Supporting Success

Improving the journey for deafblind/multi-sensory-impaired children and young people
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Supporting Success looks at the support and provision essential to the successful development and attainment of deafblind/multi-sensory-impaired (MSI) children and young people. This report looks at three core areas:
- The needs of deafblind/MSI children as a low incidence group
- The existing system of support and its strengths and weaknesses
- The Government’s Special Educational Needs and Disability (SEND) reforms set out in their Green Paper¹ and the Next Steps document

Supporting Success is based on a number of evidence sources, including two recent online surveys – one for MSI professionals in front line teaching and learning positions, and another for parents of children with deafblindness/MSI. It also builds on previous evidence gathered from parents as part of Sense’s response to the publication of the SEN Green Paper.

Our research reveals the experiences of parents in the existing system of SEN support, their aspirations for the future of SEN provision and the initial challenges experienced on the front line by MSI professionals in local authorities. We seek to understand the impact these might have on delivering the ambitions of the Government, set out in the SEN Green Paper.

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Recommendations

1. Introduce a new single duty for education, health and social care agencies, and in all settings to:
   - Identify deafblind/MSI children in their area
   - Identify a senior manager with responsibility for deafblind services
   - Provide diagnosis, a health and wellbeing plan and an annual health check
   - Provide specialist assessments by a suitably qualified person
   - Provide appropriate information and specialist services designed to meet the needs of deafblind/MSI children and young people, including one-to-one support services and equipment

   The new duty would identify the needs of deafblind/MSI children and young people, which will inform service planning, commissioning and the provision of early intervention and support at key stages of need through to the transition to adulthood

2. To support both the development of expertise and the maintenance of suitably qualified practitioners through a regional approach to service delivery, which protects the specialist services required by deafblind/MSI children and young people

3. To include deafblind/MSI children and young people in the piloting activities of the pathfinder areas to ensure that the proposed reforms are tested to meet the needs of this unique low incidence group

4. To develop shared quality standards across education, health and social care to underpin the holistic assessment of deafblind/MSI children and young people

5. To recognise and promote a key-working approach which delivers co-ordinated support and an outcome driven, holistic single assessment process and single plan
About deafblindness/multi-sensory impairment

The Centre for Disability Research (CeDR) Report\(^2\) estimates that there are a minimum of 4,000 children who are deafblind/multi-sensory-impaired (MSI) in the UK. These children will require early intervention, support and expertise from qualified practitioners who understand the impact that deafblindness/MSI can have on children and families from an early age/onset.

Deafblindness has been defined in educational terms as:

“a heterogeneous group of children who may suffer from varying degrees of visual and hearing impairment, perhaps combined with learning difficulties and physical disabilities, which can cause severe communication, developmental and educational problems. A precise description is difficult because of the degrees of deafness and blindness – possibly combined with different degrees of other disabilities – are not uniform, and the educational needs of each child will have to be decided individually.”\(^3\)

The Department for Education (DfE) also use the following definition for the purposes of data collection:

Children with multi-sensory impairment are defined as having: “a combination of visual and hearing difficulties. They are sometimes referred to as deaf blind (sic) but may have some residual sight and/or hearing. Many also have additional disabilities but their complex needs mean that it can be difficult to ascertain their intellectual abilities.”\(^4\)

MSI is considered a low incidence disability due to the small number of children who meet the definition of deafblindness. A useful descriptor of low incidence is:

Low incidence special educational need and disability (LISEND)\(^5\):

- “A need which has the potential to have an adverse impact on learning and development unless additional measures are taken to support the child/young person.
- The prevalence rate is so low that a mainstream setting is unlikely to have sufficient knowledge and experience to meet these requirements. Settings will need to obtain specialist support and advice on how to ensure equitable access and progression (against national standards).
- The prevalence rate is so low that any formula for allocating resources for additional needs, which is based on proxy indicators of need, will not reflect the true distribution of children and young people identified as having low incidence SEND.”
Identification

For deafblind/MSI children identification and early intervention is critical. Local authorities have duties under the Education Act 1996 to make provision for children with SEND. They also have a statutory responsibility under the Deafblind Guidance to:

- Identify deafblind/MSI children in their area
- Identify a senior manager with responsibility for deafblind services
- Provide specialist assessments by a suitably qualified person
- Provide appropriate information and specialist services designed to meet the needs of deafblind/MSI children and young people, including one-to-one support services and equipment

In a recent survey of Local Authority (LA) Children’s Services, endorsed by the Research Committee of the Association of Directors of Children’s Services, Sense found that:

- There had been little change in the number of deafblind/MSI children identified since the last Children’s Survey in 2010
- Local authorities identified 549 deafblind children in 2012
- Based on the CeDR research we believe there should be identification of 31 MSI children per 100,000
- This year’s LA survey results suggest an identification rate of 3 MSI children per 100,000

The Pupil Level Annual School Census for England is equally interesting in the number of MSI children identified with MSI as their primary SEN:

- 510 MSI children and young people aged 19 and under with a statement of SEN
- 480 MSI children and young people aged 16 and under with a statement of SEN
- No MSI young people aged 16-19 on School Action Plus
- 425 MSI children and young people aged 16 and under on School Action Plus
- 935 MSI children and young people aged 19 and under on School Action Plus, or with a statement of SEN in the whole school population

Whilst it is difficult to draw a comparison between the identification numbers between children and young people identified as deafblind/MSI from social care and education data sets, there is a degree of similarity between identification rates.
The education landscape

The provision of Sensory Support Services are critical to ensuring the successful engagement and positive life and learning outcomes for deafblind/MSI children and young people. Deafblind/MSI children and young people are educated in a wide range of school placements. A recent analysis of placements found that of 168 children and young people there were 15 different types of school placements. Of these children:

- 5 per cent were taught in deafblind/MSI specific placements
- 16 per cent were taught in mainstream provision
- 28 per cent were taught in sensory impairment placements (schools or units for the visually/hearing impaired), and
- 43 per cent were taught in learning disability placements (moderate learning disability (MLD), severe learning disability (SLD) or profound and multiple learning disability (PMLD)).

The local landscape of educational provision has been changing for the last two years. In the vast majority of local authority areas in England there is now a more diverse educational mix, with maintained schools sitting alongside Academies and Free Schools.

It is critical that choice is extended to deafblind/MSI children, young people and parents. The choice of a place at a maintained, Academy or Free School must be matched by access to the support services that will ensure such choice becomes a reality for deafblind/MSI children. Since 2010 Government has recognised the significant impact that specialist support provision has on disabled children, and has continued to fund these services centrally through local authorities, until the future of school funding has been settled.

Unfortunately, the continuation of this support has not necessarily sheltered specialist services from the implications of reductions in government spending across local government and we have yet to see the Government’s final proposals for school funding which will have a definite impact on SEND provision.
Specialist Sensory Support Services

The work of Sensory Support Service staff is widely regarded as exemplary in the field of SEND. The dedication and commitment of staff is arguably unparalleled and the impact that they have on children with deafblindness/MSI and other single-sensory impairments is immeasurable.

Interventions
Deafblind/MSI children require a wide range of interventions to support their successful development. Factors such as communication, access to information, mobility and learning, are all significant barriers, which are closely linked and depend on each other for holistic development. These barriers can delay development, and result in later achievement and attainment than their age-matched peers, for example, disabled people are twice as likely to not hold any formal qualification than their non-disabled peers.10

Support
Sensory services play a really important role in supporting both the understanding and impact of early diagnosis and the provision of early intervention. Their contribution and value has been recognised by an array of independent work, including that delivered by the Bercow, Rose, Lamb and Salt Reviews, which all found compelling evidence that support services (such as deafblind/multi-sensory impairment services) can make a real difference to a disabled child’s achievement and attainment. Such services could include assessing and monitoring development throughout the time they work with the child, and ensuring that as a child’s needs change appropriate interventions and support continue to be put in place.

Specialist teaching
Mandatory qualified MSI teachers also advise on appropriate placements for children and young people and, when an appropriate placement has been secured, discuss reasonable adjustments to support children in education and learning. This often includes the provision of aids and equipment, through to the adaptation of the curriculum. Mandatory qualified MSI teachers also help with the development of education programmes and individual education plans. They may also provide direct teaching for particular aspects of the child’s education, for example learning tactile communication methods, such as tactile sign language, reading braille, using British Sign Language (BSL), developing listening skills or other augmentative communication methods.

One to one support
Deafblind/MSI children and young people often require highly specialised, individual support to enable them to participate fully in the learning environment – whether that is school, college or another setting. Given the unique impact of combined vision and hearing loss, accessing the learning environment does not stop at the classroom door, but extends beyond into the dining hall, playground, extra-curricular activities and into the home.

Many deafblind/MSI children and young people use one-to-one support workers, such as an intervenor or communicator-guide to enable them to successfully access the classroom, home and community environment.

One-to-one support helps to bridge some of the barriers that deafblind/MSI children and young people face in terms of accessing information, communicating with others by acting as an interpreter (for example using BSL or deafblind manual) and promoting mobility by acting as a sighted guide in a range of settings from school to shopping.
Reforming the Special Educational Needs and Disability framework

The SEN Green Paper set out a number of key proposals for overhauling the SEN system, these include:

- An outcomes focused approach
- Better identification of SEND at an early age
- A single assessment process and an Education, Health and Care Plan (EHCP)
- A ‘Local Offer’ of SEND support by local authorities
- The right to a personal budget
- Improved choice and control

The response of parents and professionals to the principles of the Government’s reform proposals were positive. Early identification is an important aspect of ensuring appropriate interventions are made at the earliest possible age, along with the engagement of agencies to support the child and family. Parents also welcomed the idea of a less adversarial system, as well as the concept of a single assessment process. The development of a single EHCP plan was welcomed, but concerns were raised that children might experience a loss of entitlement to existing provision. Parents and professionals both felt that strengthened accountability, and affirmation of legal entitlements and accountability mechanisms, were critical to securing and delivering the support set out in a single EHCP plan, along with certainty and consistency over what a Local Offer might look like across the country.

Intervenors

An intervenor’s role is significantly different from that of other support staff. They have specific training in understanding the needs of deafblind children and enable the individual to access the world around them as much as possible. An intervenor promotes the person’s social and personal development, encouraging their independence and facilitating communication with others. Intervenor support may be provided at home, in the wider community, in an educational or work setting – or a combination of these. Intervenor schemes are usually paid for by direct payments, individual budgets, social service, local health or education authorities.

Communicator-guides

Communicator-guides may also provide individual support for some deafblind/MSI children and young people. Mostly they work with young people who have acquired deafblindness. The role focuses on providing accurate communication and sighted guide support, and facilitating the young person’s access so that they remain independent. Communicator-guides work to the needs and requirements specified by the young person, whereas an intervenor supports and facilitates the child or young person’s developmental needs in addition to supporting the requirements of the person.
Our findings

Our research has looked to identify broad themes in the experiences of parents, their views on SEN reform, and the provision of sensory support services. In particular we sought to understand some key issues that lie at the heart of the existing SEN system and that the proposed SEN reforms seek to resolve. Themes which emerged from our research included:

1. Reform must improve the journey

The purpose of the proposed reforms are clearly stated: a more accessible system, less confrontation, earlier identification, better support from all agencies around the family, a new single assessment and EHCP plan, accompanied by greater choice and control. Sense supports these aspirations, alongside the children, families and professionals we work with. We want to see better outcomes and improved life chances for children and young people with deafblindness/MSI. Crucially we want the experience of the journey to those destinations to be a productive, supportive and person-centred one.

Sense, and the children and families we work with, want to see that the journey a family undertakes in any new system is effective, underpinned by specialist assessments and delivered by informed multi-disciplinary teams. There should be a well co-ordinated assessment process with support delivered by suitably qualified staff who are able to identify existing needs, respond to and plan for, future needs.

We know that the transition between school stages, and children’s to adult’s services present huge challenges to deafblind/MSI children and young people. These must be acknowledged, planned and resourced properly.
2. Early identification of deafblindness/MSI is critical

A child who is born deafblind or with MSI will face immense challenges from birth. Early identification is critical to ensuring that the correct support is put in place to enable deafblind/MSI children to learn, develop and achieve.

Evidence shows that where early diagnosis of deafblindness/MSI is made by a paediatrician a child is less likely to face delays in securing a statutory assessment. Conversely, we found that 75 per cent of children whose needs were identified later by a GP or health visitor experienced delays in obtaining a statement of SEN. Startlingly 9 per cent of parents surveyed by Sense reported that their child did not even have a statement of SEN.

Sense is aware that early diagnosis provides a medical model to address the analysis of a child’s needs. Whilst this is critical when looking at underlying complex health conditions, early identification needs to be part of a wider, holistic approach to the needs of the child and family.

Referrals need to be made to suitably qualified MSI professionals in education and social care at the point of diagnosis. There is a real danger that by only focusing on meeting health needs this will create an imbalanced approach to early childhood which could have severe implications for a deafblind/MSI child’s development. This means that regardless of the agency through which the child enters a new single assessment process, the process needs to address the holistic needs of the child involving all agencies.

Only 549 children with deafblindness/MSI were reported in Sense’s survey alongside low levels of identification by schools. The Care Quality Commission’s Special Review: Health Care for Disabled Children and Young People found five Primary Care Trusts reporting that they had no disabled children or young people with significant variation in numbers identified between the remaining 146 thus demonstrating the challenges surrounding early identification in clinical settings. It is unsurprising therefore that there is a significant disparity between our estimated prevalence of 4,000 children and the numbers of disabled children identified by agencies. A key challenge for government, locally and nationally, alongside partners in the NHS will be developing a robust system of identification that can be linked to a rapid passport into the assessment process.

For reform to be successful there are two significant barriers to early identification to tackle:

1. The medical conditions which may result in deafblindness/MSI are complicated by the low incidence nature, variety and rarity of conditions. Where a condition can be identified (such as Usher or Alström syndromes) the later onset sensory loss (hearing and sight) associated with these degenerative conditions means a diagnosis of deafblindness may not occur until much later in childhood – this has different, yet significant negative consequences for the young person and their family.

2. The low incidence nature of deafblindness/MSI means there is little to no awareness of the unique impact multi-sensory impairment has and the special educational need that results. We are concerned that expertise in this field is being developed in a fragmented way, often in reaction to diagnosis or identification, meaning significant variability across provision in geographical areas.
3. A single assessment process supported by a single plan

Sense welcomes the principle of a single plan drawing together education, health and social care needs. The Council for Disabled Children have suggested that a child may have as many as 32 separate assessments whilst growing up. This is a huge burden on any family, especially for a child with deafblindness/MSI who may find the experience of continual assessment highly traumatic and destabilising. Education, health and care agencies all play a critical role in supporting deafblind/MSI children and young people. An agency’s failure to deliver provision in any aspect of a child’s life will have far-reaching consequences, and impact disproportionately on their life and learning outcomes.

An existing weakness of the statementing system is the lack of awareness and understanding of multi-sensory impairment – one parent told us: “Sadly our local sensory teachers had no experience of Usher syndrome. At the first school planning meeting after confirmation of Usher it was agreed to hand over the drafting of the Statement of SEN to the Sense deafblind education specialist that I myself had drafted in, because no professionals locally knew what to do!”

In our recent parent survey 45 per cent of parents stated that they did not believe their child’s needs (as identified in a statement of SEN) were being met. Eighty-seven per cent of responses about the quality of the assessment processes cited a lack of understanding of deafblindness or multi-sensory impairments as a reason for a delay in obtaining a statement. From a previous survey Sense found 57 per cent of parents with children in the early years group reported an average seven month delay in obtaining a statement. This is potentially highly damaging given the need for specialist support, advice and interventions at this age.

Early identification and diagnosis should start a rapid response to an informed specialist multi-disciplinary assessment and an integrated plan that details critical interventions at the earliest point of need from all agencies. Parents tell us that an holistic approach that looks at the life of the child and the family is critical in ensuring the right packages of support are delivered to support success, health and wellbeing of the whole family. Sense believes that a child or young person should be entitled to a holistic EHCP, regardless of where or when they enter the assessment process.
4. Specialist support and multi-agency working

The complex nature and low incidence of deafblindness/MSI alongside associated health conditions, means that specialist clinical expertise is essential. Similarly, support and advice is critical to the child and their family, with a need for immediate referrals to secure specialist education assessments for a Statement of SEN, and assessments for social care under the Deafblind Guidance. Deafblindness/MSI is a unique disability, the net effect of the combination of both vision and hearing loss is more substantial than the sum of its parts. The Department of Health guidance recognises this:

“in which one sensory impairment impacts upon, or compounds the second impairment, which causes difficulties, even if, taken separately each single-sensory impairment appears relatively mild.”

The Departments for Education and Health both recognise the uniqueness of deafblindness/MSI, yet Government and local authorities are failing to capture accurate data on the number of deafblind/MSI children and their needs.

The landscape for both education and health is increasingly localised, with changes to commissioning and provision combined with reductions in resources for local authorities. We are concerned that the cumulative effect of poor, inaccurate data and the low levels of awareness of deafblindness/MSI amongst education, health and social care professionals will impact on the unique and significant needs of this low-incidence group of children.

Sense practitioners tell us that there are real tensions in the current system amongst different agencies when assessing support, making decisions about delivery of support and, crucially, taking responsibility for resourcing it. Ensuring an appropriate and balanced package of support is in place can be challenging in cases where a child with deafblindness/MSI also has complex health and social care needs. Our practitioners’ experience tells us there is potential for health and care needs to dominate over the need to provide appropriate educational support. Similarly, different agencies, with different funding pressures and outcomes frameworks will experience competing tensions over who will provide support and within what context.

Sense practitioners say that “it is not uncommon for agencies to lose sight of the child or young person at the centre of the process in establishing needs and support due to the complexities of clarifying joint funding arrangements, or debating which agency provides which aspect of support.”

The potential complexity of a deafblind/MSI child’s package of support from education, health and social care agencies is underpinned by the need for diverse specialist assessments to deliver the right kind of package to support development.
Sense believes that a ‘one assessment’ approach would limit the quality of assessment and provision. Professionals around a child need to have a shared assessment pathway underpinned by core quality standards to ensure that an holistic view is taken of the whole child and his/her needs.

Specialist support varies for deafblind/MSI children based on their unique needs. For many children one-to-one support is crucial, with communication being one of the biggest barriers to learning and development, others need interventions, such as specialist teaching input to physiotherapy. Our recent research found that deafblind/MSI children were provided with a wide range of support including:

- One-to-one communication support
- One-to-one medical support
- One-to-one British Sign Language support
- One-to-one general support
- Intervenor support
- Input from a mandatory qualified MSI teacher
- Input from a mandatory qualified teacher of the deaf
- Input from a mandatory qualified teacher of the visually impaired
- Teaching assistants
- Occupational therapy
- Physiotherapy
- Speech and Language Therapy
- Residential school
- Vision or Hearing Support/Services
- Specialist input from Sense
- After-school clubs

The wide range of support required by children with deafblindness/MSI demonstrates the breadth and complexity of need, and emphasises the importance of a multi-disciplinary, multi-agency approach, bringing specialist expertise together at the earliest possible stage. A single assessment process must give an entitlement to an EHCP, regardless of age or route of entry. This must be based on a clear and transparent discussion about funding, which informs firm commitments from all agencies to deliver agreed support with clear accountability mechanisms.
5. The importance of a lead agency and a key-working approach

The unique nature of deafblindness/MSI, coupled with the varied types of education, health and social care support required, must be met with a co-ordinated response from a range of agencies. These agencies must bring together a range of practitioners who have expertise and knowledge that will help the child develop through a key-working approach. The ‘outcomes focus’ set out in the SEN Green Paper means that joined-up support must be delivered early, effectively and efficiently to give both children and families the best possible opportunities to be healthy, happy and successful. The involvement of a number of different agencies with no clear responsibility for co-ordination is likely to cause problems in achieving this goal.

Sense practitioners suggest that a multi-agency approach to assessment of deafblind children and families will rely on the presence of a co-ordinating agency:

“[A coordinator] does not need to have in-depth knowledge about MSI but does need to know who to draw in…”19

Transitions throughout school stages and into adulthood are particularly fraught and challenging times for deafblind/MSI young people and their families. A local lead agency would be able to play a vital role in identifying local partners as part of transition planning to ensure that needs were understood, resources identified and robust plans put in place to enable young people to make effective and supportive transitions between child and adult services.

Sense recognises the important function of the duty to co-operate in ensuring momentum and giving purpose to local joint working, however this needs to work in tandem with the practical support of an agency responsible for identifying essential local partners. The duty to co-operate is even more significant following changes to health, education and local government funding and accountability structures. Resources will always remain a crucial part of delivering meaningful support, and parental confidence firmly rests on resources being in place so that professional agencies can work together to develop packages that make a difference to deafblind/MSI children and young people. Sense practitioners told us that successful multi-agency approaches involved:

“... joint funding from health, social care and education to appoint a team around the Child Coordinator – [a] designated role recognised by all parties.”20
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Acknowledgements

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Sense

Sense is a national charity that supports and campaigns for children and adults who are deafblind. We provide tailored support, advice and information as well as specialist services to all deafblind people, their families, carers and the professionals who work with them. In addition, we support people who have a single-sensory impairment with additional needs.

Getting in touch

To find out more about Sense and our work with children, or if you are interested in our campaigning or public policy work, please contact the Information & Advice Service who will ensure you are put in touch with the right person.

If you would like a copy of this report in another format – such as braille or audio CD, or if you would like it to be translated into another language, please contact us.

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