Law Commission
Adult Social Care: A consultation paper
Sense response

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. We also provide leading specialist advice, for example on education options and assistive technology.

Deafblind people’s experience of social care law

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.

Deafblind people’s needs are varied and personal to the individual. However, there are some common factors which create problems in relation to the way social care law operates in England.

- The specialist nature of deafblindness;
- The type of support deafblind people need;
- The cost of providing this support;
- The difficulty of identifying suitable support in many local areas;
- Some specific issues about the boundaries between NHS and social care responsibilities.
The specialist nature of deafblindness

Sensory loss in general and deafblindness in particular are specialist areas, requiring specialist understanding of the impact on the person and the support that is likely to enable that person to remain independent. The needs of a deafblind person are completely different from those of a physically disabled person, yet they are often categorised under physical disability.

The specialist requirements of deafblind people’s needs were recognised in 2001 with the issuing of the deafblind guidance, which set out how community care services should operate for someone with a dual sensory loss. Whilst not completely solving the problems encountered by deafblind people, this made a significant difference to deafblind services in England. For instance, in the 5 years immediately following the issue of the guidance, the number of deafblind people per 100,000 population identified by local authorities increased by 80% and the number receiving a communicator guide service increased by 60%.

The type of support deafblind people need

Deafblind people’s needs relate to their need for support with mobility, access to information and communication. They do not relate to personal care. Social care services tend to prioritise personal care above other types of support.

“I go for 3 weeks at a time without contact with another person and I go for months without leaving my house, but because I can pull my own knickers up and down they are not interested” Jo, deafblind woman age 65.

Yet failure to support someone with mobility and access to communication can have a profound effect on their health and quality of life, every bit as critical as failure to meet personal care needs.

One deafblind older person said: “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.” The impact of the isolation caused by deafblindness where support with mobility and communication is not provided is significant. Research has found depressive symptoms are between 1.6 times and 2.7 times higher amongst older deafblind people than older people with no significant hearing and vision loss.

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2 Sense (2007) Sense local authority survey
Physical health is also affected with people with dual sensory impairment the risk of

- high blood pressure was 1.5 times higher;
- heart problems was 2.4 times higher;
- stroke was 3.6 times higher;
- arthritis was 2.2 times higher;
- diabetes was 2.1 times higher.

than in those with no sensory impairment.\(5\)

Social care law does not distinguish between personal and other types of care, and Fair Access to Care Services (FACS) specifically states that all the domains are of equal status. Yet deafblind people continue in some areas to be denied services because FACS is misapplied, and only needs related to the health and safety domain are met.

Cost of meeting need

In general deafblind people’s support needs are more expensive to meet than those of people with a physical disability. The specialist nature of their needs, particularly the communication support needs, mean that hourly rates are relatively high for support workers. Where a person requires someone with a level of British Sign Language qualification that would take years to acquire, or scarce skills, such as fluent deafblind manual, rates of pay will be high. We know of authorities paying £30 per hour in direct payments because this is the rate local agencies charge for communicator guides.

The difficulty of identifying suitable support in many local areas

The specialist nature of the support needed by deafblind people makes it difficult to identify suitably qualified and experienced people to provide support. This issue is particularly acute for people using direct payments. Sense consulted deafblind people about their experiences of using direct payments in 2008. 42% of respondents who had chosen not to use direct payments gave the reason as difficulty finding suitable staff or services.\(6\)

’[Using direct payments is] a great option if you know someone already or are looking for bog-standard personal care at home. It's a nightmare if you need specialist support and know no-one.’

One aspect of the transformation of social care which is often under resourced is what is termed “place shaping”, the development of a market in social care services. The current direct payments guidance states:

Commissioners will need to focus on their use of resources, for example the local balance of investment in preventive services, community-based services

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5 Crews JE, Campbell VA (2004) as above
6 Sense (2002) Deafblind Direct consultation report: Deafblind people and families' experiences of direct payments
and other services, so that funds can be used more flexibly. Informed by the Joint Strategic Needs Assessment, they will also need to shape local markets so that new services develop and existing services adapt to meet individual needs in more person-centred ways. Both will rely on commissioners and providers working together in partnership, with citizens at the centre of the process.\(^7\)

Sense believes that with the increasing move towards giving people greater choice and control by giving them a budget to purchase their own services, consideration should be given to introducing a target duty on local authorities to ensure sufficient supply of services, including specialist services, to meet the needs of their local population.

The boundary between NHS and social care

There are some areas where local authorities refuse to fund support on the grounds that it is an NHS responsibility, but the NHS denies responsibility. The most common of these is related to support to attend hospital appointments. Hospitals may pay for an interpreter for the appointment itself, but will not provide support for travel to and from the hospital. Hospital transport will not allow a communicator guide to travel with the person, so they are unable to use it as they can’t communicate with the driver or other passengers. Some deafblind people have to travel long distances to specialist hospitals by public transport. The dispute between the NHS and social services about who should pay for this results in people being unable to attend appointments, having to fund them out of their own pocket because local authorities refuse to allow social care funding to be used for this or travelling alone in a way which is unsafe.

Another area of dispute is exercise. If a person cannot leave the house without support from a guide, they are not able to take part in regular exercise. When Sense asked members what they would do if they had additional support, one of the most common responses was that they would like to take some form of exercise. PCTs will not fund a guide to allow a person to take exercise, but neither will many local authorities. This means that whilst prisoners have a right to take exercise, and have at least half an hour each day in the open air,\(^8\) some deafblind people are unable to do either at any time.

Deafblind people therefore need a social care law which will support them in accessing specialist assessments and support at a sufficient level to meet their needs and which recognises the importance of meeting needs other than personal care needs, and which reduces the conflict over the boundary between NHS and social care provision. The test of the new statute for deafblind people will be how well it delivers in these four areas.

\(^7\) Department of Health (2009) Guidance on direct payments for community care, services for carers’ and children’s services para 31
\(^8\) The Prison Rules 1999, SI 1999 No.728 Paragraphs 29 and 30
Law reform

Sense supports the principle of a single adult social care statute. We also support the idea of bringing together statutory guidance into a code of practice. However, the requirement for new guidance in the future is inevitable, and we would not want the Code of Practice to act as a brake on issuing guidance where it was needed. As noted above, the deafblind guidance was issued in 2001 because there was evidence of significant failings in the way the law worked for deafblind people.9

The importance of the deafblind guidance

As noted above, the deafblind guidance has made a significant difference to local authority provision of appropriate services for deafblind people. The guidance makes several requirements of local authorities:

- Identify, make contact with and keep a record of deafblind people in their catchment area (including those who have multiple disabilities including dual sensory impairment);
- Ensure that an assessment is carried out by a specifically trained person/team, equipped to assess the needs of a deafblind person - in particular to assess need for one-to-one human contact, assistive technology and rehabilitation;
- Ensure that appropriate services are provided to deafblind people, who are not necessarily able to benefit from mainstream services or those services aimed primarily at blind people or deaf people who are able to rely on their other senses;
- Ensure they are able to access specifically trained one-to-one support workers for those people they assess as requiring one;
- Provide information about services in formats and methods that are accessible to deafblind people;
- Ensure that one member of senior management includes, within his/her responsibilities, overall responsibility for deafblind services.

Whilst the guidance has made a difference to deafblind people’s services, it is not universally implemented. Five years after the guidance came in 20% of authorities still had not identified a single deafblind person. And of those identified, less than half had been offered a specialist assessment.

The new Statute needs to look at how to strengthen and emphasise the legal duty to provide specialist assessment and services to deafblind people.

The other issue related to the deafblind guidance is that both the Department of Health and Welsh Assembly versions cover both children and adults. Since this statute relates only to adult services, some means needs to be found to ensure that deafblind children do not lose the protection afforded by the guidance. This is particularly important in relation to children, since many people make the assumption that provided children’s educational needs are met they have discharged their duty and parents will provide the rest of the support. The older a children gets the less

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9 Sense and Deafblind UK (1999) Out of this world: Evidence of the systematic exclusion of deafblind people from society
appropriate it is for parents to provide all of their out of school support, so the explicit recognition of the importance of social care support for deafblind children is vital.

**Statutory principles**

Sense strongly supports the idea of statutory principles in the statute. We believe that the principles in the Mental Capacity Act work well, both legally but also to emphasise the importance of certain underlying factors. We think that the following principles would be useful:

**Choice and control**
Sense supports a principle to ensure that people are able to exercise choice and control over their lives and over the services they receive. Whilst it is true that this is now fundamental to adult social care law, it can mean different things to different people. For instance, direct payments are often seen as a mechanism whereby people are given more choice and control over their services. However, for many deafblind people the complexities of managing a budget are not something they wish to take on. Indeed they can reduce the person’s control over their own life because they take so much time and energy to manage which could otherwise be spent on other activities. We believe that the choice and control principle should protect those who wish the local authority to continue providing a service. So we would see this principle as ruling out any presumption in favour of one or another delivery option.

**Person centred planning**
Whilst we agree that this might be difficult to form the basis of a statutory principle we do think that something about basing decisions on the individual circumstances and not on blanket assumptions would be useful.

**Viewing needs broadly**
We believe that this principle is of critical importance to deafblind people in the light of the issues outlined above related to personal care. We would like to see a principle that when considering a person’s needs, all aspects of their life should be considered and the person’s own view of what is most important should be taken into account. Whilst it could be argued that this is already the case in law, it is not how the law is implemented. We feel that giving this the status of a principle will help ensure that it is carried out.

**Independent living**
Sense feels that this is too vague a concept to be useful as a principle. For some it means the same as home based living (see below). For others it is much broader than the scope of adult social care. The aspects of this which relate to adult social care seem to us to be encompassed in the concept of viewing needs broadly.

**Home based living**
Sense does not believe that any part of the statute should be based on an assumption of one type of support or another. This seems to us to contradict the principle of choice and control by biasing the system in favour of one form of living. A young deafblind adult with high support needs, for instance, might much prefer a small registered care home sharing with two others of similar age and interest to continuing to live in their parent’s home. A principle of home based living would
presumably favour the family home over the care home, thus mitigating against the young person’s ability to live independently from their parents.

Dignity in care
Deafblind people have told Sense that this was an important principle to be included. We do not agree that the difficulty of defining the term dignity make it unworkable as a principle. The consultation paper recognises that the principle of dignity has been successfully applied by the courts. Sense would argue therefore that dignity is an enforceable term.

Sense sees the fact that dignity is not written into the ECHR as a strong argument to include it in the statute. In addition, the UK is a signatory of the Universal Declaration of Human Rights, International Convention on Economic and Social Rights, UN Convention on the Rights of Disabled People and International Convention on Civil and Political Rights which do include dignity. The legal rights and principles found in those treaties are not directly legally enforceable in the UK because they need to be incorporated into UK law via statute to be given force. Including dignity as one of the principles in the statute would be one way to recognise this aspect of these treaties.

The concept of dignity is helpful to define a type of minimum level of provision which must be delivered for the care to be moral and ethical. Dignity in care implies a human rights based approach to care, the right to respect and the right to ethical treatment. Where there is disagreement over what is meant by human dignity or dignity in care the courts have shown that they have a good track record of determining what dignity means in any given context.

Dignity is a core value and relates closely to some of the other values which are deemed to be important by policy makers including choice and control. Inclusion of dignity as a legal principle in the context of social care should safeguard the individual. Dignity is an invaluable interpretative tool and should help social care providers and assessors to keep their moral compass – e.g. for deafblind people no-one could say that expecting a person to live without human contact for months at a time was consistent with human dignity

Safeguarding
We feel it is important that safeguarding should be a significant part of the new statute. However, there is a risk that placing it as part of the principles will lead to risk-averse practice. The principle of choice and control should allow people who have the capacity to make decisions about this to take more risks in their own lives than professionals might if they were the decision makers. We therefore do not think it is necessary to make this one of the principles. However, this is not because we feel safeguarding is unimportant, particularly for those who lack capacity to take decisions about risk.

Sense believes that the point of principles should be that they underlie everything that follows in the statute. Since all the principles should apply to everything, elevating one above all others contradicts their value.
The principles we would like to see included are therefore:

- That the individual’s choice and control should be maximised through offering them the maximum alternatives of how support should be provided.
- That decisions should be based on individual circumstances, not based on assumptions based on age, impairment or diagnosis.
- That any consideration of needs should take a broad definition of need considering all aspects of the person’s life and their desired outcomes.
- That the individual should have the maximum possible involvement in decisions about their support. That they should be given the support they need to permit this involvement, including communication support and information provided in an appropriate format.

Community care assessments

Assessment is a critical part of the process of providing adult social care support. For deafblind people this is doubly important due to the specialist nature of their experiences and of the support that they need. Some of the problems that deafblind people have identified with assessments are:

- Unreasonable delays in getting an assessment. Until the assessment is carried out, no services will be provided.
- Having an assessment carried out by someone not trained to work with deafblind people and therefore not able to understand their needs

Duty to assess/right to request

Sense agrees with the proposal for the trigger for assessment. It needs to be clear that this is not dependent on the person being entitled to social care services from the local authority.

We also strongly support the right to request an assessment. There is evidence from the people Sense supports that they can struggle to get an assessment and to get that assessment provided by a suitably qualified person. The formal request needs to be clear, for example letter or email, but what is accepted as a request should be broad. If it is clear to a reasonable person that the document is a request for an assessment then this should be acceptable. The right to request should not become a new bureaucratic hurdle that must be overcome in order to access an assessment.

Given the difficulty deafblind people experience in getting an assessment we support the idea of a request triggering a duty to assess. Many deafblind people also struggle to get a reassessment when their needs change. Since many of the conditions causing deafblindness are progressive, needs can change without any specific change in circumstances. We are therefore concerned that the approach of simply requiring the local authority to state why they were not willing to carry out an assessment would result in this group being told that they could not have an assessment because they had already had one. Any move to prevent vexations requests would need to avoid putting this group of people into the same situation.

The right to request should carry a time limit for carrying out an assessment. Deafblind people have pointed out that the right to an assessment is meaningless
unless accompanied by such a time limit. Deafblind people can experience long delays in getting an assessment (one person told us they had to wait 2 years). Some authorities have recently responded to budget cuts by laying off staff who carry out assessments which will only make the delays longer.

The time limit would have to apply to everyone, not just to those who make a formal request, otherwise this would lead effectively to a person having to request an assessment as all the resources for assessment would be focused on meeting the deadline for those who requested.

The time limit is important. This must not be too short, or assessments of poor quality will be carried out simply in order to meet the deadline. However we feel that even the most complex assessment should be completed within three months. Where a person has high levels of need, the provision of an interim service pending the completion of the assessment is important (see comments on urgent provision of services below).

The assessment process

We agree that the assessment should focus on outcomes and needs and not on suitability for a specific service. We believe that the assessment should start with the outcome the person wants and then look at any needs for support to enable that outcome. The principle of choice and control should mean that the person can determine their own outcomes. For example, a deafblind older person may need a loop to allow them to watch TV without disturbing the neighbours. Or they may need a communicator guide so they can go out and take part in activities in the community. Only the individual can say which outcome – watching TV or taking part in activities locally – is the outcome they wish to achieve. The desired outcome must be the starting point as this determines the needs.

For older people the ability to state their own outcomes is particularly important. Too often sitting in front of a TV all day is considered a suitable daytime activity for older people, without any reference to the person’s own preferences.

We would therefore slightly re-word the proposal. The focus of the community care assessment duty should be an assessment of the person’s desired outcomes and the social care needs to achieve these outcomes. The process is therefore identification of outcomes, then identification of needs to support these, then provision of support to meet these needs.

Self-assessment

Deafblind people have different opinions on self-assessments. For those with very complex needs they often feel they have a better understanding of their own or their son or daughter’s needs. However, this is often an indication that the person carrying out the assessment is not sufficiently qualified and experienced in deafblindness. One deafblind person told us: “I know more than the professionals who only know about single sensory loss.”
In general, a co-produced assessment can be very appropriate for many people who have stable long term conditions and have built up a good understanding of their needs. For these people, a minimum of professional input may be required. For those newly entering the social care system or with changing or specialist conditions, input from a specialist is essential.

A deafblind person is entitled to an assessment carried out by a specialist with experience of deafblindness and many of the problems deafblind people face stem from their not having been given information about what support might be helpful to them. Most people are not familiar with the technology that allows a blind person to access the internet, that doorbells with vibrating pagers are available, or the existence of a communicator guide. The principle of choice should apply; a person may wish to take a lead in their assessment with minimal professional input but they should be offered the option of significant professional input.

Whilst pure self-assessment might possibly be valid for those who need a small one-off piece of equipment or adaptation, there is a risk that by having pure self-assessment bigger issues may not be picked up. For instance, many older people who need a grab rail might also have unrecognised dual sensory loss, which they themselves assume is a natural part of the ageing process and therefore don’t ask for help with. If some level of professional involvement was required then there is a greater chance of this being picked up.

Other than for very small pieces of equipment, pure self-assessment is unlikely to be possible. Assessment is the trigger to the provision of services and without local authority involvement it is not likely to be possible to commit anything more than very small amounts of resources. The number of people for whom this is appropriate is likely to be small.

**Regulations on the assessment process**

We agree that there should be regulations prescribing the assessment process in order to reduce the variability of assessments. Whilst professional judgement is a crucial part of assessment, Sense has come across too many examples of poor assessments which have failed to address the needs of a deafblind person. There are two areas which must be covered by regulations. Firstly the deafblind guidance requires that an assessment of a deafblind person must be carried out by someone specifically trained to assess a deafblind person. Where this does not happen, the outcomes for the person are significantly poorer because crucial aspects of deafblindness are not addressed. Professionals with knowledge only of single sensory loss are often unaware of the combined impact of dual sensory loss. For instance, a specialist in deaf services may not understand that although a person can read standard size print, their peripheral vision loss means it is not safe for them to walk in unfamiliar places without a guide.

Secondly, assessment must specifically look at all aspects of life, including leisure and social interaction. Some deafblind people are told that the assessment cannot cover these, or that there are arbitrary maximum limits on the amount of support that can be given for these. Regulations need to recognise that the need for social
interaction and exercise are every bit as important as other aspects of care and support.

Regulations should also include the time scales for completing assessments and the fact that assessment should start with outcomes and then look at needs. The requirement to involve the individual and carers should also be covered. For deafblind people, involvement in the process is not possible without communication support and accessible information.

It would be useful for the statute to set out what the regulations must cover as a minimum and we would see this as being:

- The time limit on the assessment;
- The involvement of the service user and carer where appropriate;
- The provision of communication support and accessible information to enable this involvement;
- The involvement of specialists in the assessment;
- That the assessment must look at all aspects of life;
- That the starting point for the assessment should be the desired outcomes of the individual.

**Urgent service provision**

We agree that this should be retained; in fact we would go further and say that it should be a duty. People with high levels of need go longer without support than those with lower levels of need simply because the assessment is more complex and therefore takes longer. There are also instances where the authority delays the assessment in order to avoid having to pay for a service. If the authority was under a duty to provide for any urgent needs until a full assessment was carried out then this effect would be reduced.

**Carers’ assessments**

We agree with the proposed approach to carers’ assessments. We agree that the need to specifically request a carers’ assessment should not be a requirement. However, we do think that a right to request an assessment, similar to the right to request a community care assessment, should apply to carers’ assessments. It seems sensible for the trigger to be that a carer appears to be in need of carers’ services, rather than providing substantial amounts of care threshold. Those providing very small amounts of care are unlikely to have needs which could be met through a carers’ service so this change will not significantly increase the number of assessments.

We support the proposal not to exclude the three groups of carers from the carers’ assessment. There are important issues about paying people who have a personal relationship with the cared for person, or a history of providing unpaid support, some of which may be addressed by a carers’ assessment. The relationship between a cared-for person and a previously unpaid carer can be complex. In addition to the issues identified in the consultation paper. We are aware of people who used to support friends to take part in leisure activity, for example acting as an unpaid
communicator guide. When some, or all, of this support becomes paid, the power relationship between the two individuals changes. What was previously a fairly equal relationship in which two friends agree to take part in leisure activity together becomes one of employer and employee. Many people are not aware of the implications of this change.

We are also aware of situations where paying family members to provide substantial amounts of care can result in a family becoming financially dependent on the income this provides, and thus on the continuation of the caring arrangement. We are not convinced that a carers’ assessment would necessarily address all of these issues.

We support the proposal for a more unified assessment, but agree that the merged duty is impractical. When carrying out a carers’ assessment it is essential that carers are able to provide information confidentially. This is particularly important where it comes to talking about the impact of caring on the carer, which carers are unlikely to be willing to speak about honestly if they feel the person they care for will know what they have said.

Eligibility for services

For deafblind people there are two important principles related to eligibility which must be retained in the new statute.

- The principle that eligible needs must be met;
- The principle that all needs must be included, not just those related to personal care.

These must be addressed in the statute, not simply in regulations.

In Control and the Individual Budget Pilots first introduced the idea of the Resource Allocation System as part of personalisation of services. This involved a person answering a series of questions, their answers were allocated points and these points had a cash value. The number of points determined the amount of budget allocated. Many local authorities are using a version of this system. This fails to meet the needs of deafblind people for a number of reasons.

Firstly, the questions asked determine how well deafblind people fare in terms of points. For instance, of the RAS questionnaires Sense has seen, less than half ask about communication needs. Almost none ask about the ability to get out of the house and mobility around the local community.

Secondly, judgements are made about the relative value of different aspects of the RAS. For instance, the ADASS Common Allocation Framework asks about the need for support with personal care and with accessing the local community. A person needing support with personal care several times a day (the highest level) receives 13 points. If a person needs support to access the community several times a day this rates only 6 points. So those whose needs are not related to personal care are disadvantaged compared with someone with the same level of need related to personal care. We see this as a contradiction of the FACS guidance, which states that the domains are all equal. As noted above, the failure to meet needs related to
communication and mobility can have serious implications for the physical and mental health of deafblind people.

Finally the points take no account of the cost of meeting the need. In the example above, needing a support worker to help with personal care, is likely to require a fairly low wage; a deafblind person needing support to access the community is likely to require a support worker with specific communication skills attracting a far higher hourly rate. Yet the points value for the latter is lower.

Whilst the budget indicated by the points is intended to be indicative, local authorities vary in how clear they make this and there is a danger that people will tailor their support plan to the cash available, rather than asking for what they really need. The protection that deafblind people have currently is the requirement to meet all eligible needs. This needs to be very clearly included in the new statute. A “fair” system is one where those who meet the eligibility threshold have enough resource to meet their needs, not where those who have expensive to meet needs have some of their needs unmet.

The current FACS eligibility system explicitly recognises that people may need support in four domains, including involvement in family and community life. This explicitly includes leisure, hobbies, learning and volunteering. Where FACS is operated correctly, this recognition is crucial to deafblind people receiving the support they need. However, deafblind people have told us, this is not universal and in some areas getting support for leisure activity is difficult or impossible.

We support the proposal that eligibility criteria be subject to parliamentary scrutiny. To prevent discrimination the statute must state that the regulations on eligibility must include eligibility criteria that are equal across all areas of life.

Re-ablement services

We agree that the statute should include any entitlement to re-ablement services. However, it would be useful to define this more clearly. For instance, rehabilitation training for visually impaired people is often confused with re-ablement. Rehabilitation can be seen as re-ablement in the sense that it aims to provide skills which will enable the person to develop independence and reduce the need for services in the longer term. However, six weeks is totally insufficient for this type of training.

The entitlement to re-ablement services needs to include the entitlement to rehabilitation training without charge. Since this is currently the case in practice, adding this to the statute would not have a significant impact on local authorities.

Personal budget

We agree that the entitlement to a personal budget should be included in the new statute. However it is essential that the statute is clearer about what is meant by the term personal budget. We are aware of a range of differing definitions, including people who have been told that their direct payments have been converted into a personal budget, but without any change other than the name, areas where the term
is seen a synonymous with direct payments, individuals who have been told that they should not ask for a personal budget because this will result in their getting less money than they currently have and areas where personal budget means a strict RAS system with the budget equating to the points value with no willingness to vary this. As noted above, a RAS system does not work well for deafblind people.

It is our understanding that the crucial feature of a personal budget is the additional freedom it gives the individual to choose how they want to be supported, rather than have this decided by the local authority. However, Putting Everyone First implies that an up front allocation of money is the essential feature. We do not see how this can be compatible with the duty to meet eligible needs.

A personal budget may be taken as a direct payment or not, although not all local authorities make this clear and some equate a personal budget and a direct payment. For deafblind people it is essential that the ability to ask the local authority 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.

We agree that the right to a personal budget should be included in regulations, and we would argue that this should be subject to affirmative resolution by Parliament to ensure parliamentary scrutiny. However, the statute needs to set out the key points related to personal budgets:

- Some clarity over what is meant by the term personal budget.
- That the budget must be sufficient to meet all eligible needs
- That there must be choice over how the budget is delivered – direct payment or a directly provided service

**Ordinary residence and portability**

We do not believe that the problem of ordinary residence disputes is primarily one of law. We believe that in the vast majority of cases the ordinary residence of a person is clear in law. The problems come from the lack of a funding mechanism to deal with the transfer of the cost of high cost placements. The only way to solve this will be to create a funding mechanism similar to that used when the long stay hospitals closed in order to compensate local authorities for the additional costs, or to introduce a central fund for all very high cost packages so that the impact of high cost packages on local authorities is effectively capped.

Some of the barriers to portability however could be improved with more clarity in law. The main barriers are:

- A person has to move house before they are considered for assessment;
- The delay in carrying out that assessment can be long;
- Once the assessment is carried out there is further delay while a service is put in place.

If a person has high support needs this effectively prevents them, or any member of their family living with them, from moving out of the local area.
We support the enhanced duty to co-operate. However, whilst the enhanced duty to co-operate would assist with portability, we do not feel it is sufficient. We would like to see the duty to assess where a person is likely to move house much clearer in the statute. Once it is clear that a person is going to move to an area they should be able to request an assessment and trigger the three month deadline as discussed above. The local authority should then be under a duty to conduct the assessment within the required time, even if the person has not yet moved. This would also help in cases where care homes are de-registered as once the decision to de-register has been taken the process of putting in place a support package could begin.

This might involve some local authorities in a small number of assessments of a person who appears to have a firm intention of moving house, but once the authority begins the assessment the move does not take place. However, we feel that the potential benefits to the vast majority of people outweigh the cost of occasional cases where time is wasted on unnecessary assessments.

We also believe there need to be transition arrangements, whereby until the new local authority has carried out an assessment the person should receive services as close as possible to those they received in the previous local authority. In the case of direct payments this would be straightforward and they should receive the same amount of direct payment as they did under the old authority.

If portable needs assessment and national eligibility are introduced then these should be included in the new statute and they will help in portability. However, we feel that the above proposals would still be essential. It is unclear exactly how a portable assessment would work, since once a person moves house they may well have very different needs, e.g. if they move out of a family home to live alone, nearer to or further from work, from urban to rural setting or vice versa. So even if a portable assessment were introduced, many people would still need to be re-assessed after a move, with the consequent delays.

**Scope of adult social care services**

We agree with the proposal to have a short and broad list of services, but there are some specific items which need to be included related to sensory impairment. We would propose that they include specific mention:

- Rehabilitation for visually impaired people and deafblind people
- Specialist one-to-one deafblind support (communicator guides and intervenors).

The deafblind guidance specifically mentions access to one to one support for deafblind people as there was evidence that this was not being adequately provided. Including it in the list of services would help to give this aspect of the guidance more prominence.

We do not think community care services should be defined as we agree that there is a risk of excluding new services in the future. We agree that there is no requirement to define disabled person as having eligible needs is the defining characteristic.
We agree with the proposal that a legal definition of user groups covered by the statute is unnecessary. However, if such a list is to be included, then the groups listed in paragraph 9.40 (1) omits the mention of sensory loss. This group needs to be specifically included as their needs are very different from those of people with a physical impairment.

**Delivery of services**

We strongly agree with the requirement to produce a care plan or support plan but we feel this has a slightly different function depending on whether the local authority is providing the services or the service user has a direct payment.

Where a local authority is responsible for delivering services then it is critical that the service user has a detailed outline of what they can expect to be provided with and in what way. This applies equally where this is a care plan following a traditional assessment, or where this is a support plan outlining how a personal budget will be spent. The critical element is that the person is dependent on the local authority to provide the service, so a clear outline of what is to be provided is essential.

Where the care or support plan is to be delivered through a direct payment we still feel there should be a requirement to have a written plan setting out the expectations of the local authority for the service. Where there are restrictions on how a direct payment may be spent these need to be clear to the service user. Where the payment is a personal budget with a high degree of flexibility in how it is spent, then the service user still needs something clearly setting out the outcomes that are expected. Without this there is a risk of disagreement or misunderstanding between the local authority and the service user over the use of the funds.

We agree that there should be regulations setting out what should be in such a care or support plan. This must be sufficiently flexible to allow for a personal budget with very few restrictions on how it is spent. However, it must be sufficiently robust to ensure that where the local authority is delivering the service it is clear what will be delivered.

**Direct payments for residential accommodation**

We can see no reason to continue the restriction on direct payments which prevents them being given for residential accommodation. If we are to have a statute that makes no assumptions about the best way to deliver care, allowing the individual maximum choice and control, then it follows that direct payments should be an option for any type of service. It may be that many of those in residential services feel direct payments are of limited relevance. But this should not preclude others from making a different choice. High quality residential care can be a means of retaining independence, dignity and choice for some people and is not always seen as a last resort by everyone. We certainly cannot see how extending direct payments to cover residential care could possibly reduce or undermine a policy of choice and control.
We agree that in all other respects the provision for direct payments should remain the same. However, we know of many deafblind people who are offered no choice about whether to accept a direct payment. They are either told that they can have a direct payment without being informed that there are other options, or in some cases informed that the local authority is unable to provide a service but willing to provide a direct payment. Neither of these is acceptable. The decision about direct payments for direct service needs to continue to be a choice, with both options being offered along with sufficient information and support to be able to make an informed choice.

**Joint working**

**Transition from child to adult services**

The importance of an effective transition from children’s to adult’s services is recognised in guidance, but often not realised in practice. It is often those with the highest needs who fare worst, either because their needs are complex to meet or because they are expensive to meet. Too often family end up filling the sometimes lengthy gap between the end of education and the provision of an adult service. This is detrimental to both the family who provide unpaid care that they are not necessarily willing to provide and to the young person if support from parents is not appropriate.

We strongly support the duty to co-operate in transition. This could help ensure that local authorities implement the good practice guidance on transition planning, which if implemented correctly would help to eliminate many of the problems currently experienced.

We also strongly support the right to request an assessment for 16 and 17 year olds. The same time limit of three months for completing an assessment should apply as in the right to request assessment for adults.

**Duty to co-operate**

We strongly support the general duty to co-operate and the ability of local authorities to request assistance in certain circumstances. However, we feel this should be stronger than simply the requested authority to be under a duty to give the request due consideration. We believe that if the authority is not willing to give the requested assistance they should have to state why not. If the requested authority is able to simply not respond to the requesting authority then this will mean that in the most difficult situations where this power is most needed, such as transition of people with high support needs, there is a risk that authorities will simply not respond.

The circumstances in which authorities must co-operate should include:

- Where an assessment is taking place;
- Where a person’s ordinary residence is changing;
- Where a person is making a transition from children’s to adults services;
- Where there are safeguarding concerns.
The authorities that should be included should include:

- Health services;
- Education authority;
- Children’s and adult’s social services;
- Housing;
- Police;
- Service providers.

**Safeguarding adults at risk**

We agree that local authorities should have a duty to investigate and take action in cases where there are safeguarding concerns. We also think there should be a duty on workers to report suspected abuse. Where someone paid to provide support to an individual could reasonably be aware that abuse may be occurring and fails to report this, this should be an offence.

Using the term “adult at risk” fails to make it clear that the risk we are talking about here is the risk of abuse or neglect. Where a person has capacity they should be able to make decisions about the risks they are happy to face in their own lives. The term “adult at risk due to abuse or neglect” would be much clearer, whilst still addressing the concerns about the term “vulnerable adult”.

We strongly support the proposal to place a duty on each social services authority to establish an adult safeguarding board. This should include the requirement for bodies other than the local authority, such as policy authority to be represented and to co-operate.

**Section 47 of National Assistance Act 1948**

Whilst we do not feel able to comment on the use of S47 in general, Sense is aware of at least one use which gives rise to serious human rights concerns. This relates to an older deafblind person, living at home. His deafblindness had progressed to such a degree that he was no longer able to receive formal communication by any means. The local authority had concerns about his welfare living at home and so wanted to place him in residential care. There was no reason to think he lacked capacity but it was not possible to get his consent to residential care. S47 was therefore used to remove him from his home and place him in a care home.

Since he had no communication it was not possible to explain to him what was happening, where he now was, where the facilities such as toilet and bathroom were. The move to residential care therefore did not allow the local authority to meet his needs any better than they could have done in his own home. At least he would then have remained in a familiar environment. We know that this situation occurs from time to time with deafblind older people. It seems to us that using S47 in these circumstances, rather than providing support in the home, raises serious human rights concerns.
Strategic planning

Disability register

The requirement of the deafblind guidance to keep a record of deafblind people in the area is not a formal register. This requirement is essential to a local authorities ability to monitor how well they are implementing the guidance and in particular how well they are identifying the deafblind people in their area. Whatever happens with registers, we would not want to see this requirement to keep a record removed or weakened.

We also feel that there is merit in the continuation at the very minimum of the blind and partially sighted register. The numbers of visually impaired people who choose to register is high enough to make this worthwhile.

Duty to provide information

Sense very strongly agrees with the proposal to make information about services available. There are many self-funders and those with direct payments who need help to find suitable services in their area. 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 essential that mainstream services are 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.

For deafblind people it is also essential that this information is available in alternative formats, and includes information about specialist and not just mainstream services. In order to exercise choice and control, deafblind people need access to information about the choices available to them. This is not possible without the provision of accessible information.

The deafblind guidance recognises this fact, and requires local authorities to provide information in an accessible format. It lists a number of different formats in which information may need to be provided:

- Various sizes of large print;
- Braille;
- Moon;
- Audio;
- video (subtitled or signed);
- computer disk or use of e-mail;
- text-phones and Type-Talk.
It also states:

For some Deafblind people no method of communication other than tactile communication delivered by another person is available (e.g. hands-on sign, Deafblind manual). In these rare circumstances, the provision of a suitably skilled communicator e.g. an interpreter and/or LSP to deliver information would be appropriate.

It needs to be clear that all these methods of information provision should be available if needed.

**Conclusion**

Deafblind people need a social care law which recognises their specific needs. This includes specialist assessments and support at a sufficient level to meet needs, a recognition of the importance of meeting needs other than personal care needs, and clarity over the boundary between NHS and social care provision. These are the key issues that deafblind people will look for in the new statute.

30 June 2010