001)**¹ is statutory guidance from the Department for Education and Skills on the development of inclusive education services for children with special educational needs. It should be read alongside the two Codes of Practice (see first and last items in this section).
- **National Service Framework for Children** The Department of Health is developing the Children's National Service Framework for the NHS during 2002/03. One area that the Framework will focus on is the needs of children with special needs or disabilities.

¹ DfES, reference 0774/2001, DfES Publications, PO Box 5050, Sherwood Park, Annesley, Notts. NG15 0DJ (Tel 0845 60 222 60) and from DfES website: www.dfes.gov.uk/sen.

- **Quality Protects (QP)** requires local authorities to submit action plans on their services for children. One of the main objectives of QP is to 'ensure that children with specific social needs arising out of disability or a health condition are living in families or other appropriate settings in the community where their assessed needs are adequately met and reviewed'.

- **SEN Guide for Parents and Carers**² gives the main points of the Code of Practice, explains procedures and tells parents their rights. It also lists the relevant voluntary agencies and contact numbers for LEA parent partnership services.

- **Special Educational Needs Code of Practice (SEN) plus the related SEN Toolkit 2001**³. The Code and SEN Toolkit provide practical advice on the identification, assessment and provision for children and young people with special educational needs. It includes a section on early years education. Providers of government funded early education must have regard to this Code and they cannot ignore it. If they depart from it in any way they must have good reason for doing so and be able to show that their actions provide an equally good deal for the child.

2 Available from DfES Publications, (as above).

3 Available from DfES Publications, (as above).

Annex B

Useful organisations

- **ACE, Advisory Centre for Education**
1c Aberdeen Studios
22 Highbury Grove
London N5 2DQ
Advice Line: 0808 800 5793
(Monday to Friday, 2-5pm)
Tel: 020 7354 8318
www.ace-ed.org.uk
Offers guidance and advice on all aspects of state education.
- **Action for Leisure**
C/o Warwickshire College
Moreton Morrell
Warwick CV35 9BL
Tel: 01926 650 195
www.actionforleisure.org.uk
Provides information on play, leisure and recreation for children, young people and adults with special needs or disabilities.
- **Child Bereavement Trust**
Aston House
High Street
West Wycombe
High Wycombe HP14 3AG
Tel: 01494 446 648
www.childbereavement.org.uk
Provides specialised training and support for professionals to improve their response to the needs of bereaved families.
- **Children's Legal Centre**
University of Essex
Wivenhoe Park
Colchester CO4 3SQ
Advice Line: 01206 873 820
(Mon to Fri, 10am-12.30pm & 2-4.30pm)
Tel: 01206 872 466
www.childrenslegalcentre.com
Offers free advice and information on law affecting children and young people.
- **Contact a Family**
209-211 City Road
London EC1V 1JN
Helpline: 0808 808 3555
(Mon-Fri, 10am-4pm)
Tel: 020 7608 8700
www.cafamily.org.uk
Supports families caring for children with any disability, chronic illness, special need or rare condition. The Helpline is a national free telephone service offering information, advice and support to parents and carers. Contact a Family has a database of organisations, support groups and networks relating to specific and rare conditions, if you would like to make contact with a relevant group please contact the Helpline.

Contact a Family produces a range of useful publications:

- *A Genetic Condition in the Family.*
- *A Guide to Assessments and Services in England.*
- *Fathers.*
- *An introduction to benefits and other financial help.*
- *Benefits for disabled children and their families*
- *Holidays.*
- *A Parents Guide to Statements of SEN in England and Wales.*
- *Siblings and Special Needs.*
- *Caring for Children with Disabilities and Special Needs – A Guide for Students and Professional Workers.*
- *Living without a diagnosis.*
- *Transition.*
- *Grandparents.*
- *The Directory of Specific Conditions and Rare Disorders.*
- *When Your Child Has Special Needs – A guide for parents who care for a child with a disability, special need or rare disorder.*

- **Council for Disabled Children**
C/O National Children's Bureau
8 Wakley Street
London
EC1V 7QE
Tel: 020 7843 1900
E-mail: cdc@ncb.org.uk
www.ncb.org/cdc
The council provides a national forum for the discussion, development and dissemination of a wide range of policy and practice, issues relating to service provision and support for

children and young people with disabilities and special educational needs. Their membership is drawn from a wide range of professional, voluntary and statutory organisations, which includes parent representatives and representatives of disabled people, ensuring that they have a good balance of interests and expertise.

- **Daycare Trust**
21 St. George's Road
London SE1 6ES
Helpline: 020 7840 3350
(Mon-Fri, 10am-5pm)
www.daycaretrust.org.uk
Provides information and advice for parents, childcare providers, employers, trade unions and policymakers on childcare.
- **Disabled Parents Network**
National Centre
for Disabled Parents
Unit F9, 89-93 Fonthill Road
London N4 3JH
Tel: 0870 241 0450
E-mail:
info@disabledparentsnetwork.org.uk
A national network of disabled parents helping one another and bringing about change.
- **Disability Alliance**
Universal House
88-94 Wentworth Street
London E1 7SA
Rights Advice Line: 0117 247 8763
(Mon-Wed, 2pm to 4pm)
Tel: 020 7247 8776
www.disabilityalliance.org
Provides information and advice on benefits and helps with filling in claim forms.

- **Disability Pregnancy & Parenthood International (DPPI)**
 c/o the National Centre for Disabled Parents.
 Unit F9, 89-93 Fonthill Road
 London N4 3JH
 Helpline: 0800 018 4730
 (Mon-Thur, 10-5)
 Tel: 020 7263 3088
<http://freespace.virgin.net/disabled.parents>
 Promotes the networking of experience on all aspects of disability, pregnancy and parenthood.
- **Disabled Living Foundation**
 380-384 Harrow Road
 London W9 2HU
 Helpline: 0845 130 9177
 (Mon to Fri, 10-4)
 Tel: 020 7289 6111
www.dlf.org.uk
 Provides information about aids and equipment.
- **Enuresis Resource & Information Centre**
 34 Old School House
 Britannia Road
 Kingswood
 Bristol BS15 8DB
 Helpline: 0117 960 3060
 (Mon-Fri, 10am-4pm)
www.eric.org.uk
 Gives advice on incontinence in both adults and children.
- **Family Fund Trust**
 PO Box 50
 York YO1 9ZX
 Tel: 01904 621115
www.familyfundtrust.org.uk
 Provides financial help for families looking after severely disabled children under 16. Publishes information leaflets on many aspects of caring.
- **Gingerbread**
 First floor, 7 Sovereign Close
 London E1W 3HW
 Helpline: 0800 018 4318
 (Monday, 10am - 7pm,
 Tues-Friday, 10am - 4pm)
 Tel: 020 7488 9300
www.gingerbread.org.uk
 Puts people in touch with local support and self-help groups for lone parents.
- **Holiday Care**
 2nd Floor, Imperial Buildings
 Victoria Road
 Horley
 Surrey RH6 7PZ
 Information line: 01293 774 535
 (Mon & Tues, 9-5, Wed,
 Thurs & Fri, 9am-1pm)
 Tel: 01293 771500
www.holidaycare.org.uk
 Provides information about all types of holidays for people with special needs: family holidays, group holidays, activity holidays and holidays for unaccompanied children and young adults. They do not offer financial support, nor organise holidays, but do run a Reservation Service for accessible accommodation in the UK.

- **Home-Start UK**
 2 Salisbury Road
 Leicester LE1 7QR
 Tel: 0116 233 9955
www.home-start.org.uk
 Supports and gives guidance for families in their own homes. They can offer the support of one volunteer parent to another parent who is facing difficulties and has at least one child under five.
- **Kidsactive**
 Pryors Bank, Bishops Park
 London SW6 3LA
 Information Line: 020 7731 1435
 Tel: 020 7736 4443
www.kidsactive.org.uk
 Offers a National Information Service with advice and resources on all aspects of play.
- **Language Line**
 11-21 Northdown Street
 London N1 9BN
 Tel: 020 7520 1430
 Telephone interpreting: 0845 310 9900
 E-mail: info@languageline.co.uk
www.languageline.co.uk
 Puts professional interpreters on the phone (covers over 100 languages).
- **Motability**
 Goodman House
 Station Approach
 Harlow CM20 2ET
 Helpline: 01279 635 666
 Tel: 01279 635 999
www.motability.co.uk
 Helps people with disabilities in receipt of Mobility Allowance to obtain new cars on lease or hire purchase, or used cars and Electric Wheelchairs on hire purchase.
- **National Children's Bureau**
 8 Wakley Street
 London EC1V 7QE
 Tel: 020 7843 6000
www.ncb.org.uk
 A national inter-disciplinary representative body concerned with all aspects of the welfare of children and young people. Among its many interests are child development and children with disabilities. The Council for Disabled Children comes under its umbrella.
- **The National Early Years Network**
 77 Holloway Road
 London N7 8JZ
 Tel: 020 7607 9573
 Supports early years practitioners and those who manage them.
- **National Portage Association**
 127 Monks Dale
 Yeovil BA21 3JE
 Tel: 01935 471 641
www.portage.org.uk
 Provides home learning schemes for pre-school children.

- **Network 81**
 1-7 Woodfield Terrace
 Stanstead
 Essex CM24 8AJ
 Helpline: 0870 770 3306
 (Mon-Fri, 10-2pm)
 Tel: 0870 770 3262
www.network81.co.uk
 Gives information, guidance, help and advice on the Education Act and other procedures concerned with special educational provision and training.
- **Parentline Plus**
 Highgate Studios
 53-79 Highgate Road
 London NW5 1TL
 Tel: 020 7284 5500
 Helpline: 0808 800 2222
www.parentlineplus.org.uk
 Aims to provide Education for Parenthood by establishing a national network of parent support groups.
- **Parents at Work**
 Murray House
 Fifth Floor, 45 Beech Street
 London EC2Y 8AD
 Tel: 020 7628 3565
 Children with disabilities Project
 Special Needs Helpline:
 020 7588 0802
 (Wed-Fri, 2pm-4.30pm)
www.parentsatwork.org.uk
 Offers information and advice to working parents.
- **Parents for Inclusion**
 Unit 2, Ground Floor
 70 South Lambeth Road
 London SW8 1RL
 Helpline: 020 7582 5008
 (10-12 Tuesdays,
 Wednesdays and Thursdays)
 Tel: 020 7735 7735
www.parentsforinclusion.org
 Promotes the rights of disabled children to attend their local mainstream school.
- **Pre-school Learning Alliance**
 69 Kings Cross Road
 London WC1X 9LL
 Tel: 020 7833 0991
www.pre-school.org.uk
 Provides information about playgroups for under 5s. Contact their Special Needs Officer.
- **SCOPE**
 6 Market Road
 London N7 9PW
 Cerebral palsy helpline:
 0808 800 3333
 E-mail: cphelpline@scope.org.uk
www.scope.org.uk
 A disability organisation for people with cerebral palsy.
- **TAMBA Special Needs Group**
 Harnott House
 309 Chester Road
 Little Sutton
 Ellesmere Port CH66 1QQ
 Helpline: 01732 868 000
 (7-11pm weekdays &
 10am-11pm Sat/Sun)
 Tel: 0870 121 4000
www.tamba.org.uk
 Helps families who have twins with special needs.

Annex C

Key References and Resources

This short list of references is intended to give Sure Start staff an indication of some important publications and resources that you may wish to consider for inclusion in your own library or resource bank. It is not intended to be comprehensive but Contact a Family supplies a substantial bibliography with the assistance of the Library and Information Service of the National Children's Bureau. It is available through Contact a Family's website at www.cafamily.org.uk.

- *All together: how to create inclusive services for disabled children and their families.* Dickins, M and Denizloe, J, The National Early Years Network 1998.
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- *Disability Rights Handbook,* Disability Alliance. New edition produced each year.
- *Inclusive Schooling,* DfES 2001.
- *Inspecting for Excellence: guidance for inspecting for equality in early years settings.* Early Years Trainers Anti Racist Network, 1999.
- *Learning Disabilities and the Family – the young child with a learning disability.* The Mental Health Foundation, 1997.
- *Making Portage Work: proceedings of the National Portage Conference.* National Portage Association, 1997.
- *SEN Guide for Parents and Carers,* DfES 2001.

- *SEN Toolkit*, DfES 2001.
- *Share an Idea: quarterly magazine for parents caring for disabled children.*
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- *Special Educational Needs Code of Practice*, DfES 2001.
- *Special needs in the early years: snapshots of practice.*
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- *Taking Care.* Cowen A,
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- *The Contact a Family Directory of Specific Conditions and Rare Disorders.* Contact a Family,
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- *The High/Scope programme for children with special needs (0-3 years).* Hopkins P, High/Scope
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- *The Voluntary Agencies Directory.*
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- *Together from The Start.*
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and Skills. Consultation
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due course.
- *Valuing People: a new strategy for learning disability for the 21st century.* Department of Health,
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Also available are versions on
tape and CD ROM.
- *What works in services for families with a disabled child?*
Bryony Beresford et al.
Barnardos, 1996.
- *When Your Child Has Special Needs,* Contact a Family 2002.
- *Working Together to Safeguard Children: a guide to inter-agency working to safeguard and promote the welfare of children.*
Department of Health,
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Employment, 2000.

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