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## Shaping the Future of Care together

A Sense response

### Summary of key points

- Deafblind people must get access to specialist assessment and sufficient support.
- Support should ensure that people have a reasonable quality of life, including the ability to get out of the house, interact with others and engage in leisure activities and work.
- Government intervention may be needed to ensure sufficient specialist services are available in all areas.
- Reablement is wider than just people leaving hospital and should include support to anyone with changing needs who would benefit.
- There should be a national assessment and eligibility system to end the postcode lottery.
- Information and advice services must be accessible to deafblind people who may need information in different formats and/or interpreters in order to access such services.
- In addition to information and advice, people need advocacy to ensure that they can access their rights.
- There must be a fair funding system where what people pay in is related to their ability to pay and what they receive is related to their needs.
- Benefits such as Attendance Allowance and DLA should be maintained to support prevention.

## 1. 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.

Our services include on-going support for deafblind people and families. These range from day services where deafblind people have the opportunity to learn new skills and Sense-run houses in the community – where people are supported to live as independently as possible. Our communicator-guides offer a vital lifeline to deafblind people living in their own homes. We also provide leading specialist advice, for example on education options and assistive technology.

Sense has worked with deafblind people and their families for nearly 60 years. We have established services and campaigned vigorously for change where it is wanted - earning us our worldwide reputation as the leading experts in deafblindness. Last year we provided 87,000 hours of communicator guide support in the community and 24 hour support to 296 congenitally deafblind adults with complex needs.

Our response is based on this experience of service provision and our knowledge gained through providing information to and campaigning with deafblind people and families. In addition we have consulted out members on the specific issues contained in the Green Paper through discussions, focus groups and a survey. Many of the quotes we include came from these responses.

Deafblindness is a combination of both sight *and* hearing difficulties. Most of what we learn about the world comes through our ears and eyes, so deafblind people face major problems with communication, access to information and mobility. People can be born deafblind, or become deafblind through illness, accident or in older age.

The commonest cause of deafblindness is older age. Around 4.6% of the over 75 population are estimated to be deafblind<sup>1</sup>. Any system which is put in place to support an ageing population must take account of the fact that a significant number of those it aims to support are deafblind; services will need to take account of this fact. Deafblind older people cannot easily use mainstream services unless those services are aware of how to adapt to the needs of a deafblind person. If this is their only option they will be failed, with consequences both for the individual and for their future support needs.

## 2. Introduction

Sense welcomes the Green Paper as it raises some crucial issues about the way social care provision needs to change. Social care has had too low a profile for too long. There are some difficult realities that need to be faced by Government and by

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<sup>1</sup> Estimated by Sense (2007) based on Astrid Fletcher, London School of Hygiene and Tropical Medicine, and others, "MRC trial of assessment and management of older people in the community"

the country as a whole. This can only be done if social care is given the same level of importance as the health service or education. We are pleased to see that the Green Paper has begun to raise the profile of social care in a way which we hope will contribute to this.

Social care is vital to deafblind people of all ages. By definition, deafblind people experience problems with access to information, communication and mobility. They will therefore need social care support to address these barriers to being able to lead full and active lives as citizens within their local communities. Without such support they risk becoming prisoners in their own homes, isolated from friends and family. Any debate on the future of social care needs to be able to meet these needs, not just those for help with washing and dressing and other traditional “personal care” support.

In our view the questions about the future of social care fall into 3 areas: how should social care be organised; what should people be expected to pay into the system; what should people expect from the system? Our response addresses each of these issues in turn.

### **3. How should social care be organised: Chapter 3 The vision for the future**

Sense welcomes the proposal for a National Care Service underpinned by national rights and entitlements. There is increasing opposition to the postcode lottery that currently exists within social care. We agree with the six broad areas that people should be able to expect from such a service. There is one thing that we think is missing, which is advocacy. In addition to information and advice, people need support to navigate the system and make representations in order to ensure that they are receiving the appropriate services to which they are entitled.

#### **3.1 Prevention services**

Sense supports a real and sustainable commitment to meeting individuals’ low and moderate needs. A number of hours of support for deafblind people can maintain good physical and mental wellbeing, as well as preserve independence and involvement in their local community. Prevention must encompass healthy living, access to exercise and falls prevention. For deafblind people, preventative services and support can take on many forms. For this reason, we call on the Government to consider what can be a preventative service in the broadest terms.

If deafblind people do not get the support they need, the impact on their physical and mental health can be profound. For example, research has found that older people with dual sensory loss (by far the largest number of deafblind people) are more likely to develop certain additional health conditions such as stroke, arthritis, heart disease, hypertension and depressive symptoms. They are also more likely to have

falls.<sup>2</sup> By definition, deafblind older people will be more likely to have difficulty with all the activities recommended in order to remain healthy: moderate exercise, mental stimulation, maintaining social contact and healthy eating. We estimate that the cost to the NHS of these additional health conditions is £365,000,000.<sup>3</sup> Offering deafblind older people the right preventative support could reduce this cost and crucially preserve their wellbeing.

Many deafblind people will benefit from one to one support staff such as communicator guides who have knowledge of the impact of deafblindness and the right skills such as in guiding and communication support. Many Sense members' responses to our consultation on the Green Paper called for access to gyms, exercise classes, leisure facilities and social groups. It can be difficult for deafblind people to access such activities for various reasons. Classes often depend on being able to watch and copy a tutor, hearing aids can fall out during some activities, induction loops are unavailable or staff have a low level of deafblind awareness.

### **Case Study**

*John is Deaf and visually impaired. His GP gave him an exercise prescription so that he could go to the local gym free of charge. However, staff at the gym were concerned about John's health and safety and said that he must go with a communicator-guide. However, social services would not pay for a communicator-guide to accompany John to the gym. Therefore, John was unable to make use of his exercise prescription.*

It should be clear that access to these services will have a significant preventative impact, particularly in promoting good physical and mental health and specifically in preventing falls. Deafblind people may need one to one support to access such services, though it will also be important for staff in these services to be deafblind aware.

Equipment can have a preventative impact, but should be used in partnership with human contact and support such as communicator guides. For example ensuring a deafblind person has access to email and the internet can support them to maintain contact with family and friends as well as perform some household tasks such as shopping. But this kind of provision should be used in addition to, rather than as an alternative to, human support.

Indeed, we are concerned at the focus of the Green Paper on using telecare to keep people 'safe' in their homes. Many deafblind people may be able to maintain personal safety in the home, whereas accessing the community outside of the home can be challenging. Such barriers for deafblind people can have a profound impact on both their physical and mental health. This kind of access to the community is essential in providing preventative services to ensure individuals have good physical and mental health; many deafblind people will need one to one support to achieve this.

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<sup>2</sup> Crews J.E., Campbell V.A., 2004, Vision impairment and hearing loss among community-dwelling older Americans: implications for health and functioning. American Journal of Public Health; 94 (5); 823-9

<sup>3</sup> Sense, 2008, Sense paper on the health of deafblind older people. Cost estimates are based on government statistics for specific conditions.

While we recognise the role that telecare can have, the government must ensure provision of appropriate equipment for deafblind people. This may range from canes to Braille displays for computers, as well as more mainstream telecare products. Prevention, and specifically telecare, is not simply about keeping people safe in their own homes. Accessible equipment can enable independent living for deafblind people, yet too often we come across equipment that may be accessible for people with single sensory impairments, not dual sensory loss. The majority of deafblind people do have some remaining hearing and/or vision but equipment must be able to be used through tactile methods too. Provision for tactile operation can enable individuals to use make better use of any remaining sight and/or hearing.

We recognise the need to support individuals on leaving hospital, and for deafblind people this may include a number of hours of support from a communicator guide, as well as appropriate and accessible equipment. However, reablement must be seen in much broader terms. A person who has recently lost a significant level of sight, for instance, needs reablement to continue to access their local community.

Therefore, government must address the shortage of reablement/rehabilitation workers. Guide Dogs have noted the low level of rehabilitation workers in relation to the incidence of sight loss<sup>4</sup> and we can conclude that the number of those with knowledge of dual sensory loss is lower. Government must address this shortage in the long-term.

To achieve better outcomes for individuals there must be adequately resourced and universally available prevention services. Prevention must be seen as a broad spectrum of services and government and professionals must be inclusive in what is considered an appropriate preventative service. Deafblind people who require one to one support to lead healthy and active lifestyles should receive this support. There should be ring-fenced funding for prevention services to ensure they are not diverted into general social care services.

### **3.2 National Assessment**

In general Sense members were in favour of a national assessment system, seeing it as a step towards ending the postcode lottery, as well as solving the difficulty of people moving from one area to another. However, assessment is only the first step in the process. For those with complex needs or requiring skills that are in short supply or are expensive, agreeing on a package of support can be the most difficult part of the process. To avoid a postcode lottery it must be clear that not just the assessment of need but also the entitlement to services to meet that need should be national.

There would need to be local flexibility in terms of exactly what support was provided, but the basic entitlement should be equivalent, leading to the same outcomes.

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<sup>4</sup> Guide Dogs, 2008, Independence and well-being in sight

### **Case study**

*A Sense member receives a communicator guide to support him with a range of activities, one of which is shopping. If he moved to an area where the shops were much further from his house, his need for support to go shopping would increase, to take account of the increased travel time. There would need to be sufficient local flexibility to take account of this, but the outcome – that he is able to do all his shopping himself – should be achieved wherever he lived.*

### **3.3 Information and advice**

Information and advice play an essential role in prevention and personalisation, making them successful for everyone. Information can enable individuals to take control of their lives as well as prevent unmet needs escalating; appropriate and accessible information provision is a preventative measure. Information could be about individuals' rights, as well as what services are available at a national and local level. As noted above, this service also needs to include advocacy to help people ensure that they receive their entitlements.

It is vital that efforts to make information easier to access recognise the needs of people with dual sensory loss. Indeed one of the major impacts of dual sensory loss is that individuals have less access to information. Too often we hear of cases where individuals learn about services by chance or because they have been lucky to meet someone who is well informed.

*'I wasn't told about blind club, my daughter lived opposite a man who went, that's how I found out about it.'* (Deafblind woman)

Most deafblind people, especially deafblind older people, do not have their first contact with specialists in deafblindness. So it is often up to mainstream services to be able to identify when someone may be deafblind, know how to offer them or their families the right information about services and entitlements and how to refer on for specialist support (to the local social services sensory team). Information on rights and entitlements should include deafblind people's right to a specialist assessment and one to one support.

Depending on where deafblind people live, there may or may not be appropriate services available. It is therefore key that an information and advice service can also offer support if the right service is not currently available locally and the different steps that can be taken to meet their needs. This may include the local authority taking action to commission a service, the local authority or individuals talking to existing providers to see if they can offer a new service, as well as more personalised ways of buying support. It should be noted that even if individuals do take more control of their support, the local authority maintains a duty to ensure the local market can meet everyone's needs.

We know from experience that deafblind people often struggle to get the support to which they are entitled. Information and advice needs to be supplemented by advocacy services to assist them in challenging the barriers to accessing their rights.

Information and advice services must be accessible for deafblind people. They should not be solely web or telephone based. For some deafblind people face-to-face communication will be the only effective way to communicate information. This could take place in a service's premises or in a deafblind person's home. Being accessible is not a one-off task; with changing technology, services need to keep up to date with the changing methods that are used by their customers. Information providers should recognise that individuals' needs change too and they may request information in different formats.

Information services must also be able to identify individuals with sensory loss. Often deafblind people do not know about their rights or the kind of support that could be useful to them. Services must be proactive in thinking about whether individuals may have sensory impairments and offering advice accordingly. It can be as simple as making sure someone knows about the formal and informal ways to register as having a single or dual sensory loss. This can open up access to services and contact with the right professionals as well as peer support opportunities (where they exist).

*'They didn't even register me as deaf until I requested it.'*  
(Deafblind person)

The personalisation agenda has further exposed the lack of information for disabled and older people or the confusion that can occur when people receive inappropriate or partial information. Yet more awareness of this issue has not led to enough concrete action. We are calling for a long-term commitment to adequately fund a universal and sustainable information, advocacy and advice service that is accessible to deafblind people.

### **3.4 Personalised care and support**

Sense supports the aim of providing a support package which is based around the person's individual circumstances and designed by them. However, the way in which this has been implemented thus far is problematic and sometimes not delivering on this aim.

Sense believes that for a deafblind person to receive personalised support requires the following:

- Assessment and advice from a specialist in deafblindness, particularly for those who have recently become deafblind.
- Assistance to plan their support from professionals who listen to their views and understand the impact of deafblindness on a person's life.
- Sufficient resource to meet support needs effectively.
- Where the person wishes to manage the budget themselves, support from a brokerage service that can meet their access needs.

We do not feel that the current transformation of services is delivering effectively in relation to these.

## Assessment

Self assessment works well for those with a long term condition who know their own situation and what works for them. For those with complex needs, or those recently experiencing sensory loss, specialist professional input to the assessment is essential to ensure that people understand what is possible for them. It is essential that everyone who wants one receives an assessment from a professional and for those with a dual sensory loss, that this assessment is carried out by someone specifically trained to do so.

## Support planning

Too often people are not listened to by social workers, rules around funding streams are used to restrict what people can do rather than to legitimately control public spending. Changing this requires a culture change amongst professionals. We do not believe that introducing a mechanistic Resource Allocation System (RAS) will achieve this change. Indeed in our view the tick box nature of some RAS works against this. People receive their “personal budget” but are still told of restrictions on the way it can be spent. What is needed is a culture change within social care, so that social workers can be flexible in how to meet a person’s needs, provided that this will still achieve the desired outcome.

This restrictive culture is linked to lack of resources, as local authorities struggle to restrict spending. It is hard to see how a more flexible approach can be encouraged without also addressing the funding of social care.

## Resource allocation

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 PA with no specific training or qualifications. This results in those with specialist needs receiving less support than those with cheaper to meet needs.

Whatever system is used to decide on resource allocation must take into account not just an assessment of “need” but also what it would cost to meet that need. The RAS, which assesses “need” by a number of questions and then allocates a cash sum according to the answers does not adequately measure the resource needed by many disabled people. The areas of need covered by the questionnaires differ, and many omit crucial aspects of support needed by some people. For deafblind people, for instance, less than half of the questionnaires seen by Sense ask about communication, almost none ask about mobility outside the home. The system also fails to reflect the needs of those with complex or expensive to meet needs. No account is taken of the difference in cost of meeting what appears to be a similar need, where specialist skills, such as sign language are required, with the result that those with complex needs lose out.

Since a RAS asks a set number of questions, there is a maximum possible allocation, leading to an effective cap on funding. Those with very high levels of need also find that the maximum amount allocated is insufficient to meet needs. A

standard national resource allocation system based on this approach will mean that deafblind people do not get sufficient support. At best a RAS can only give an indicative amount which may well need to be adjusted in the light of support planning and assessment.

### Brokerage

The availability of brokerage services which can meet the needs of deafblind people is critical to their ability to benefit from a personalised approach. Deafblind people will need a brokerage service which can provide information and services, such as payroll support, in Braille or email; which can support a person who has sign language as their first language; which can support a person to get sufficient funding for a suitably trained support worker. Those with complex needs, who may have no formal communication, will need support from a service which understands the complexities of supporting someone with such complex needs and what an excellent service for such a person would look like. This is unlikely to be provided by a generic service which supports everyone who receives a personal budget.

## **4. How should social care be organised: Chapter 4 Making the vision a reality**

Clearly no one could disagree with the proposals that the National Care Service should provide services that are joined-up, give you choice around what kind of care and support you get, and are high quality. However, there are some significant challenges to achieving this for deafblind people.

### **4.1 More joined-up working**

The care and support needs of deafblind people are diverse and many different services have important roles to play in enabling deafblind people to live the way they want to. This includes social care, healthcare, disability benefits and housing, which are widely recognised as being part of the care and support system. However, it also includes other services such as information, advice, advocacy, leisure, transport, highway design and maintenance, and so on. Although not traditionally thought of as part of the care and support system, these can have big impacts on people's ability to access their local community and live independently. There needs to be greater cooperation and collaboration between all services. In particular, there needs to be a shared understanding of the quality of life that a deafblind person has a right to, such that all services are working towards the same outcomes for an individual.

The earlier case study on page 4 gave an example of someone unable to use his exercise prescription. If the GP, leisure services and social services had worked together towards the common outcome of John being able to exercise, between them they should have been able to find a solution.

The needs of deafblind people are complex and unique and, therefore, it is vital that deafblind people's needs are assessed by people with specialist knowledge of deafblindness. It is also important that people carrying out assessments understand

the possibilities in all the different areas of care and support. Therefore, although collaborative working towards joint outcomes is important, the procedures for joint working must ensure that people with specialist knowledge in all areas are involved.

## **4.2 A wider range of care and support services**

This is a critical issue for deafblind people. Choice of services is important and there must be a genuine choice between high quality, suitable services. Choice is critical to the success of personalisation. There is no point being given a budget to spend flexibly on whatever services you choose if the services you need do not exist in your area. This is the situation too many deafblind people are faced with. Across the country there is a shortage of the specialist services, such as communicator-guides and intervenors, that deafblind people need. If deafblind people are to have choice in the services they use, this shortage must be addressed.

### **Case Study**

*Lucy is blind and has a progressive hearing loss. Until recently she communicated using clear speech but now uses deafblind manual. Lucy uses direct payments to employ communicator-guides but has been unable to find qualified people. When she was able to communicate using speech she felt able to train her own staff. However, now she is using deafblind manual to communicate it is much harder to find people with the potential to learn deafblind manual to the necessary standard, and much harder to train them herself. She receives no assistance with finding qualified people or with training her staff. Her support has become less effective and more problems have arisen as a result.*

There is no guarantee that the market will develop services to meet the needs of deafblind people. Specific skills are needed to deliver such services, such as skills in communication and guiding. British Sign Language, for instance, may take many years to learn to a sufficiently high standard, requiring significant investment of resource. This, combined with the relatively small numbers of deafblind people means that intervention by local or national government is likely to be required in order to ensure sufficient choice of services. Local authorities must also be able to provide funding for training so that where an individual needs a service that is not currently available in the area, new staff can be recruited and trained to provide it. Where there are low numbers of people needing a particular specialism, there may also be a need to develop these services across local authority boundaries.

It is vital that the funding made available to deafblind people is sufficient to cover the higher costs of specialist support. A communicator-guide or intervenor, who needs specialist training and skills, such as hands-on signing or deafblind manual, is more expensive than a personal assistant who needs no specific skills or qualifications. As we have discussed above, there is a risk that resource allocation systems do not take account of the extra cost of specialist support and so leave deafblind people unable to afford the specialist support they need. Choice must be between appropriate specialist services and funding must be adequate to allow this.

### 4.3 Better quality innovation

High quality, specialist services are essential for deafblind people. The way in which the proposed independent body looking at the evidence base for support decides on priorities is crucial. It must not focus only on seeking evidence for cost savings. Determining what services provide an increased quality of life for disabled people is also important. Relatively low incidence disabilities, such as deafblindness, must also not be excluded.

Any advice or decisions about what services work best must take appropriate account of the unique and specialised services needed by deafblind people. This means that any evidence gathering or research must include deafblind people, their families and specialists providing services to deafblind people. Deafblind people are a seldom-heard group. There are many reasons for this including inaccessible research methods. For example, deafblind people are unlikely to respond to a questionnaire if they cannot read it or have no accessible way to complete it. Similarly, many deafblind people cannot take part in a telephone survey. To take part in face-to-face interviews or focus groups many deafblind people need support such as an interpreter and/or communicator-guide. We are aware of a number of deafblind people who have been unable to participate in this kind of research because it has been inaccessible to them and so their views have not been heard and their needs subsequently ignored.

These issues are critical to any research related to older people. The numbers of older people with a dual sensory loss are high. Any research with older people must take steps to ensure that those with single and dual sensory loss are represented in proportion to the numbers expected in the general population.

There is an increasing move towards consultation taking place through user-led organisations. Deafblind people are often not represented within these organisations. This is, at least in part, because there is generally no funding to pay for the interpreters and communicator-guides that deafblind people would need in order to get involved with user-led organisations. In addition, people who are born deafblind often lack formal communication skills and are unable to participate in this way. In such cases it may be more appropriate to seek the views of family members or service providers but this is rarely done by user-led organisations.

#### **Case Study**

*Lucy, who is deafblind, was invited to participate in a Delivery Empowerment Board, which aimed to involve service users in planning, delivering and evaluating local services. The organisers agreed to provide electronic notetakers to enable Lucy to communicate during meetings. However, they refused to provide a communicator-guide to travel with Lucy to and from meetings. This meant that Lucy had to choose between not taking part, paying a communicator-guide out of her direct payments or paying a communicator-guide out of her own money. She chose to use some of her direct payments to pay for a communicator-guide but this meant that she was disadvantaged by having fewer hours of support for meeting her assessed needs.*

Ensuring that the needs of deafblind people are properly considered is vital for any body aimed at maintaining or improving quality.

## **5. Funding options: Chapter 6**

It is clear that additional funding is required to meet the future care needs of the population. This is an unavoidable truth which must be faced up to honestly and openly by Government. It is also essential that Government introduces a system which will solve the problem in the long term. Sense welcomes the Government's desire to find a funding system that is "fair", and the rejection of the option that people simply pay for their own care with no support. We do not believe that this would have been seen as fair by the general population.

The desire for a system which is fair is strongly supported by our members. Those who responded to our consultation on the Green Paper made it clear what they consider to be fair. A fair system of funding care was seen as one where everyone pays into the system, but what they pay is related to their ability to pay. Everyone can take out of the system. What they take out is related to their needs and not to where they live, with any charges leaving a person with sufficient savings and income for a reasonable quality of life.

We would therefore assess any funding system against the following criteria:

- Will it cover everyone?
- Will people's contributions be related to their ability to pay?
- Will people's entitlements be related to their need, not disadvantaging those with expensive needs?

### **5.1 What people should be expected to pay in**

The simplest way to fund the system in this way would seem to be through taxation/National Insurance, and a number of our members stated that they thought either tax or National Insurance were the way to achieve this. This is backed up by the report of the Government's own engagement findings.

*In general, participants felt that government is best placed to collect and administer funding for care and support.<sup>5</sup>*

There was a great deal of concern amongst our members about the fact that older people, who were seen as having "paid in all their lives" were then going to be expected to pay again. Successive governments over the last few decades have allowed what people pay in to remain static, while the costs of care rise. The result of this is that people believe they have paid in a sufficient amount for a reasonable level of support but in fact have paid only for a bare minimum safety net. We believe that the only way to avoid this in future is for people to pay into a system during their working life with the amount they pay adjusted to take account of any changes in the level of contribution required to ensure a good entitlement to services.

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<sup>5</sup> Department of Health & Ipsos MORI (2009) The case for change – Why England needs a new care and support system: Engagement findings

We believe that in the long term some form of ring-fenced, government backed compulsory National Insurance, with contributions based on income and regularly reviewed is the only way to achieve the aim of a funding system that is fair and affordable in the long run. If it was clear what people would be paying in and what they would get out, we do not believe this would be as unpopular as general taxation which might be subject to the whims of future governments. We urge that in future discussion about the future funding of care, this option is included and considered.

The current generation of older people have significant wealth held in property, having benefitted from an era of house price boom and easily obtainable mortgages. We believe the options considered by Government aim to release this capital into the system, which in the short term could be successful. However, we do not believe future generations will be in the same position. Therefore, even if Government selects one of the three options for the current generation, we believe it should see this as temporary and put in place a system of working age payment, as outlined above.

Of the three options considered by Government, Sense prefers the comprehensive system, but with Government providing the insurance. This appears to be the most likely to meet our three criteria. This option would need to be designed to be “fair”, in other words that what people pay in should be related in some way to what they could afford. As it is put forward in the paper the payment would be a flat amount with everyone paying in the same, which would in no way be seen as fair. A payment system such as a percentage of estate on death would be more likely to be considered fair.

We do not believe that a system based on private insurance can work. One group who would not be able to benefit would be those with a deteriorating condition. They may live their working lives with low or even no support needs, but as they age their needs increase. Many people with Usher syndrome, who are born deaf or hearing impaired and gradually lose their sight may work until retirement age. However, they will know that their sight will continue to deteriorate as they age, and their support needs will increase. No private insurance system will allow them to pay in to insure against a future need which is already known. For this reason Sense cannot support a voluntary insurance system, nor a comprehensive system which relies entirely on commercial insurance companies.

### Attendance Allowance

Without access to the financial modelling it is impossible to comment on the costs of any of the proposed models. Sense opposes the suggestion that it should be part funded by the abolition of benefits such as Attendance Allowance. We welcome clear statements from government that DLA for people of working age will not be abolished. However we reject the proposal to abolish Attendance Allowance. We also oppose the implication that individuals could lose their DLA once they reach 65. We recognise the need to fill the gap in funding for care and support but do not see this as the solution. Absorbing this funding into the social care pot will make it vulnerable to funding cuts and future spending decisions. The crucial support that AA and DLA provide to people over 65 cannot be at the mercy of such decisions.

Both AA and DLA are aimed at meeting the extra cost of disability. The additional cost of dual sensory loss can take many forms including human support, equipment and transport costs. A JRF study provides some indication of the costs to meet needs rising out of single sensory impairments,<sup>6</sup> while some of these costs will be the same for deafblind people, some will be higher. For example the cost for communication support is likely to be higher if a deafblind person uses an adapted version of BSL, such as hands-on signing, to take account of their co-existing visual impairment.

We do not agree with the perception that AA is poorly targeted. Indeed research indicates that the more impaired someone's vision is and the more difficulties they report (with preparing a meal, household cleaning, getting about the home), the more likely they are to receive AA.<sup>7</sup> We believe that early provision of support through a universal benefit fits well with the Government's prevention agenda, allowing people to purchase low level support of their choice rapidly and without the need for complex care planning associated with formal social care packages.

We know from our work with deafblind people that there are a range of additional costs of deafblindness which DLA and AA are used to meet. Members' responses to our consultation on the Green Paper listed a whole range of examples of entirely valid and crucial support that people use their AA or DLA to pay for, including human support, paying informal carers' expenses, transport costs, and audio books. Many of these would help to prevent deterioration of physical and mental health in a deafblind person.

As part of our members' consultation on the Green Paper, we also asked what would be the impact of losing AA or DLA.

*'Threat to hygiene, threat to health, threat to quality of care, threat to social needs, increased vulnerability in all areas of life...would have to consider 52 week nursing home accommodation.'*

*'I would not be able to choose my own carers.'*

*'I would be without a carer.'*

*'Carers would not be reimbursed.'*

*'Couldn't go on holidays or days out near as often.'*

*'Find it hard to live independently.'*

*'Terrible, no money for transport and the care I need.'*

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<sup>6</sup> Joseph Rowntree Foundation, 2004, Disabled people's costs of living: More than you would think, 50-67

<sup>7</sup> Vision 2020 UK and University of Birmingham, February 2008, Finance and entitlement: Visually impaired people's take up of Disability Living Allowance and Attendance Allowance, 14

*'I would have major financial difficulties.'*

*'Poverty. No chances to help me around.'*

*'Angry, worried, depression.'*

Again, we know from our direct work with thousands of deafblind people that these are representative. These specific comments powerfully make the point that abolishing AA and/or DLA for people over 65 will have a profound impact on the physical health and wellbeing of deafblind people, as well as their ability to lead independent lives and access their local community.

## **5.2 What people should expect to get out of the system**

The other side of the debate on a fair funding system is clarity about what people gain for their payment: what entitlements are they buying? For deafblind people this means recognising two things: that their support often costs more to provide than for some other disabled people and that their support is not predominantly personal care.

There needs to be a nationally agreed understanding of what quality of life is acceptable for a person who needs social care support. People's payments must buy an entitlement to sufficient support to meet this quality of life. This should include the ability to get out of the house, interact with others, have leisure activities, work if appropriate and to take some form of exercise sufficient to maintain good physical and mental health. A number of our members told us that one of the things that they wanted to do but were unable to for lack of support was exercise – join a gym or go for a walk. This is important to their health and to their quality of life. We know from our experience of supporting deafblind people that this is exactly the sort of support that social care rarely provides.

Although the current FACS eligibility criteria recognise that involvement is as important as health and safety, the needs of deafblind people for social interaction are too often deemed not to meet critical or substantial eligibility criteria. They are simply not seen to be as important as personal care. A care service which meets the government's agenda of treating people with care needs as citizens with rights, having their human rights respected must provide sufficient support to enable deafblind people to be part of their community. Too often we hear of deafblind older people who are considered to 'safe' in their favourite chair at home with little other support or intervention. Without support, they become prisoners in their own home, isolated from friends, family and community, with a lifestyle that threatens their physical and mental health.

*"From leading an enjoyable, full and active life – I am now down to nothing...now I can only watch TV (close seat) and have to make up my own dialogues. Strange but friends do desert you when you cannot communicate."  
(Deafblind older person)<sup>8</sup>*

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<sup>8</sup> VICTAR, 2007, Secondary data analysis with a focus on the needs of older people with acquired hearing and sight loss: An analysis of the 'Network 1000' and 'Cambridge' datasets, 45

Deafblind people have a right and a need to maintain social contact and access their local community. The Government must not fall into a default position where being safe at home is all that an older person can expect; this also goes for the professionals who work with them. When a person becomes deafblind, they must be able to expect that their needs for support with mobility, communication and access to information will be met, as well as any personal care needs.

### Cost of support

Deafblind people often need support provided by someone with specialist skills and training, particularly in communication methods, which often has a higher hourly cost. This means that their support needs will often be greater than someone who requires, for instance, a PA with no specific specialist qualifications. However the decision is made about how much support a person is entitled to take out of the system, the higher costs for those who have higher cost, specialist needs must be accounted for, so that they also get their fair allocation of support.

For this reason we do not support the partnership model, since the person pays a proportion of their care costs, meaning that those with higher needs pay more. We do not consider this to be fair.

### Working age adults

The Green Paper sets out clearly the facts about the ageing population and the increasing number of older people who will need support in the future. There is another demographic change occurring alongside this one, which is the increasing number of younger disabled people, born with significant disabilities and now becoming adults. Amongst this group are congenitally deafblind people, born with hearing and sight loss alongside other, often complex, health conditions. The numbers of people in this group are growing for a number of reasons, including advances in medical science meaning premature babies surviving who would not have done so decades ago. Many of these people will have extremely complex support needs, requiring significant funding. They will not have the assets and savings to be able to pay into the funding models proposed for older people. Funds will have to be found to meet this increasing need as well. Without access to the modelling on which the Green Paper proposals are based it is impossible to comment on whether this has been taken sufficiently into account.

The Green Paper states that disabled people of working age would be entitled to “basic care” needs to be met free of charge. We would argue that the term “basic care needs” should include that support which is needed to have a basic quality of life, to live as citizens in a local community, not to simply be alive, trapped in your own home as outlined above. For deafblind people this will include the need for a range of support outlined above, including mobility and other skills training, communicator guide or intervenor support, specialist equipment. Not only older people who have paid into the system, but also those born deafblind or developing dual sensory loss in earlier life should have a right to this level of support.

## **6. Conclusion**

Sense welcomes the long needed debate about the future of social care. We will measure the success of any changes by the extent to which they deliver a care system that gives disabled people the right to live as active citizens of their local communities and the extent to which the system is funded fairly: with people paying in according to ability to pay and getting sufficient care to meet their needs, including their needs for access to information, mobility and communication.

12 November 2009