A practical guide to implementing the Care Act for deafblind people
Who is this guide for?

This guide is intended to support senior managers and policy makers involved in implementing the Care Act to enable them to understand the key aspects of the Act that have a bearing on care and support for deafblind people and people with complex needs. It will also be useful to anyone working in deafblind care and support to understand how the Care Act will impact on their work. It is not intended as a detailed guide to all the provisions of the Act, merely to draw out the key points in relation to deafblind people. It is a supplement to other training and information on the Act, not a replacement.

The guide highlights the points in the regulations and guidance of the Care Act which make specific reference to deafblind people as well as examining other areas of the Act with particular relevance for this group. The guide covers first the specific duties in relation to a deafblind individual throughout the care journey and then factors to consider in relation to the general duties on local authorities. Quotes included here from the Care Act guidance include the paragraph reference number in parentheses.

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What is deafblindness?

The term deafblind covers a wide range of different conditions and situations. People are regarded as deafblind “if their combined hearing and sight loss causes problems with communication, access to information and mobility” (6.91). Most deafblind people have some remaining hearing and/or sight. The most common cause of deafblindness is older age and most older deafblind people communicate using clear speech. But all have difficulties in these three areas caused by the interaction of the two impairments. Even those with expertise in a single sensory loss do not necessarily understand the way that a loss of both distance senses interacts to cause unique difficulties. Many are unable to use services designed for people with a single sensory loss or mainstream services. Those born deafblind often have other impairments and complex needs which can make implementing the Act for this group challenging.

Communication – deafblind people use a range of communication including clear speech, sign language, tactile communication based on the alphabet. People born deafblind may have little or no formal communication. See Appendix A for detail on deafblindness and communication.

Access to information – this includes difficulty with written information such as timetables, websites, bus numbers, use by dates on food; spoken information such as train platform announcements; environmental information such as the layout of a room, finding a seat on public transport, busy traffic, potholes, obstacles on pavements, etc.

Mobility – this refers to the ability to safely move around the home and outside the home. A deafblind person may appear to have no difficulty in moving around a familiar place, or taking a regular journey but be unable to safely manage an unfamiliar journey or cope with a change such as a blocked pavement on a usual route. A deafblind person’s ability to move safely out of doors can also vary depending on light levels, for instance between daytime and at night.

Failure to recognise and address the impact of a person’s dual sensory loss can have a detrimental effect on their well-being. Getting things right first time will save time and cost to the local authority in the long term. Involving the right specialist in the assessment and care planning process will ensure that needs are met appropriately. Unless this happens, needs may escalate, requiring a new assessment and a more costly support plan.
Deafblind guidance

The Department of Health issued the statutory guidance “Social Care for Deafblind Children and Adults” in 2001, reissuing it in 2009. New guidance – “Care and Support for Deafblind Children and Adults” – has now been issued. This is largely based on current deafblind guidance updated to reflect the new context of the Care Act. The requirement for specialist assessment is included in the Care Act regulations and guidance. In all other respects the deafblind guidance requirements remain broadly similar. This is that local authorities are required to:

- identify, make contact with and keep a record of all Deafblind people in their catchment area (including those people who have multiple disabilities including dual sensory impairment);

- ensure that when an assessment is required or requested, it is carried out by a person or team that has specific training, expertise and experience to assess the needs of a Deafblind person – in particular to assess the need for communication, one-to-one human contact, social interaction and emotional wellbeing, support with mobility assistive technology and habilitation/rehabilitation;

- ensure services provided to Deafblind people are appropriate, recognising that they may not necessarily be 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 that Deafblind people are able to access specifically-trained one-to-one support workers if they are assessed as requiring one;

- Provide information about services in ways which are accessible to Deafblind people; and

- Ensure that one Director-level member of the local authority senior team has overall responsibility for Deafblind services.
Assessment

Care Act regulations on assessment include provision for the assessment of deafblind people. They state that:

“An assessment which relates to an individual who is deafblind must be carried out by a person who has specific training and expertise relating to individuals who are deafblind.” (Care and Support Assessment regulations 2014, 6(1))

The Care Act guidance states that “the type and degree of specialism required should be judged on a case by case basis, according to the extent of the person’s condition and their communication needs.” (6.93)

What level of training is appropriate?

The guidance sets out what level of training is appropriate and a range of areas which should be covered by the training and expertise. Training should be “a minimum of OCN or QCF level 3, or above where the person has higher or more complex needs” (6.92). This means that, for instance, a deafblind awareness course would not give sufficient knowledge of deafblindness for assessing a deafblind person. Level 3 would not be sufficient for assessment of a person born deafblind. Level 3 is also not sufficient for someone whose acquired deafblindness is complex, for instance someone who needs significant adaptations to their communication such as learning a new method or moving to hands-on signing. Conditions such as dementia or brain injury also impact on communication and so make assessment more complex.

Currently the highest level qualifications in deafblindness are the Diploma in Deafblind Studies, which is a QCF level 5 course accredited by the Open University, and the University of Birmingham post graduate diploma in Multi sensory impairment. There is also a level 4 Certificate in Deafblind Studies.

A person carrying out an assessment of a deafblind person would also need to meet the training and experience requirements of the guidance on assessments more generally. A person with a level 3 communicator guide qualification, for instance, is likely to meet the level 3 deafblind specialist qualification requirements of the guidance, but unless they have other training or experience in carrying out assessments would not be a suitable person to carry out an assessment.

What should the training cover?

The guidance also sets out the minimum areas that the training and expertise should include:

- communication;
- one-to-one human contact;
- social interaction and emotional wellbeing;
- support with mobility;
- assistive technology and rehabilitation.
There are a range of courses available which meet these requirements. Local authorities should ensure that their assessors have a qualification which meets both the level and the range required by the guidance. It is unlikely, for instance, that a course for people with no prior knowledge of deafblindness could cover all the areas outlined above to level 3 in one day.

Assessing a deafblind person Case studies

All of the staff in the sensory team in Local authority A have received a basic deafblind course which covered deafblind awareness and how to identify deafblind people. All of them are qualified social workers and have a range of other qualifications in either hearing or sight loss.

However, the basic deafblind awareness course did not cover the full range of areas required by the Act, in the level of detail required for an assessment. Local authority A therefore would need to contract externally to enable them to assess a deafblind person.

Local authority B employs a deafblind specialist within the sensory team. She has a level 3 qualification related to supporting deafblind people and several years’ experience managing a communicator guide service. She carries out the majority of assessments of deafblind people in local authority B. However a level 3 course would not be sufficiently detailed to enable her to assess a person born deafblind with profound and multiple needs, nor a complex acquired deafblind case. For these more complex assessments local authority B has a contract with a local voluntary organisation with staff that hold the University of Birmingham post graduate diploma in multisensory impairment and the Diploma in Deafblind Studies.

Local authority C has a member of staff who has completed the diploma in deafblind studies, which gives a wide range of knowledge and understanding of the range of different needs. The staff member has only level 2 sign language so when assessing a person who uses BSL always books an interpreter.

Note that the above applies to any assessment of a deafblind person, regardless of whether they have had a previous assessment. Assessments must be appropriate and proportionate, but regardless of the format or detail required, a specialist assessor must be used.

The Act gives a requirement for specialist involvement at several points in a deafblind person’s care journey. It will therefore be important that local authorities consider the likely deafblind population in their area and whether they have access to sufficient trained staff (which can be their own staff or delegated to external providers) to meet all the requirements.
Use of interpreters

All the requirements set out in the Care Act assessment guidance also apply to deafblind specialist assessments, such as the requirement to ensure that the person is involved in the assessment as fully as possible. This will require that the person carrying out the assessment is able to communicate with the adult, and the guidance makes reference to the need for a qualified interpreter with training appropriate for the deafblind person’s communication where necessary.

For instance, where the person uses British Sign Language (BSL) adapted for a person with a visual impairment (e.g. visual frame or hands on BSL) the interpreter must be experienced in using this form of BSL. See Appendix A for more information on this.

The guidance states that it is not normally appropriate to use a family member as an interpreter. An exception might be where no interpreter exists, e.g. where the person uses idiosyncratic communication. Therefore local authorities will need to ensure that they have access to sufficient qualified interpreters to meet the likely needs of their deafblind population.

Advocacy

The Act requires that where a person will have substantial difficulty engaging with the process of assessment and care planning they should be provided with the support of an advocate if they have no one else able to support them. Substantial difficulty is defined as difficulty understanding relevant information; retaining that information; using or weighing that information; communicating the individual’s views, wishes or feelings. Some deafblind people will be in this position, for instance if they have an additional learning disability, or dementia.

They may also have limited knowledge because of their difficulty accessing information and so need additional support to understand their choices. In all these situations a person will require the support of an advocate who is able to appropriately support them. Not all advocates will be able to support those with communication difficulties. It is essential that the advocate employed has an appropriate understanding of communication and sensory loss otherwise they will be unable to fulfil the role of advocate.

The advocacy duty is not intended to cover those whose difficulty accessing the assessment or care planning process is purely related to communication and access to information because of sensory loss. A person who can engage with the process with appropriate communication support or accessible information should be provided with this. They will only require an advocate if they are unable to engage with the process even with such support. A person may require both an interpreter and an advocate.
Considerations when assessing a deafblind person

- What level of knowledge of deafblindness will the assessor need? Is level 3 sufficient, or is a higher level needed?
- Does the person need information in an accessible format?
- Does the person need an interpreter? If so, what specific skills will the interpreter need?
- Will the person need an advocate? What specific skills will the advocate need to work with this person?

First contact

The Care Act guidance is clear that the process of assessment begins “from when the local authorities start to collect information about the person”. (6.22) There are implications for the training of first contact teams in relation to deafblind adults. Whilst it is unrealistic for first contact teams to have the skills and qualifications to assess a deafblind person they should all be able to identify someone who may be deafblind and know how to refer for a specialist assessment.

The group most likely to be misidentified by first contact teams is older people who have acquired dual sensory loss. Older deafblind people who approach the local authority for support may not consider themselves deafblind, or even recognise that their sensory loss is an issue, since they may see it merely as an inevitable part of ageing.

People with learning difficulties may also not be recognised as having a dual sensory loss as they are often not able to access hearing and sight tests. Learning disability teams should ensure that they have considered the possibility that people they work with also have a sensory loss. Dementia may mask sensory loss and other conditions such as stroke may result in dual sensory loss.

Local authorities will also need to consider how a deafblind person will make contact with an authority, since telephone contact may be difficult or impossible. The guidance makes it clear that assessment should be proportionate and appropriate, and that care should be taken with telephone or online assessments to ensure that it is possible to identify all needs in this way.

The guidance makes reference to a “triage” process, helping people with lower needs to access support in the community (6.4). Care must be taken to ensure that deafblind people are not judged to have lower needs because their difficulties are not recognised. For instance, on the telephone a person may find the communication so difficult that they seek to end the conversation and fail to mention some of their needs.
The Skills for Care training materials on the Care Act include a factsheet on deafblindness which can be provided to everyone likely to need this information. There is also a range of basic deafblind awareness and identification of deafblindness training available. Local authorities will need to ensure that there is a range of ways for people to make contact with them. Telephone or online only, for instance, will not be accessible to many deafblind people.

Some local authorities allow a range of contact methods including SMS, fax and Skype to ensure accessibility. Local authorities should involve their sensory team in planning their first contact arrangements to ensure that they are accessible to deafblind people and staff are sufficiently skilled in identification of dual sensory loss.

**Supported self-assessment**

The guidance is clear that for any assessment the local authority must ensure that it identifies the totality of needs before moving on to determine eligibility and care planning. Where a person chooses to self-assess, the local authority is required to ensure that this self-assessment does accurately reflect the needs. Many people understate their needs, for example many older people assume that sensory loss is an inevitable part of ageing and downplay the difficulties it creates.

Where the person carrying out self-assessment is deafblind, the guidance states that the person “leading this assurance process must be seen as the assessor”. (6.46) They must therefore have specific training and expertise in deafblindness. Where a deafblind person chooses to self-assess then the sensory team may be able to ensure that they fully understand the process.
Fluctuating needs

Deafblind people’s needs may fluctuate for two reasons. Firstly, their condition may fluctuate, for instance people’s sight loss is often more severe when they are tired or stressed. But it may also vary due to environmental conditions. For instance, people with Usher syndrome will have more severe problems with mobility after dark. An assessment carried out during summer would have to take account of the impact of longer hours of darkness during winter. A person with Usher may find they have no issues accessing necessary services and facilities in the community during summer, but in winter need to access facilities during hours of darkness and so are eligible for support, or for more support, according to the time of year.

Carer’s assessments for deafblind people

The Care Act introduces a requirement to carry out a carer’s assessment regardless of the number of hours of care a person is providing. The trigger for an assessment is that the carer may need support. It is possible that a number of deafblind people will become eligible for carers assessment due to this change. Many older deafblind people will be living with a spouse who also has care and support needs. For a deafblind person providing care, small amounts of caring can impact on well-being because of the additional challenges of their dual sensory loss. A carer’s assessment of a person who is deafblind must be carried out by someone with specific training in deafblindness.

Where a person is caring for a deafblind person, it will be important that their assessment recognises the full emotional impact of caring. Although the caring may not be physical or involve personal care, the nature of deafblind communication can mean caring is equally exhausting.

Strengths based approaches

When carrying out an assessment, the Local Authority must also consider what else, other than the provision of care and support, might assist the adult in meeting the outcomes they wish to achieve. This should include considering the person’s own strengths and capabilities, and support available in the community. Local authorities must ensure that support in the community is fully accessible. Deafblind people may need additional support to use community facilities and services, and to use their own strengths.

In particular, continuing to engage in social activity can be a challenge since communication in a group or a noisy environment is too difficult. Being in a room full of people but unable to communicate is an extremely isolating experience. Ensuring that communication needs will be met might include provision of a hearing loop, deafblind awareness training for staff. For some deafblind people, care and support, e.g. a communicator guide, may be necessary to enable them to access universal services in the community.
Eligibility

The Care Act guidance makes it clear that an assessment must establish the totality of a person’s needs before a decision is made on eligibility. Anyone who is deafblind must be assessed by a specialist before a decision is made that they are not eligible for support.

Once the assessment has been completed and the authority has assured itself that it has established the full extent of the need, the next step is to assess whether the person meets the eligibility criteria. This should also be carried out by a person with training and expertise in deafblindness to ensure that the impact of those needs on outcomes and well-being is fully understood.

Some of the ways in which deafblindness, and the associated difficulty with access to information, mobility and communication, are likely to impact on the outcomes listed in the eligibility criteria:

- Managing and maintaining nutrition – because accessing shops and food preparation is difficult and because food identification as well as the ability to read use by dates is compromised.

- Being appropriately clothed – because it is hard to identify clothing (so as to wear matching outfits) and know when clothing is dirty.

- Being able to make use of the home safely – specialist equipment such as vibrating smoke alarms and door bells may need to be fitted, home adjustments such as better lighting may be necessary. Support may be required to use kitchen equipment safely and answering the front door safely may be problematic. Trips and falls are a risk if lighting is not adequate and appropriate.

- Maintaining a habitable home environment-keeping the home clean is often problematic for visually impaired people. Health and safety risks may arise from the inability to see or hear hazards in the home, as well as difficulties accessing information relating to utilities (which often arrives by mail in an inaccessible format).

- Developing and maintaining family and other personal relationships – both mobility and communication difficulties can be a barrier to developing and maintaining relationships, as they impact on essential activities such as travelling to visit friends, holding a conversation, using the telephone or accessing correspondence.

- Accessing and engaging in work, education, training or volunteering – mobility, access to information and communication all present barriers to this type of involvement.
• Making use of necessary facilities or services in the local community including public transport, and recreational facilities or services – challenges include accessing information about timetables, opening times and services, getting to the facilities and making use of them once there if moving around safely and communicating with strangers are difficult.

• Carrying out any caring responsibilities the adult has for a child – for a deafblind person many aspects of parenting can be difficult. Deafblind older people may wish to provide support to their family by caring for grandchildren.

A person is considered unable to achieve an outcome if it is possible but would cause high levels of stress or take significantly longer than normal. This will apply to many deafblind people, who may find travel to unfamiliar places theoretically possible, but the stress of navigating the environment and communicating can be severe. This is particularly true of people who have previously experienced difficult or dangerous situations when travelling alone. Many of the outcomes will take significantly longer than normal because of, for instance, very slow communication methods.

Many of the conditions which cause deafblindness are progressive, so even where a person is not deemed eligible it will be important to consider both prevention and that they understand that they can ask for another assessment if their condition changes.

**Eligibility for support to access to NHS services**

Accessing health services is one area where deafblind people experience significant difficulties and the Care Act guidance makes specific reference to this. “Local authorities do not have responsibility for the provision of NHS services such as patient transport, however they should consider needs for support when the adult is attending healthcare appointments.” (6.107i)

The NHS has two duties in relation to accessing services and the Care Act is not intended to place these duties on local authorities.

1. The provision of hospital transport
2. The duty to make reasonable adjustments under the Equalities Act, e.g. provide an interpreter for an appointment.

However, there may be deafblind people who are unable to access health services even where the NHS has complied with both of these duties because the support they require is greater than would be considered a “reasonable” adjustment. This might be, for instance, a person who requires a communicator guide to navigate around a hospital or to communicate with the hospital transport driver. In these cases, the person may be eligible for the additional support needed to access the health service.
Note that whilst hospital transport for the patient is a duty on the NHS, hospital transport for an escort is only a power, and in some places communicator guides are not allowed to travel with the deafblind person. If this means that the deafblind person cannot use hospital transport safely then the local authority should ensure that they can attend the appointment by other means.

The concept of reasonable adjustment can sometimes be subject to dispute. It is important that deafblind people are not denied access to NHS care as a result of such a dispute. The guidance requires that local authorities and Clinical Commissioning Groups must agree a local dispute resolution process, including arrangements for how funding will be provided during the dispute. This should be applied to situations where deafblind people are unable to access health services because of dispute over which agency is liable for particular support. A deafblind person should not be left without access to NHS services simply because of a dispute.

Case study: Accessing NHS facilities where there is a dispute

Jane needs to attend a hospital appointment and cannot travel or find her way around the hospital without a communicator guide. The hospital will provide an interpreter for the appointment but say that Jane should use hospital transport to get to the hospital. Jane does not feel safe using this unless she has a communicator guide.

The hospital says they are happy to transport the communicator guide, but will not pay for the guide. The local authority say that it is a reasonable adjustment for the hospital to provide the communicator guide since Jane cannot use their services without. But until the hospital agrees to this, Jane is unable to access the appointment. The local authority therefore funds the communicator guide and uses the dispute resolution process to decide if the hospital should reimburse the cost.
Care Planning

An adult with care and support needs must be as involved in the development of their care plan as they wish to be. Some deafblind people who are to receive minimal support may not wish to be heavily involved in their care plan and complex processes should not be put in place which delay the development of the plan.

However, where the deafblind person does wish to be involved there are some specific issues to bear in mind. Some deafblind people will need communication support, such as an interpreter, in order to be involved. Thought will have to be given to ensuring the process is accessible. Materials for support planning which are designed to be user-friendly through the use of graphics and visual aids will not be accessible to those with little or no sight, so alternatives must be provided.

The Care Act guidance states that “where a person with specific expertise or training in a particular condition (for example, deafblindness) has carried out the assessment, someone with similar knowledge (and preferably the same person to ensure continuity) should also be involved in production of the plan.” (10.34). This is to ensure that the person has support from someone who understands what type of support options, including specialist support, are available to a deafblind person. It should, for instance, mean that they have information about technology or other support services of which they might otherwise be unaware. This will also apply to reviews of care plans, since the same processes must be followed for these. (13.8) The involvement of a specialist is not intended to override the deafblind person’s ability to make their own decisions about their care and support. It should mean that they have access to the relevant specialist information required to make those decisions.

Local authorities who commission external providers to support care planning will want to ensure that those providers are able to make their support accessible to deafblind people. Alternatively, local authorities may wish to retain responsibility for support for deafblind care and support planning, for instance in the sensory team.

Sign off of plans

The guidance on care planning covers the possibility of use of panels to sign off care plans. In addition to other requirements where panels are used, the guidance states: “In cases or circumstances where a panel is to be used, and where an expert assessor has been involved in the care and support journey, the same person or another person with similar expertise should be part of the panel to ensure decisions take into account complex or specialist issues.” (10.85) This will mean that a panel considering a care plan for a deafblind person must have at least one member with deafblind training and expertise (see section on assessment above).
Personal budgets

The Care Act guidance sets out that the process for setting a person’s personal budget must meet three key requirements: transparency, timeliness and sufficiency. For deafblind people the sufficiency of the budget is of crucial importance as some of the methods local authorities use to calculate indicative budgets are problematic.

The indicative budget should be identified prior to care and support planning, and then adjusted after the planning process if it proves insufficient (or too high). This can cause difficulty for those with complex needs, or needs which are expensive to meet, such as deafblind people who need support from people with specialist qualifications. Generic methods of identifying the personal budget, particularly those which are points-based, can be so inaccurate that the care planning process is impossible. The low budget closes off the options that the person should be considering because they are too expensive.

The guidance recognises this and states that:
“Complex RAS models of allocation may not work for all client groups, especially where people have multiple complex needs, or where needs are comparatively costly to meet, such as deaf-blind people. It is important that these factors are taken into account, and that a ‘one size fits all’ approach to resource allocation is not taken. If a RAS model is being used local authorities should consider alternative approaches where the process may be more suitable to particular client groups to ensure that the personal budget is an appropriate amount to meet needs.” (11.23)

The final budget must be sufficient to meet the needs which the authority is under a duty to meet. Where there are shortages of particular types of specialist support in an area this may mean the authority paying significantly higher hourly rates and/or significant travel costs for staff. The local authority should not control this cost by expecting the deafblind person to accept a smaller quantity of support – this would not meet their needs.

Where the higher cost is an issue of supply, the local authority should address this through their duty to shape the market. Where it is simply a case that the type of support required is more expensive than average then the personal budget must reflect this. Local authorities can take account of finances when deciding how to meet needs, but not whether to meet needs.

Where a local authority is suggesting a cheaper option they must assure themselves that the support provided will meet the particular needs of a deafblind person. For example, a person with little or no BSL is unlikely to be able to meet the needs of a BSL user. An untrained PA without guiding or communication skills may provide poor or even dangerous support. These options might be cheaper, but they would not be an appropriate way to take finance into account, since the person’s needs would not be met.
Direct Payments

Deafblind people may wish to take some or all of their personal budget as a direct payment. Deafblind people can face significant barriers to managing direct payments, and in some cases this means they do not wish to do so and the local authority should manage the budget on their behalf.

However, the Care Act guidance states that local authorities should also take all reasonable steps to provide those who wish to use direct payments with the support they would need to do so. The guidance states that local authorities should consider if, where a specialist was involved in an assessment, that specialist should also be involved in advising on what support might enable a person to manage direct payments.

There is a case study in the guidance of a support service which makes their services accessible to a deafblind man. Local authorities will need to ensure that whatever direct payments support services they provide are able to support deafblind people appropriately. Sense has a series of factsheets on deafblind people and direct payments. www.sense.org.uk/content/direct-payments-and-personal-budgets

Direct payments and family members.

Generally direct payments cannot be used to pay family members to provide support, except in exceptional circumstances. It should be noted that one of the common exceptions to this is people who use British Sign Language where there is a shortage of suitable BSL users able to provide support. Another is people with idiosyncratic communication where only family members are able to understand the person’s communication.

Direct payments and hospital stays

The following case study appears in the guidance.

Example of using a direct payment whilst in hospital

Peter is deafblind and is required to stay in hospital for an operation. Whilst the hospital pays for an interpreter for the medical interventions, Peter needs additional support to be able to move around the ward, and to communicate informally with staff and his family.

The local authority and the NHS Trust agree that Peter’s communicator guide continues to support him in hospital, and is paid for via the direct payment, as it was when Peter was at home. Personal and medical care is provided by NHS staff but Peter’s communicator guide is on hand to provide specialist communication and guiding support to make his hospital stay is as comfortable as possible.
Transition from children’s to Adult’s services

The Care Act introduces a new “transition assessment” which must be carried out before a young person reaches the age of 18. The regulations and guidance related to assessment apply also to transition assessments. Therefore where the person being assessed is deafblind (Multi sensory Impaired, or MSI is the common term for children who are deafblind), then the person carrying out the assessment should have the relevant skills and training in deafblindness to be able to carry out the assessment.

It is unlikely that the minimum level of training at level 3 will be sufficient for most deafblind young people since having dual sensory impairment from a young age is likely to result in more complex needs. An MSI qualification such as Advanced Certificate, Bachelor in Philosophy, Postgraduate Certificate/ Diploma, Master of Education, in Multi-sensory Impairment (MSI) and Deafblindness or Certificate and Diploma in Deafblind Studies would be more appropriate.

The timing of the transition assessment is also critical. The assessment must be carried out at a time where it will provide significant benefit to the young person. Where a person has complex needs this assessment must be carried out early enough to allow for planning of services when the person reaches the age of 18. For most deafblind young people, an assessment after they have turned 17 is likely to be too late. There is a case study in the guidance illustrating how this should be taken into account for young people with complex needs.

If the local authority will meet the young person’s care and support needs after the age of 18, then it must ensure that the care planning process is carried out early enough that the package is in place at the time of transition. The same requirements for specialist involvement in care planning will apply as for other adults.

The guidance states that “local authorities must not allow a gap in care and support when young people and carers move from children’s to adult services.” 16.66.

General duties on local authorities

Prevention

Local authorities have a duty to provide services, facilities and support which can reduce, prevent and delay the development of needs for care and support. Most of the preventative support for deafblind people will fall into what the guidance terms tertiary prevention, i.e. support for those who already have a care and support need but who, with support, can either reduce their need for care and support or prevent it from becoming greater. This might include:

- Mobility training to enable a person to make some regular journeys without a guide meaning their need for a communicator guide was reduced.
• Teaching a person and their spouse to use deafblind manual to communicate meaning they need significantly less support if their spouse is willing to provide support.

• Teaching someone daily living skills such as how to cook for yourself having lost your sight meaning the person is able to continue living independently.

• Ongoing support can prevent severe isolation or challenging behaviour which would lead to higher support needs.

As with other services, deafblind people may not be able to access mainstream prevention services and will need something specifically tailored to take account of their dual sensory loss. For example, not all Rehabilitation Officers for visually impaired people have an understanding of the impact of hearing loss on mobility skills.

Many authorities provide packages of reablement for up to six weeks aimed at enabling people to develop skills to live independently often following a hospital admission. This can mean that people need no further support, or a significantly reduced package of support. The same can be true of deafblind people but the timescales are much longer than six weeks. For instance, learning new mobility skills, or to communicate using deafblind manual rather than speech, can take months rather than weeks.

The guidance recognises the need for longer interventions: “Whilst they are both time-limited interventions, neither intermediate care nor reablement should have a strict time limit, since the period of time for which the support is provided should depend on the needs and outcomes of the individual.” (2.61)

Six weeks of reablement must be provided without charge, even where the authority would normally be able to charge the person for support. However, starting to charge for a preventative service after six weeks may undermine the preventative aim of the support and can lead to people refusing the support. The guidance states that: “In some cases, for instance a period of reablement for a person who has recently become sight-impaired, the support may be expected to last longer than six weeks. Whilst the local authority does have the power to charge for such types of support where it is provided beyond six weeks, local authorities should consider continuing to provide it free of charge beyond six weeks in such circumstances, in view of the clear preventative benefits to the individual and, in many cases, the reduced risk of hospital admissions.” (2.61)

The same will be true of mobility, daily living skills and communication development with deafblind people.
Providing prompt and appropriate support to a deafblind person can also have a prevention impact. For instance, deafblind people are more likely to have a range of physical and mental health conditions and to be isolated and lonely. It is not hard to see why this would be – difficulties with accessing healthy food, keeping in touch with friends and family, getting exercise, being involved in the local community will all contribute to poor outcomes.

Providing intervention when someone has first begun to have difficulty with hearing and sight can help prevent these problems occurring and reduce the long term need that person will have for support.

Mary is an elderly deafblind woman who had good hearing and sight for most of her life. She is now profoundly deaf and blind. Mary became increasingly confused due to her deafblindness and her brother who helped with her care found he was unable to cope.

The decision was made against Mary’s wishes to place her in residential care but this has not been a success. The staff at the home do not know how to support her and she is isolated, frustrated, anxious, and angry.

If Mary had been given two hours per day of support at an early stage to help her to readjust to her sensory impairments and thereafter three hours twice a week of communicator guide support, then she could have remained in her own home.

Some prevention services available more generally may be inaccessible to deafblind people. Many interventions for loneliness rely on people being able to access the telephone or communicate in groups. One way to address this might be the provision of a communicator guide or specialist technology to assist the person in accessing the service.

Another would be to arrange a similar service but tailored to the needs of deafblind people. This might be social groups or activities in venues with good lighting and acoustics run by staff or volunteers with some understanding of deafblindness, and where the speed of communication is more appropriate. A befriending scheme might need volunteers with training in deafblind communication and guiding to enable them to support those with these needs.
**Information and advice**

The Care Act requires that a local authority establish a service for providing information and advice to people about care and support for adults and about support to carers. There is a section of the guidance on accessibility of information and advice, and people with sensory impairments are listed as one group whose needs must be considered.

In relation to deafblind people, the deafblind guidance also requires that authorities are able to provide information to people in a range of formats such as braille, large print, electronically. In exceptional circumstances a person may only be able to receive information in deafblind manual. For these small number of people it will be necessary to provide the information in person.

Accessibility is not only related to formats. Because deafblind people have difficulty accessing general information about the world around them, there may be gaps in their knowledge which mean they need more support to understand the information provided.

The second factor to be aware of in relation to deafblind people’s needs of information is that they need specialist information which takes account of their needs as a deafblind person. Information and advice services should know how to refer people to specialist organisations such as Sense or organisations working on a specific condition. The websites of both Sense and the Alzheimer’s society, for instance, are referenced in the guidance and in the Think Local Act Personal information and advice strategy tool. The Sense website has a list of conditions and the relevant support groups: www.sense.org.uk/a-z-of-conditions

**Involving deafblind people**

Local authorities will need to involve deafblind people in some of the implementation of the Care Act. The information and advice plan, for instance must involve the engagement with people, carers and family members. Deafblind people are often left out of such engagement because it can be difficult to make processes accessible to them.
Market shaping duties

The Act gives local authorities a duty to ensure that there are sufficient high quality services in their area to meet the needs of those with care and support. The guidance on market shaping makes it clear that this must include consideration of the appropriateness of the services. The example given is of a young person expected to use a service for older people.

However, the same applies to deafblind people who require specialist support or are unable to access mainstream services. The guidance makes specific reference to the need to consider low incidence and specialist services. This will include specialist services for people with complex needs. Mainstream learning disability services may not be suitable for congenitally deafblind people, for instance. Mainstream older people’s services may not be accessible to people with a dual sensory loss unless they have been designed with this in mind.

Local authorities should have in place a published strategy for how they plan to deliver their market shaping and commissioning duties. This should take account of their Joint Strategic Needs Assessment (JSNA) and of the need for preventative services. Local authorities should therefore be considering the likely number of people with dual sensory loss and with complex needs and therefore the need for specialist support to meet these needs. This should include specialist prevention services, such as rehabilitation, accessible befriending and social support.

Local authorities may need to invest in training for specialist staff, or commission in a way that enables providers of specialist support to be confident their services will be sustainable in the long term. The highest incidence of deafblindness is amongst the older population, so local authorities should commission services for older people in a way that ensures sufficient support which is accessible to deafblind people.

Research by Professor Emmerson will help local authorities estimate the likely deafblind population of different ages in their area.

www.sense.org.uk/content/regional-data-future-deafblind-population
Checklist

Strategic
✓ Do we understand the size of our deafblind population and their likely characteristics? Research on the estimated deafblind population in each authority area will help with this.
www.sense.org.uk/content/regional-data-future-deafblind-population

✓ Have we linked this to our JSNA and our market development plan?

✓ Have we involved our sensory team in planning how to implement the Care Act?

Specialist staff
✓ Have we assessed the likely need for specialist input to assessment, care planning and panels resulting from this population?

✓ Do we know where we will access staff to carry out assessments, including staff suitably qualified to carry out complex assessments?

✓ Do we have sufficient staff with the relevant levels of training in –house or will we need to contract out?

✓ Do all our first contact team know how to identify a deafblind person and how to refer appropriately?

✓ Have our trainers used the Skills for Care factsheet on deafblindness?

✓ Can we access advocates with communication skills where necessary?

Meeting needs
✓ Do we have methods of calculating a personal budget which are appropriate for people with complex needs and deafblind people?

✓ Do we have appropriate care planning support available for deafblind people?

✓ Is our direct payment support service able to support deafblind direct payments users? Are they aware of the Sense factsheets?

Prevention
✓ Have we assessed our prevention services for their suitability for deafblind people? Do we have rehabilitation suitable for those with sensory loss and access to specialist skills development for deafblind people?

✓ Are our community prevention services such as befriending accessible to people with dual sensory loss?
Do we understand the prevention benefits of support such as communicator guides and intervenors and do we commission those services with prevention in mind?

Do we have access to skilled rehabilitation workers to support deafblind people to develop new skills?

**Information and advice**

Is our information and advice service accessible to deafblind people and would staff know how to provide information in a range of formats?

Do staff in our information and advice service know how to refer people with specialist needs to relevant national specialist information services?

**Market shaping**

Have we considered the likely need for specialist services for people born deafblind with complex needs? This is likely to be a small number of people.

Have we considered the need for appropriate support for older deafblind people with more complex needs?

Is the support available for older people in our area appropriate for the likely numbers of older people with dual sensory loss?

Do we commission older people’s support with sensory loss in mind?
Appendices

Appendix A: Deafblind people and communication

Speech based communication

Clear speech
Speaking clearly is one of the most effective and common ways of communicating with deafblind people who have some remaining vision and a hearing loss.

Lipreading
Lipreading involves the deafblind person watching the lip shapes, gestures and facial movements of the person they are talking to so that they get a fuller understanding of what they are saying.

Tadoma
Tadoma involves a deafblind person placing their thumb on a speaker’s lips and spreading their remaining fingers along the speaker’s face and neck. Communication is transmitted through jaw movement, vibration and facial expressions of the speaker.

Letter based communication

Deafblind manual alphabet
The deafblind manual alphabet is a method of spelling out words onto a deafblind person’s hand. Each letter is denoted by a particular sign or place on the hand. It is straightforward to learn but is more complex to receive.

Block
Block is a manual form of communication where words are spelled out on to the palm of the deafblind person’s hand.

Braille
Braille is a system of writing and printing for visually impaired people, in which arrangements of raised dots representing letters and numbers are identified by touch. Braille can now be used as a digital aid to conversation, with some smartphones offering braille displays, and computer braille keyboards allowing access to instant messaging software, Skype or chatrooms.

Moon
Moon is similar to braille in that it is based on touch. Instead of raised dots, letters are represented by 14 raised characters at various angles. It is less commonly used than Braille, but easier to learn.
Signed communication

British Sign Language or BSL

BSL is a language in its own right, with its own word order and grammar. It uses hand signs and facial expressions as a visual form of communication. For people with visual impairment it can be adapted in two ways:

1. **Visual frame signing** – someone using BSL will sign within the restricted visual field of the person so that they can see it.

2. **Hands-on signing** – some people may use tactile or ‘hands-on’ signing by placing their hands over the hands of the signer, so that they can feel the signs being used.

Sign-supported English

Sign Supported English uses BSL signs but in the order that they would be used in spoken English.

Haptic communication

This is becoming more recognised. It consists of tactile signs describing the environment, emotional responses, descriptions of people and other additional information which would otherwise be provided by sight. The signs are given through touch, commonly to the back, but it can be anywhere on the body that doesn’t interfere with other communication methods being used that the recipient is comfortable with.

Makaton

Makaton uses signs, symbols and speech to develop communication, language and literacy skills.
Symbol systems

Symbol systems are often used to assist deafblind people to communicate. Photos, pictures and objects can be added to other structured forms of communication.

Objects of reference

Some congenitally deafblind or multi-sensory-impaired people learn to use particular objects to symbolise a significant activity. For example, a towel may indicate swimming, or a fork may be used to show that it is time for a meal. This method allows people who are deafblind to make choices and enables others to let them know what is planned.

Picture symbols

Picture symbols are sometimes used to support the development of language, either accompanying text or in their own right.

There are a number of symbol sets available including Widgit and Mayer Johnson.

Nonverbal communication

Many congenitally deafblind and multi-sensory-impaired people with no formal verbal communication methods will use non-verbal improvised forms instead. Through observation it is often possible to understand the meaning of these unique methods of communication and to learn how to react to and interact with the deafblind person.

Total communication

The total communication approach is about using the right combination of communication methods for an individual to ensure the most successful forms of contact, information exchange and conversation. For example, an individual may receive information via speech and signs while expressing themselves via signs and symbols.
Appendix B: Making information accessible

Check with the deafblind person how they prefer to receive information. Your information service will need to be able to access transcription into the different formats as required.

**Large print**

No single size is suitable for everyone, but most people prefer their large print in the range of 16 to 20 point. Ensure that you record the preferred size and not just the fact that the person needs large print. Arial is an example of a clear font. You can word process simple large print documents yourself. Some people will also prefer a particular colour paper.

**Braille**

Documents can be transcribed into braille through a transcription service. However, many people who use braille prefer information electronically. With a braille display, emails, word documents and web pages can be accessible to braille users, provided they are designed accessibly. Check with the person how they prefer to receive information before arranging for transcription.

**Moon**

Moon is a much less commonly used system of tactile written information, based on raised versions of the alphabet.

**Audio**

Transcription services can produce Audio tape or disk versions of written documents. Some people will have screen reader software on computers and be able to access electronic documents in audio.

**Telephone**

Ensure information services have access to text phones and/or staff know how to use text relay (which allows a text phone user to communicate with a voice phone user through an operator).

**Email**

For people with access to computers, email and word documents can be the easiest way to access information as they can adapt the font size and colours to their preference.
Face to face
For a small number of people, face to face communication is the only way to access information. This may be because their only way to receive information is through deafblind manual.

Sign language
Some people who use British sign language (BSL) find written English difficult to understand. For many BSL users a signed video is easier to understand. Professionals BSL services are required to produce good quality BSL versions of information.

Easy read
For some deafblind people who have some vision but an additional learning disability, easy read will be required.
Appendix C: Glossary

Communicator Guide

Communicator-guides offer guiding skills, practical help and communication support – such as helping with shopping or dealing with mail – to enable deafblind people to continue to live independently.

Intervenor

An intervenor works one-to-one with deafblind individuals. For example, children are encouraged to develop new skills through co-active play and tactile stimulation; adults are helped to develop their communication and independence skills and use local community resources.

Mobility

In the context of deafblindness, mobility refers to the ability to safely move around the home and outside the home. A deafblind person may appear to have no difficulty in moving around a familiar place, or taking a regular journey but be unable to safely manage an unfamiliar journey or cope with a change such as a blocked pavement on a usual route. A deafblind person’s ability to move safely out of doors can also vary depending on light levels, for instance between daytime and at night.
Rehabilitation workers for people who are blind or partially sighted are qualified professionals who design and provide programmes of rehabilitation for people losing their sight or people who have always had poor sight but need to adapt to new personal circumstances. Their service usually include orientation and mobility training, for example, learning how to navigate road crossings and using public transport, daily living skills training, communication skills, such as learning Braille or learning to use magnifiers, or assessing for lighting adaptations.
About Sense

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

We believe that every deafblind person has the right to choose the support and lifestyle that is right for them; one that takes into account their long-term hopes and aspirations. Our specialist services enable deafblind people to live as independently as possible, offering a range of housing, educational and leisure opportunities.

We welcome your feedback on this information – let us know at knowledge@sense.org.uk

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