The Northern Ireland Draft Physical and Sensory Disability Strategy
A response from Sense
April 2011

Key points

- We welcome the recognition of deafblindness as a unique disability in the strategy.
- The implementation of statutory guidance in Northern Ireland on meeting the needs of deafblind people should be included in the action plan.
- A definition of deafblindness needs to be included in the strategy.
- Proactive action to raise awareness of dual sensory loss with GPs and other health and social care professionals is an essential part of identifying deafblind people.
- There is a need for specially trained staff to assess the needs of people with dual sensory impairments.
- Specially trained staff must be in place to offer the right support to deafblind people.
- The strategy must recognise that deafblind people have specific communication and mobility needs rather than personal care needs. Personal care needs must not be given priority over communication and mobility needs as they are of equal importance.
- Direct payments must be offered as one of the options for meeting needs and the amount of direct payment must be sufficient to pay for specialist support.
- In exploring personalised budgets, it will be essential to think about the needs of those with specialist needs and allocate resources accordingly.
- Sense is keen to work with the Department and Trusts to ensure that the strategy makes a difference to the lives of deafblind people through provision of training, publications and facilitating practice sharing amongst professionals.
Sense

Sense is the leading national charity that supports and campaigns for children and adults who are deafblind. We provide expert advice and information as well as specialist services to deafblind people, their families, carers and the professionals who work with them. We also support people who have sensory impairments with additional disabilities. We have established services and campaigned vigorously for change where it is wanted - earning us our worldwide reputation as the leading experts in deafblindness.

Our services in Northern Ireland include day services, which provide training in life skills, residential services, domiciliary care and personal support services for adults who are deafblind. We also provide a pre-school nursery, after schools and summer scheme service for children and information, training and advice services for deafblind people of all ages throughout the Province. Sense has worked with deafblind people and their families in Northern Ireland for 25 years.

Deafblindness

Deafblindness is a combination of both sight and hearing difficulties. The complex impact of dual sensory loss means that it is a unique disability. Deafblind people need support with communication, access to information and mobility. Based on independent research, there are an estimated 365,000 deafblind people in the UK.¹ The current deafblind population in Northern Ireland is estimated at more than 8,700 with a rise to more than 14,800 predicted by 2030.²

There are many causes of deafblindness. These include premature birth, birth trauma and rubella during pregnancy, which can cause babies to be born deafblind. Some genetic conditions also result in deafblindness. And any of us can become deafblind at any time through illness, accident or as we grow older. People who are born deafblind often have additional disabilities, including learning and physical disabilities.

About our response

Sense has been keen to ensure that the views of deafblind people, families and the professionals who support them are reflected in our response. We consulted directly with people from across these groups and have based our response on the key priorities emerging from these discussions.

¹ Robertson, J., and Emerson, E., Centre for Disability Research, 2010, Estimating the Number of People with Co-occurring Vision and Hearing Impairments in the UK
² http://www.sense.org.uk/Resources/Sense/Publications/Documents/N%20Ireland%20five%20yearly.xls
Unmet need among deafblind people and families

Deafblind people’s needs relate to support with mobility, access to information and communication; they do not primarily relate to personal care.

Evidence from deafblind people and their family members living in Northern Ireland suggests that they are offered the bare minimum of services, unless they ask for more. Then the general feeling is that you have to be prepared to fight to get specialist services. These feelings are compounded by a gap in support for communication and mobility needs, especially when support for personal care needs is readily available.

In addition, there is evidence which shows that some social workers are unaware of the issues affecting deafblind people. This can put strains on the relationships between deafblind individuals and social workers. One deafblind person stated:

“There is a lack of support, lack of understanding about what it is like to be deafblind.”

Due to lack of appropriate support, many deafblind people face boredom and isolation. This in turn can lead to problems with health and fitness and mental health. Therefore, deafblind people overwhelmingly feel that they would like opportunities to socialise with friends, visit relatives or take part in leisure activities on a more regular basis. Assessment and provision of services that meet communication and mobility needs is key to achieving this.

One deafblind person lives in shared supported living and has his own Motability car, but staff are not provided on a one-to-one basis. He said:

“It’s great living in my own house and the people I live with are nice but I wish I could just go out for a cup of coffee when I want to instead of waiting until everybody wants to go.”

Another deafblind man lives alone and receives care at home. Although he is very grateful for the support he has to make meals, he feels he lacks company and would like somebody to visit him for a chat, especially at weekends when he does not have chance to get out of the house. This sentiment is reiterated by another deafblind individual who said:

“I would just love to have a friend to call and visit me.”
Therefore, it would be appropriate to provide communicator guide services or support to get out and about and maintain relationships for deafblind people. Communicator guides act as the eyes and ears of a deafblind person and are trained to provide one-to-one communication support and guiding. The communicator guide’s role is to provide practical help with everyday tasks such as shopping, dealing with mail. Again, this requires staff to be properly trained in guiding and communicating with deafblind people. These services have shown to be vital in preventing deafblind people becoming isolated, feeling depressed and even developing mental health problems.

Some deafblind people also feel they would like support to enable them to have a job. Having the chance to work can be very empowering for deafblind people by allowing them to play a part in the community and support others. Deafblind individuals can meet the requirements of a job based on their skills, but may need support around some of the physical aspects of the work.

**Defining deafblindness in the strategy**

Sense welcomes the recognition of deafblindness as a unique disability in the strategy. However, within the strategy there is no definition of deafblindness which can be used to identify and assess people with dual sensory loss. This is vital in ensuring that the strategy’s aims to target deafblind people can be achieved.

The internationally accepted working description of deafblindness is:

“Persons are regarded as deafblind if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility.”

This definition is used in the Deafblind Guidance in England and Wales where this is clarified further:

“The term dual sensory loss can be used interchangeably with deafblindness denoting the fact that combined losses of sight and hearing are significant for the individual even where they are not profoundly deaf and totally blind. It is the way in which one sensory impairment impacts upon or compounds the second impairment, which causes the difficulties, even if, taken separately, each single sensory impairment appears relatively mild.”

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3 Department of Health (1995) Think Dual Sensory
It is also vital to emphasise the uniqueness of deafblindness in relation to single sensory impairments and driving this home with professionals; this description from a deafblind person can be useful in this:

“If you think of deafness as the colour yellow and blindness as the colour blue, when you mix the two together you don’t get yellow-blue but a completely different colour – green.”

The strategy must also emphasise that deafblind people are present in all age groups, including children, although the significant proportion of deafblind people are older adults.

**Issuing guidance on meeting the needs of deafblind people**

A piece of statutory guidance for Northern Ireland could set out how community care services should operate for someone with a dual sensory loss. In the ten years since the Deafblind Guidance was introduced in England and Wales, it has made a significant difference to services for deafblind people. For example, the number of deafblind people in England receiving communicator guide support has increased year on year since the Deafblind Guidance was introduced. This shows that statutory guidance is a key part of encouraging positive change, as well as giving a clear framework for the Health and Social Care Trusts. It is also important to ensure there are members of senior management whose remit includes specific responsibility for services for either deafblind children or adults or both.

**Identification of deafblind people**

Sense welcomes the draft strategy’s recognition for a need for greater emphasis on earlier detection of people with disabilities. The Health and Social Care Trusts must take proactive approaches in identifying deafblind people.

Where local authorities in England and Wales have been proactive in identifying deafblind people, an increased number of people have had their needs assessed and services put in place. The relevant agencies cannot wait for deafblind people to make contact as, for example, many older people with dual sensory impairments are unlikely to contact social services and individuals may not have contact with the right part of social services departments; for example they may have contact with the learning disability or older people’s team.

In order to do this, there is a need to raise awareness of deafblindness with health and social care professionals such as GPs, nurses, children with disabilities teams, learning disability and older people’s teams. The generic professionals should be able to spot indicators of dual sensory loss.
If this is the case there must be a clear referral route to ensure individuals are assessed appropriately for social care support. Professionals should know how to contact the local HSCT’s sensory team and dual sensory loss specialist (where they exist).

**Assessing the needs of deafblind people**

Assessments are very important and are key to ensuring the funding is in place for suitable services. Sense welcomes the recognition in the strategy that assessments of deafblind people are carried out by properly trained personnel. Our evidence shows that very few dual sensory impaired people in Northern Ireland have received a specialist assessment.

Feedback we have received highlights issues with the current Single Assessment Tool. The multiple choice answers allow very little room to add the specific needs of a dual sensory impaired person. Generally, the assessment will be carried out by a person who has an expertise in one sensory impairment, but there may be limited consultation with a person who specialises in the other sensory impairment.

Assessments are also, on occasions, carried out by staff from the learning disability teams. This can mean that some of the questions in the assessment are inappropriate to people with sensory impairments. For example, as part of the learning disability assessment, a person could be asked: “If you saw an envelope in the street, what would you do with it?” This is an irrelevant question for a person with a visual impairment who may not even be able to see the envelope. Their inability to answer this question may impact on them being viewed as having a learning disability.

The consequences of inadequate assessment are that:

- The unique impact of deafblindness is not recognised;
- The communication and mobility needs of deafblind people are missed;
- Parents experience long delays when trying to ensure their child receives early intervention, prompt assessment and access to the right services;
- Deafblind people are mistakenly thought of as having learning disabilities;
- Where a deafblind person does have learning disabilities, the impact of the dual sensory loss is ignored or not fully recognised;
- Deafblind people do not receive appropriate services;
- Resources are wasted on inappropriate services.
To overcome these issues, Sense recommends that each Health and Social Care Trust ensures that deafblind people can be assessed by professionals with specialist knowledge of deafblindness, whether that be by staff employed by the Trust or an external agency. For this to be achieved, more members of staff will first need to be trained to carry out assessments. We appreciate that this will take time and resources. Therefore, we are concerned that the target for completion for this in the Action Plan of December 2011 is unrealistic.

**Direct payments**

Sense welcomes the idea in the strategy to increase awareness of direct payments. Our evidence shows that, if implemented correctly, direct payments can help deafblind people to live independently in their own homes. For example, one older deafblind man uses direct payments to pay for a support worker of his choice who has some specialist knowledge of deafblindness and is therefore able to communicate with him effectively.

Unfortunately, we know from our work with deafblind people that there are some key issues in ensuring that direct payments are offered successfully to deafblind people and families and they have genuine choice of how their needs are met. The key factors for success include:

- Individuals must have a real choice about whether to receive direct payments or not and what level of responsibility they take on when receiving direct payments;
- The rate of direct payment must be enough to purchase specialist support to meet assessed needs;
- Support services for people who receive direct payments must be relevant and accessible to deafblind people and families;
- A sufficient level of specialist services provided by organisations and individuals that individuals can purchase.

There is also a current feeling among the families and carers of deafblind people that direct payments are used as a last resort when a Trust is not willing to find or manage a service.

Additionally there is still a need for a 'safety net', so if support workers with specialist skills are away or off sick, a replacement with adequate training can step in to support the deafblind person. This is important in both ensuring individuals’ needs are met and carers do not experience unsustainable demands.

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**Personalised budgets**

We agree that it is essential to explore the implementation of personal/individual budgets and self-directed support as exists in other parts of the UK. In England, we have seen very significant problems in ensuring that the amount allocated to a personal budget is sufficient to meet eligible needs, especially where deafblind people require specialist services, which may be more expensive. It is critical that people receive sufficient budget to adequately meet their needs. Too often deafblind people, who may need support from someone with specific communication skills, receive an allocation on the same basis as someone who requires a Personal Assistant with no specific training or qualifications. This results in those with specialist needs receiving less support than those whose needs are cheaper to meet. Receiving an inadequate budget does not empower individuals.

In England local authorities have developed Resource Allocation Systems (RAS) to determine an indicative budget. Too often the questionnaires used do not take account of deafblind people’s needs, resulting in inadequate budgets to meet eligible needs. Sense is part of a group of organisations who have led work in pointing out the flawed nature of the RAS.\(^6\) We strongly recommend that RAS are not used in Northern Ireland to determine the size of personalised budgets.

If in the future personalised budgets are pursued in Northern Ireland it will be vital to ensure that there is:

- Clarity over what is meant by the term personal budget;
- A clear principle that the budget must be sufficient to meet all eligible needs;
- That there must be choice over how the budget is delivered, whether by direct payment or a directly provided service.

A personal budget may be taken as a direct payment or not and the HSCTs should be aware of this issue and clearly explain it to those individuals exploring this option. For deafblind people it is essential that the ability to ask the HSCT to provide services is retained, since the process of holding and managing a budget can be a challenge that people do not wish to take on.

\(^6\) Sense et al, 2009, Putting Everyone First, [http://www.sense.org.uk/help_and_advice/social_services/putting_everyone_first](http://www.sense.org.uk/help_and_advice/social_services/putting_everyone_first)
Information and support services for people who use direct payments or personalised budgets

It is vital to ensure that people have access to the full range of ways to meet their needs, whether via a service from the council, or direct payments managed by themselves or others on their behalf. In other words deafblind people and families must be able to access information about the different services available to them in order for them to make the right choice.

Many individuals managing their own support will request some level of support and it is essential that relevant and accessible support is available. There are currently only two Centres for Independent Living in Northern Ireland, which can offer such support. Consideration should be given to the mobility and communication needs of deafblind people which may make access to these valuable services extremely difficult. Training should be offered to Centres of Independent Living providing them with information about deafblindness and what this means to the service they offer. Sense successfully ran training for Centres of Independent Living in England.

Recommendations for inclusion in the strategy

- The implementation of statutory guidance in Northern Ireland on meeting the needs of deafblind people should be included in the action plan.
- A definition of deafblindness needs to be included in the strategy.
- Proactive action to raise awareness of dual sensory loss with GPs and other health and social care professionals.
- A plan to specially train staff who can then assess the needs of people with dual sensory impairments.
- A recognition that specially trained staff must be in place to offer the right support to deafblind people.
- The strategy must recognise that deafblind people have specific communication and mobility needs rather than personal care needs. Personal care needs must not be given priority over communication and mobility needs as they are of equal importance.
- Direct payments must be offered as one option for meeting needs and the amount of direct payment must be sufficient to pay for specialist support.
- In exploring personalised budgets, it will be essential to think about those with specialist needs and allocate resources accordingly.
- Sense is keen to work with the Department and Trusts to ensure that the strategy makes a difference to the lives of deafblind people through provision of training, publications and facilitating practice sharing amongst professionals.
Recommendations for inclusion in the Action Plan

We welcome the specific inclusion of identifying, assessing a providing appropriate services to deafblind people as part of the Action Plan. However we feel that this needs to be expanded over the period of the implementation of the strategy in order to systematically improve provision for deafblind people.

<table>
<thead>
<tr>
<th>Actions</th>
<th>Expected outcomes</th>
<th>Lead Responsibility</th>
<th>Target completion</th>
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<tbody>
<tr>
<td>Introduce statutory guidance on meeting the social care needs of children and adults</td>
<td>Deafblind children and adults have statutory rights to specialist assessment and appropriate services, including one to one services. Trusts will have a duty to identify, assess and provide appropriate services to deafblind people.</td>
<td>DHSSPS</td>
<td>End of year 1</td>
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<td>Awareness campaign with health and social care professionals explaining how to recognise indicators of deafblindness</td>
<td>Health and social care professionals are better equipped to spot a person with dual sensory loss. An increase in referrals of deafblind people to Trust sensory teams.</td>
<td>DHSSPS</td>
<td>End of year 1</td>
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<td>Provide training to professionals in communication with deafblind people</td>
<td>Health and social care professionals can work more effectively with deafblind people.</td>
<td>HSCTs</td>
<td>In place from end of year 1 Ongoing</td>
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<tr>
<td>Train staff to assess deafblind people</td>
<td>Deafblind people receive a specialist assessment of their communication and mobility needs.</td>
<td>HSCTs</td>
<td>In place from end of year 2 Ongoing</td>
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<td>Provide specialist services for deafblind people</td>
<td>Deafblind people receive services that meet eligible assessed needs as identified through a specialist assessment.</td>
<td>HSCTs</td>
<td>Ongoing expansion of current specialist services from</td>
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Consider the introduction of self directed support / personalised budgets

Commission a feasibility study, including a key explanation of learning from other parts of the UK and the impact on people with dual sensory loss and those with specialist support needs.

DHSSPS

End of year 2

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