

Reaching out

Local authorities now have statutory responsibilities towards deafblind children arising from the guidance "Social Care for Deafblind Children and Adults" LAC 2001(8).

They are required to provide specialist assessments, appropriate information and services designed to meet the needs of deafblind people. This toolkit explains how to put this guidance into action for children.

About Sense

Sense is a national membership organisation working with, and campaigning for, people who are deafblind, their families, carers and the professionals who work with them. People of all ages and with widely varying conditions use Sense's specialist services. These include family centres offering specialist assessments and support to deafblind children and their families, intervenor schemes, activity breaks and a network of branches across the country that support families.

Sense would like to thank the Department for Education and Skills (DfES) for providing the funding to produce this toolkit.

Researched and written by Gerda Loosemore-Reppen

Sense
11-13 Clifton Terrace
Finsbury Park,
London
N4 3SR

- tel 020 7272 7774
- fax 020 7272 6012
- text 020 7272 9648
- enquiries@sense.org.uk
- www.sense.org.uk

Patron: HRH The Princess Royal
Charity no: 289868



reaching out

A toolkit for deafblind children's services



Many deafblind children and young people are living lives that are much more restricted than they need be. They're missing out on opportunities to learn about the world around them, to grow in confidence and to join in the life of the community. The very nature of deafblindness is isolating, but these children are even more isolated from the world they live in because so much of it is inaccessible to them. But it doesn't have to be like this. If the right services and opportunities are available then their life experience can be greatly enhanced.

Local authorities now have statutory responsibilities towards deafblind children arising from the guidance "Social Care for Deafblind Children and Adults" LAC 2001(8). They are required to provide specialist assessments, appropriate information and services designed to meet the needs of deafblind people. This toolkit explains how to put this guidance into action for children.

Contents

The deafblind guidance for children	4
What does it say? Who is it for?	
What is deafblindness?	7
How should the guidance be implemented?	
Identifying and assessing deafblind children	10
Surveys to identify deafblind children How should the assessment be carried out?	
Services	17
Importance of one-to-one support Intervenors Communicator guides Other support Support for families Short breaks and holidays Home help Direct payments	
Co-ordination	21
Key workers Early support family service planning Transition arrangements Accessible information	
Resources	26
Self-assessment checklist References Useful organisations	



The deafblind guidance for children



This toolkit has been produced to highlight children's services statutory responsibilities arising from the guidance "Social Care for Deafblind Children and Adults" LAC 2001(8).

In 2002 and 2003 Sense carried out surveys of how local authorities were implementing the new provisions. It found that local authorities had not grasped the implications for children clearly enough – often because lead responsibility for deafblind people was allocated to a senior manager in the adults division, usually someone in charge of services for disabled people. This toolkit explains the implications for children's services and provides practical advice on what steps can be taken to implement the guidance.

This toolkit explains the importance of social care services to the well-being of deafblind children and their families and to their social needs outside school.

In the future, many services will be provided by Children's Trusts or joint Children's Departments composed from Local Education Authorities and Children's Social Services departments, sometimes additionally through a joint agency arrangement with the Primary Care Trust. This toolkit is timely and will coincide with the National Service Framework for Children, Young People and Maternity Services. The responsibilities of teachers and others in regard to children with special educational needs (SEN) are laid down in primary legislation (SENDA, 2001) and the accompanying Code of Practice on the Identification and Assessment of Pupils with Special Educational Needs (2001). These relate to learning and access to formal education.

Given the slow and limited implementation of the guidance in children's services and the low incidence of deafblindness in children across the country, there are few examples of positive practice. However, some authorities have interpreted the guidance creatively and developed services which meet the needs of children and their families. These examples are described.

This material focuses on the role of managers in children's services in councils with social services responsibilities, but it may also be of value to health visitors, paediatric staff, support teachers and early years service providers working in partnership with social workers. Some resources for further reference are also appended.



What does the guidance say?

The guidance provides a statutory framework for all social services for deafblind people. It outlines the rights of deafblind people and the duties placed on local authorities.

Local authorities must

- **identify**, make contact with, and keep a record of deafblind people in their catchment area – including those who have multiple disabilities that include dual sensory impairment;

In addition local authorities must ensure that:

- an **assessment** is carried out by a specifically trained person/team, equipped to assess the needs of a deafblind person – in particular to assess the need for one-to-one human support, assistive technology and rehabilitation;
- **appropriate services** are provided to deafblind people, who are not necessarily able to benefit from mainstream services or those services aimed primarily at blind people or deaf people who are able to rely on their other senses;
- specifically trained, **one-to-one support workers** are available for those assessed as requiring one;
- **information** about services is provided in formats and using methods that are accessible to deafblind people;
- one member of **senior management** includes in his responsibilities overall responsibility for deafblind services.

The guidance and its duties are **mandatory**. Failure to comply could result in a challenge through judicial review.

What is deafblindness?



Who is the guidance for?

This is statutory guidance for councils with social services responsibilities (CSSRs). With structural changes occurring locally and nationally in the context of the Children Bill and the creation of Children's Trusts responsibility for the implementation of the guidance will be firmly located within the remit of the new post of Director of Children's Services.

The implementation of the guidance requires partnership between all agencies and professionals working for and on behalf of deafblind children. Clear accountability and effective communication between the partners will assist a successful implementation process.

The Commission for Social Care Inspection (CSCI) will be reviewing compliance with the guidance as part of its regular inspection function.



Deafblindness is a low incidence condition and is particularly rare in children. It is estimated that there are 3 deafblind children in every 10 000. The guidance says that "persons are regarded as deafblind if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility". People do not have to be completely deaf and blind. As with other conditions, deafblindness spans a continuum of need ranging from slight sensory impairment to severe/total dual sensory loss and to complex disabilities.

There is a distinction between **congenital deafblindness** and **acquired deafblindness**. Congenital deafblindness – a significant hearing and sight loss from birth or very early childhood – leads to a child finding it difficult or impossible to develop formal language. Acquired deafblindness occurs after the development of spoken or signed language. Children with hearing and visual impairments are often referred to as children with **MSI (multi sensory impairment)**.

There are a variety of causes of deafblindness amongst children. Some conditions, such as CHARGE for example, combine a range of sensory and physical disabilities that affect children with varying degrees of severity. To give another example, people affected by Usher syndrome, a genetic condition, will be deaf or hearing impaired from birth, but their vision will also deteriorate in their teens, so that they will effectively be deafblind by early adulthood.

There will be some young people with acquired deafblindness, through illness, such as Meningitis. And with increasing numbers of very premature babies surviving, there will be a greater number of children with a range of disabilities.

Deafblindness can be an additional disability for a child with complex needs, such as learning disabilities, medical needs and/or physical disabilities. For various reasons – including the difficulties involved in testing children with severe learning disabilities accurately – their additional sensory impairments often go unrecognised.

How does your authority measure up?

	Yes	No
● Allocation of lead responsibility for deafblind children at appropriate senior level.	<input type="checkbox"/>	<input type="checkbox"/>
● Communicating this role to relevant staff.	<input type="checkbox"/>	<input type="checkbox"/>
● Survey of local services in regard to deafblind children.	<input type="checkbox"/>	<input type="checkbox"/>
● Record of deafblind children.	<input type="checkbox"/>	<input type="checkbox"/>
● Service protocol for joint working and referral of deafblind children within statutory sector.	<input type="checkbox"/>	<input type="checkbox"/>
● Assessment procedures for deafblind children – with input from specialists as required.	<input type="checkbox"/>	<input type="checkbox"/>
● Budget for deafblind children's services, including provision of one-to-one support such as intervenors.	<input type="checkbox"/>	<input type="checkbox"/>
● Establishment of key working approaches.	<input type="checkbox"/>	<input type="checkbox"/>
● Information in accessible formats.	<input type="checkbox"/>	<input type="checkbox"/>
● Transition policies and agreements for deafblind young people.	<input type="checkbox"/>	<input type="checkbox"/>

What do deafblind children have in common?

Lack of useful hearing and/or vision from birth impacts considerably on a child's ability to acquire language, communication and independence skills. Deafblind children are acutely deprived of sensory information and accidental learning. This combined disability restricts the child's ability to make sense of the environment and will profoundly affect their ability to learn. Children with MSI may be very slow to learn to use their residual senses, because it is much harder to learn to understand, discriminate and use sensory information that is partial and/or distorted. This does not necessarily mean that these children have a cognitive impairment, but rather that it is a very slow process for them to learn to generalise from poor auditory and visual information and smell and touch.

The needs of children with MSI are usually complex and unique so that they require specialist assessments and extensive **individually tailored** support packages throughout their lives.

How should the guidance be implemented for deafblind children?

Different approaches have been used in different areas– depending to some extent on the pattern and structure of local service provision.

Given the small numbers of deafblind children in any area, careful thought will have to be given to how the legal requirements can be met best. In places where there are local experts on deafblindness this will be helpful in responding to the requirements of the guidance. It is unlikely that small unitary authorities can afford to set up a fully-fledged service by themselves, but they may find that joining neighbouring boroughs in collective provision could be a cost effective solution.

To ensure that this area of work is properly discharged a senior member of the children's services management team should be made responsible for the task of leading on the implementation of the guidance for deafblind children. This is likely to be at least a third tier officer with strategic responsibility for children with disabilities.



Given the likelihood of more deafblind children being identified earlier – due to the roll-out of the Newborn Hearing Screening Programme, authorities will be faced with the challenge of very young babies being identified and requiring support. The important thing is to have a process mapped out for the support of a deafblind child **before** this actually happens since delay in service provision can have serious implications for the well-being of the child and family.

Successful approaches could include:

- joint working with neighbouring authorities,
- regional partnerships,
- spot purchasing externally provided expert services when required, and
- having an agency arrangement with a voluntary agency.



Identifying and assessing deafblind children

How should identification, making contact, and record keeping be organised?

Again this will depend on the pattern of resources established at local level. If there is a local specialist on deafblindness it is likely that this worker will be central to these tasks.

Training in deafblindness for the frontline teams concerned with disabled children will help in raising the profile of dual sensory impairment.

Authorities should specifically review and adapt their existing working protocols for deafblind children and agree them between the agencies involved in providing health, social care and education services. Such protocols will clarify which agency or professional group is responsible for which services. This task could be carried out in the context of the Children’s Hearing Services Working Group (CHSWG), which is being established in all LEAs in response to the Newborn Hearing Screening Programme. CHSWGs tend to be in the forefront of developing joint working protocols and often become a resource for monitoring local services for hearing impaired children. Steps would need to be taken to ensure that these protocols are appropriate for children with a dual sensory impairment.

Surveys to identify deafblind children

Dedicated surveys have been found to yield good information on deafblind children. The key to a successful survey of deafblind children is a clear, shared definition of deafblindness.

In past surveys, the target group was usually defined as children with a single or dual sensory impairment plus a significant communication impairment. Several groups of children are distinguished, for eg:

- children with a significant visual impairment which cannot be corrected by the prescription of lenses and/or where there were concerns about their functional use of vision;
- children with a hearing impairment and/or concerns with their functional use of hearing;
- children with few or no formal communication skills (including speech, sign, writing or symbol use);
- children with few or no pre-formal communication skills (including gesture, vocalisation, no attempt to interact physically).

Checklist for identifying deafblind children

	Yes	No
● Have you adopted the definition of deafblindness within the guidance?	<input type="checkbox"/>	<input type="checkbox"/>
● Has this been accepted by:		
– colleagues from special educational needs	<input type="checkbox"/>	<input type="checkbox"/>
– paediatricians	<input type="checkbox"/>	<input type="checkbox"/>
– paediatric audiology	<input type="checkbox"/>	<input type="checkbox"/>
– support teachers for pupils with visual impairment	<input type="checkbox"/>	<input type="checkbox"/>
– teachers for the deaf	<input type="checkbox"/>	<input type="checkbox"/>
– teachers for children with multi sensory impairment	<input type="checkbox"/>	<input type="checkbox"/>
– health visitors	<input type="checkbox"/>	<input type="checkbox"/>
– physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>
– occupational therapy	<input type="checkbox"/>	<input type="checkbox"/>
– speech and language therapy and	<input type="checkbox"/>	<input type="checkbox"/>
– social workers for disabled children?	<input type="checkbox"/>	<input type="checkbox"/>
● Have you surveyed special needs nurseries and toddler groups?	<input type="checkbox"/>	<input type="checkbox"/>
● Have you agreed an exchange of information with paediatric development centres?	<input type="checkbox"/>	<input type="checkbox"/>
● Have you liaised with paediatric audiologists and with ophthalmologists?	<input type="checkbox"/>	<input type="checkbox"/>
● Have you contacted Health Visitors?	<input type="checkbox"/>	<input type="checkbox"/>
● Are you in touch with local support groups for parents of children with complex needs?	<input type="checkbox"/>	<input type="checkbox"/>
● Have you circulated all special schools?	<input type="checkbox"/>	<input type="checkbox"/>
● Have you searched the existing social services registers for deaf, visual impaired people and disabled children?	<input type="checkbox"/>	<input type="checkbox"/>

The survey should be distributed to:

- special schools
- child care development centres/teams
- children's centres, early excellence centres etc.
- special needs health visitors
- optometry services
- paediatricians
- children with disabilities social work teams
- audiology services
- ophthalmology services
- local voluntary support groups
- special needs teams in the LEA
- local branches of specialist voluntary organisations.

A simple questionnaire asking professionals to identify children who fit the definitions is all that is required. This is to gauge unmet need and to offer, if required, a specialist assessment.

The different statutory social services registers (deaf, visually impaired, disabled children) should be investigated and any overlap noted. With the advent of more powerful computerised database systems, a search for children with multiple needs should be made easier – likewise the maintenance of a deafblind children's database, as a sub set of the disabled children's register.

The DfES Early Support Pilot Programme (ESPP) has produced a wealth of well researched and presented materials on the processes of supporting children with disabilities aged 0–3 of benefit to families and professionals. (www.espp.org.uk) This programme is helping to improve local multi-agency approaches to disabled children.

How can you make sure that all deafblind children are known?

The key to identification is clear understanding of the definition of deafblindness in the guidance, effective working with partners, good recording practices and exchange of information between agencies. Authorities should have a policy of sharing information on children with medical and educational needs who are likely to be subject of multi agency assessment and service provision. Cross referral protocols between audiology, ophthalmology, social services, special education teams and paediatric clinics will be essential.

It is also important to identify and support those children whose primary disability is not seen as sensory impairment, but who are also deafblind. In particular it is vital that those who provide services for **children with learning disabilities** are targeted since deafblindness coincides frequently with forms of developmental delay. If this is not done it can mean that children with learning disabilities are excluded from receiving skilled support for their deafblindness and thus never fulfil their potential.

How should the assessment be carried out?

How should the assessment be carried out, bearing in mind that the deafblind guidance states that a specifically trained person/team should undertake it?

Although many different professionals will have a contribution to make, according to the guidance a trained person should take the lead in the assessment process. Training in deafblindness and a high level of specialist communication skills is required. Such expertise may be brought in from specialist agencies.

For example, most deafblind children have difficulties integrating sensory information. They get very tired when asked to cooperate in activities and require regular breaks to enable them to refocus on the tasks concerned. A deafblind specialist would be able to inject such knowledge into the multi disciplinary assessment, which would result in a more meaningful and accurate assessment.

The first stage of the assessment process is to gather information about the child's medical history, physical and social environment and abilities and disabilities. Families will know their child best and should be listened to. Their views on where the assessment should take place, which activities need to be examined and how the child should best be engaged should be respected. Parents' aspirations and fears should also be acknowledged. The ESPP materials include a family held file and much guidance for families on the role of the different agencies and professionals involved in assessment and services.

As the child grows assessments will need to be reviewed and updated so that age appropriate goals can be formulated and progress toward them charted.

At transition stage – when a child moves into adult services – inputs from deafblind specialists are essential to ensure that the child's unique support needs are properly identified and realistic plans for further education, work experience, leisure and housing can be formulated. Timely advice will be needed to facilitate the return of young deafblind people from special residential schools or their transfer to further education and training.



Good practice in action: Exeter

A joint agency has been created in Exeter involving Social Services, Health and Education. All professionals are working closely together and work to joint protocols, assessment criteria, using the same pro formas to record information and services plans.

Many different professionals (teachers for hearing impaired pupils, teachers for visually impaired pupils, occupational therapists, physiotherapists, nursery workers, teachers for multi sensory impaired children, speech and language therapists) were involved in supporting a young child with multi sensory impairments placed in a nursery. The potential for lack of consistency was therefore great and this can lead to additional delay in the already delayed development of the deafblind child.

Following a specialist assessment, intervenor support at home was funded and supplied. Nursery staff were funded to attend the Sense intervenor course, and so was the mother. Social services supplied the funding. This has created shared understanding and consistent care approaches towards the deafblind child. It is essential that all professionals understand the implications of dual sensory impairment and work to similar objectives. Using the same paperwork and criteria facilitates joint working.

What should the assessment consist of?

An assessment is a structured process for gathering information to help professionals, in close liaison with the family, to determine the support a deafblind child may need to access social, leisure and educational services.

Assessors should base their assessment on the government advice on assessing children in need. (Framework for the Assessment of Children in Need and their Families, DH, 2000 and associated practice guidance). This takes the child's environment, its abilities and needs, and the needs and capacity of the child's parents into account. This is usually called the **core assessment** and assumes that a range of professionals will contribute to this.



Assessments will be based on existing assessments from all areas, detailed observations, discussion with the family and those who know the child well, hands on activities and assessment tools.

Any assessment of a deafblind child is likely to cover the following areas:

- Use of vision and hearing
- Use of other senses
- Physical skills
- Orientation and mobility skills
- Communication
- Access to information
- Social skills and personal relationships
- Emotional, cultural and spiritual needs
- Health and medical needs
- Behaviour
- Personal care/domestic skills
- Educational needs – including approaches to learning, curriculum support needs at school or college, adapted materials or specialist equipment, and the possible role of an intervenor
- Leisure needs
- Housing, including need for aids and adaptations
- Financial support.

The assessment should make recommendations including:

- Teaching methods to be used
- Activities to encourage the child's development
- Type of service that should be provided
- Support required such as – intervenor, communicator-guide (including outside school for social involvement)
- Training needs for staff
- Additional activities such as holidays, local clubs which might benefit the child/young person.



Sense can provide specialist assessments. These would usually take place in the child's home and/or school, but in some areas Sense centres are available as a specialist setting for an in-depth exploration of the child's abilities and the family's needs. A specialist setting will be helpful for an in-depth assessment where specialist equipment including toys may be available.



The benefits of specialist assessment and support

C is deafblind due to CHARGE Syndrome. He is 12 years old and lives at home with his parents. Because of his frustration at not being understood he can be very challenging, scratching and hitting both himself and those around him. He must be watched all the time.

When C had an Intervenor to support him for 3 years he began to make good progress. However, this support was withdrawn some years ago and since then, C's progress has been minimal and he has regressed in some areas including communication development, and behaviour.

However, there is no-one employed by the authority with the necessary expertise to carry out a suitable assessment. As a consequence, adequate support is not provided. The lack of support puts pressure on the whole family. Recently C went on a holiday organised by Sense and his parents were able to enjoy an evening out together for the first time in 10 years. The Local Authority has now contracted an outside agency to provide a specialist assessment.

C's progress when he had an intervenor showed how he could make progress with adequate support. Without that support he is unable to develop communication, independent mobility and personal skills like eating, social interaction, and building relationships. Now that a specialist assessment is to be carried out, his progress is expected to improve if appropriate services follow.

What services may be appropriate for deafblind children?

The support that a child requires will depend on the assessment of their needs and whether the child has congenital or acquired deafblindness. The needs of the whole family and the developmental stage of the child should also be considered.

The ESPP programme for disabled children under 3 years of age recommends as good practice the development of a services plan for the whole family – which is owned and held by the family. There is every reason why a family held service plan would be helpful for older children, too.

Importance of one-to-one support

Being deafblind is very confusing for a child because they are not able to access the world around them independently. Contact has to be mediated through people and technology. Consistency in approach and continuity of care are therefore particularly important in work with deafblind people.

For some deafblind children, glasses and hearing aid technology can help. However, some children who have some residual vision and hearing are likely to experience significant distortions of sound or sight. Multi sensory impairment also frequently leads to balance problems and difficulty in concentration. CHARGE children also often have sensory integration difficulties and can find walking and balancing difficult.

In all cases there is a need for skilled intervention to develop a child's learning and self-control. Multi sensory impairment will usually lead to developmental delay, and delay in the development of motor skills and language, whether spoken or signed. Skilled one-to-one support will assist the parents in stimulating sensory experience and learning for the child.

One to one support is also needed for deafblind children to access mainstream social and leisure activities. There are two main types of one to one support: intervenors and communicator-guides. Some children, particularly those who acquire deafblindness at an older age, will require the support of a communicator-guide, who will assist with communication and mobility in everyday activities. However, the majority of deafblind children will require an intervenor, who plays a role in supporting the child's development.

As the child gets older she should be acquiring a greater degree of independence from her main caregivers. For example, it would be

inappropriate for parents to accompany a teenage child who is socialising with their peers – whereas an intervenor or communicator-guide would be more acceptable. This independence from parents is a vital part of the development of a young person and should be considered in any assessment.

Intervenors

Intervenors, who have been specifically trained to work with deafblind children and their families, offer one-to-one attention and support to enable the child to learn about, and interact with, the world around them.

An intervenor's role is:

- To provide individual support for a deafblind child or adult to encourage effective communication and the reception of clear information;
- To work closely in partnership with parents and carers, offering support, guidance and encouragement;
- To enable the child or adult to take full advantage of learning and social experiences and to gain fuller access to the wider community;
- To encourage a child's potential for learning, increase their confidence and reduce the prospect of social exclusion.

It is likely that any deafblind child will have – as a minimum – communication, learning and mobility needs. Specialist intervenors, who are trained in deafblindness, will develop programmes to extend the experience of the child, encourage communication and language and help towards increased independence.



Good practice in action: Suffolk

Social services funding was found – following a specialist assessment – for an intervenor service for a very young deafblind boy. Other workers and family members were also funded to attend a training course on deafblindness so that they could work together effectively and provide a consistent environment suited to the development of the deafblind child. The key worker is a social worker who is coordinating the service.

Communicator-guides

A communicator-guide works with a deafblind person, assisting with communication and mobility to enable their involvement in every day activities. They do not provide the sort of developmental support which an intervenor would, so are not suitable for the majority of deafblind children. However, for those who acquire deafblindness in late childhood/adolescence, a communicator-guide may be more appropriate.

Other support

Deafblind children may need a range of other support in addition to one to one human support. This could include occupational therapy, speech therapy, assistive technology, aids and adaptations to the home.

Support for families

Deafblind children require constant watching and attention from parents or other care-givers. It is exhausting to look after a deafblind child, and carers will need a break and support so that other family members – especially siblings of the deafblind child – are not neglected.

Short breaks and holidays

Given the extremely demanding nature of this disability, short term breaks and home based support services for parents of deafblind children will be needed. As the support needs of each deafblind child are unique, short break services will be a costly challenge for local authorities to commission. In some localities intervenors have provided sitting services, since there will be few placements capable of providing high quality short breaks. Sense provides summer holidays for deafblind children, which local authorities can purchase. These holidays provide stimulating experiences for deafblind children whilst giving parents a much needed break. They are available for children aged 6 and above.

Home help

Caring for a deafblind child is often an exhausting process for families. Given this, many will greatly benefit from receiving some form of home help to support them with the day-to-day running of their households.



Direct payments

Direct payments should be offered as an alternative to direct social services for those families who are capable and willing to make their own arrangements for support services. Parents should be supported in their decision-making and the possibility of mixing direct services augmented by Direct Payments should be discussed. However, the decision should be the parents', and their individual circumstances and preferences be respected. Direct payments should not be used as an excuse for not developing direct services for this client group. (Direct Payments Guidance, DH September 2003. www.doh.gov.uk/directpayments)

Direct payments, can assist families to put together flexible support packages.



Good practice in action: Newport – Gwent

Two brothers with Usher syndrome had an assessment, undertaken by a Sense specialist worker. The assessment was coordinated to involve the family, the school and the social worker of the deaf. As a result a one-to-one communicator-guide with understanding of the boy's culture – they were of Arabic descent – was required. The need for a signing communicator-guide was evidenced by the boys' needs to access community facilities and the local deaf club. The Council accepted the recommendations and agreed to fund Sense to employ and train a communicator-guide.

How can services be co-ordinated?

Different professionals need to agree on how they want to work together – and how multi disciplinary support should best be organised. If you have a child development centre or an early excellence centre in your locality, joint working is likely to be easier as it will become the focal point for all early years services.

It is important that all communications with the family of the deafblind child are managed and the family is not overloaded and confused by demands and inputs from different professionals. The flowchart on page 26 indicates when these materials might be used. The ESPP has devised a number of materials likely to be very helpful to families and professionals. For example:

- the family held record
- information on some key disabilities, including deafblindness
- the role of the different services
- financial help
- special educational needs assessment and statementing and
- where to go for advice.

All materials can be downloaded from the ESPP website or acquired free of charge in hard copy. Newly diagnosed children's families are to receive the family pack early on so that they can relate to the assessments and services better and are empowered to play their key role as parents.

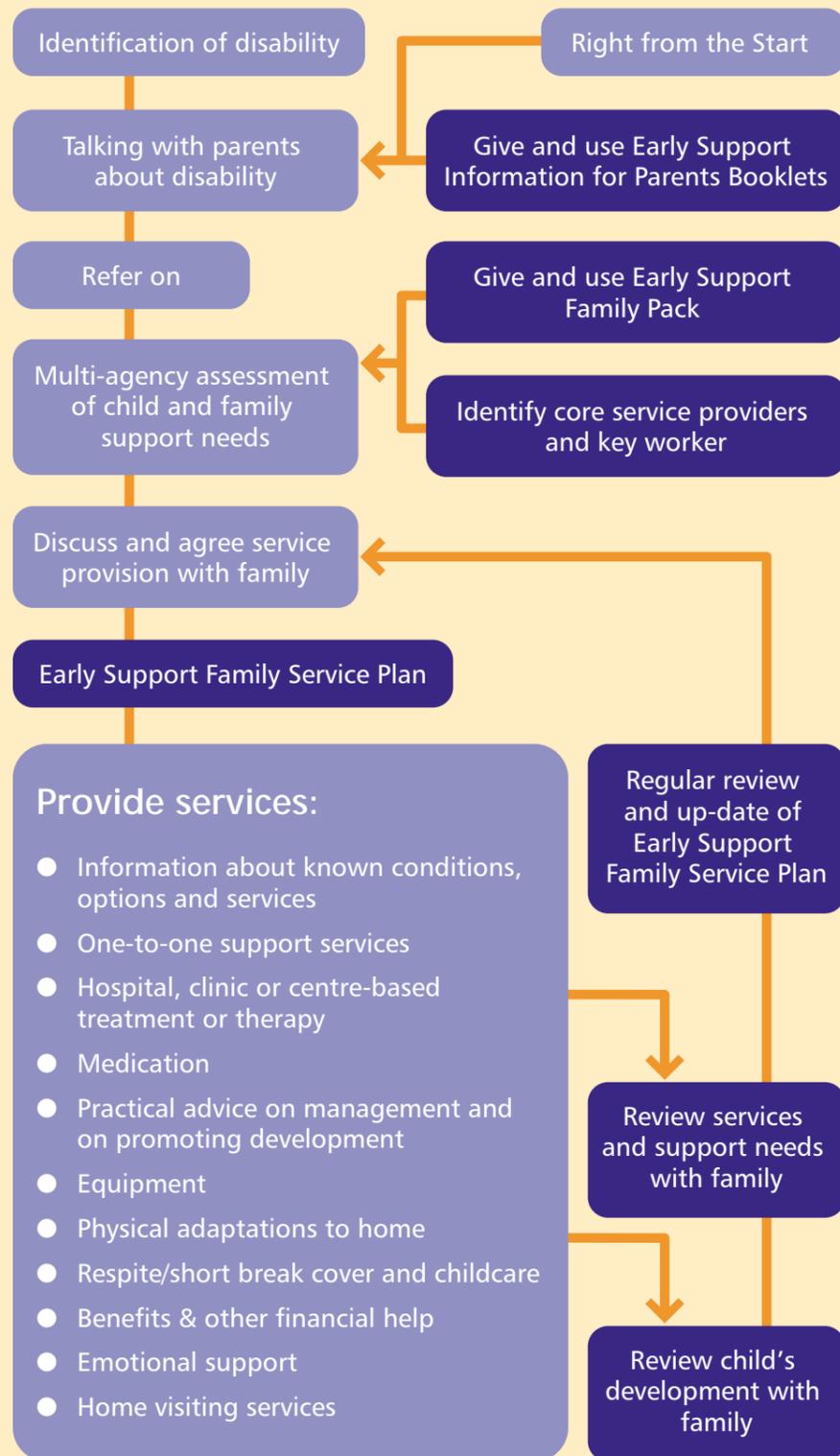
The site also links to good practice guidance from the DfES and lessons from research.

Key workers

Families' accounts and research point to the value of key workers or care coordinators. They ensure that different services work together, that information is coordinated, decisions are communicated effectively, services monitored and families supported. The appointment of key workers recognises the strain on families with a disabled child with complex needs and thus complex service packages. Deafblind children will usually have complex care packages.

Key workers can smooth communications and help agree the pattern of service delivery most suited to the family. This is particularly true at transition where deafblind young people and their families need clear information about the process at an early stage. The value of

Early support family service planning



a key worker is in having a consistent point of contact. Constant change of key worker will reduce or eliminate their effectiveness.

How should transition arrangements be made?

Deafblind children in transition from children to adult services need effective service coordination. As they will usually have had complex care packages and support from a range of agencies effective transition planning is vital.

Deafblind young people need someone who understands deafblindness to be involved in the assessment and care planning process. The young person's communication and access needs should be properly investigated and age appropriate services arranged to meet them. The young person should be enabled to make choices, if necessary through the provision of a skilled advocate. An advocate should be able to establish communication with the deafblind person, and listen to their social aspirations and interests – including any plans for further education and training and where they want to live.

Involvement of adult services at an early stage to ensure adequate provision at transition is essential – particularly where a child's support needs are complex.

How can information be accessible to deafblind children and their families?

Parents of deafblind children require easy to read materials on the:

- implications of deafblindness
- services that are available locally, regionally and nationally
- equipment likely to assist at home
- access to early years provision
- education provision

- statementing
- support services at home and
- benefits available to families.

This information is now meant to be routinely provided to parents as part of the DfES Early Support Programme following identification.

For deafblind young people at transition between children and adult services authorities, accessible information should be provided where appropriate – depending on the assessed communication requirements of the individual.

Alternative formats might include:

- tape
- braille
- large print
- videos
- DVDs,
- face-to-face communication.

For advice about these other formats contact Sense.

How can responsibility for deafblind services be allocated?

Work with deafblind children and young people should be overseen by the children's services director, with lead responsibility allocated to a third tier officer with strategic responsibility for children with disabilities.

It is important that the senior manager has sufficient standing and influence in the organisation to initiate policies, procedures, make decisions with financial effects and ensure compliance.

The senior managers should receive training both deafblind awareness and some hands-on communication skills, including those used by congenitally deafblind people – to appreciate the challenges presented by deafblindness. With some expertise in deafblindness residing in the physical disability teams services managers need to ensure that this expertise can also be tapped into and that joined up working occurs within the local authority and with health colleagues.



Good practice in action: Carmarthen

The team supporting the transition of a young woman with multi-sensory impairment from a special school to adult placement requested a specialist assessment from Sense – funded by the social services department – to look at the support she would need when she left school. The team included her mother, representatives from school and social services. The Life Options project based at SCOVO (Standing Conference of Voluntary Organisations in Wales) was included to ensure that the family's opinions were taken note of. Initially when the group had started to meet it had been assumed that G would go to a day centre.

The assessment was undertaken at school and in G's home in consultation with her support team. It recommended that with one-to-one support she would be able to access a mainstream college course and a work experience scheme following her interests. It was also suggested that G should have support from an intervenor to enable her to go shopping at weekends and go out one evening a week and that she may benefit from a Sense holiday with other young deafblind adults.

G was indeed able to access a college course four days a week with one-to-one support provided by the college with ELWa (Education Learning Wales) funding and to attend a work experience programme run by Mencap one day a week – also with one-to-one support. G receives support in the evenings and at weekends to allow her to access community social facilities – she often goes shopping at the weekends and to friends' houses in the week, which is funded through ILF. Sense was asked to provide training for the staff team supporting G. This was hosted by the college and included her Mencap work experience staff and ILF staff. G has also enjoyed a Sense holiday. The experience of being involved in planning for and working with G has changed the college's perceptions of the range of young adults they can cater for. G – with support – can lead the life other young adults enjoy in her local community.



Self-assessment checklist for directors of children services

	Achieved	Partially achieved	Work just started	Not at all
Awareness of the section 7 guidance and its implications for children's services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lead responsibility for deafblindness allocated to a senior member of your management team.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Adequate training in deafblind awareness for lead officer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children's services, local health services and education are aware of lead officer's role.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Survey of deafblind children undertaken.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interagency protocol for joint working and for multi-disciplinary assessments for deafblind children is in place.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Agreement on the exchange of data regarding children in need, including deafblind children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Access to staff trained to assess deafblind children is sufficient to allow timely assessments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Up to date record of deafblind children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information relating to the database of deafblind children is co-ordinated with partner agencies, such as audiology, ophthalmology, special education, paediatrics, learning disability, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Progress of deafblind children is tracked with partners.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easy access to plain English information is available for families with a deafblind child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
This information has been independently audited for content and accessibility.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identified budget is available for one-to-one support for deafblind children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Achieved	Partially achieved	Work just started	Not at all
Key worker system is in place to support deafblind children and their families.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Families with a deafblind child are put in touch with other families or national, local or regional support groups and voluntary organisations.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Assessments of deafblind children are holistic, taking note of social needs in addition to educational needs.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The need for families and siblings to be supported separately from, and in addition to, the deafblind child is taken account of in assessment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Budget for short term breaks which can be accessed for the families of deafblind children is identified.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Intervenors are provided to support deafblind children's communication and daily independence skills outside school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Communicator-guides are provided for young people with acquired deafblindness for access to social activities and leisure pursuits.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transition work ensures smooth transfer of care/ support arrangements when deafblind children become the responsibility of adult services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Measures to ensure effective communication with the deafblind young person are in place.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Measures to ensure arrangements for assessment and service provision are communicated to the parents and carers of deafblind children.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Systems to monitor and respond to deafblind children and their families' satisfaction with the service.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



References

- Assessing Children in Need and Their Families: Practice Guidance*
Department of Health, 2000
- Every Child Matters*, Department for Education and Skills, 2003
- Every Child Matters – the next steps*, Department for Education and Skills, 2004
- Framework for the Assessment of Children in Need and their families*, Department of Health 2000
- National Service Framework for Children, Young People and Maternity Services*, Department for Education and Skills, 2004
- Removing Barriers to Achievement: the government's strategy for SEN*, Department for Education and Skills, 2003
- SEN Code of Practice*, Department for Education and Skills, 2002
- Services for Disabled Children*, Audit Commission, 2003
- Social Care for Deafblind Children and Adults* LAC 2001(8)
- Social Care for Deafblind Children and Adults: A Practical Guide for local authorities implementing the department of health guidance*, Sense, 2002
- Special Educational Needs and Disability Act (SENDA)* 2001
- Together from the Start – Practical guidance for professionals working with disabled children (birth to third birthday) and their families*, Department for Education and Skills, 2003

Web based resources

- Early Support Pilot Programme (ESPP) website on good practice in early years services for disabled children and materials to be downloaded www.espp.org.uk
- Integrated Community Equipment Store website offering a virtual store for children's equipment www.icesdoh.org.uk/cevs.asp
- Newborn Hearing Screening website www.nhsp.info/
- The Scottish Sensory Centre www.ssc.mhie.ac.uk
- Sense www.sense.org.uk/professionals/

Publications about deafblindness

- Miles, B and Riggio, (1999) M, *Remarkable Conversations: A guide to developing meaningful communication with children and young adults who are deafblind* Perkins School for the Blind
- Murdoch, H (2002) *Early Intervention for children who are deafblind*, Sense (Available on Sense website. Extensive reference section.)
- Sense, (2002) *Breaking Out: Opening the community for deafblind children and young people*, A Sense campaign report, Sense

Useful organisations

Sense

11-13 Clifton Terrace
Finsbury Park
London N4 3SR
Tel: 020 7272 7774
www.sense.org.uk
info@sense.org.uk

Sense provides information on congenital and acquired deafblindness, community and residential services for deafblind people of all ages, including leisure activities. Sense can provide specialist assessments and services for children as well as advice and support to professionals.

Deafblind UK

National Centre for Deafblindness
John and Lucille van Geest Place
Cygnet Road
Hampton, Peterborough
Cambridgeshire PE7 8FD
Tel: 01733 358100
Helpline: 0800 132 320
www.deafblind.org.uk

Deafblind UK provides information and training for those working with people with acquired deafblindness.

Contact a Family

209-211 City Rd.
London EC1V 1JN
Tel: 020 7608 8700
Helpline 0808 808 3555
www.cafamily.org.uk
info@cafamily.org.uk

Contact a Family is the main support organisation for parents of children with rare conditions. They provide information and access to support organisations and self help groups.

RNID

19-23 Featherstone Street
London EC 1Y 8SL
Tel: 020 7296 8000

Helpline: 0808 808 0123
www.rnid.org.uk

RNID provides information on deafness and technologies and publications for parents and professionals. Through Sound Advantage assistive equipment can be purchased. Residential and community support for adults and employment guidance are also available.

RNIB

105 Judd Street
London
WC1H 9NE
Tel: 020 7388 1266
Helpline: 0845 766 9999
www.rnib.org.uk

RNIB provides information on visual impairment and blindness, they sell equipment and provide benefits and employment advice.

Council for Disabled Children

C/o National Children's Bureau
8 Wakley Street
London
EC1V 7EQ
Tel: 020 7843 6000
www.ncb.org.uk

This is affiliated to the National Children's Bureau and campaigns for better services for disabled children. It also has information resources and conducts research.

National Deaf Children's Society

15 Dufferin Street
London EC1Y 8UR
Tel: 020 7490 8656
Helpline: 020 7250 0123
www.ndcs.org.uk

NDCS support families with deaf children through information, support groups, advice on benefits, equipment and special educational needs procedures.