

Sense, the national organisation working with deafblind and multi-sensory-impaired children and their families

Response to the Review of Disabled Children (Annex B2)

About Sense

Sense is a national organisation that supports people with deafblindness and associated disabilities. Sense has pioneered early intervention with deafblind children and their families and supports specialist teachers and support staff in developing their skills and knowledge.

Deafblindness is a distinct disability that is more than simply vision loss and hearing loss. The combined effects of not seeing or hearing clearly are experienced uniquely by each deafblind person. Whether they are born with dual loss or acquire it as they start to grow up, their lives are profoundly affected.

Review of disabled children

Sense warmly welcomes this review “to improve outcomes and life chances of disabled children through the development of effective and accessible services for disabled children and their families”.

Our response relates the experiences of deafblind and multi-sensory impaired children and their families to the questions outlined in the terms of reference of the review.

Key questions

The changing profile of the children

The number of complex babies and young children whose families contact Sense for advice and support has risen over recent years. Extreme prematurity and birth trauma, as well as improved diagnosis of genetic and syndromic conditions, either at birth or later on during school life, are the reported causes of this change.¹ A recently published paper outlines a large number of very rare conditions that result in dual sensory loss and, for some, other physical difficulties.² This is helpful for families and service providers. Work on the developing brain in premature babies³ also provides valuable information for all those wanting to understand more about caring for and maximising potential for this group of children. The behaviour, usually associated with Autistic Spectrum Disorders, is being identified much more frequently, but, as always, assessing deafblind children with procedures designed to measure hearing/sighted children do not provide useful results.⁴

As a membership organisation dedicated to a large group of children with emerging complex conditions we depend on new research and ideas to maximise an effective practical response to children and their families. At present it takes too long for new information in these emerging aetiologies to reach the range of key professionals who need to either keep up to date in order to improve practice or take influential planning decisions.

¹ *Trends in the population of children with multi-sensory impairment*, David Brown, Talking Sense, 43, 2 12-14p

² *Evidence-based overview of Ophthalmic disorders in deaf children: a literature update*, TPNikolopoulos et al, Otolology and Neurology, vol 27, no2, February 2006

³ *Axial and radial diffusivity in preterm infants who have diffuse white matter changes on MRI in term-equivalent age*, Mary A Rutherford et al, Paediatrics, 2006; 117; 376386

⁴ *Autism spectrum disorders and underlying brain pathology in CHARGE association*, Developmental medicine and Child Neurology 2006, 48: 40-50

- **Structures need to be put in place to ensure new research is commissioned, reported and disseminated quickly in order that targeted, individual and specialised services are properly underpinned and delivered more effectively**

Government also needs to know how many children are affected by changes in aetiology. The exact number of children is unclear and because data are collected in different ways they are difficult to interpret with confidence. The lack of this kind of hard evidence means that this group of children cannot be properly planned for. Hard evidence would provide a firm platform and a real incentive for services to be developed or improved. PLASC⁵ has attempted to capture this data to support school age education services but it is not a robust enough tool to adequately represent children who have multiple needs.

- **Government should commission work to gather the information on child aetiology/numbers to inform the development of new services**

What are the challenges this changing profile poses to services?

The low incidence, complexity and individuality of the children

Multi-sensory-impaired children, who have medical, physical and possibly cognitive problems, are still very rare in our child population. They require *specialist* support from birth in order to access universal services at an appropriate future time. But because of their very low incidence and heterogeneity, specialist support is not available in many parts of the country.

The major challenges for families are

- getting a diagnosis/functional assessment, as this depends where you live
- getting a specialist, integrated service involving all agencies
- family life with a severely disabled child

The major challenge to services providers is

- ensuring each family a specialist integrated service (health, education and social care) in a climate where local priorities *do not* include the provision of such specialist support and where local funding decisions certainly to *do not* favour children and families who require complex support.

Ensuring a diagnosis and a specialist integrated service – right from the start

High satisfaction levels are expressed by families who are referred on to specialist centres (like Great Ormond Street Hospital, Manchester and Birmingham) where they are able to see specialist staff who *really know* about the cause of their child's condition, and see their child as "whole". This health relationship is then ongoing through childhood and any fluctuation or deterioration can be acknowledged and supported properly. Having good information and consistent contact puts families in control.

National Service Framework standards⁶ support the development of a "pathway" designed to ensure that *every child* with these and other rare conditions (and complex needs) whenever diagnosed and wherever he lives can access a specialist clinic as a matter of course. All children should be seen and referred on to local services in health, social, care and education. For children with life-limiting conditions this would provide a level of continuity that is absent at the moment.

⁵ Pupil level annual school census, DfES

⁶ *The National Service Framework for Children, Young People and Maternity Services*, Standard 8, 2004 DfES/DH

- **A care “pathway” should be nationally agreed to ensure that every child with rare conditions (and complex needs) wherever they live can access a specialist clinic as a matter of course.**
- **Local authority criteria should not exclude the most disabled children from receiving a service for reasons of funding or absence of skills. Targeted inspection should be introduced.**

Family concerns - having a disabled child

No family is prepared for this. Delays in diagnosis, poor early support leads to an increasing sense of family isolation.⁷ The stress caused for the entire family is immense. Lack of sleep, lack of support and facing the unknown are all cited by Sense families as contributing to stress levels. Childcare is almost impossible to find and even harder to pay for. Employment opportunities are reduced for the primary carer, family budgets are cut and 55% of families⁸ join the poorest in the country. All this pressure can lead to family breakdown, causing personal misery and on going costs to the state. The waste of time and talent needs redressing as a priority.

- **There is an urgent need to renew the initiative to bring together all policy related to the development of an integrated approach to all disabled children and their families in the areas of health, social care and education but also of employment and housing**

Evidence for the success of early intervention

Deafblindness is a unique disability causing extreme developmental disadvantage, especially regarding access to information from the environment, communication and social and emotional development. Despite the consensus that intervention in the early years should be provided, little research has been carried out to assess its effectiveness. In part this is because of the difficulties of evaluating early intervention programmes in general.

Children who are deafblind present particular issues for researchers:

- changes in attributes relevant to learning, such as curiosity and attention, cannot be assessed;
- standardised tests of performance are often inappropriate for children with special needs where criterion-referenced test of performance will vary between programmes and may be unreliable;
- Children’s progress during intervention needs to be compared to the progress they would have made without intervention, and there are obvious ethical problems in denying intervention to some children who would benefit in order to create a control group.

Two studies *do* indicate the effectiveness of early intervention in deafblind children and they are discussed, along with other relevant material in “Early Intervention for Children who are Deafblind”.⁹

Early Support, the government’s co-ordinated initiative has demonstrated its value for Sense members with its focus on families. Sense is very pleased to be able to play a part in the developments it has brought about. It now has a valuable role to widen knowledge with its training initiative and extend its remit nation-wide.

- **DfES “Early Support” should be rolled out and developed nationally and alongside its focus on generic focus retain its specialist elements**

⁷ Services to Disabled Children, Audit Commission, 2003

⁸ DfES source

⁹ Heather Murdoch, 2002, Sense

Progress for multi-sensory-impaired infants, children and young people

Guidance specifically related to deafblind/multi-sensory impairment

In addition to the generic guidance a number of specialist documents have made a huge difference in making local authorities aware of this new, and increasing, number of children who have complex sensory needs and of their duties to accurately assess their needs and provide services.

Education

DES Policy Statement¹⁰ (recognising deafblindness and requiring LA to make provision)

Specialist Teacher Training¹¹ (mandatory post-graduate teacher training)

QCA Guidelines¹² on access to the curriculum (for all teachers)

Social care

Social Care for Deafblind Children and Adults 2001¹³ (offering assessment and support for activities outside school)

Early Support¹⁴ (government's on-going flagship programme for 0-5year olds)

Health

National Service Framework for Children and Maternity Services - Standard 8 Disabled Children

- **The policy documents are in place. It is the willingness/funding to properly recognise, plan for and deliver services at a local or regional level that is missing.**

What are the barriers currently restricting access to services and effective intervention?

“I've never met a child quite like you before!”

In spite of the huge policy strides that have been taken for this group of children - both education and social care - barriers still exist for families across the country. Parents report difficulties in

- getting support after diagnosis
- getting an appropriate specialist assessment, either developmental or for educational purposes
- accessing therapeutic support (physiotherapy, communication, occupational, speech & language)
- getting a regular respite break for the family with a service that meets the child's needs
- finding suitable school places
- getting the individual curriculum support the child needs (including therapeutic and communication)
- having transport that is flexible enough to allow the child to take up after school clubs or extended school provision
- having proper transitional support and further education provision

The work of the Children's Trusts has not emerged **yet** to solve these difficulties.

¹⁰ *Education provision for deaf-blind children, 1989 DES, London*

¹¹ University of Birmingham and Whitefield School and Centre, London

¹² *Shared World – Different Experiences – Designing the curriculum for deafblind pupils, QCA 2001*

¹³ *Social care for Deafblind Children and Adults LAC2001 (8)*

¹⁴ www.earlysupport.org.uk

Making cost-effective arrangements for low incidence highly specialist children

The fact that the children are very “rare” provides a perfect excuse for the poor response from local authorities to families. Quite understandably, small and/or unitary authorities have a legitimate challenge to find funding. High cost, low incidence children require imaginative responses. Most local authorities are not yet geared to up to be individually responsive, even though this concept is on the governments change agenda and examples exist in some areas.

Working in partnership, including sharing staff and managing joint budgets would appear to be one way forward. There are some examples in the education sector, where multi-authority/regional approaches have already demonstrated success for the support of children with low incidence highly complex needs¹⁵. They offer a more cost-effective answer to providing the specialist staff that make all the difference for families and children. This model could work across agencies, including social care to provide the co-ordinated and integrated support children need.

Examples of successful joint working

1.

A joint service¹⁶ of four local authorities provides outstanding support for deafblind children: Bristol, Bath and North East Somerset, and South Gloucestershire have maintained their five star service that was established when they were all one county, Avon. They have been going since 1996. The professional teams working with children from birth to 19 years old are able to cover the entire area using their specialist expertise to maximum potential working with multi-sensory-impaired children and families.

2.

In Wales, a joint service runs in Greater Gwent. Five South East Wales¹⁷ authorities receive support for pupils from birth to nineteen from Blaenau Gwent, Caerphilly, Monmouthshire, Newport and Torfaen. Again, children with deafblindness/multi-sensory impairment with highly specialist needs are provided for in a cost-effective manner.

3.

After two years' study and consultation, the Welsh Assembly Government has decided to develop a regional response to the deafblind and multi-sensory impaired children in Wales, in an effort to ensure equality of access for low incidence children. Three regions (SE, SW and N) have had plans accepted, WAG Grant provided to assist in embedding this development over the next few years. Greater Gwent will continue to develop the service already in operation, Neath and Port Talbot will lead in SW Wales and Wrexham will be the focus for the northern authorities.¹⁸

Low incidence/highly specialist ...competing for resources and vulnerable to cuts

Arrangements for these low incidence children are always subject to scrutiny and liable to be lost in any budget cutting exercise. Small in number and viewed as expensive and complicated to provide for they cannot “compete” to get high enough on the local agenda.

¹⁵ *Deafblind Education - Sharing a Regional Approach*, DFE and Sense 1996

¹⁶ www.sensorysupportservice.org.uk/page2.html

¹⁷ www.caerphilly.gov.uk

¹⁸ www.learning.wales.gov.uk

“Securing and equalising services” is part of the Every Child Matters agenda but how will multi-sensory-impaired children fare (and others) if they are competing for resources against the more visible young people whose disaffection has a physical cost?

- **National guidance should be explicit about the provision of services for low incidence groups of children.** Otherwise they will not find the protection that present government policy aims to provide for *all children*.

Are services sufficiently co-ordinated at a local level to allow families to access support to meet their needs?

Sense families find local services problematical for all the reasons we have already put forward in this paper. Certain specialist services are going to more effective and efficiently delivered at a regional or even, national service level, whereas others must be locally based. Almost all the children will require an individualised package that takes into account child/family factors.

Co-ordination of services across agencies (i.e. education, social care and health) is very patchy. The new local authority Children’s Services structure has not made any significant impact on delivery - yet.

Education services have become more co-ordinated in the years since the deafblind policy statement and the introduction of the specialist courses. Delivered through school or local authority sensory support services support is provided in a flexible and professional way. Manchester, Worcestershire, Herefordshire, Hertfordshire, Leicestershire, Bedfordshire, Cheshire, Surrey, Kirklees, Wandsworth, York and Wakefield are just a few of the authorities with good support services. Neath/Post Talbot, Caerphilly, Birmingham, Wrexham, Bradford, Exeter, Margate, Walthamstow, Manchester, Wandsworth, Northampton (not an exhaustive list) all have notable schools with qualified staff and curriculum differentiation. In all these authorities qualified staff support the children wherever they are taught and often a one-to-one worker, intervenor, or sign language interpreter is recognised as essential. Standard “respite” care packages (short breaks etc) are reported as inadequate and inappropriate as they are almost always designed around hearing/sighted children-and the communication support is not available. There is no consistency across the UK about criteria for a care package - each area is different depending on where the family live. Having to “prove” you are at breaking point before anyone is ready to listen is a scandal. One parent described this attitude in these terms; “Sorry your child is too disabled and our services can’t meet her needs. Go away and carry on yourself.”

Even with government guidance¹⁹ requiring each local authority to identify and assess deafblind children and provide communication support to allow the children to join in community social activities, most local authorities are ignoring their responsibilities.²⁰

- **Inspection processes for LA services should include all aspects of performance in order to ensure duties like this one, that relate to a very few children, register as requiring action**

Transitional planning

Co-ordination is particularly woeful for the transition between school and adult services. With a perfectly sound structure for planning from age 14,²¹ social care services fail in their

¹⁹ *Social care for Children and Adults*, LAC 2001(8)

²⁰ *Deafblind Guidance: Five Years On*, Sense Local Authority Survey Report Children’s Services 2005
Sense survey - implementation of the Deafblind Guidance in children’s services, Sense 2006

²¹ SEN Code of Practice 2001

responsibilities and willingly admit that any agreement they might make will not “stand” unless approved in adult services. Separate budgets for adults and children are the reason. Young people are left stranded between school and young adult life, families are frustrated and employment suffers as the wheels of decision making, (that should have been in operation for at least two years beforehand) grind slowly forward. Families turn into warriors, positions become polarised and the young person marks time as issues related to funding and appropriate support are discussed and revisited.

- **Responsibilities relating to young people moving from children’s services to adult services must be explicitly set out in order to close this loophole which allows such professional**

What family support services are currently available and how do these relate to other services?

Family support is not universally available. Key working is developing in some areas, thanks partly to the impact of the Early Support programme.

“I have no preference for who should lead in keyworking but they must be able to tackle the amount of work for complex children and have some clout. Getting sick or stressed and being off and unable to deliver is a feature of services to my daughter”.
Sense member (mother)

If key worker services were a more common feature this professional would be able to liaise with others for a co-ordinated approach.

Access to “short breaks” depends on a number of factors including satisfying eligibility criteria related to the child’s needs rather than those of the carers. No authority has the same pattern and criteria for admission. This is unhelpful. Although the Carers Act sets out clearly what carers should expect, assessment and support is not offered routinely.

Sense provides advice and support to families and a whole range of events for both children and carers including specialist short breaks and holidays for deafblind/multi-sensory-impaired children and young people. This service was developed to fill the gap in local authority services and continues to do so – 20 years later. In spite of contributions from local authorities, charitable income is used to meet the real cost. Last year (as in every year) Sense organised a holiday programme and 109 people had a great time. This activity provided both “respite” for the family, as well as a holiday for the child. However, the reality is that only 16 local authorities paid the full price for their client’s holiday, a further 14 made a donation (ranging from £50 to £630.00) and the rest, 79, (or 72% of the total) paid nothing at all.

- **The present ad hoc system of providing breaks for families and good support for their children is not working and needs immediate review**

How does the system of support for deafblind/msi children and their families compare across the country and abroad? Are there any lessons we can learn to improve outcomes?

Because deafblindness is such a low incidence condition thriving networks exist to link interested professionals, families and deafblind people themselves. *Deafblind International* is a world organisation and has 40 corporate and 350 individual members from all over the world, from both developed and emerging nations. It runs specialist interest groups in a wide range of areas, and these groups network together for their own professional development.

Those with experience assist those who are just starting up by sharing information and knowledge but also work together to pioneer new work. Dbl demonstrates that collaboration can deliver good outcomes it requires a commitment that is properly funded and planned:

Nordisk Uddannelsescenter for Dovblindepersonale (NUD) – developing high quality training and CPD across a European region

One of the Dbl members is NUD – the Nordic Staff Training Centre for Deafblind Services²² based in Denmark. This centre, funded by all the Nordic countries, provides high quality information training courses and research facilities to Denmark, Norway, Sweden and Finland. It plays a key role in developing high level training open to others in Europe.

The Dbl Communication Network – developing excellent materials for use by families, teachers and support staff and produced by experts working together from five European countries

The Dbl Communication Network²³ is a working group of professional educators, psychologists and specialist teachers from Norway, the Netherlands, France, Belgium and Denmark. They are exceptional individuals who have been working together for 8 years. They have developed ideas, created videos, held training courses and are launching a whole set of materials on deafblind communication methods on the Dbl web site for use by others.

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²² www.nud.org.dk

²³ www.deafblindinternational.org