



# Somerset Sensory Review

## Appendices to the final report

**Appendix 1** Sensory Loss Review of research, guidance and best practice – pages 2 to 84

**Appendix 2** Protocol for joint working between vision support team and adult social care – pages 85 to 92

**Appendix 3** Care pathways – pages 93 and 94

**Appendix 4** Record of Phase 1 Consultation Meetings – page 95

**Appendix 5** Interview Schedule – pages 96 and 97

**Appendix 6** Case example – page 98

**Appendix 7** Somerset Sensory Review Questionnaire – pages 99 to 102

**Appendix 8** Summary of feedback from Sensory Loss workers – pages 103 to 106

**Appendix 9** Record of Phase 2 consultation meetings - page 107

# Appendix 1

## **Sensory Loss Review of research, guidance and best practice**

**Research paper  
by  
Peter Fletcher Associates Ltd**

**Version 2, June 2010**



**Peter Fletcher Associates Ltd**  
*Research and Consultancy*

# **Sensory Loss Review of research, guidance and best practice**

## **Team**

**Trevor Eardley  
Heather Eardley  
David Hess  
Peter Wareham**

Peter Fletcher Associates Ltd  
Chesterwood Grange  
Haydon Bridge  
Northumberland NE47 6HW  
Tel: 01434 684944  
Fax: 01434 684945

Email: [info@peterfletcherassociates.co.uk](mailto:info@peterfletcherassociates.co.uk)  
Website: [www.peterfletcherassociates.co.uk](http://www.peterfletcherassociates.co.uk)

# Sensory Loss Review of research, guidance and best practice

<b>Contents</b>	<b>Page</b>
<b>Glossary .....</b>	<b>v</b>
<b>1. Purpose of project.....</b>	<b>1</b>
<b>2. Definitions.....</b>	<b>3</b>
<b>2.1 Visual Impairment .....</b>	<b>3</b>
<b>2.2 Deaf and hearing impairment.....</b>	<b>4</b>
<b>2.3 Dual Sensory Impairment.....</b>	<b>5</b>
<b>3. Prevalence .....</b>	<b>6</b>
<b>3.1 Visual impairment .....</b>	<b>6</b>
<b>3.2 Deaf and hearing impairment.....</b>	<b>8</b>
<b>3.3 Dual Sensory Impairment.....</b>	<b>9</b>
<b>4. Impact: Inclusion, participation and independence.....</b>	<b>11</b>
<b>4.1 Visual impairment.....</b>	<b>11</b>
<b>4.2 Deaf and hearing impairment.....</b>	<b>12</b>
<b>4.3 Dual Sensory Impairment.....</b>	<b>13</b>
<b>5. Legislative and Policy Background.....</b>	<b>16</b>
<b>6. Prevention and Early Intervention .....</b>	<b>19</b>
<b>6.1 Visual impairment .....</b>	<b>19</b>
<b>6.2 Deaf and hearing impairment.....</b>	<b>20</b>
<b>7. Universal information, advice and advocacy .....</b>	<b>21</b>
<b>7.1 Visual impairment .....</b>	<b>23</b>
<b>7.2 Deaf and hearing impairment.....</b>	<b>24</b>
<b>7.3 Dual sensory impairment .....</b>	<b>26</b>
<b>8. Assessment / diagnosis, Care Pathways and Provision</b>	<b>28</b>
<b>8.1 Assessment for Adult Social Care.....</b>	<b>28</b>
<b>8.2 Equipment – self-assessment.....</b>	<b>31</b>
<b>8.3 Visual Impairment .....</b>	<b>32</b>
<b>8.4 Deaf and hearing impairment.....</b>	<b>41</b>
<b>8.5 Dual sensory impairment .....</b>	<b>44</b>

<b>8.6 Learning Disability .....</b>	<b>46</b>
<b>9. Resource allocation .....</b>	<b>48</b>
<b>10. Commissioning .....</b>	<b>55</b>
<b>10.1 Visual impairment .....</b>	<b>56</b>
<b>10.2 Deaf and hearing impairment.....</b>	<b>57</b>
<b>10.3 Dual sensory Impairment .....</b>	<b>58</b>
<b>11. Workforce .....</b>	<b>59</b>
<b>12. References .....</b>	<b>63</b>
<b>13. Useful links .....</b>	<b>75</b>

## Figures

<b>Fig. 4.1a Percentage of people registered blind who are deaf or hard of hearing .....</b>	<b>7</b>
<b>Fig. 4.1b Percentage of people registered as partially sighted who are deaf or hard of hearing .....</b>	<b>7</b>
<b>Fig. 5.1 Putting People First approach.....</b>	<b>18</b>
<b>Fig. 8.1 Proposed low vision pathway .....</b>	<b>27</b>
<b>Fig. 8.2 Good practice model.....</b>	<b>42</b>
<b>Fig. 8.3 Commissioning pathway.....</b>	<b>43</b>
<b>Fig. 9.1 In Control’s RAS development cycle .....</b>	<b>39</b>
<b>Fig. 10.1 Guide to Commissioning Community Care Eye Services .....</b>	<b>56</b>

## Glossary

**Advocacy** – the provision of independent support for service users in helping them speak up for themselves and ensuring that their views are heard, understood and taken into account.

**Brokerage** – Assistance provided or commissioned by local authorities to help service users and carers plan and organise the support they want. It can include help with developing support plans or how a personal budget will be used. Some councils have in-house brokers who work exclusively at piecing together the best care package. Other local authorities now fund independent organisations to broker with users. And users on personal budgets can also fund a broker themselves. (Service users should be able to choose who they want to assist them in this way, e.g. a relative, friend, neighbour, or social care professional.)

**Care pathway** – Care pathways describe the route that a service user will take from their first contact with adult social care to the time when they no longer need to use services. The term ‘integrated care pathway’ is used to describe care that goes across several disciplines, for example across social and health care or across different forms of health treatment.

**Direct payments** – Budgets paid directly to social care users to meet their needs. They are a form of personal budgets, giving service users direct control of the money allocated to them for care.

**Fair Access to Care Services (FACS)** – The national framework on which decisions about eligibility criteria must be based.

**In Control** – Social enterprise set up to transform the current social care system into a system of self-directed support. For more information see [www.in-control.org.uk](http://www.in-control.org.uk).

**Individual budget** – Sum allocated to an individual user of services, originally drawn from a number of funding streams in the individual budget pilots. Now often used interchangeably with ‘personal budget’.

**Personal budget** – The amount of money allocated for an individual's social care, either paid directly to the individual in direct payments or held by social services or a third party. Now often used interchangeably with 'individual budget'.

**Personalisation** – The theory behind the current transformation of social services; also refers to the process of providing individualised, flexible care that is intended to promote the independence of those who need care; usually associated with self-directed assessment, individual budgets and self-directed support.

**Resource Allocation System (RAS)** – System each council has for allocating social care budgets to individuals, based on need determined by assessment/self-directed assessment.

**Re-ablement** – Short-term intensive support following illness, accident or hospital stay. It is intended to help people live as independently as possible in their own homes.

**Self-directed assessment** – The assessment process involved in self-directed support – a simplified assessment process that is led as far as possible by the service user in partnership with professional staff, focusing on outcomes service users want to achieve.

**Self-directed support (SDS)** – The means used by each council to enable service users to control how their personal/individual budget is used. The term comes from the organisation In Control, which champions the rights of people to control their care budget.

**Self-funder** – Someone who, because of their income, is not eligible for council-funded care. They are still entitled to advice and help from the council to make their social care arrangements, which they pay for themselves.

**Support plan** – Summary of the agreed care that an individual is to receive, based on outcomes and using their personal/individual budget. May refer to outcomes or aspirations not covered by their social care budget (e.g. aspirations to make use of universal services such as leisure or learning facilities).

**Universal services** – Unlike personal social care services, which are means-tested, universal services are available to everybody, including those who need social care and support. For example, people who are not eligible for free social services (self-funders) are entitled to advice from the council on where they can find services, such as home care or residential care, which they will pay for themselves.

## 1. Purpose of project

The purpose of the project is to appraise existing sensory loss provision, and prepare the service for the Personalisation process, so that it will dovetail into Somerset's "You First" Transformation Programme.

The project will consult with service users, carers, providers, staff and the wider community, and will explore models of service and best models of practice elsewhere. Ultimately, the project will recommend a new strategic vision for sensory support services.

Research and consultation work undertaken will ensure that models of best practice for sensory impairment services will be incorporated in the "You First" Transformation Programme.

The project will look at all elements of our social care provision for people with sensory loss including:

- Legislation and statutory obligations
- Service provision
- Wider access to the service
- Roles and training of staff
- Interfaces with other branches of social care which provide services for people with sensory loss, e.g. Children and Young People, Mental Health, Learning Disabilities
- Links with Health

The following interim research summary has been compiled to inform the project with regard to this task and provide an outline of key research, good practice examples and guidance. It identifies core legislation, guidelines and standards for service provision across the various categories that constitute sensory loss. It considers research that identifies the needs and implications for people with sensory loss. It identifies examples of good practice and national recommendations for service improvements. Research into 'what is needed and what works' will continue to inform the second stage of the project, with a particular focus on how other authorities are adapting the sensory service for

personalisation. The report does not intend to be a comprehensive review of all relevant research as that is beyond the terms of reference, rather it is designed to be a summary of key pointers for the review and possible redesign of services for people with sensory loss.

## **2. Definitions**

### **2.1 Visual Impairment**

Widely accepted definitions of blindness and partial sight are drawn from two sources, the National Assistance Act (1948) and Disability Rights Commission guidance for the Disability Discrimination Act (DDA). Section 64 of the National Assistance Act 1948 defines “blindness” as being “so blind as to be unable to perform any work for which eyesight is essential”. The certificate of blindness qualifies this as being a disability referring “to any work and not to a person’s own occupation”.

Under the DDA blindness is defined in terms of substantial and long-term adverse effect. Examples of substantial effect can be time taken to complete a task, fatigue caused by the repeat reading of newsprint, and the effect of the environment, such as little light, on an individual’s vision. A long-term effect is any condition that has lasted at least 12 months, or is likely to last 12 months or longer.

There is no statutory definition of partial sight within either the 1948 National Assistance Act or the DDA Guidance. However, if a person has a substantial and permanent sight loss a Consultant Ophthalmologist will consider if the person is eligible for inclusion on the Partially Sighted Register, held by the local authority. The registration is voluntary and the actual registration process is carried out by the local authority. The term, “partial sight” is widely accepted including by the Royal National Institute for the Blind.

The new terminology now for the registration categories:

- Severely sight-impaired/blind
- Sight-impaired/partially-sighted

According to the RNIB, only three per cent of people registered blind are totally blind, ninety-seven per cent of people have some residual vision.

## 2.2 Deaf and hearing impairment

There is some disagreement within the Deaf community about these terms, for example whether people with some hearing can claim to be deaf. The Department of Health states that there is no formal examination procedure to determine if a person is deaf or hard of hearing (Local Authority Circular (93) 10 Appendix 4 - relating to section 29 of the National Assistance Act 1948). They categorise deaf and hard of hearing people as follows (Circular 25/61)

Deaf without speech	Those who have no useful hearing and whose normal method of communication is by signs, finger spelling or writing
Deaf with speech	Those who (even with or without a hearing aid) have little or no useful hearing but whose normal method of communication is by speech and lip-reading
Hard of hearing	Those who (with or without a hearing aid) have some useful hearing and whose normal method of communication is by speech, listening and lip-reading

Under the DDA people qualify as 'disabled' with regard to hearing loss if they experience 'a physical or mental impairment which has a substantial and long term adverse effect on their ability to carry out normal day to day activities'. Guidance indicates that an inability 'to hold a conversation with someone talking in a normal voice', or an 'inability to hear and understand another person speaking clearly over the voice telephone', counts as a substantial adverse effect under the Act. 'Substantial' means 'more than minor or trivial', so only a relatively minor hearing loss is unlikely to fit the definition.

Hard of hearing is a term generally used to describe people who have some but not complete hearing loss. This term is prevalent in the literature and is endorsed by the Royal National Institute for the Deaf

Many deaf people whose first or preferred language is British Sign Language (BSL) consider themselves part of the Deaf community. They may describe themselves as Deaf with a capital D to emphasise their Deaf identity. They have usually been educated

at special schools geared to their needs and have Deaf friends and peers.

People who were born hearing and became severely or profoundly deaf after learning to speak are often described as deafened. This can happen suddenly or gradually.

### **2.3 Dual Sensory Impairment**

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

Whilst there is no generally accepted definition of Deafblindness there is a working description that has been accepted over many years. Persons are regarded as Deafblind 'if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility'. This includes people with a progressive sight and hearing loss.

## 3. Prevalence

### 3.1 Visual impairment

Demographic forecasts show that by 2021, 40 per cent of the population will be over 50; a significant proportion of sight loss is related to age and one in eight over-75s and one in three over-90s have serious sight loss.<sup>(1)</sup> Diabetes, and hence diabetic retinopathy among children and young adults is also increasing and this too will prove a challenge to service providers.

Some black and ethnic minority communities have a higher incidence of eye disease than a comparable population of white Europeans- for example African Caribbean people are four times more likely to have glaucoma while conditions like diabetic retinopathy are more prevalent in the Asian community.

The following estimates were obtained from a report prepared for the RNIB that informed the UK Vision Strategy 2010.<sup>(2)</sup>

#### ***Sight loss from both types of Age-related Macular Degeneration (AMD).***

In the UK it is estimated that by 2010, 132,970 people will be partially sighted and 90,254 people will be blind. This is assuming that the new treatment for NV AMD covers 75 per cent of those eligible from 2010. By 2020, the numbers of people expected to be partially sighted are 171,530, and 120,452 people are expected to be blind. This is under the same assumption that 75 per cent of people with NV AMD will be treated, but it also allows for an increase in the older population.

#### ***Sight loss from cataract***

For 2010, the estimated prevalence of partial sight due to cataract for the UK will be 206,224 and blindness to be 27,907. In 2020, should this condition remain visually impairing at this level in the

---

<sup>1</sup> Evans J R et al. Prevalence of visual impairment in people aged 75 years and older in Britain. *British Journal of Ophthalmology* 2002

<sup>2</sup> Minassian, D. et al. *Future sight loss in the decade 2010 to 2020: an epidemiological and economic model, EpiVision 2009*

population, it is estimated that 248,504 people will be partially sighted, and 32,750 will be blind.

### ***Sight loss from diabetic retinopathy***

In the UK 40,982 people in 2010 will be partially sighted from diabetic retinopathy and 24,976 will be blind. In 2020, 46,473 people are expected to be partially sighted and an additional 29,957 to be blind.

In the UK 57,646 people in 2010 will be partially sighted from glaucoma and 17,511 will be blind, assuming that the level of detection of this disease in the population is at 50 per cent.

### ***Sight loss from glaucoma***

71,806 people are expected to be partially sighted by 2020, and 22,261 to be blind under the same assumption about detection.

### ***Prevalence Of Undetected Eye Disease***

There is a significant proportion of the older population in the UK that have undetected partial sight and blindness. For example, Evans and Rowlands (2004) estimated that between 20 per cent and 50 per cent of older people have undetected reduced vision, with the majority of this group having correctable visual problems, such as refractive error and cataracts.<sup>(3)</sup> Also, due to the greater risks of developing certain eye conditions, and the additional barriers to eye care services faced by minority ethnic groups, it is expected that prevalence of undetected eye conditions is greater in this population.<sup>(4)</sup>

### ***Learning Disability***

Amongst adults, the prevalence of visual impairment increases with the severity of the learning disability and with age. A literature review by the Valuing People Support Team found people with learning disabilities to be between 8.5 and 200 times more likely to have a visual impairment compared to the general population.

---

<sup>3</sup> Minnasian, D. et al. p. 146

<sup>4</sup> Minnasian, p.160

In March 2006, the Down Syndrome Medical Interest Group reported [36] a high incidence of ocular disorder among people with Down's syndrome:

- Refractive errors and/or squint often present from an early age
- Cataract and/or glaucoma occurring in infancy
- Nystagmus present in at least 10% of the DS population
- Keratoconus more common in adolescents and young adults

### **3.2 Deaf and hearing impairment**

It is estimated that there are 8.9 million people in the United Kingdom who have some degree of hearing loss. Of these around 5.9 million are thought to be sufficiently deaf or hard of hearing to be considered disabled in terms of the Act. The great majority are older people, who have age related hearing loss. As more people live longer, there will be more deaf people in the population. About 673,000 of these people are thought to be severely or profoundly deaf. 42,000 people are too deaf to use the telephone.

It is difficult to obtain reliable information about deaf people. It has been shown that registers of deaf people are inevitably inaccurate and that there is usually a tendency to underestimate the numbers.

According to LINK 150,000 UK residents live with the effects of acquired total deafness. Around 70,000 people grow up with deafness.

These are the percentages of those over the age of 50 and over the age of 70 who have various degrees of hearing loss in the UK.(5)

- 71.1% of over 70-year-olds will have some kind of hearing loss
- 26.7% of over 70-year-olds will have mild hearing loss
- 36.8% of over 70-year-olds will have moderate hearing loss

---

<sup>5</sup> [http://www.rnid.org.uk/information\\_resources/aboutdeafness/statistics/](http://www.rnid.org.uk/information_resources/aboutdeafness/statistics/)

- 6.3% of over 70-year-olds will have severe hearing loss
- 1.3% of over 70-year-olds will have profound hearing loss
- 41.7% of over 50-year-olds will have some kind of hearing loss
- 21.6% of over 50-year-olds will have mild hearing loss
- 16.8% of over 50-year-olds will have moderate hearing loss
- 2.7% of over 50-year-olds will have severe hearing loss
- 0.6% of over 50-year-olds will have profound hearing loss.

High levels of sensory impairment are common in people with learning disabilities. An institutional survey of vision (McCulloch et al, 1996) showed that 12% of mildly disabled people, more than 40% of severely disabled and 100% of profoundly disabled people had poor visual acuity. The prevalence of ocular health problems ranged from 25% in the mildly disabled group to 60% in the profoundly disabled group. A study of severely disabled children and adolescents in another residential institution reflected this high prevalence (Kwok et al, 1996). Here 25% had severe visual impairment and 24% refractive errors. Evenhuis et al (1997) identified hearing loss in 25–42% of community samples of people with learning disabilities.(6)

### 3.3 Dual Sensory Impairment

Many Deafblind people are not known to their local social services authority. Of those who are in contact with social services, not all are identified as having dual sensory impairment nor are they in receipt of appropriate services. This applies to both adults and children.(7) The Department of Health estimated the number of deafblind people at 40 per 100,000 of the population.(8) Sense is a national deafblind charity which focuses on the individual needs of children and adults who are deafblind, estimates that this is likely to be an underestimate, suggesting that there may be 10

---

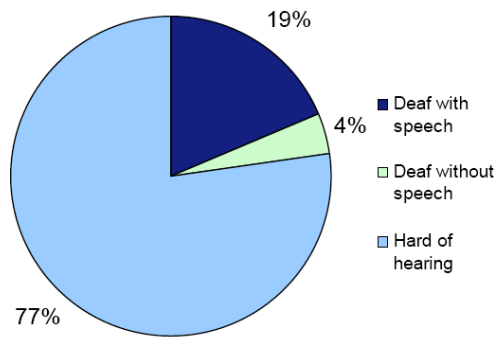
6 Kerr, M, *Improving the general health of people with learning disabilities*, *Advances in Psychiatric Treatment* (2004) 10: 200-206

7 Local Authority Circular LAC(DH)(2009)6, *Social Care For Deafblind Children and Adults*

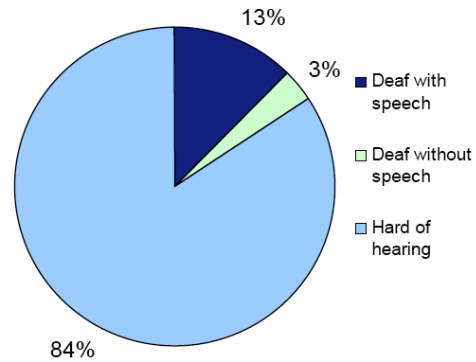
8 Local Authority Circular LAC(2001) 8, *Social Care for Deafblind Children and Adults*

times that number. They suggest that 4.6% of over 75s, or almost 1 in 20, are sufficiently sensory impaired to be considered deafblind. This is approximately 186,000 people in England, Wales and Northern Ireland. However, further research is needed to reach a clear conclusion about the numbers, and for this reason Sense support the fact that the re-issued guidance contains no reference to numbers of deafblind people. Sense state that many local authorities who have made serious efforts to identify deafblind people in their area have certainly identified over three times the 40 per 100,000 figure. The Office of National Statistics published the following graph based on registration figures.(9)

**Figure 4.1a: Percentage of people registered as blind who are deaf or hard of hearing.**



**Figure 4.1b: Percentage of people registered as partially sighted who are deaf or hard of hearing.**



Source : IC triennial return SSDA902

Many people do not define themselves either as Deafblind or having dual sensory loss. They may use such phrases as 'I don't see too well or hear too well'. However, they do describe their vision and hearing loss in terms, which indicate that they have significant difficulties in their day-to-day functioning and may need support to live independently.

9 Information Centre, *People Registered Deaf or Hard of Hearing Year ending 31 march 2007, in England*

## **4. Impact: Inclusion, participation and independence**

The social model of disability should provide the key principle underpinning services. This model defines disability in terms, not merely of impairment, but in terms of the various barriers which society puts in the way of people in their efforts to access services. For example, a wheelchair user who cannot get into a building is 'disabled' by virtue of the limitations of the building, rather than his/her 'per se' disability.

### **4.1 Visual impairment**

Three out of four blind or partially sighted older people live in poverty or on its margins, living on less than half the mean national income.<sup>(10)</sup> Only 34 per cent of blind and partially sighted people are in employment, compared to 75 per cent of the population overall.<sup>(11)</sup> 24 per cent of blind and partially sighted people of working age have no qualifications, compared to 15 per cent of the working age population.<sup>(12)</sup>

Sight loss has a huge impact on a person's quality of life. People with sight loss are far more likely to have a fall, suffer from depression and become isolated. The prevalence of depression is at least twice as high in visually impaired older adults than in older people with good vision.

Gaps in the transition from children's and young people's services to adult services, which have different funding mechanisms and criteria, may mean that young people do not receive the support or information they need to enable them to fulfill their potential and maintain control of their lives.<sup>(13)</sup>

---

<sup>10</sup> Unseen: Neglect, isolation and household poverty amongst older people with sight loss. RNIB 2004

<sup>11</sup> Douglas et al. Network 1000: Opinions and circumstances of visually impaired people in Great Britain. VICTAR/VISION 2020 UK 2006

<sup>12</sup> Pey, T et al. Functionality and the Needs of Blind and Partially Sighted Adults in the UK. Guide Dogs 2007

<sup>13</sup> Special Educational Needs SEN Regional Partnerships Case Study 7: Transition planning. DfES 2003

Over 180,000 registered blind and partially sighted adults in the UK never or rarely go out because the social care system does not meet their needs.<sup>(14)</sup> The cost of public transport, coupled with access difficulties, reduces mobility. Housing is often too far from local amenities, or poorly connected to these.

Public buildings such as theatres, cinemas and libraries, and even hospitals and surgeries, are often not designed to be accessible, leading to isolation and social exclusion of blind and partially sighted people.

Design fails to take into account the needs of people with sight loss, in particular those who are blind and partially sighted. Areas that fall short include (but are not exclusive to): transport; signage for those on foot; food labelling; medicine labelling; white goods and technology (for example, mobile phones with small buttons and poor contrast); the written word – less than 5 per cent of books are available in accessible formats.<sup>(15)</sup> Disability discrimination legislation is too often not enforced.

Apart from the health and social impacts, there are also significant economic impacts resulting from sight loss. RNIB estimates indicate that the total costs of sight loss in the UK are in the region of £4.9 billion a year.<sup>(16)</sup>

## **4.2 Deaf and hearing impairment**

People with poor hearing are more likely to be isolated socially and to suffer reduced quality of life. The charity Sense stated that, 'deaf, deafened and hard of hearing people are vulnerable to isolation and depression'. The 'Hidden Lives' report suggests that rates of depression amongst deafened individuals is five times higher than the national average and that anxiety levels are two and one half times higher. Newly deafened people have to learn a new set of communication skills, which can have a massive impact on relationships, everyday tasks and employment. The study found

---

<sup>14</sup> Pey, T et al. Functionality and the Needs of Blind and Partially Sighted Adults in the UK. Guide Dogs 2007

<sup>15</sup> Lockyer S et al. Availability of accessible publications. RNIB/Loughborough University, 2004.

<sup>16</sup> Royal National Institute of Blind People, (2004) The cost of sight loss in the UK: Campaign report 23, RNIB

that society has little concept of what deafness means and underestimate the serious effects and consequences.(17)

There are many misconceptions about Deaf people and Deafness itself. One of these is that Deaf people generally have a command of the English language within the normal range. There tends also to be an assumption that all deaf people can lip read and that with a little adjustment communication can be quite satisfactory. In the case of most people who are deafened, small adjustments are adequate but Deaf people who consider themselves to be culturally deaf and their first and preferred language is BSL, find the written and spoken word to be foreign. Their choice is to use BSL particularly in situations where crucial decisions have to be made. It is essential, therefore, that appropriate communication support is made available without cost to the individual and only suitably qualified personnel are commissioned.

Deaf and hard of hearing people rarely have access to the social support available to hearing people. Few Citizens Advice Bureaux or marriage counselling services have arrangements for booking and paying for interpreters. It is to be remembered that the exclusion of Deaf and hard of hearing people from these services may also increase their eligibility for social services' help.(18)

In terms of adult mental health, it has been established that there is an above average incidence of mental health problems among deaf and hard of hearing people.

'Sign', a charity which campaign for deaf people with mental health problems has produced a report 'Mental Health Services for Deaf People', which states that mental health services for deaf people do not take account of the needs of local deaf people.

### **4.3 Dual Sensory Impairment**

The impact of dual sensory impairment on an individual will vary according to the learning opportunities they have had. People who are born Deafblind may have little or no formal language and only limited understanding of the world because they have never been

---

17 Hallam et al., *Hidden Lives: The psychological and social impact of becoming deafened in adult life.*, The LINK Centre and The University of Greenwich, 2005  
18 DOH, *Stepping Away from the Edge*, 1999

able to watch/listen to other people and the things going on around them. In contrast people who acquire their Deafblindness may have the advantage of remembered sight and /or hearing and are more likely to have had access to language learning. Methods of communication will therefore vary, and may include:

- Clear speech and lip reading
- Lipspeaking
- British Sign Language or a sign system e.g. Sign Supported English
- Visual Frame Signing, Close-up Signing, Hands-on Signing, Hand on Hand Signing
- Braille and Moon
- Block Alphabet
- Deafblind Manual Alphabet
- Note taking
- Electronic communication (with Braille output or large font on screen)
- Individual's own personal signs
- Makaton
- Large Print (font size 16 or above)
- A combination of any of the above or any method preferred by the individual

A survey by DEAFBLIND UK looking at deafblind people's experience of the NHS suggested that while the majority of deafblind people had a positive attitude towards NHS staff, in a large number of these cases there was a lack of awareness of their particular needs.

Because NHS staff did not understand the particularly challenging difficulties that people with a dual sensory loss face they would get impatient or fail to address the individual directly but rather talk to the carer or interpreter.

There was little recognition of the communication needs of deafblind people by providing extra appointment time or ensuring appropriate communication methods. Family and friends were still relied on to interpret for the patient and the NHS professional.

### **Older people**

Sense estimates that 90% of deafblind people are over the age of 75, but that sensory loss in this group is often overlooked. Sense response says that deafblind people over the age of 75 are 3.6 times more likely to have a Stroke, 2.2 times more likely to have arthritis, 2.5 times more likely to have heart disease, 1.5 times more likely to have hypertension, 3 times more likely to fall and 2.7 times more likely to have depression.

Research shows that people with sight impairments are very likely to experience exclusion in a range of spheres, such as access to services, ability to take part in social and cultural activities and contact with friends and family.<sup>(19)</sup> This is even more likely to be the case for deafblind people.

Sense highlights that ‘People with dual sensory impairment are no less likely to suffer from a whole range of serious psychiatric conditions than anyone else. Psychotic, manic and depressive illnesses exist in the deafblind community as they exist in the hearing/sighted community. There are, however, specific problems associated with the loss of sight and hearing. The difficult process associated with the loss of a major sense is multiplied, as is the need for support in learning new coping strategies’.<sup>(20)</sup>

### **BME**

Those from BME backgrounds are also less likely to be involved with services and are less likely to be involved in a consultative capacity. Deafblind UK’s project on Black and Ethnic minorities aim is to raise the levels of deafblind awareness within BME communities in London. The BME project was funded by the Big Lottery Fund until July 2009. Deafblind UK will use the learning experiences from this project to ensure that the needs of BME deafblind people are mainstreamed within their work.

---

<sup>19</sup> A Sure Start for Later Life; Ending Inequalities for older people” (SEU, 2006)

<sup>20</sup> Standards for Services for adults who are deafblind or have a dual sensory impairment, Sense, B Lewin supported by DoH

## 5. Legislative and Policy Background

- NHS and Community Care Act 1990
- Disabled Persons (Services & Consultation & Representation) Act 1986
- The Identification, Referral & Recognition of Sight Loss: Action for Social Services Departments & Optometrists 2005
- Community Care Act 1996
- National Assistance Act 1948
- Chronically Sick & Disabled Persons Act 1969
- Children's Act 1989
- Disability Discrimination Act 1995
- Modernising Social Services. Department of Health 1998
- Human Rights Act 1998
- Progress in Sight. National Standards. ADSS/RNIB/GDBA 2002
- Good Practice in Sight. RNIB 2008
- National Service Framework for People with Long Term Conditions 2004
- Stepping Away from the Edge. Department of Health. SSI. 2003
- Working with People with Sensory Impairment. TOPSS England 2004
- Our Health, Our Care, Our Say
- Mental Health & Deafness. Department of Health 2005
- Future Sight Loss UK – An Epidemiological & Economic Model for Sight Loss in the Decade 2010 – 2020. RNIB
- Prioritising Need in the Context of Putting People First. Department of Health. 2010.
- A Sharper Focus. Department of Health. SSI 1998
- Responding to Diversity. 2001
- UK Vision Strategy 20/20. 2008.

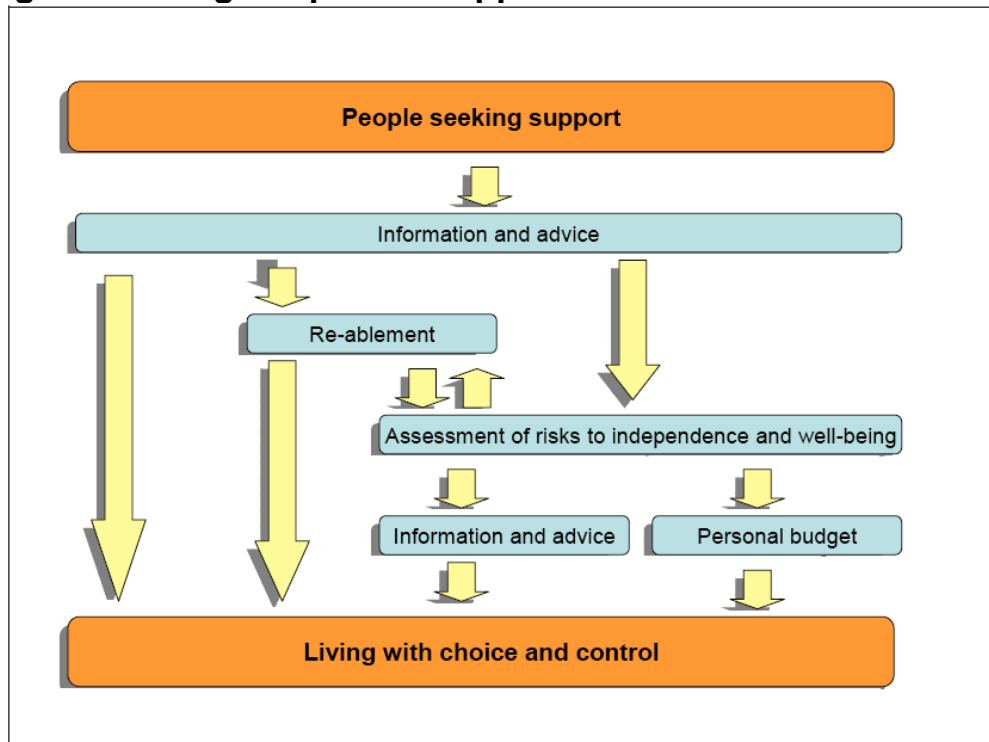
- Think Dual Sensory. Social Services Act 1970. Section 7
- Standards for Services for Adults who are Deaf Blind or have a Dual Sensory Impairment. Department of Health. 2000
- Best Practice Standards. Social Services for Deaf & Hard of Hearing People. ADSS/BDA/LGA/RNID. 1999. (Out of print, unavailable).

The 'Putting People First' (PPF) concordat was published by the Department of Health (DH) in December 2007. It set out information to support the transformation of social care, as outlined in the Health White Paper, 'Our Health, Our Care, Our Say: a New Direction for Community Services' in 2006. It describes the vision for development of a personalised approach to the delivery of adult social care.

Putting People First is underpinned by four key themes:

1. Access to universal services such as transport, leisure and education as well as information, advice and advocacy – planning for these to consider the implications for disabled and older people.
2. Prevention and early intervention – helping people early enough or in the right way, so that they stay healthy and recover quickly from illness.
3. Choice and control – people who need support can design it themselves, understanding quickly how much money is available for this, and having a choice about how they receive support and who manages it.
4. Social capital – making sure that everyone has the opportunity to be part of a community and experience the friendships and care that can come from families and friends.

**Fig. 5.1 Putting People First approach**



Guidance on Eligibility Criteria for Adult Social Care, England, DH, Feb. 2010

Please see Chapter 12 below for further legislative and policy guidance and related research.

## 6. Prevention and Early Intervention

To effectively deliver the transformation envisaged in *Putting People First* and beyond, councils should have both a strong focus on the overall well-being of their communities and a recognition that people should be helped in a way that may prevent, reduce or delay their need for social care support. This shift in focus to community well-being and preventative approaches is also fundamental to the effective application of eligibility criteria. There is a growing evidence base that interventions can prevent or delay people entering the social care system and therefore produce better outcomes for people at a lower overall cost. (21)

### 6.1 Visual impairment

Failure to invest in early detection and treatment of eye conditions means increased spending on health, social care, education and training to support people in the later stages of eye disease. Evidence suggests that over 50 per cent of sight loss is due to preventable or treatable causes. This is most marked in the older population, where it is estimated to be between 50-70 per cent. Research suggests a clear economic case for early and effective intervention: an Australian study has found that for each dollar spent on eye care and the prevention of sight loss, there could be a five-dollar return to the community.(22)

Indirect costs such as those relating to falls or increased care costs are also significant; for example, the medical cost of falls related to visual impairment was estimated at £128 million over a 12-month period.(23)

---

21 DoH, *Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care - Guidance on Eligibility Criteria for Adult Social Care, England 2010*

22 Taylor H R et al. *Costs of interventions for visual impairment*. American Journal of Ophthalmology)

23 Scuffham PA et al. *The incidence and cost of injurious falls associated with visual impairment in the UK*. Visual Impairment Research 2002 April Vol 4, 1-14

**Good practice model Leeds: prevention/screening  
Save Your Sight Campaign**

The Save Your Sight (SYS) Leaflet is part of an existing public health programme, The Save Your Sight Campaign, supported by Leeds

PCT Public Health. The leaflet uses a health promotion initiative as a vehicle for a case detection tool designed to increase primary eye health care usage in the over 60s. Present distribution includes Neighbourhood Network Schemes - community groups for the over 60s, sheltered accommodation and community eye centres.

Apart from the health and social impacts, there are also significant economic impacts resulting from sight loss. RNIB estimates indicate that the total costs of sight loss in the UK are in the region of £4.9 billion a year.(24)

## **6.2 Deaf and hearing impairment**

Noise-induced hearing loss can be caused by a variety of loud noises from work and leisure, including explosions, loud music and drilling. RNIB estimates that 12.6 million people in western countries currently suffer from noise-induced hearing loss. Groups most at risk include military servicemen, construction workers, musicians and people who regularly listen to loud MP3 players.

---

24 Tate, R., Smeeth, L., Evans, J., Fletcher, A., (2005) *The prevalence of visual impairment in the UK; A review of the literature*, [www.rnib.org.uk/xpedio/groups/public/documents/PublicWebsite/public\\_prevalencereport.doc](http://www.rnib.org.uk/xpedio/groups/public/documents/PublicWebsite/public_prevalencereport.doc)

## **7. Universal information, advice and advocacy**

In order that information advice and advocacy needs are more broadly met, agencies and local government need to have a sense of what service users want from such a service, requiring some form of consultation or research.<sup>25</sup>

The Social Exclusion Unit (SEU, 2005, taken from ODI, 2005) estimates that one in 20 people requires some form of literacy support, one in seven requires translation support and one in 15 some form of communication support for sensory impairments. In addition, Coulter et al. (2006) found that in relation to health information provision, the combination of verbal and written information can be more effective for service users than verbal information alone. This suggests the importance of imparting information in a variety of formats, even for the same group of people or an individual.<sup>(26)</sup>

Lewington and Clipson (2004) report that there is inadequate independent advocacy provision for people with physical, sensory, communication and profound and multiple impairments. This often linked to a lack of funding and/or skills in working with these client groups and that the support provided may not always meet their needs. Funding issues not only included a direct lack of funding, but complexities within the funding relationship with local authorities and health trusts, where rigid service level agreements, fixed short-term funding and monitoring arrangements were seen to be discouraging work with these client groups, which can be very time consuming and not always conducive to measurable outcomes. <sup>(27)</sup>

The most robust Information, advocacy and advice services can therefore be rendered useless if accessibility issues are not fully considered from the onset. This research also raises issues about the extent to which current information advocacy and advice

---

<sup>25</sup> (HM Government, 2007; Disability Equality Duty, 2006).

<sup>26</sup> Taken from Transforming Adult Social Care: information, advice and advocacy report, I&DeA, 2009

<sup>27</sup> Taken from Lewington & Clipson, 2004:15

provision adheres to the Disability Discrimination Act.(28)

### **Models and recommendations for the development of information, advice and advocacy services (29)**

- Articulate and re-iterate the principle that transformation and personalisation are dependent upon good information, advice, advocacy, support planning and brokerage being available. These services need to encompass developments in both consumer and social inclusion and community or citizenship models
- Frame the development of information, advice and advocacy in the context of the spectrum of interpersonal support including support planning, support brokerage, the ongoing management of services and underpin all of these with the dimension of safeguarding
- Frame the development of information, advice and advocacy in three dimensions: managing the information, managing awareness and knowledge and the management of the delivery mechanisms
- Market the sources of information, advice and advocacy services that are available currently
- Build the statutory information base on the DirectGov and local authority website core that currently exists. Raise the access to local authority sites to a higher level of navigation on Direct Gov. Ensure that there are clear links between Direct Gov and local authority websites and between them and key independent sector sites
- In relation to the market for support and services set out in information and advice, frame standards linked to sufficiency: affordability, availability, quality, cultural appropriateness and type
- Map and model the ideal type relating to the balance between national and local provision based on the principles of what is applicable across the country and what is best delivered locally. This could include

---

28 Taken from Transforming Adult Social Care: information, advice and advocacy report, I&DeA, 2009 ('deaf' here is used to include all those people who are deaf, hard of hearing, deafblind, or deafened)

29 Scrutinising the Transformation of Adult Social care: Practice Guide, Centre for Public Scrutiny, I&DEA, ADASS, LGA, 2010

rationalising provision and developing frameworks for information

**Good Practice example: West Sussex**

Information is available in a range of formats and is routinely monitored and, where necessary, amended. It can be translated on request. The 'Reach Out' website offers easy read information for people with disabilities, including "browse aloud" software which reads text out loud.

## 7.1 Visual impairment

Reliable, accessible and relevant information on eye conditions, eye care, sight loss services, support networks and legal entitlements should be easily available in a range of formats, to enable people to understand their options, select services and make informed decisions. Without good access to information one cannot have real choice and control.

A recent national study commissioned by the RNIB reported that 95% of blind or partially sighted people felt it important to have health information in a format that they could read themselves and though most healthcare professionals agree with them on this, 90% were not asked by NHS staff about the format they required when they were given information.(30)

The report also found that nearly three quarters (72 per cent) of blind and partially sighted people cannot read the personal health information provided by their GP. A similar proportion does not receive information from their hospital (either as an outpatient (74 per cent) or an inpatient (77 per cent)) in a format they can read themselves. Four out of five blind and partially sighted people cannot access the written information provided about their prescriptions.

---

30 Dr. Foster Research, *Towards an inclusive health service: a report into the availability of health information for blind and partially sighted people*, RNIB, 2008

### ***What blind and partially sighted people need***

Respondents who had used GP services were asked for their single preferred format for receiving health information. The most popular formats were large print (36 per cent) audiotape/CD (25 per cent) followed by email (15 per cent) and braille (10 per cent). Only four per cent preferred information face to face from a healthcare professional and just one per cent preferred information over the telephone. Receiving health information via a carer was similarly unpopular, with just one per cent preferring this option.

## **7.2 Deaf and hearing impairment**

The RNID carried out research into deaf people's experiences of accessing services (RNID, 2004) and found that nearly a fifth of those consulted received the wrong form of communication support when accessing public services; a further quarter reported no support provided to enable them to access services, highlighting the importance of considering accessibility in IAA provision. Nearly half of those researched (46 per cent) reported that they were unable to interact with public services 'all of the time' or 'often' due to a lack of communication support.

### **Good Practice example: Bristol City Council**

The use of brief video clips in sign language, for BSL users, can be found on the Bristol City Council website. This give access to a wide range of information such as advice and benefits, starting a business, crime prevention, health and social care, deaf access, education and learning, environment and planning, housing, leisure and culture, transport etc.

### **Good practice example: West Sussex County Council**

At least one member of staff in each Help Point has attended a day course on basic signing which included awareness training on responding appropriately to customers with hearing impairment e.g. standing facing the enquirer to allow them to lip read, or offering pen and paper. Help Point staff have also attended a telephone handling course which covered all aspects of how to respond to the wide range of customers that may contact them and the behaviour they may exhibit e.g. aggression, fear. All staff

are aware of the Tynetalk facility: a demonstration and training was arranged at a Help Point quarterly liaison meeting.

Some members of the Contact Centre staff have now had deaf awareness training - these are the supervisors and team leaders that will be manning the Textphone system. The dedicated Textphone number is now available for services to use in their literature and written communications.

### **Good practice example: West Sussex County Council**

SMS (mobile phone text service) - This is fast becoming the most popular way for the Deaf community to contact people/services, and is widely used by the general public, especially young people. Examples of where this is already in place include the Community Equipment Service and the Adults' Services Sensory Services team. The Library Service's Marketing Strategy includes communication with people by SMS (e.g. to tell them that a requested book is available), but they have been unable to move forward on this due to resources and the need for it to be compatible with current technology.

The White Paper 'Our health, our care, our say' set out the commitment by the Department of Health for information prescriptions. Personal Information Prescriptions will direct people to relevant and personal sources of information about services and treatments that they will need at key points in their care journey, for example, at diagnosis, at different stages of their treatment, for care planning and when they are discharged from hospital. They will signpost anyone with a long term condition information on where to get advice and support, how to make contact with others with a similar condition and important national and local information other than health and social care - like information about benefits.

### **Oxfordshire good practice example**

Personal Information Prescriptions will be given to people and their carers by health and social care professionals (for example GPs, social workers) to signpost them to further information and advice to help take care of their own condition. In addition the web site provides a gateway to a wide range of specialist information for people with a sensory loss. It can be found at the Personal Information Prescription website for Oxfordshire (*pip-ox*); *pip-ox* is an initiative funded by the Dept of Health, Oxfordshire County Council, Oxford Radcliffe Hospitals (Audiology) and Deaf Direct Oxford.

## **7.3 Dual sensory impairment**

Deafblindness poses particular challenges in ensuring that information and services are accessible in ways that comply with the requirements of the Disability Discrimination Act 1995 and the regulations made under that Act. In the same way that Local Authorities ensure that information they produce and issue about services, procedures etc. is accessible to those with one sensory impairment, so they should ensure that such information is also available in formats and methods that are accessible to Deafblind people. Local Authorities will need to consider not only various sizes of Large Print, as well as Braille, Moon, audio or video (subtitled or signed) versions but also computer disk or use of e-mail (to be accessed by specialist technology), text-phones and Type-Talk. 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.(31)

---

31 Department of Health, LAC(DH)(2009)6, *Social care for Deafblind Children and Adults*

**Good practice example: Lancashire County Council**

Some local authorities such as Lancashire CC provide Guide-helpers or Communicator-guides who act as 'communicators' for a deafblind person, helping them to take an active part in everyday life. This may mean helping them to go out shopping, or to sort out their bills, or interpreting at the doctors - depending on the needs of each individual.

## 8. Assessment / diagnosis, Care Pathways and Provision

### 8.1 Assessment for Adult Social Care

Under Section 47 of the NHS and Community Care Act, a local authority is obliged to carry out an assessment and make a service provision decision where it appears that a person may be in need of services. The duty to assess is proactive; it is triggered by an appearance of need and is not dependent on a request. The assessment must be provided within a reasonable period of time. Therefore, as soon as a local authority becomes aware of someone who may be in need of their (low vision or rehabilitation) services they should take steps to organize the assessment. The Department of Health guidance on eligibility criteria in the light of *Putting People First* (32) sets out the assessment process for social care, which will need to be kept in mind when reviewing services for people with sensory loss. The key elements are repeated below.

Given the necessity of prioritising needs for social care, fair and transparent allocation of available resources depends upon effective assessment. Decisions as to who gets local authority support should be made after an assessment, which should be centred on the person's aspirations and support needs, involving both the person seeking support and their carers.

Evidence suggests that the quality of response to a person's first contact with the council is crucial to the outcomes they later experience. However, submissions to the CSCI review and evidence from CSCI inspectors have raised concerns about the quality of this first response across councils. In particular, the review highlighted the inexperience of staff making judgements, that people's needs (and the willingness and ability of their carers) are often insufficiently explored and that people are screened out too early or not given adequate signposting to other sources of support.

The purpose of a community care assessment is to identify and

---

32 Guidance on Eligibility Criteria for Adult Social Care, England, DH, Feb. 2010

evaluate an individual's presenting needs and how these needs impose barriers to that person's independence and/or well-being.

From their very first contact with the council, an individual seeking support should be given as much information as possible about the assessment process. As part of the self-directed support process, assessment should be carried out as a collaborative process, in a way that is both transparent and understandable for the person seeking support so that they are able to:

- Gain a better understanding of the purpose of assessment and its implications for their situation
- Actively participate in the process
- Identify and articulate the outcomes they wish to achieve
- Identify the options that are available to meet those outcomes and to support their independence and well-being in whatever capacity
- Understand the basis on which decisions are reached

Councils should help individuals who may wish to approach them for support by publishing and disseminating information about access, eligibility and social care support, including personal budgets, in a range of languages and formats. The information should also describe what usually happens during assessment and care management processes, related time-scales, and how individuals can benefit from self-directed support. Councils should promote the development of services that provide interpreters, translators, advocates, and supporters to help individuals access and make best use of the assessment process. Particular attention should be paid to those least able to articulate their views and choices.

Councils have a duty under the Community Care Assessment Directions 2004 to consult the person being assessed (and their carers where appropriate); to take all reasonable steps to reach agreement with the person about the kind of support to be provided; and inform the person about the amount of the payment (if any) which they will be required to contribute. In July 2009, the Government issued new guidance to accompany the existing Fairer Charging guidance, which provides councils with a model to help them decide how much (if anything) a person should contribute to their personal budget

The assessment process should be person-centred throughout and also consider the wider family context. Councils should recognise that individuals are the experts on their own situation and encourage a partnership approach, based on a person's aspirations and the outcomes they wish to achieve, rather than what they are unable to do. Professionals should fully involve the person seeking support by listening to their views about how they want to live their lives and the type of care and support that best suits them and by helping them to make informed choices. This includes identifying the support the person needs to make a valued contribution to their community.

Councils may wish to consider encouraging those who can and wish to do so to undertake an assessment of their own needs prior to the council doing so. Although self-assessment does not negate a council's duty to carry out its own assessment, which may differ from the person's own views of their needs, it can serve as a very useful tool for putting the person seeking support at the heart of the process

Where appropriate, assessment should involve a full discussion not only with the person seeking support, but also with carers and other close family members, to consider the impact of a person's needs on those around them, taking into account their views about the person's needs and recognising the contribution that they are willing and able to make to the person's support and life.

Assessment should be co-ordinated and integrated across local agencies relevant to the individual concerned. Agencies should work together to ensure that information from assessment and related activities is shared among professionals, with due regard to data protection, in such a way that duplication of assessment is minimised for service users, carers and professionals alike. In coordinating assessment, agencies should maintain an emphasis on outcomes rather than functions or services. The result will be an assessment process that individuals experience as consistent, seamless and timely. The Department of Health has recently consulted on proposals for the development of a Common Assessment Framework (CAF) for Adults with the aim of promoting more person-centred assessments and facilitating more efficient, timely and secure sharing of information around assessments. Further work to test and fully evaluate assessment processes within the context of personalisation and supporting IT to share

information across organisational boundaries is being undertaken by local authority led CAF Demonstrator sites.

Evaluation of this developmental work is not expected until 2012, but learning from the sites is being shared throughout the programme. This approach is endorsed by the Care and Support Green Paper which sets out the ambition for one joined-up assessment process that considers people's individual needs, means and eligibility for all forms of support.

Councils should make sure that they are able to draw on sufficient expertise to understand and support people with a range of needs so that specific groups of people are not marginalised by the assessment process. They should help people prepare for the assessment process and find the best way for each individual to state their views. The use of interpreters, translators, advocates or supporters can be critical in this regard.

## 8.2 Equipment – self-assessment

### **Good practice model - Croydon Council**

#### **SARA - Self Assessment Rapid Access**

SARA is an online self assessment questionnaire that asks a series of questions about your daily life and the difficulties you are having, and gives you tips and information on equipment and minor adaptations to your home. They have developed the SARA questionnaire in partnership with the Disabled Living Foundation to include information on local services.

<http://www.asksara.org.uk/introduction.php?auth=croydon2009>

### 8.3 Visual Impairment

When social care assessment fails to identify the serious consequences of being blind or partially sighted, people may receive little or no support.<sup>(33)</sup> A clear and smooth transition pathway from children’s and young people’s services to adult services should be established or maintained, to ensure that rights to benefits and support are not lost during this process and young people are enabled to fulfil their potential. This applies equally to health services and social care services. Broader integration of these services with other services such as education and employment is also needed.

According to Guide Dogs, the overall status and funding of services to rehabilitate and support people with sight loss has improved little in the past 10 to 15 years.

<sup>33</sup> Dementia and serious sight loss. Thomas Pocklington Trust 2007

Overcoming the psychological impact of sight loss and social isolation are two factors in improving the self-confidence, independent functioning and quality of life for many blind and partially sighted people. These are the findings and challenges of research undertaken by the charity and the Northern Ireland Rehabilitation Project Group.

The principal recommendations contained within 'Investing in the potential of blind and partially sighted adults in Northern Ireland' are:

- Blind and partially sighted people being entitled to an agreed level and quality of service to help them respond to the impact of sight loss, maintaining independence and quality of life
- Future services being based on a 'middle step' model, incorporating timely information and provision of emotional support; an 'outcomes-based' assessment during which the individual identifies their own personal goals; and services that are user led
- Integration of a multi-disciplinary rehabilitation workforce, provided by a variety of practitioners in different team settings, and with support from other professional staff in the health, social care and voluntary sectors

The UK Vision Strategy 2020 suggests that there is inconsistent integration of primary and secondary eye care services. Services that could be delivered in a primary care setting are still often based in hospitals, leading to backlogs, and community resources are in the main vastly under-utilised.<sup>(34)</sup> Only 20 per cent of low vision and rehabilitation service providers have links to counselors.<sup>(35)</sup> The report makes the following recommendations:

- Eye care and sight loss services should include emotional support as an integrated part of the service
- Services such as counselling should be available to users and to those supporting them as soon as a potential problem is identified
- Links to peer support networks should also be offered

---

<sup>34</sup> UK Vision Strategy 2020

<sup>35</sup> McLaughlan B et al. A Question of Independence. RNIB/AMD Alliance 2006

- Assessments, from the initial stage onwards, should consider daily living, mobility needs and communication needs, and should be followed up at regular intervals
- Services, support, community equipment, housing adaptations or a personal budget should be provided, when required, to enable blind and partially sighted people to exercise choice and control in their lives
- The traditional model of rehabilitation should be reviewed to ensure that the support package provided meets the needs of modern living
- Services for disabled and older people should be easy to access and have easy referral paths to eye care and sight loss services, so that individuals experiencing other major health conditions or disabilities do not miss out on eye care and sight loss support
- Service users should be able to make informed decisions relating to their treatment, care and support. Where the user would find it helpful, those who support them or an independent advocate should be involved
- People with sight loss should have equal access to job opportunities and the present negative attitudes should be tackled
- Current and future advances in technology should be made readily available to people with sight loss, in particular the continuing development of the web and mobile communication technologies. This should include low-cost, affordable adaptations and equipment. Training in the use of new technologies should be available, affordable and on-going.
- Leisure activities should be accessible to everyone with sight loss, including (but not exclusive to) sport, exercise, holidays, hobbies, television, radio, reading, films and the visual and performing arts.
- Public and commercial services should be fully accessible to people with sight loss.
- Moving around the external environment safely should be made as easy as possible for people with sight loss. This involves clear pavements, safe crossings and bold signage

- Transport providers need to make their services fully accessible. Additional travel costs need to be recognised by the benefits system

The ADASS and RNIB launched a good practice guide shortly after the *UK Vision Strategy in 2008*. The ADASS suggested that the implementation of the good practice would make a major contribution to implementing two key elements of the UK Vision Strategy that was launched in April 2008. Its main focus is on services provided or commissioned by adult social services departments, but the guide also recognises the important links to those health services that ensure people with sight-threatening conditions experience a smooth journey from diagnosis to independent living support. *Good Practice in Sight* explains what needs to be done to achieve a number of key outcomes and how this fits in with local authorities' performance targets.

The Department of Health set up the National Eye Care Services Steering Group, which included representation from service users in the form of two people from the RNIB and one from Vision 2020. The Group published its first report in May 2004, which included a number of recommendations relating to service delivery, funding, regulatory issues and key outcomes.

The care pathways developed for the Eye Care Services Steering Group Report are designed to achieve:

- Support for the development of integrated eye care services across
- Primary and secondary care and social services;
- Better use of the skills available in primary care;
- An increased amount of care for all sectors of the community in accessible primary care settings; and
- An increased role for the professional groups, such as Optometrists and Dispensing Opticians, working in primary care.

The Eye Care Services Steering Group (36) developed four model evidence-based pathways for the major eye conditions:

---

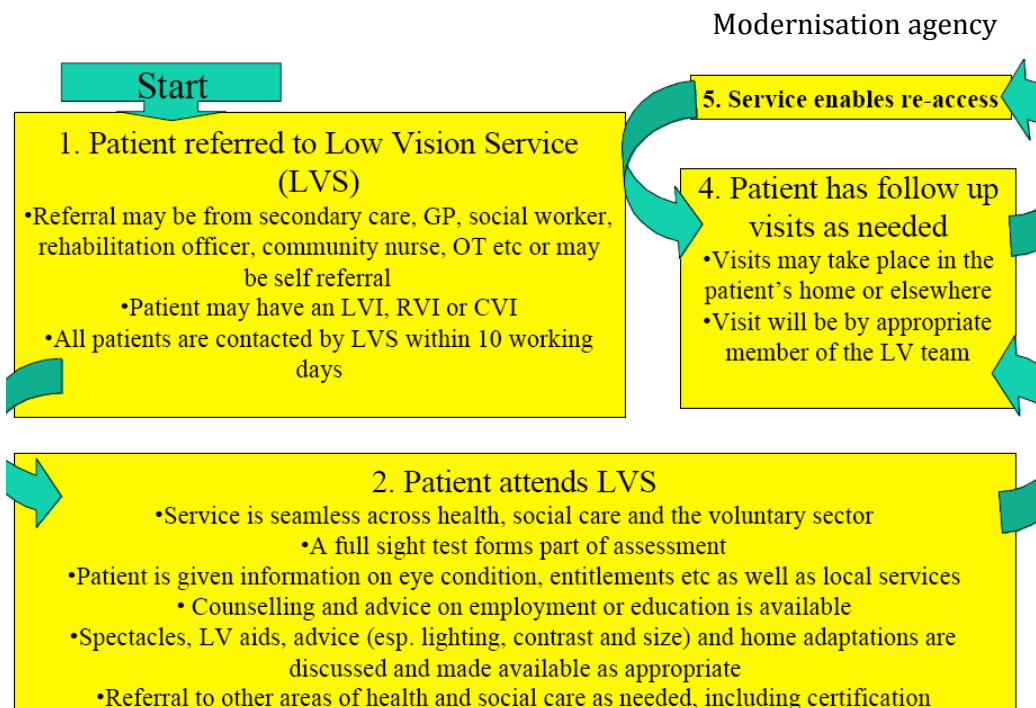
36 First Report of the National Eye Care Services Steering Group, DoH, 2004

- Cataract
- Low Vision
- Age Related Macular Degeneration
- Glaucoma

**Key issues**

- Vast majority of people with low vision are over 70
- Most people with low vision retain some sight
- Sight can be maximised by:
  - Prompt advice and counselling
  - Early assessment
  - Provision of appropriate low vision aids (LVAs) and training in their use
- Effective low vision services can reduce admissions to residential care

**Fig. 8.1 Proposed low vision pathway**



The low vision pathway was originally piloted across four sites. These were Gateshead, Barking, Dagenham and Havering, Sutton

and Merton and Wandsworth and Waltham Forest. Quite quickly it was then extended across a further eight associate sites. These are Brighton and Hove, Hartlepool, South West Lincolnshire and Northumberland, Morecombe Bay, Devon, Worcester and New Forest.

An independent review of the low vision pilot sites provides a detailed description of the different 'one stop shop' models and findings and is well worth more detailed scrutiny. The key overall findings are set out below together with some examples from the pilot sites covering rural areas similar to Somerset.(37)

The low vision pathway offers a multi-disciplinary approach – involving collaboration between health, social and voluntary sectors – towards the delivery of clinical and non-clinical low vision services. Its main aims are:

To develop an integrated low vision and rehabilitation assessment pathway (by an optometrist or dispensing optician (trained in low vision) and a rehabilitation officer respectively)

To provide services locally within community settings

To involve patients in the setting up and on-going evaluation of the service

Service models include: "one-stop-shop" low vision and rehabilitation clinics based in local voluntary society premises, that also include a resource centre, optometry based satellite low vision and rehabilitation clinics and separate low vision and rehabilitation services delivered from different locations.

Subtle variations in the pathway also exist, such as, in one project, the inclusion of a home based pre-rehabilitation assessment prior to the clinic assessment. There are also differences with respect to professional participation, such as in the involvement of: an outreach worker to integrate services between low vision and more general voluntary services or an eye clinic liaison officer to help provide information, emotional support and co-ordinate appointments.

---

37 Mehta, P. (2007) Review of the NHS Eyecare Services Programme, Low Vision Associate Pilot Sites, RNIB

The elderly adult population, which represent the majority of blind and partially sighted people, are the main focus of these pilot projects. Services have been generally designed to respond to this specific client group's health and social needs. One project, however, has also piloted a specific children's pathway, which it has developed through partnership between the health, social and education sectors. This pathway is provided in a specialist residential college for blind and partially sighted students.

The projects demonstrate significant innovation such as: in the integration of low vision and rehabilitation services with voluntary sector services, the conversion of a community building into a purpose based clinic, the training of nursing and residential home staff in order to raise awareness about low vision and in the development of volunteer programmes.

Multi-sector staff involved in the pilot projects emphasise the value of low vision services and highlight the wider issues with respect to low vision. Their feedback confirms the devastating consequences of low vision such as the loneliness and depression that is experienced, the need for early intervention and holistic approaches that include information and emotional support, particular issues with respect to the elderly and the need to raise awareness among user and professional groups

Patient experience of the pilot projects has been positive.

Comments from patient satisfaction surveys include the following:

- The whole package is wonderful
- Haven't been able to see for years, it's given me confidence
- The support is a lifeline - had difficulty dealing with social services - now there is plenty of support through the society, particularly in finding friends
- Most thorough eye examination ever had
- Feel that we are being valued

There is thus strong indication of improved opportunities and outcomes for patients, and evidence of improved waiting times, early intervention, integration of services, and provision of patient centred care. Equality of access is however, still a key concern,

particularly with respect to minority ethnic groups and people with learning disabilities. Children's services are also under-developed.

### **South West Lincolnshire – 'one stop shop' service model**

South Lincolnshire Society for the Blind worked in partnership with Lincolnshire PCT, Lincolnshire County Council and Lincolnshire Visual Impairment Services (LVIS) to pilot a low vision service for adults living in Grantham and Sleaford areas.

This pilot, which has now evolved into a mainstream service, was based at the South Lincolnshire Society for the Blind. Its chief aim was to be fully integrated between the low vision service, the rehabilitation service, and the local voluntary society, enabling a seamless, one-stop shop for all aspects of low vision support. One of its main objectives was to also develop a patient database and recall system in order to ensure patient re-assessments were carried out (where necessary) appropriately.

In the South West Lincolnshire model the patient is initially contacted via telephone by a low vision co-ordinator to book the appointment. On arrival, however, before being seen by the optometrist, the patient first receives a pre-assessment of rehabilitation needs with a rehabilitation officer. Following the low vision assessment with the optometrist the patient is again seen by the rehabilitation officer – for training and assistance on issues such as lighting and CCTV. The project manager's description of this pathway is provided below:

### **Morecambe Bay – 'one stop shop' service model**

Patients of the Morecambe Bay pilot also begin their consultation with a low vision assessment carried out by a dispensing optician (specialising in low vision). However the patient is then seen jointly by a rehabilitation officer, but more uniquely, by an out-reach worker. Follow up is carried out as needed (60 -70 per cent)

The out-reach worker's general role is to take the advice centre out to people who can't reach it. They are usually the first point of contact and works closely with adult social care where they can

usually refer if a person is found to be in need of extra services. The out-reach worker also runs a group three times a year looking at issues such as registration, mobility services, how to use equipment properly as well as on benefits and concessions; and eight support groups. For those that do not wish to join, they also co-ordinate a network of volunteers that would make home visits. The specific low vision role involves taking equipment out and the loaning of magnifiers in Kendal and extended areas. This has improved access to low vision aids and has enabled more people to be seen from a wider spectrum.

Clearly, the involvement of an out-reach worker during the low vision pathway is thus likely to generate additional benefits for the patient including integration between low vision services and more general voluntary services.

Main factors reported that are likely to present challenges to the future sustainability and development of the programme are: PCT reorganisation; insufficient resources; lack of professional awareness; barriers within professional community; and the national shortage of rehabilitation officers

It is recommended that the four pathways from the Eye Care Services Steering Group are compared against the current position in Somerset.

#### **Good Practice model**

Since 1994, the Low Vision Service in South Devon has been provided by a multi-agency, multi-disciplinary team. The team comprises of staff from Devon Social Services Sensory Team, Optima Low Vision Services Ltd, Royal National Institute for the Blind (RNIB) Manor House, Devon and Torbay Special Education Services and South Devon Healthcare Trust. In the 9 years of operation this service has been independently audited twice for patient satisfaction levels and compliance level in the use of low vision aids (LVAs). The results of the most recent service audit questionnaire reveal a high and constant patient satisfaction level with 92% of patients who answered the question reporting that the service was sufficient to meet their needs. The number of patients who used LVAs at least weekly was 88% of those answering the question. Plans for the future expansion of the service include the further development of interdisciplinary working.(38)

---

38 Collins J, Skilton K., *Low vision services in South Devon: a multi-agency, multi-disciplinary approach*. *Ophthalmic Physiol Opt*. 2004 Jul;24(4):355-9.

### ***British Minority Ethnic Groups***

Although minority ethnic groups have a greater risk of eye disease the evidence suggests they do not receive the same level of access to eye care services. For example, black British communities are 20 per cent less likely to have had an eye test than the rest of the population (RNIB, 2008). A twelve-month audit of selected opticians in Wales found that 42 per cent of white diabetic patients had an eye exam within the past twelve months compared to 14 per cent of ethnic patients (Woolf, 2003).

## **8.4 Deaf and hearing impairment**

*Improving Access to Audiology Services in England* sets out the context for the transformation of adult hearing services in England in relation to the key patient outcomes of improving health and well being, through the provision of safe, effective and responsive services which are efficient, affordable and equitable. In particular it seeks to improve responsiveness to the needs of individual patients and to make a maximum wait of 18 weeks from referral to treatment possible for all audiology referrals.

Older people make up a large proportion of hearing aid users and the National Clinical Director, in his recent 'Recipe for Care' report identified the need to bring care closer to home and to provide early intervention and assessment for older patients with hearing problems. A small number of audiology services are provided by PCTs in primary care settings.(39)

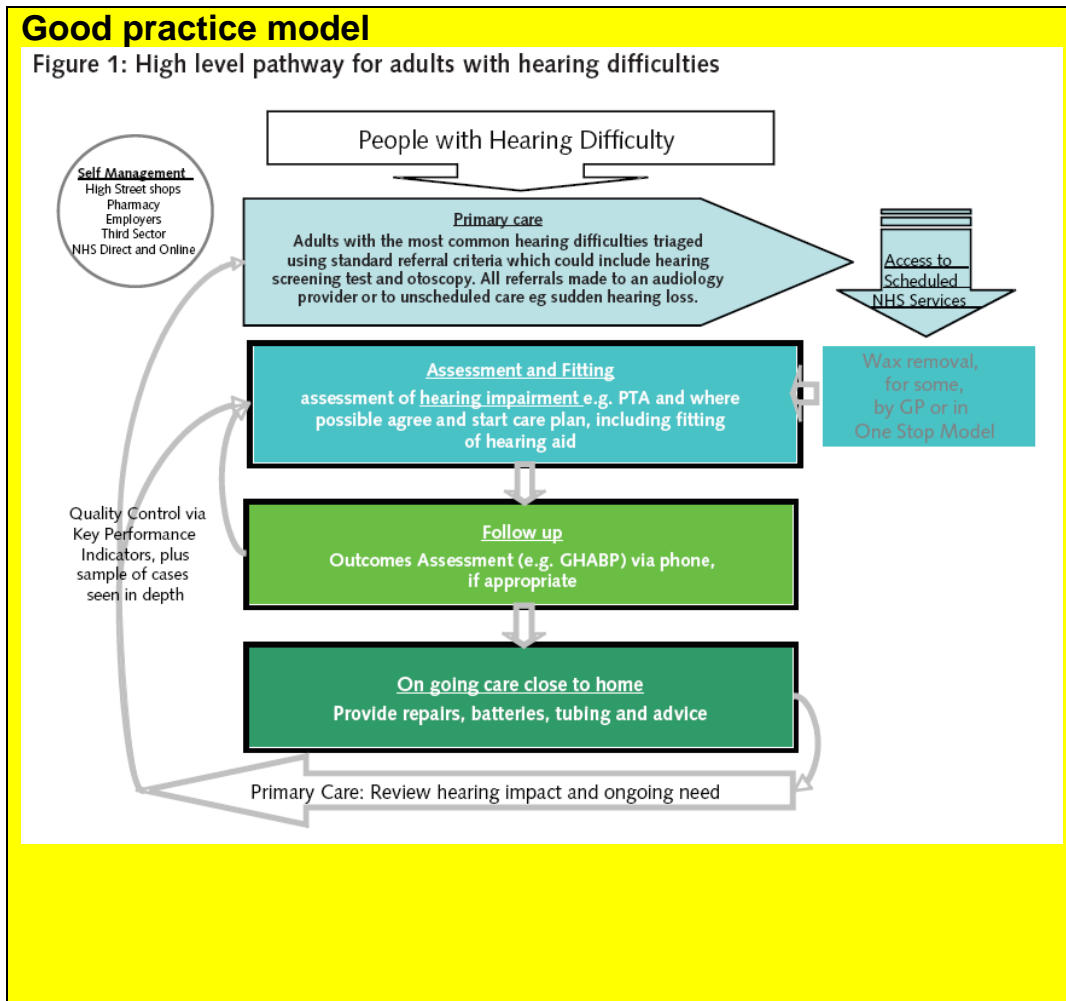
The Care Closer to Home ENT demonstrator sites have taken forward the White Paper, 'Our Health, Our Care, Our Say', vision for people to have greater independence, choice, control and empowerment. A report from this work will be produced shortly, which touches on audiology services. Initial reports of the six pilot ENT sites is available (see footnote for weblink).(40)

---

39 'A Recipe for Care – Not a single ingredient' (January 2007)

40 [http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Ourhealthourcareoursay/DH\\_4139717](http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Ourhealthourcareoursay/DH_4139717)

**Fig. 8.2 Good practice model**

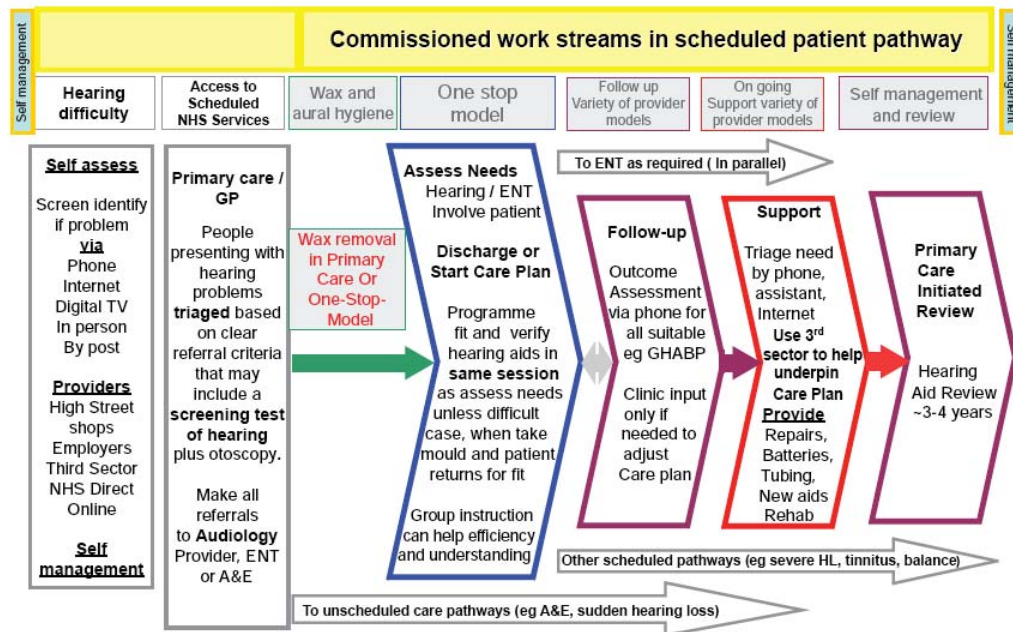


(41)

A more comprehensive pathway for all adults with hearing difficulties is also embedded within a ‘symptom based’ commissioning pathway published as one of a series of commissioning pathways to support delivery of 18 weeks. The good practice in this document refers mostly to the column headed ‘primary assessment’. The 18 week target has now been withdrawn by the government though the relevant web site states that standards and quality should be maintained pending the development of more outcomes-focused measures.

41 Department of Health (2007) *Good Practice in Transforming Adult Hearing Services for Patients with Hearing Difficulty*

Fig. 8.3 Commissioning pathway



Research carried out by the LINK Centre and University of Greenwich in 2005 suggests the following provision should be available:

- Timely and appropriate rehabilitation support for newly deafened people and their close family
- Specialised counselling support for deafened people and their families
- Employers need better awareness of their obligations under the Disability Discrimination Act
- More communication technology installed and in working order

### Supplying Equipment

National guidance (42) makes the following recommendations:

42 ADSS, 'Best Practice Standards': 'Social Services for Deaf and Hard of Hearing People' was produced by the Association of Directors of Social Services (ADSS), the British Association for the Deaf ( BDA ), The Local Government Association ( LGA ) and the Royal National Institute for the Deaf ( RNID ) 1999.

- Technological knowledge about equipment should be continually updated
- A one stop shop should be created within the Audiology department so that people may receive an initial assessment for equipment when they are tested for a hearing aid
- Eligibility criteria should be made clear and based on the 'Fair Access to Care' guidance
- People are not always clear about what help they may receive with equipment and therefore attempts should be made to ensure that information about this service is available
- Training on how to use equipment should be available
- Direct Payments schemes should enable people to purchase equipment
- Deaf people should be consulted about the kind of equipment they would wish to have available

## **8.5 Dual sensory impairment**

Many deafblind people are not known to their local social services authority. Of those who are in contact with social services, not all are identified as having dual sensory impairment nor are they in receipt of appropriate services. For this reason, the Department of Health issued, under section 7 of the Local Authority Social Services Act 1970 guidance for local authorities about how to identify and keep records on deafblind people in their area.<sup>(43)</sup>

Sense state that deafblind people are isolated and social services are often not aware of their existence. Once social services are alerted to the fact that there is a deafblind person in need of services, assessments often fail to understand the needs of a person with both hearing and sight loss or the services and support that can make a difference. Where people need an assessment, social workers with expertise in one sensory loss often fail to understand the different problems faced by deafblind people. Sensory specialism is usually based in the working age

---

<sup>43</sup> Department of Health, Social care for deafblind children and adults, LAC(DH)(2009)6

adults department so that children's services, older people's services and learning disability services often failed to properly address the needs of deafblind people.

Local Authorities should ensure that as soon as an initial assessment identifies that a person may have a dual sensory impairment, a specialist assessment is arranged, to be carried out by a specifically trained experienced person/team equipped to assess the needs of a Deafblind person - including communication, one-to-one human contact, social interaction and emotional wellbeing, support with mobility, assistive technology and rehabilitation.(44)

Local Authorities need to recognise the importance of providing appropriate personalised services to Deafblind people. This may mean commissioning services that are specifically designed for Deafblind people.

Local Authorities will want to ensure that they are able to access the services of specifically trained one-to-one support workers (e.g. communicator-guides, interveners, Language Service Professionals (LSPs) for both adults and children whether from within their own staff, by the use of consortia arrangements or by contracting with independent providers, for those people they assess as requiring one.(45)

Recent research into deafblind people's experience of the NHS suggests that changes in attitudes, practices and procedures are needed to ensure more equitable treatment and better access to healthcare for this group. Particular areas of improvement recommended in "Cause and Cure" – Deafblind people's experience of the NHS" (46)

- Need for raised awareness of NHS staff of the particular difficulties faced by people with dual sensory impairment
- Promoting the work of the NHS Patient Advice and Liaison Service and Independent Complaints Advocacy Service to deafblind people, to empower them to use these services

---

44 Department of Health, Social Care for Deafblind children and adults, LAC(DH)(2009)6

45 LAC(DH)(2009)6

46 Deafblind UK (2007) "Cause and Cure" – Deafblind people's experience of the NHS

- Individualising patient records to enable healthcare staff identify a deafblind patients' support needs and communication requirements
- Large print to be used for all letters, appointment cards and information leaflets
- Ensure that NHS contracts for interpreting and communication support meet the needs of all deafblind people
- Empowering deafblind people to request extended NHS appointments to assist with their communication needs

The care pathways are probably the same as for visually impairment and hearing impairment but with greater awareness and recognition required of individual communication requirements and issues of living.

## **8.6 Learning Disability**

Children and adults with learning disabilities are less likely to be referred to specialists in sensory services because of the structures of social services departments with separate departments for adults and children.

The International Association for the Scientific Study of Intellectual Disability conducted a review of the research for adults with an intellectual disability and recommended that routine screening for age-related visual loss at 45 years and every 5 years thereafter. If possible this should be done by an ophthalmologist. An extra vision check at age 30 years has been recommended for adults with Downs syndrome. The literature highlighted high levels of unmet need among people with learning disabilities in relation to impaired vision, but almost no literature was found on access to mainstream and specialist optometry services.

## **8.7 Mental health**

The NHS Advisory Service 'HAS 2000, Review of Mental Health Services. Forging New Channels: Commissioning and Delivering Mental Health Services for People who are Deaf' offers guidance

in this area. A good gateway to deaf mental health issues and research can be found at Deaf Info <http://www.deafinfo.org.uk/>.

Dementia and visual impairment are among the most common medical conditions in later life. Almost nothing is known about the experiences and needs of older adults with both conditions. Impaired memory and a lack of visual cues can create profound disorientation and distress, which could be manifested in disruptive behaviour. Visual hallucinations can compound older adults' disorientation. Visual impairments reduce the ability of older adults to perform certain activities safely, while dementia impairs their ability to assess the risks accurately. Concerns about safety prompted family members to limit their relatives' activities even in early stages of dementia. A recent qualitative study suggested that Low-vision services perceived themselves to be ill equipped to manage dementia-related needs, whilst visual needs were accorded a low priority by dementia services. A lack of joint working by the two services led to an overcautious approach. The research identified considerable unmet needs and opportunities to improve care. The provision of clear verbal communication and optimised visual inputs is likely to reduce disorientation, distress and agitated behaviour, while one-to-one contact is needed to overcome feelings of isolation. Family caregivers require additional respite services and advice on managing hallucinations. Increased sharing of information and skills between mental health and low-vision professionals would help maximize older adults' independence. (47)

---

47 Out of sight, out of mind": a qualitative study of visual impairment and dementia from three perspectives; by Vanessa Lawrence, Joanna Murray, Dominic Ffytche (et al). *International Psychogeriatrics*, vol 21, no 3, June 2009, pp 511-518.

## 9. Resource allocation

### ***Resource Allocation***

Assessment of eligibility for services and the application of the eligibility criteria should be undertaken before decisions are taken on the overall amount of resource which will be available through the use of a Resource Allocation System (RAS) or by some other transparent local mechanism.

The good practice guide for Local Authority Scrutiny Committees sets out the following summary of *Putting People First* milestones.(48)

- April 2010 - That every council has introduced personal budgets, which are being used by existing or new service users/carers.
- October 2010 - That all new service users/carers (with assessed need for ongoing support) are offered a personal budget.
- That all service users whose care plans are subject to review are offered a personal budget.
- April 2011- That at least 30% of eligible service users/carers have a personal budget.

It then goes on to helpfully describe the expected process as follows:

An important factor in moving to personal budgets is the development of a resource allocation system (RAS), which ensures that resources are fairly allocated on the basis of need. Following assessment, people eligible for services will be told their 'indicative allocation' so they know roughly how much funding to which they will be entitled. There are varied multiple approaches to RAS, but many are based on a points system, which converts needs into points with the total score determining the indicative allocation. ADASS (October 2009) has produced a common framework for

---

48 Scrutinising the Transformation of Adult Social Care: Practice Guide, Centre for Public Scrutiny, I&DEA, ADASS, LGA, 2010

resource allocation, which helps authorities develop effective systems, including advice on legal and technical issues. ADASS advises that systems should be kept relatively simple in the early stages, e.g. focused on long-term support rather than short-term interventions like intermediate care.

Following assessment, people who are eligible for council support under Guidance on eligibility criteria for Adult Social Care (DH 2010) will draw up a self-directed support plan with help where needed from professionals, family and friends. This should be outcome based, e.g. one goal might be that the individual is able to do their food shopping. The support plan will determine the final personal budget which should be sufficient to cover the individual's goals, and which will also take into account their financial contribution, if any.

In addition to people with long-term or fluctuating conditions, councils should be aware that there are other groups whose disabilities are such that they are at risk of being over looked in the assessment of eligible need. Such groups might include people who have very specific communication needs, or blind and partially sighted people who may be disadvantaged by assessors who are unaware of the impact of loss of vision. To maximise what individuals are able to do for themselves, councils should consider the benefits of making available rehabilitation services to those who have newly acquired disabilities before undertaking an assessment of longer-term need.<sup>(49)</sup>

The individual will then be involved in commissioning services to meet their goals, again with support if needed. The support to help them do this is generally known as brokerage - 'assistance that people need to work out what their choices will be and support required to make it happen' (CSIP 2007).

There are many different models of brokerage and councils will be introducing this in different ways; information about different models is available from the National Brokerage Network. For example, one council gives access to a range of brokers based in the council and in voluntary organisations; details about individual brokers are given online. Another council has produced a guide, which explains self-directed support, with stories of how disabled

---

<sup>49</sup> Guidance on eligibility criteria for Adult Social Care (DH 2010)

and older people have been using individual budgets. Most local authorities are developing lists of registered care providers to which those planning self-directed support have access.

#### **Good practice model - Oxford**

- The Support with Confidence scheme for Approved Personal Assistants
- launched Planning of the new User Led Organisation, as umbrella organisation for a number of voluntary organisations
- We are researching **payment cards** to make it easier for people to use their personal budgets

*The ADASS Good practice in sight* guide suggests that “Fair Access to Care” Services has had a major impact on the level of support provided by local authorities. However, financial pressures on local authorities have led to a tightening of the criteria against which users or potential users are assessed as to their eligibility for social care. Currently 73 per cent of local authorities in England only provide services for people whose needs fall into the top two bands of need, “critical” or “substantial”. This is a worrying trend, especially when there is widespread concern that the impact of needs arising from sensory loss is often missed or underestimated by mainstream or generic practitioners. There is no doubt that many more blind and partially sighted people should have their needs considered critical or substantial.”(50)

A personalised approach to assessment and support planning should be better able to meet the needs of everyone. However, the evaluation of the Individual Budget pilots concluded that there was no consensus about the benefits of RAS questionnaires and called for a debate about the relative merits of RAS, outcomes focussed approaches and the system currently used for direct payments allocations.

---

50 McLaughlan, B., *Good practice in sight*, 2008, p. 10

*Putting Everyone First* highlighted a number of issues that need to be carefully considered for people with special needs.<sup>51</sup> Some examples of the issues for people with sensory loss are as follows:

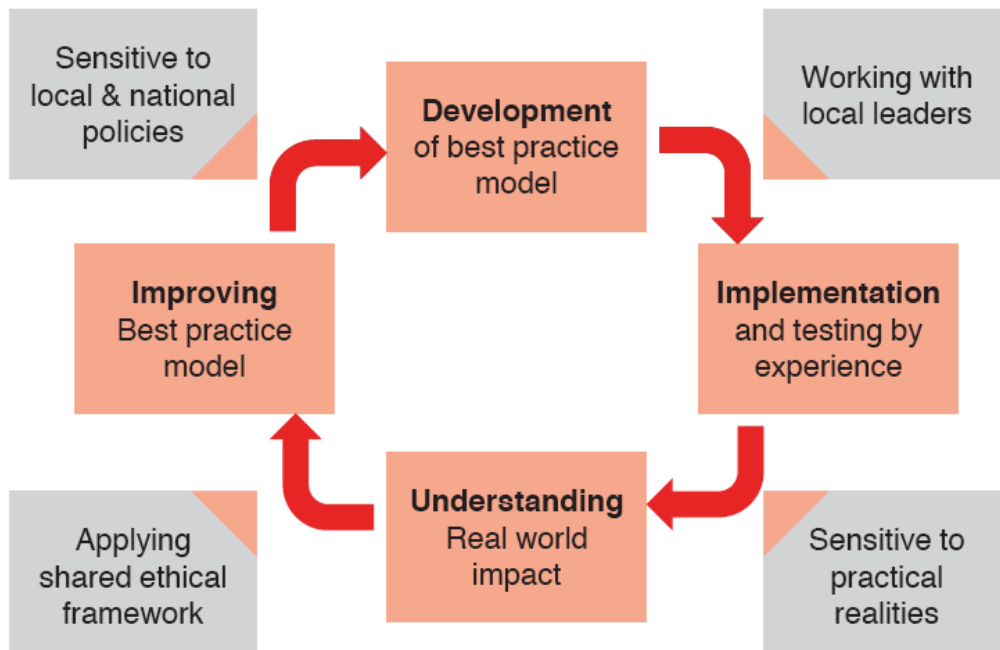
- Need for an interpreter if they have a sensory impairment or equipment if they have a disability affecting speech
- Someone with sight loss may get around a familiar environment with minimal difficulty, but busy streets or unfamiliar routes may be impossible
- A person with profound hearing loss may find it difficult to use public transport because they cannot hear announcements
- People may need support with access to information because they need different formats such as large print Braille, audio, British Sign Language or easy read documents, or because they need support to understand that information, or communication support
- For people with visual impairment, the degree of difficulty they face may well fluctuate depending on lighting conditions, either because of lighting in different locations, dark winter evenings or glare from low sun at some times of year

It recommends that RAS questionnaires are piloted by people with sensory impairments before implementation.

---

<sup>51</sup> *Putting Everyone First*, Guide Dogs, Mencap, The National Autistic Society, RNIB, RNID, Sense, 2009

**Fig. 9.1 In Control’s RAS development cycle**



**Good practice model - Bolton**

In Bolton, the majority of Sensory work will come under the Reablement umbrella and will be seen as preventative, therefore free of charge to the Service user and rehabilitative, and will take place "pre" the RAS and personal budget stage, the idea being that most people will not proceed to a personal budgets. In many areas, this has long been the model used with vision impaired services and we are currently developing it within Deaf/HoH services to mirror it - i.e. direct referrals to Sensory service specialist assessment, rehab training, including info and advice and equipment provision.

Obviously this is a simplified description. Some cases will have further needs and will proceed via RAS and Personal Budgets but the above will apply to most.

Some recent research found that for working age people with physical or sensory impairments, individual budgets had positive effects on all dimensions of social care outcomes, although these did not reach statistical significance. As already demonstrated by their take-up of direct payments, this group has most experience of

and enthusiasm for taking control of their support arrangements. Active peer-support networks, again often developed around direct payments, provide opportunities for shared learning. Moreover, the levels of resources allocated through Individual Budgets to working age people with physical or sensory impairments were relatively high, particularly compared to older people. People with physical or sensory impairments were also more likely to be able to access additional funding streams such as the Independent Living Fund (ILF). It is therefore likely that these more extensive allocations of resources offered greater flexibility and more opportunity for innovative approaches to addressing support needs.(52)

### **Good practice example - Lancashire**

Lancashire Support Services (LSS), a User-led organisation, has supported a network of local disabled people who have all had experience of using either direct payments or personal budgets. LSS has offered training and support to the volunteers and provides expenses. Volunteers (peer advisors) are matched to new people who are exploring the ideas around self-directed support. Peer advisors offer the unique experience of living the reality of managing a budget and designing their own support, which often provides a trusted perspective for the new recipients. Examples of how this approach has benefited people include matching a peer advisor, who is visually impaired, with a person who is also visually impaired – the peer advisor's unique experience and interpretation of the process helped the man to explore and relate his own experiences so far and develop a creative approach to planning the support for his own life. A peer advisor who is well connected to the local Asian Forum within the community used his own connections and trusted status within the community to build further connections and offer awareness of self-directed support to over 50 Asian carers.(53)

---

52 Glendenning C, et al., *Evaluation of the Individual Budgets Pilot Programme Final Report*, October 2008, [www.york.ac.uk/spru](http://www.york.ac.uk/spru), p. 237

53 *Good Practice in Support. Planning and Brokerage*, DoH, 2008

**Support to manage direct payments: An example of good practice by a local direct payments support service**

A deafblind person who is a Braille user employs several staff through direct payments. He receives payroll support from the local direct payments support service. At the end of the month, he emails the support service with details of the hours that his staff have worked.

The support service work out any deductions from pay (such as National Insurance and tax) and email him to tell him how much he should pay the staff via cheque. They then send him pay slips to be given to staff. The envelope that the payslips are sent in has two staples in the corner so that he knows who the letter is from. The payslips themselves are labelled in Braille so that he knows which staff to give them to. The support service also tells him how much he needs to pay each quarter in National Insurance and tax. The service also fills in quarterly Inland Revenue paperwork.

At the end of the year, the support service sends relevant information to the local authority, so that they are aware of how the direct payments are being spent. The support service also uses Typetalk to communicate with him. This individual has taken on only some of the responsibilities of employing people and the support service has taken on what he wants support with. Control still remains with the individual and confidentiality is maintained by using accessible labelling. These accessible systems were suggested by the direct payments user, and the support service has adjusted its service to meet this individual's preferred means of communication.(54)

---

54 Deafblind Direct Consultation Report Deafblind people and families' experiences of direct payments February 2008, [www.sense.org.uk/directpayments](http://www.sense.org.uk/directpayments)

## 10. Commissioning

Good practice for transformation of Adult Social Care (55) suggest that Councils will need to:

- Establish ways of aggregating individual commissioning decisions taken by people who control their own care plans, so that the sum of these individual decisions can influence macro-commissioning
- Focus on return on investment rather than performance against budget, i.e. looking at outcomes rather than costs to see whether value for money is being delivered across the whole system. (An example would be that the Partnerships for Older People Programme's investment in 'low level interventions' such as adaptations and minor repairs in people's homes has been shown to save hospital bed days (Skidmore, 2008).)
- Demonstrate increased investment in prevention, early intervention and re-ablement (DH2009c provides a benchmark, updated in March 2009, for how councils are progressing in developing Homecare Re-ablement Schemes)
- Retain capacity to commission services that provide intensive care and support for those with high-level complex needs. Workforce planning should be embedded in the commissioning process (see section on workforce issues below)
- Have a market development and stimulation strategy, either locally or in their regions, with actions identified to deliver the necessary changes. This may include, for example, a transformed community equipment service, consistent with the retail model, which uses accredited retailers to give users a choice of equipment (CSED2009)
- Encourage a meaningful role for user groups in the design of services and their delivery and development

---

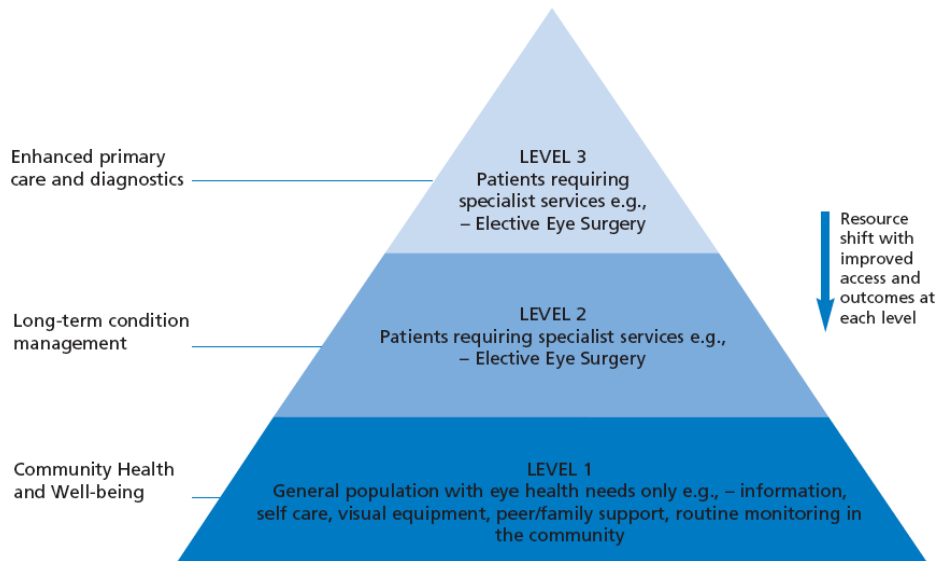
55 Scrutinising the Transformation of Adult Social Care: Practice Guide, Centre for Public Scrutiny, I&DEA, ADASS, LGA, 2010

## 10.1 Visual impairment

Representative bodies within the eye health and sight loss sector should consider how they can support the implementation of the UK Vision Strategy. Barriers to inter-professional and inter-organisational working and collaboration should be identified and removed, and ways that service delivery would be supported by rationalisation of bodies and professions should be identified.

The UK Vision strategy recommends the commissioning of fully integrated and effective eye care and sight loss services, including low vision services. This should ensure the integration of primary and secondary eye care to achieve the most effective, timely and accessible services and treatments for each individual, and the best use of community and hospital resources. Services should be person-centred and create seamless pathways through health, social care and the voluntary sector.

**Fig. 10.1 Guide to Commissioning Community Care Eye Services**



The document ‘Progress in Sight’ details sixteen standards, which should inform the commissioning and provision of services. It recommends that a combination of ‘Best Value’ principles and national standards should inform the commissioning of services. It also recommends that Social Services should consult a cross section of the population in order to identify their collective needs.

### ***User Involvement in contract development, monitoring and evaluation***

#### **Good practice model - Sandwell Metropolitan Borough Council (MBC)**

Sandwell Metropolitan Borough Council (MBC) were one of thirteen volunteer local authorities who signed up to the Improving Lives: Raising Standards project that ran from 2003 to 2005 and which encouraged implementation of Progress in Sight. A group of service users was formed to help audit Sandwell's performance against the 16 standards for services to blind and partially sighted adults in the borough. A facilitator undertook capacity building work with the group to build their skills and confidence and enable them to engage with local planners in a meaningful way. Sandwell MBC has in recent years established very good links with Sandwell Visual Impairment Group and works closely with them to ensure the standards set out in Progress in Sight are implemented and adhered to. Representatives from the group meet five times a year with the social services team to discuss planning future services and the impact on service users.

## **10.2 Deaf and hearing impairment**

Specialised mental health services for deaf adults are listed in the Specialised Services National Definition Set, yet at present there is no commissioning guidance for those services. Signhealth (an organisation focusing on mental health and deafness) was retained in 2007 for three years by the DH to improve the commissioning of mental health services for deaf people. Matthew James, working in the North East, has led this national project with Signhealth in conjunction with the three specialised deaf mental health services in England. It recommends that Specialised Commissioning Groups (SCGs) should establish a group to support the commissioning of "Mental health services for Deaf people". This group should include Deaf people and should inform the SCG's commissioning of mental health services for Deaf people.

BSMHD and NHS North West announced a two-year project starting from 1st April 2010 that aims to enable all Primary Care Trusts throughout England to provide a psychological therapy

service that is culturally and linguistically accessible in sign language, through the employment and training of a new workforce of Psychological Wellbeing Practitioners (PWP) and High Intensity (HI) Therapists. The development work is focused on ensuring that deaf people will be a major part of this new workforce. The project, which will be jointly managed by NHS North West and BSMHD, produce IAPT Information in BSL on DVD and the internet. For further details visit the project website at [www.deafiapt.org.uk](http://www.deafiapt.org.uk)

### **10.3 Dual sensory Impairment**

Department of Health (2009) LAC(DH)(2009)6, *Social care for Deafblind Children and Adults* recommends the following commissioning outcomes:

- The Local Authority, working with its local partners, include the needs of Deafblind people in their Joint Strategic Needs Assessment (JSNA)
- The Local Authority monitor its progress in contacting Deafblind people in its area, for example by comparing the number of people with whom it has contact with the number identified by other councils as well as with national estimates of the incidence of Deafblindness
- Deafblind people are able where appropriate to live independently
- Deafblind people are able to sustain a family unit which avoids children being required to take on inappropriate caring roles
- Deafblind people are able to participate as active and equal citizens, both economically and socially
- The focus should be to continue building the strengths and capacity of individual Local Authorities to make local decisions on priorities reflected through improvement targets in Local Area Agreements. Local Authorities will need to continue to work with health partners in their Local Strategic Partnerships to undertake JSNAs, which will in turn be informed by, and support other needs assessments and plans (eg. the Sustainable Community Strategy and local housing strategies). This reflects the shared responsibilities for health and wellbeing of citizens, families and communities as set out in the NHS Operating Framework

## 11. Workforce

The adult social care workforce strategy (DH2009e) describes the changes in the way that social care needs to be delivered and the consequent changes for the workforce.

- Who are the local providers of social care and how the authority communicates with them on workforce issues
- The current workforce situation, how well the workforce is integrated and opportunities for further integration (e.g. to avoid duplication, provide training, develop a common understanding of assessment and support etc)
- Whether the authority has the right service models to deliver what service users and their carers require
- Whether the authority and the local workforce has the right skills to deliver the new emphasis on universal provision and the promotion of independence
- Based on their analyses of the above points, Adult Social Services should have in place as part of their Integrated Local Area Workforce Strategy (InLAWS): a skills, knowledge and competence framework around the 'care pathway' model of delivery so that the authority knows what skills, knowledge and competencies it is seeking when commissioning from local providers
- A system to monitor and regularly review workforce knowledge, skills and competencies

Information on the size and nature of the sensory services workforce is very difficult to obtain. Such information as exists is not very helpful since it is out of date and restricted to parts of the workforce. The Health and Social Care Workforce Group's 1999 survey found some 2627 workers in England and Wales who worked specifically with people with sensory impairment, of which 15% had sensory impairment themselves. They included social workers, support workers, development workers, language aides, technicians, sign language interpreters, rehabilitation workers, team leaders and people with combined job categories. There was however a wide discrepancy in job classifications and titles which

made it even more difficult to arrive at an accurate figure.(56)

Understandably, with such a wide range of workers working in the sensory loss field there has been a certain lack of coherence in specific sensory specific qualifications and learning programmes. A review of sensory training in 2007 stated that “It is quite difficult to understand what is on offer in terms of training pathways, because no formal recognition is attached to much of what is on offer and it seems difficult for individual workers/employers to make sense of what training/development route it would be best to follow.”(57) The review identified the following qualifications as being in use and valued.

- Health and Social Care NVQ units at levels 24
- LDAF units
- CACDP qualifications in BSL at levels 24
- National Association of Intervenors qualification at Level 3 (awarding body University of Northampton)
- Certificate and Diploma in Deafblind Studies (awarding body Birmingham University)
- MSI specialist teacher qualifications (awarding body Birmingham University)
- Mobility and orientation courses (awarding body NOCN)
- Non sensory impairment qualifications relevant to the workforce eg. Learning and Development NVQs, MBAs, CIPD qualifications, Institute of Leadership and Management courses, Institute of Charity Fundraising Manager qualifications etc
- Course related to Skills for Care induction standards eg. Administration of Medication course offered by organisations like Boots
- Numerous Health and Safety courses, moving and handling, infection control etc.
- DIP HE Rehabilitation Studies, Visual Impairment from UCE Birmingham
- Dip in Rehab Studies

---

56 Grant Thornton (2007) Skills for Care and Development, Think Sensory: A Qualification Strategy for the Sensory Services Workforce

57 Ibid

- Mobility Officer Cert
- Tech officer cert
- Guide dog mobility officer cert
- OT/Physiotherapist
- Social work degree
- Ophthalmology
- Optology
- Teaching Cert in Braille
- CACDAP Communicator Guide

In 2008 the National Occupational Standards for sensory loss work were published by the Skills for Care. It sets out standards for competent practice that appear to be common to all the workforce likely to be involved in sensory loss and are therefore of a rather general value based nature rather than dealing with specific technical knowledge and skills. Competent practice is defined as a combination of the application of skills and knowledge informed by values and ethics. Communication underpins all the standards as it makes clear that it is essential that those working in the field of sensory impairment with children, young people and adults have the necessary and appropriate skills to communicate effectively with people who may use a range of communication tools/ techniques or methods.

***An example of a training package for those who working with people are deafblind***

**TRAINING OVERSEEN BY THE COUNCIL FOR THE ADVANCEMENT OF COMMUNICATION WITH DEAF PEOPLE (CACDP) (58)**

The CACDP has worked with Sense and Deafblind UK to develop a range of training courses for staff working with deafblind people. The CACDP, which is a registered charity working to raise standards of communication between deaf and hearing people, oversees these deafblind training courses, licensing moderators to deliver training across the country. CACDP courses are nationally

---

58 Sense, undated, *Deafblind guidance: a practical guide; Training for deafblind services*

recognised and all involve some form of examination, which if successfully completed can offer Accreditation for Prior Learning for other studies being undertaken. Though they do not qualify candidates for an NVQ (because NVQs require additional evidence), some of these courses do take candidates through much of the required NVQ material. This work is ongoing, with courses currently in development.

- **Level 1** is suitable for all social services staff, including senior managers and those involved in service planning.
- **Level 2** is suitable for those involved in direct contact with deafblind people, either in residential or domiciliary settings.
- **Level 3** is suitable for those who are working as Communicator Guides, specialist social workers, or those who have close contact with deafblind people. It would also be of value to those working in other disciplines or teams, e.g. teams for older people, occupational therapists, etc.
- **Level 4** aims to provide participants with a detailed understanding of the role of interpreting for deafblind people and the techniques required.
- **Level 5** (officially due to begin accepting students in 2003/04) will be aimed at those wishing to develop and extend their knowledge and practice as a deafblind specialist.

## 12. References

Below is a list of relevant legislation, national policy, standards and research

Document	Description
<b>Legislation and national policy guidance</b>	
ADSS/BDA/LGA/RNID <i>Best Practice Standards – Social Services for Deaf and Hard of Hearing People –1999</i>	Best practice recommendations from 1999.
Association of Directors of Social Services (ADSS), 2002: <i>Progress in sight: National standards of social care for visually impaired adults</i>	Although many local authorities and social services departments implemented Progress in Sight, it no longer reflects the current performance framework.
<i>ADASS &amp; RNIB, (2008) Good practice in sight. How excellent services for blind and partially sighted adults can boost the overall performance of local authorities</i>	ADASS and RNIB joint publication which shows local authorities how a holistic, person-centred approach to the delivery of services that focuses on a defined number of key outcomes for blind and partially sighted people can help them reach their performance targets. Significantly, the guide is also an integral part of the UK Vision Strategy.
Disability Discrimination Act 1995	The key requirements of the Disability Discrimination Act (1995) are that service providers are required to take reasonable steps to change practices, policies or procedures which make it impossible or unreasonably difficult for disabled people to use a service; to provide auxiliary aids or services which would enable disabled people to use a service; and to overcome physical barriers

Document	Description
<b>Legislation and national policy guidance</b>	
	by providing a service by a reasonable alternative method
Department of Health, Section 7 Guidance; “Social Care for Deafblind Children and Adults” LAC 2001(8).	The Statutory Guidance on Social Care for Deafblind Children and Adults is issued under section 7 of the Local Authority Social Services Act 1970. This guidance is now being republished under cover of LAC(DH)(2009).6
Department of Health, <i>Local Authority Circular (DH) (2009) 1: Transforming Social Care,</i>	This Local Authority Circular sets out information to support councils and their partners in the ongoing transformation of adult social care as set out in Putting People First (2007), and preceding policy documents.
Department of Health, Guidance on Eligibility Criteria for Adult Social Care, England 2010	Best Practice guidance. The aim of the revised guidance is to support fairness, transparency and consistency of application and to reflect the increased focus on personalisation and prevention as set out in Putting People First. Supersedes Fair Access to Care Services: guidance on eligibility criteria for adult social care, 2003.
Department of Health (2003) Direct Payments Guidance: Community Care, Services for Carers and Children’s Services (Direct Payments) Guidance	The aim of this statutory (compulsory) guidance is to help local councils in making direct payments. It also provides guidance on how local councils might manage and administer direct payments
Department of Health (2004) <i>First Report of the National Eye Care Services Steering Group, Best Practice Guidance - Pathways</i>	The group was set up by Ministers in December 2002 to develop proposals for the modernisation of NHS eyecare services, maintaining and developing an integrated,

Document	Description
<b>Legislation and national policy guidance</b>	
	patient-centred service, and improving access, choice, waiting times and quality for all sectors of the community. As its first priority the Steering Group established subgroups to develop model <b>care pathways</b> for cataract, glaucoma, low vision and ARMD. The group aimed to deliver proposals consistent with and to support the Vision 2020 programme.
<i>Department of Health (2008) Good Practice in Support. Planning and Brokerage</i>	It is part of <u>Putting People First Personalisation Toolkit</u> . Gives a number of models developed by Local Authorities.
<i>Department of Health (2007) Good Practice in Transforming Adult Hearing Services for Patients with Hearing Difficulty (Please note that this document has now been removed from 18 week pathway site pending review by new government)</i>	The Audiology Framework sets out the aspiration to transform patient experience of audiology services, with a series of actions that the NHS will take to help make this happen. It sets out how health reform levers can be brought to bear to improve quality,
<i>Department of Health (2007) Improving Access to Audiology Services in England</i>	The Audiology Framework sets out the aspiration to transform patient experience of audiology services, with a series of actions that the NHS will take to help make this happen. It sets out how health reform levers can be brought to bear to improve quality, efficiency and access to audiology services.
<i>Department of Health (2009) Improving community based eye health services</i>	This is a guide to support PCTs in commissioning primary eye health services
<i>Department of Health, (2010) LAC (93)10: Approvals and directions for arrangements</i>	Social services authorities are required to provide “facilities for social rehabilitation and adjustment

Document	Description
<b>Legislation and national policy guidance</b>	
<i>from 1 April 1993 made under schedule 8 to the National Health Service Act 1977 and Sections 21 and 29 of the National Assistance Act 1948</i>	to disability.” They are also required to provide “such advice and support as may be needed for people in their own homes or elsewhere”. This has been deemed to include counseling.
Department of Health LAC(DH)(2009)6, <i>Social care for Deafblind Children and Adults</i>	This guidance should be read, and given effect to, in the context of Local Authority Circular (DH) (2009) 1 <sup>1</sup> which sets out information to support councils and their partners in the ongoing transformation of adult social care as set out in <i>Putting People First (PPF)</i>
Department of Health (2005): <i>Mental Health and Deafness - Towards Equity and Access: Best Practice Guidance</i>	Provides advice on ways to promote mental health and improve services for people who are deaf.
Department of Health, 2007, <i>Putting People First: a shared vision and commitment to the transformation of Adult Social Care</i> , HMG, <a href="http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118">http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118</a>	Sets out a shared ambition for radical reform of public services, promoting personalised support through the ability to exercise choice and control against a backdrop of strong and supportive local communities. To broaden their focus beyond those with the highest needs, councils should ensure that the application of eligibility criteria is firmly situated within this wider context of personalisation, including a strong emphasis on prevention, early intervention and support for carers.
Department of Health (1948) <i>Section 29(1) of the National Assistance Act 1948 and section 2 of the Chronically</i>	Local Authorities functions relating to social services provision for disabled <u>adults</u> are set out in these provisions. Local Authorities may, and in certain circumstances must,

Document	Description
<b>Legislation and national policy guidance</b>	
<i>Sick and Disabled Persons Act 1970 ("the 1970 Act").</i>	make arrangements for promoting the welfare "of persons aged 18 or over who are blind, deaf or dumb
<i>Department of Health (2007) Step-by-Step Guide to Commissioning Community Eye Care Services NHS Primary Care Contracting</i>	The purpose of this guide is to provide information and practical tools for PCTs and Practice Based Commissioners as they commission enhanced primary eye care services. This guide offers a practical, analytical, 'how to' approach to some of the key issues in commissioning high quality community eye care services locally.
<i>Department of Health 1999, Stepping way from the Edge: Improving Services for Deaf and Hard of Hearing people</i>	This booklet is a practical tool for social services departments aiming to provide the best possible services for people who are deaf, deafened or hard of hearing. It offers practical guidance and examples of positive practice in services for adults who are hearing impaired.
<i>Department of Health (2005) The National Service Framework for Long Term Conditions, Department of Health</i>	It promotes autonomy and independence for individuals by advocating a person-centred approach, improving access to services, providing specialist support and ensuring that families and carers needs are also considered.
<i>Department of Health (1997) Think Dual Sensory – Good Practice Guidelines for Older People with Dual Sensory Loss</i>	This document sets out good practice guidelines for social and health care services when dealing with deafblindness in the elderly. It looks at the need for better provision in care and strategies for setting up new services. The development of existing sensory services are examined.

Document	Description
<b>Legislation and national policy guidance</b>	
Disability Rights Commission (2005) <i>Duty to Promote Disability Equality: Statutory Code of Practice</i>	This document provides a code of practice based on the Disability Discrimination Act 1995. <i>“Public authorities can make an enormous contribution towards removing the barriers (both environmental and attitudinal) to equal opportunities for disabled people. They can do this by addressing the way in which they run their own services and employ people, and also by exerting their considerable influence in the community at large</i>
<i>Prime Minister’s Strategy Unit, (2005) Improving the Life Chances for Disabled People</i>	This report states that by 2025: <i>“disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society”</i>
<i>RNID (2008) NHS hearing aid services commissioning</i>	You will find these guidelines useful if you are a PCT commissioner. They provide you with up-to-date information about hearing aid services in order to support effective commissioning.
<i>RNIB, (2008) UK Vision Strategy 2020:</i> <a href="http://www.vision2020uk.org.uk/">http://www.vision2020uk.org.uk/</a>	The UK Vision Strategy was formed from a desire to reduce all avoidable blindness by the year 2020 and to produce a unified framework for action on all issues relating to vision.
Sense (undated) <i>Deafblind Guidance: a practical guide</i> , Sense website	It covers issues relating to identification of deafblind people; information provision including all types of communication; assessment; service development and in particular one to one support; and finally deafblind training

<b>Research studies</b>	
Alborz et al. (2003) <i>From the Cradle to the Grave: A literature review of access to health care for people with learning disabilities across the lifespan</i> , University of Manchester	A report for the National co-ordinating Centre for NHS Service Delivery R&D. It examined evidence on access to health care for people with learning disabilities across all age groups and levels of disability.
Bosanquet, Mehta (2008) <i>Evidence base to support the UK Vision Strategy</i> , RNIB and The Guide Dogs for the Blind	Section 1: Sight loss: the current and future challenge Section 2: The services today: what is the level of access? Section 3: Developing national and local strategies for improving eye care
Centre for Policy on Ageing Information Service (2010) <i>Sensory Loss in Older Age, Selected readings</i>	A very extensive review of research between 1996 and 2010. Can be downloaded from the CPA web site.
Collins J, et al. <i>Low vision services in South Devon: a multi-agency, multi-disciplinary approach</i> . <i>Ophthalmic Physiol Opt</i> . 2004 Jul; 24(4):355-9.	In the 9 years of operation this service has been independently audited twice for patient satisfaction levels and compliance level in the use of low vision aids (LVAs). The most recent service audit questionnaire reveals a high and constant patient satisfaction level.
<i>Department of Health, Acceptability, benefit and costs of early screening for hearing disability: a study of potential screening tests and models</i> , <i>Health Technology Assessment</i> 2007; Vol. 11: No. 42	A simple systematic screen, using an audiometric screening instrument, has been shown to be acceptable to people in the age range 55–74 years, is likely to provide substantial benefit and may be cost-effective to those in that target group.
<i>Department of Health (2003) Independence Matters</i> Social Services Inspectorate	This is a report of an independent evaluation of social care services for physically and sensory disabled

<b>Research studies</b>	
	<p>people aged 16-65 living in England. The report gives areas for improvement in:</p> <ul style="list-style-type: none"> <li>• Promoting independence</li> <li>• Person-centred and specialist services</li> <li>• Social inclusion</li> <li>• The way services are provided</li> </ul>
<p><b>DOUGLAS ET. AL (2009) Visually impaired people's access to employment, UNIVERSITY OF BIRMINGHAM</b></p>	<p>A report from the Network 1000 project in support of Vision 2020 on the changing needs and circumstances of people with visual impairment. The project's aim is to create a panel survey of 1000 visually-impaired people to be interviewed regularly over the three-year period, and hopefully beyond, enabling their changing needs and circumstances to be monitored over time.</p>
<p><b>Hallam et al. (2005) Hidden Lives: The Psychological and social impact of becoming deafened in adult life, LINK Centre for Deafened People and the University of Greenwich, 2005</b></p>	<p>This study focused on the impact of deafness on individuals and their families with particular reference to close relationships, communication, public attitudes, service provision, well-being and mental health and technology.</p>
<p>Information Centre, <i>People Registered Deaf or Hard of Hearing Year ending 31 march 2007, in England</i></p>	<p>This publication contains detailed statistics of persons registered as deaf and hard of hearing with Councils with Social Services Responsibilities (CSSRs) in England. The data is compiled from the triennial return SSDA 910 submitted by Councils to The Information Centre (The IC).</p>
<p>Lewin-Leigh, B. (1997) <b>Standards for Services for</b></p>	<p>This core of common standards have been produced in an aim to</p>

<b>Research studies</b>	
Adults who are Deafblind or have a Dual Sensory Impairment, London: Sense.	iron out inconsistencies in services for deafblind people and encourage development of high quality provision and are primarily for use by social care professionals but also for families and service users.
Mehta, P. (2007) Review of the NHS Eyecare Services Programme, Low Vision Associate Pilot Sites, RNIB	This short-term review, funded by the Department of Health, was undertaken to report on the NHS Eyecare Services low vision associate pilot projects. Its aim was to inform the future development and delivery of low vision eye care services.
<b>Minassian and Reidy (2009)</b> <b><i>Future sight loss in the decade 2010 to 2020: an epidemiological and economic model</i></b> Prepared for Royal National Institute of Blind People. EpiVision, April 2009	The brief was that epidemiologists, experienced in the area of ophthalmic research, should apply the best methods to derive estimates of the numbers of people that were likely to have age-related macular degeneration, cataract, diabetic retinopathy and glaucoma at two points in time, 2010 and 2020. The baseline and cumulative costs to society of the prevailing health and social care provision and support in that time-frame were to be estimated by an economist with experience of ophthalmic research using a cost of illness approach from the societal perspective.
<i>Pavey et al. (2008) Access to information, services and support for people with visual impairment</i> , Visual Impairment Centre for Teaching and Research (VICTAR) University of Birmingham	This report presents findings from Network 1000 Survey 2. The data was collected during interviews with 884 visually impaired people between November 2006 and January 2007. All the participants were registered as either blind or

<b>Research studies</b>	
	<p>partially sighted and lived in Great Britain.</p> <p>The report focuses upon data relating to access to information, services and support.</p>
<p>Pavey et al. (2009) <i>The Needs of older people with acquired hearing and sight loss</i>, Occasional paper, June 2009, number 20, Thomas Pocklington,</p>	<p>This research study explored the needs of older people with acquired hearing and sight loss. Findings indicated that many older people with hearing and sight loss appear to experience high levels of psychological distress. In general, the study found dependence, loss of control and fear for the future.</p>
<p>Research in Practice for Adults (2007) <i>Assistive Technology</i>, Research in Practice, Outline 5</p>	<p>The research evidence suggests that the following are key considerations in understanding, procuring and monitoring the value of assistive devices:</p> <ul style="list-style-type: none"> <li>• Avoiding a 'panacea' approach to assistive devices, particularly digital</li> <li>• Technologies not always assuming that complex technologies are the best solution to environmental adjustments</li> <li>• Needing to understand assistive device use in a wider social context</li> <li>• Avoiding a medical model of disability that understands the function of assistive devices to be correcting the 'problem' of the individual</li> <li>• Predicting whether a device will be accepted and used."</li> </ul>
<p>RNIB (2009) <i>Future sight loss UK (1): The economic impact</i></p>	<p>Access Economics (Australia) was commissioned by Royal National</p>

Research studies	
<i>of partial sight and blindness in the UK adult population</i>	Institute of Blind People (RNIB) to estimate the economic impact of partial sight and blindness in the UK adult population. This comprised the direct and indirect costs of partial sight and blindness, and the burden of partial sight and blindness on health. In addition, Access Economics was asked to undertake an international comparison (with Australia, US, Japan, and Canada) and several cost effectiveness analyses on strategic interventions that are expected to prevent and ameliorate the impact of sight loss in the UK adult population.
<i>RNIB, (2004) Unseen</i>	A report of a national survey of blind and partially sighted adults in 2004 found that many were not receiving the services to which they were entitled, despite 83% being registered as blind or partially sighted.
<i>RNIB (2008) Towards an inclusive health service: a report into the availability of health information for blind and partially sighted people,</i>	The study covered 600 blind and partially sighted people and 500 healthcare professionals in both primary and secondary care. The research has highlighted that barriers to health information remain widespread, and that more progress needs to be made to ensure that health information is accessible to blind and partially sighted people.
<i>RNIB (2009) Understanding the Needs of Blind and Partially Sighted People: their experiences, perspectives, and expectations</i>	A qualitative approach was taken, which involved in-depth interviews with blind and partially sighted people, carers/family members, and representatives from organisations

Research studies	
SSMR at the University of Surrey	<p>providing services to those with sight loss.</p> <p>The overall aims was to gain a detailed understanding of the experiences, needs and expectations of blind and partially sighted people and to explore the ways in which blind and partially sighted individuals can be supported in order to lead independent and fulfilling lives.</p>
RNIB (2009) <i>Understanding the Needs of Blind and Partially Sighted People: their experiences, perspectives, and expectations, Literature review, University of Surrey, SSMR</i>	<p>This document presents a literature review, which provided background to the research study into the needs and expectations of individuals who have sight loss.</p>
<i>SCIE, Identification of deafblind dual sensory impairment in Older People, SCIE Research brief 21, 2007</i>	<p>This briefing focuses on issues relating to the identification of people over the age of 60 in the UK who have dual sensory loss in the form of a combined hearing and sight impairment (deafblind).</p>
Sense, (undated) Putting Everyone First: personal budgets, Sense website,	<p>The Putting People First document sets out a number of measures, such as personal budgets, which allows people to shape and control their own lives. This document endorsed by Guide Dogs, Mencap, The National Autistic Society, RNIB, RNID and Sense is a practical guide for local authorities to ensure that they consider a range factors that need to be taken into account to ensure that Personal Budgets meet everyone's needs.</p>

### 13. Useful links

Deafblind UK – charity offering a wide range of services to support people with a combined sight and hearing impairment. The organisation offers training to professionals and others.  
[www.deafblind.org.uk](http://www.deafblind.org.uk)

Deafblind International – Bagely, M. (1998)  
'Communication and people who have lost vision and hearing in later life', from expert meeting on older people with vision and hearing loss, Copenhagen, Denmark 18–24 March 1998.  
[www.deafblindinternational.org](http://www.deafblindinternational.org)

Department of Health – has several items of useful guidance. In particular, 'Think dual sensory: good practice guidelines for older people with dual sensory loss' (1995).

Joseph Rowntree Foundation – commissions and produces research reports on a variety of social issues. These are also published as short summaries in their Findings series. These can be downloaded at [www.jrf.org.uk](http://www.jrf.org.uk)

Link Age Plus – an initiative to make information and support for older people easier to obtain. Further details can be found at [www.communities.gov.uk](http://www.communities.gov.uk)

Partnerships for Older People projects – Two-year partnership projects led by local authorities and primary care trusts. Represent a range of preventative interventions and initiatives. Further details can be found at [www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Olderpeopleservices/DH\\_4099198](http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Olderpeopleservices/DH_4099198)

RNIB (Royal National Institute for the Blind) – charity working with and providing information for blind and visually impaired people. [www.rnib.org.uk](http://www.rnib.org.uk). Use 'Audience' quick link to 'older people' from the home page. A variety of factsheets are available.

RNID (Royal National Institute for the Deaf) – charity working with and providing information for deaf and hearing impaired people. Also has a factsheet on deafblind people.  
[www.rnid.org.uk](http://www.rnid.org.uk)

Sense – charity working with and providing information for those with dual, deafblind, sensory impairment. [www.sense.org.uk](http://www.sense.org.uk). Produces a variety of reports, factsheets and information sources including a toolkit, 'Fill the Gaps' for use by those working with or in contact with older people [www.sense.org.uk/fillinthegaps](http://www.sense.org.uk/fillinthegaps)

Thomas Pocklington Trust – charity commissioning research and providing housing, care and support services for people with sight loss in the UK. [www.pocklington-trust.org.uk](http://www.pocklington-trust.org.uk)

Vision 2020 UK, <http://www.vision2020uk.org.uk/>

Sign Health <http://www.signhealth.org.uk/index.php?pageID=1>

A good source of research on VI issues is the Vision 2020 website, which you may already know of. It does have a large library of up-to-date research.

Visual Impairment and Learning Disability Services (VILD), <http://www.rnib.org.uk/livingwithsightloss/vild/Pages/vild.aspx>

**PROTOCOL FOR JOINT WORKING BETWEEN VISION SUPPORT TEAM AND  
ADULT SOCIAL CARE – SEPTEMBER 2008  
(DRAFT)**

## **REFERRAL PROCEDURES**

### **Referrals for non-registered children**

All referrals for children with a visual impairment, aged 0-19 should be routed to the Vision Support Team at The Priory Medical centre, Glastonbury Road, Wells, Somerset BA5 1XJ using the designated form.

If the referral meets the Somerset Vision Support Team referral criteria a member of the Team will visit the child and if social care/equipment needs are identified, the child will be referred on to Adult Social Care.

A visually impaired child with complex needs who meets the relevant criteria will be referred on to the Children with Disabilities' Teams in Adult Social Care. No referrals should be made without the permission of the child and the parents.

### **Registrations**

When a CVI for the registration of a child is received by the Sensory Loss team, the sensory loss worker will contact the child and parents, and undertake a registration visit. A copy of the CVI will be sent to the Vision Support Team specialist children's mobility worker with the permission of the child and parent.

All children who are to be registered as blind/severely sight impaired or partially sighted/sight impaired should also immediately be referred to the Vision Support Team, for consideration for an assessment by the specialist children's mobility worker, providing permission from the parents and child is obtained.

Depending on the circumstances, a joint visit may be appropriate.

The sensory loss worker will add the child's name to the register, issue a card, and complete the usual administrative processes.

## **INTERBRANCH WORKING**

The Sensory Loss Teams and Vision Support Teams should work closely together to ensure the best outcomes for children with a visual impairment.

1. Local Joint liaison meetings between Sensory Loss Teams, Vision Support Teams and Children with Disabilities Teams should take place locally, three times a year.
2. Each Sensory Loss Team should have a nominated worker to act as a link with the Vision Support Team.
3. It is vital to liaise regularly over cases which are jointly held, to ensure that all agencies are aware of each others' work and role with a family.

Julie Shorrock and Marion Donaldson

# **PROTOCOL FOR JOINT WORKING BETWEEN HEARING SUPPORT TEAM AND ADULT SOCIAL CARE**

## **REFERRAL PROCEDURES**

All referrals for children who are deaf or who have hearing loss, aged 0-19, should be routed to the Hearing Support Team at The Priory Medical Centre, Glastonbury Road, Wells, BA5 1XJ, using the designated form.

If the referral meets the Hearing Support Team referral criteria, a member of the Team will visit the child, and if social care/equipment needs are identified, the child will be referred on to Adult Social Care.

A hearing-impaired child with complex needs who meets the relevant criteria will be referred on to the Children with Disabilities' Teams. No referrals should be made without the permission of the child and parents.

## **INTERBRANCH WORKING**

The Sensory Loss Teams and Hearing Support Team should work closely together to ensure the best outcomes for children who are deaf or hard of hearing.

1. Local joint liaison meetings between Sensory Loss teams and Hearing Support teams and Children with Disabilities teams should take place locally, three times a year
2. Each Sensory Loss team should have a nominated worker to act as a link with the Vision Support team
3. It is vital to liaise regularly over cases which are jointly held, to ensure that all agencies are aware of each others' work and role with a family

**PROTOCOL FOR JOINT WORKING BETWEEN VISION SUPPORT TEAM AND  
ADULT SOCIAL CARE – SEPTEMBER 2008  
(DRAFT)**

**REFERRAL PROCEDURES**

**Referrals for non-registered children**

All referrals for children with a visual impairment, aged 0-19 should be routed to the Vision Support Team at The Priory Medical centre, Glastonbury Road, Wells, Somerset BA5 1XJ using the designated form.

If the referral meets the Somerset Vision Support Team referral criteria a member of the Team will visit the child and if social care/equipment needs are identified, the child will be referred on to Adult Social Care.

A visually impaired child with complex needs who meets the relevant criteria will be referred on to the Children with Disabilities' Teams . No referrals should be made without the permission of the child and the parents.

**Registrations**

When a CVI for the registration of a child is received by the Sensory Loss team, the sensory loss worker will contact the child and parents, and undertake a registration visit. A copy of the CVI will be sent to the Vision Support Team specialist children's mobility worker with the permission of the child and parent.

All children who are to be registered as blind/severely sight impaired or partially sighted/sight impaired should also immediately be referred to the Vision Support Team, for consideration for an assessment by the specialist children's mobility worker, providing permission from the parents and child is obtained.

Depending on the circumstances, a joint visit may be appropriate.

The sensory loss worker will add the child's name to the register, issue a card, and complete the usual administrative processes.

**INTERBRANCH WORKING**

The Sensory Loss Teams and Vision Support Teams should work closely together to ensure the best outcomes for children with a visual impairment.

1. Local Joint liaison meetings between Sensory Loss Teams, Vision Support Teams and Children with Disabilities Teams should take place locally, three times a year.
2. Each Sensory Loss Team should have a nominated worker to act as a link with the Vision Support Team.
3. It is vital to liaise regularly over cases which are jointly held, to ensure that all agencies are aware of each others' work and role with a family.

# Gaps in Social Care provision for children and young people with a sensory loss

## Background

There is an identified long-standing absence of social care provision for children, young people and their families with needs relating to the child or young person's sensory loss.

This appears to have resulted from the split between children's and adult's social care when the previous funding for children's social care services did not convert into ongoing provision.

Adult Social Care hold the register for visually impaired children and young people and have carried out some work with visually impaired children and young people on an ad-hoc basis. Hearing impaired children and young people also come under the adult services, but there is no provision relating to the child or young person's sensory loss.

The impact of this absence in provision is increasingly evidenced by case examples such as no access to:

- sign language users for afterschool, weekend and holiday activity schemes
- sign language capacity building within the home
- support for mobility within the home community and activity schemes
- a system for staff who work with children and young people with no or little speech in respite or residential care to help them understand the communication needs of children who use AAC
- support to the family as a result of the newborn hearing screening
- support for a child or young person with significant medical support needs such as tube feeding or requiring access to oxygen, to access afterschool, weekend and holiday activity schemes
- support for Somerset children and young people who attend special schools out of county either as weekly or termly boarders, who when they return home, they need access to weekend or holiday activities and a support network

## Gaps in provision

Children and young people who are the hardest to provide for ie those with a support need which is physical, medical, sensory, mobility, BSL, do not necessarily meet the Social Care Disabled Children's service criteria.

## Examples of case studies

Pupil A is 3 years old and profoundly deaf.

- Parental preference is for British Sign Language approach (BSL). BSL is not an available option in Somerset
  - Pupil will attend a nursery in Bristol as from June 2009
  - A transition plan was devised which included weekly access to a deaf group for the child and a weekly family session, both in Bristol, and weekly sessions of BSL training in the home
  - The estimated cost of the package is £3,350.
-

Pupil B is 9 years old and a competent BSL user.

- There are no fluent BSL signing children or adults near the family home and signing ability within the family home is limited
- Pupil becomes very lonely and unhappy during the summer holidays
- Parent has requested funding for transport to attend a holiday play scheme in Bristol which offers a deaf peer group and fluent adult BSL signers, plus BSL training within the home
- The estimated cost of this package is £640

### **Numbers**

The Client Group is all our young people ie 440 Hearing Support Team, 378 Physical Impairment and Medical Support Team, 250 Vision Support Team ie 1068 young people. All young people with sensory physical and medical support needs ought not to be socially isolated and be able to access leisure activities.

They all need access to leisure without having to go through hurdles ie they do not need or want a CAF. A percentage of this client group may fall into the 2 lower bands of Children with Disabilities Team's criteria.

### **Feedback from parents**

Our parents have suggested that at diagnosis it would be helpful to have access to a key person who would be there to signpost families to what they need and what is out there. A changing role as the young person gets older eg at transition times eg to FE. Someone to work closely with and link communication channels between all services involved with the family eg Sensory Physical and Medical Support Service, Social Care and Health, and someone who knows what these services provide, how their systems work, how to access them etc

### **Two elements to fill**

Two strands of support are needed: access to leisure and access to everyday life.

To enable children and young people who have sensory loss/ significant medical support needs/Physical Impairment/AAC users:

- To develop access to leisure
- To increase independence
- To create a network for meeting with other young people with similar support needs
- To build capacity within families
- To build community links
- To increase awareness of support needs for these children and young people

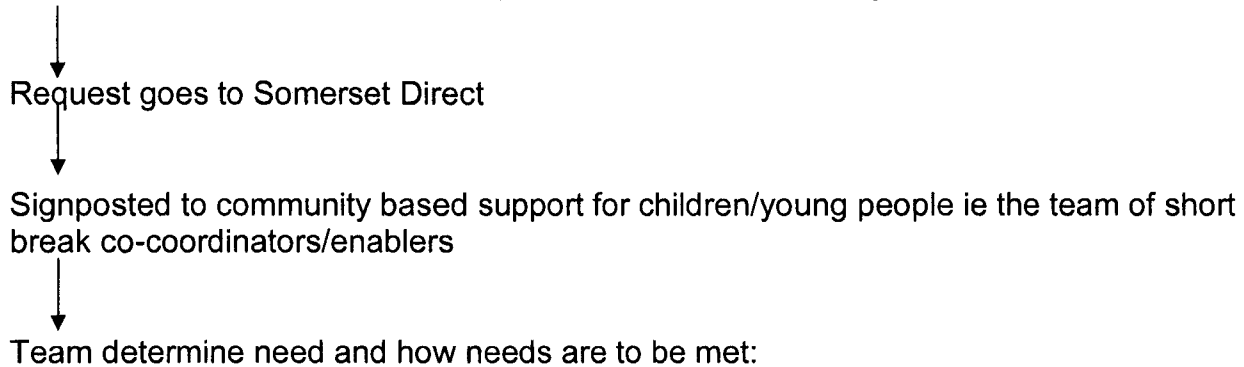
### **Referral system needed**

There has been concern about who is best placed to offer support to children and young people, and their families. Do the adult services have the skills to work with children and young people? Are children's services better placed to offer support to children and young people?

A referral system needs to be in place eg first point of contact to Somerset Direct and then signposted to a service eg to education support services such as SPMSS, to services which advise on equipment, charitable funding eg RNIB grants, allowances, access to leisure, national organisations eg Action for Blind, environmental aids, other useful services they could access, accessible swimming lessons, advocacy, help with transitions eg to University Open Days, or transition to adult services etc.

### **Example of the process**

A young person needs leisure support for the summer holidays



- Meet the need
- Know the outcomes
- Ensure outcomes are met
- Plan for future development
- Data collection of information and evidence for future development of service

### **It could be that:**

When children and young people are newly diagnosed and families need advice, Adult Social Care keep the information of the young people on their register, but they have no involvement, they simply pass the information on to Somerset Direct for it to go to the community based support for children and young people.

There would need to be a good transition process in place for transfer of the pupil back into adult Social Care at 16 years

Whatever the policy and process, it needs to be transparent and readily available eg posted on Info 4 U

### **Examples of areas of need**

- BSL
- Mobility
- Personal care, and moving and handling
- Alternative and augmentative communication
- Support to access after school clubs
- Support to access weekend groups during term time
- Support to access school holiday activity schemes
- Mainstream social work involvement

### **OUTCOMES**

Awareness made of funding streams under Aiming High and how to access them eg:

The following 4 areas of need should be made available via access to short breaks activity scheme programme

1. sign language users for afterschool, weekend and holiday activity schemes
2. support for mobility within the home community and activity schemes
3. support for a child or young person with significant medical support needs such as tube feeding or requiring access to oxygen, to access afterschool, weekend and holiday activity schemes
4. support for Somerset children and young people who attend special schools out of county either as weekly or termly boarders, who when they return home, they need access to weekend or holiday activities

The following 3 areas of need could be met via access to parent led small grant short break funding

- 1 sign language capacity building within the home – networking families together
- 2 a system for staff who work with children and young people with no or little speech in respite or residential care to help them understand the communication needs of children who use AAC
- 3 support to the family as a result of the newborn hearing screening
- 4 support for Somerset children and young people who attend special schools out of county either as weekly or termly boarders, who when they return they need a support network

Access to Short Breaks Taster Programme could provide events specific to sensory loss, physical impairment and/or communication eg communication events day, wheelchair user skills day. The Sensory Physical Medical Co-ordinator being pro-active in seeking providers.

Staffing: Develop the skills of a few existing staff to be able to staff it eg 'Specialist Somerset Supporters' or where necessary buy in skilled staff:

- Direct payments
- Somerset Supporters – ie create a skill base, specialist recruitment – a little personal assistance group
- School staff – use their skill base
- Mobility Officer
- Guide dogs for the blind
- BSL signers
- Seeability staff
- Deaf/blind communicators
- Buy in from other counties

Long term outcomes

- Service is in place regarding access to leisure and access to everyday life.
- Improved communication between the team around the child/young person
- A single point of contact
- clear process
- Registers clear
- Roles and responsibilities of Adult Social Care clear

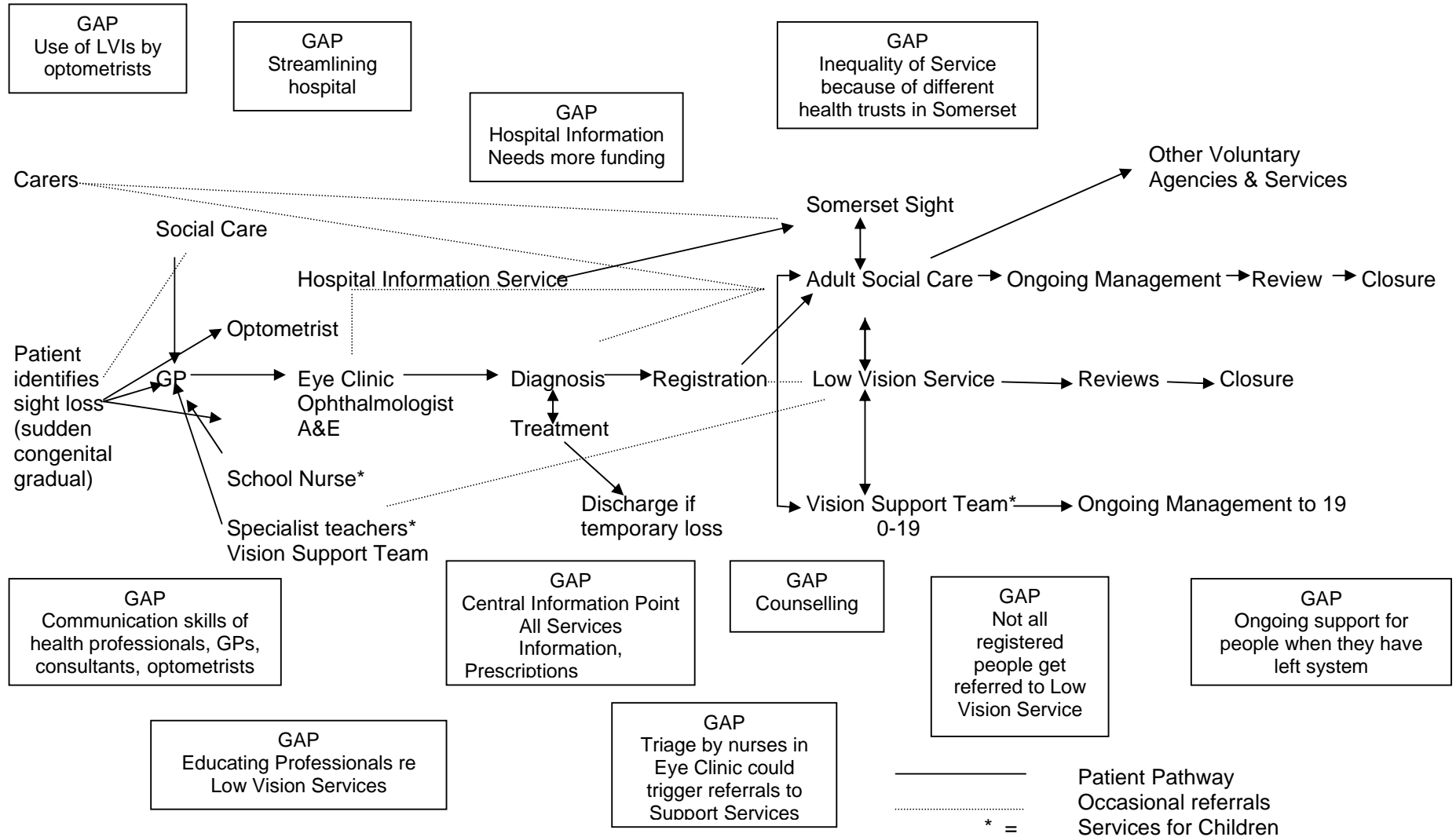
- One pro-active key person
- Good liaison between agencies
- Measured success with evidence and data
- Feedback from children/young people/families
- Increased numbers of children/young people accessing leisure
- Increased range of accessible activities now available and planned
- Trained staff
- Increased resources
- Support networks and activities in place for support for Somerset children and young people who attend special schools out of county either as weekly or termly boarders
- Heightened awareness of the needs of these children/young people and families
- Future planning
- Sustainability from resources created, links made, training delivered, outcomes met

### **Measures**

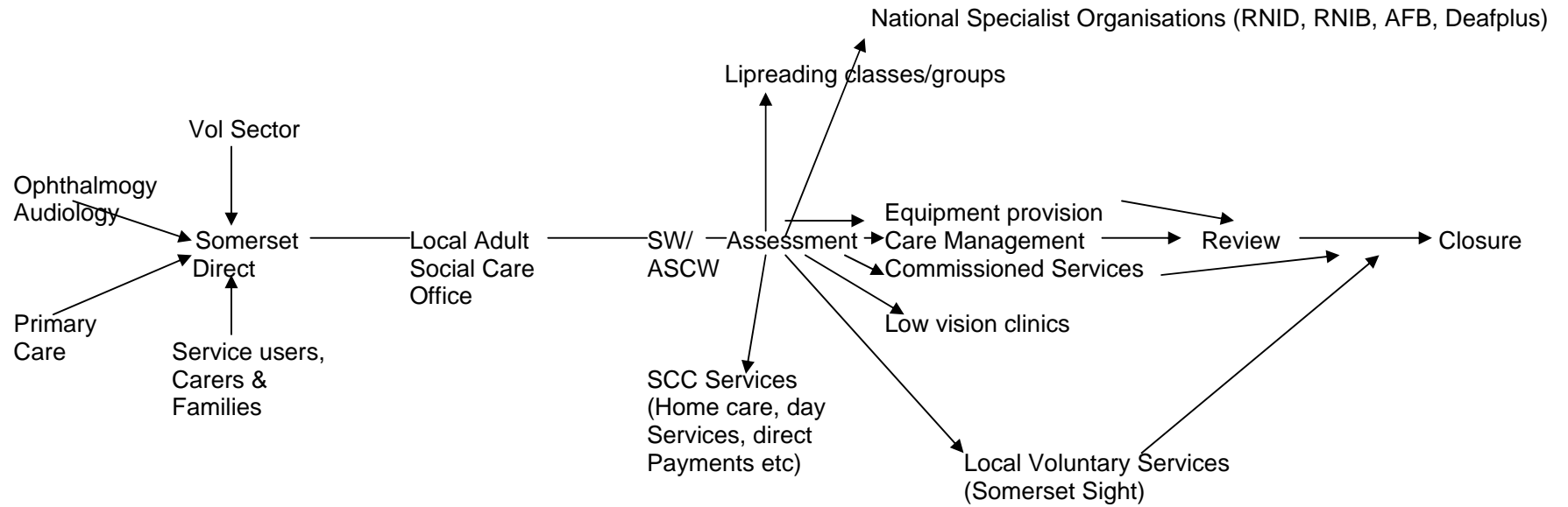
- Number of referrals to services
- How many children and young people accessing the services
- How many activities the children/young people attend
- How many existing settings/venues/facilities are more accessible and inclusive
- Training delivered
- Resources created
- Evaluation feedback from Children/young people/families/settings/monitoring processes
- Links created for the children/young people/families eg support groups, email contacts
- New accessible leisure activities created
- Events days held
- Number of new friends made

# Appendix 3: Care Pathways

## LVC Flowchart from Mapping Exercise



# The Service User Journey



## Appendix 4: Record of Phase 1 Consultation Meetings

### SOMERSET COUNTY COUNCIL

### SENSORY REVIEW

### RECORD OF PHASE 1 CONSULTATION MEETINGS

<b>DATE</b>	<b>VENUE</b>	<b>GROUP</b>	<b>ATTENDEES</b>
16/02/10	Taunton	Dual Sensory Loss users	3
23/02/10	Taunton	SOCA	10
17/02/10	Taunton	Sensory Specialists	20
27/04/10	Taunton	Deaf Club	28
28/04/10	Ashcott	Sensory Specialists and managers	24
05/05/10	Shepton Mallet	Stakeholder event	7
06/05/10	Taunton	Carers	11
10/05/10	Yeovil	Stakeholder event	11
11/05/10	Minehead	Stakeholder event	7
12/05/10	Bridgwater	Stakeholder event	7
18/05/10	Taunton	Stakeholder event	17

## **Appendix 5: Somerset Adult Social Care and Primary Care Trust Sensory Review**

### **Interview Schedule - Representatives**

Representative from Adult Social Care  
Representative from National Health Service  
Partnership  
Representative from Somerset Sight  
Representatives from Retinitis Pigmentosa Society  
Service Users  
Representative from Taunton and Bridgwater Deaf Club  
Representative from deafPLUS  
Members Forum representing Somerset Older Citizens  
Alliance  
Representative from Somerset Older Citizens Alliance,  
Bridgwater  
Representative from Somerset Older Citizens Alliance,  
Chard  
Representative from Somerset Older Citizens Alliance,  
Taunton  
Representative from Somerset Older Citizens Alliance,  
West Somerset  
Representative from Somerset Older Citizens Alliance,  
Yeovil  
Representative from Royal National Institute for the  
Deaf  
Sensory Team at Adult Social Care  
Representative from OPTIMA  
LVSC representing Primary Care Trust, Adult Social  
Care, and Volunteers  
Representative from representing Macular Disease  
Society

## Sensory Loss Appraisal

Representative from Ophthalmology  
Representative from Audiology & Hearing Therapy  
Representative from Education  
Representative from Primary Care Trust Low Vision Services  
Representative from Compass Disability  
Representative from Children's Services  
Representative from Children's Services  
Representatives from Adult Social Care  
Representative from National Health Service  
Representative from Adult Social Care (Commissioning/Policy)  
Representative from Adult Social Care (Equality before Care)  
Representative from Adult Social Care (Personalisation)  
Representative from Learning Disabilities Services  
Representative from Action for Blind People  
Service users  
Representative from Yeovil Deaf Club  
Representative from Somerset Carers  
Community Matrons representing National Health Service  
Representative from Audiology, Taunton  
Representative from Adult Learning  
Representative from Skills and Learning  
Representative from Ophthalmology, Yeovil  
Representative from Audiology, Yeovil  
Service user  
Parent  
Rehabilitation Worker / Resource Centre Manager /  
Service user  
Service user (residential care)  
Service user

## Appendix 6: Case Example

The Review team were contacted by a woman who was particularly keen for her experience to be known of. Her mother had a severe hearing and sight loss and wore 2 hearing aids. She was admitted to hospital after suffering several strokes and died whilst in hospital. Her daughter was very upset as her mother's hearing aids were lost in hospital and replacements were only found after her daughter complained. Unfortunately, the replacement aids did not fit properly so the elderly woman withdrew into herself.

The daughter maintains that staff seemed to have no understanding of how a hearing aid works or to realise its significance to the person who wears it. During her hospital stay, the elderly woman was moved to another hospital and again the aids were lost. The daughter feels that because her mother could not participate in discussions on important matters affecting herself, e.g. a move to another hospital, her final weeks were very difficult and painful for the family.

The daughter's reasons for contacting the Review, was in the hope of avoiding the same happening to anyone else. She feels that hospital staff should be given basic training in hearing and sight loss, particularly for situations where a patient has a dual sensory loss.



## **Somerset Sensory Review Questionnaire**

**NHS Somerset and Somerset County Council have appointed Peter Fletcher Associates Ltd to help understand how well supported people with a hearing and/or sight loss feel and how services might be improved for the future.**

**The survey is entirely voluntary and returns will be kept strictly confidential.**

**Please tell us what you think of support and services provided to people with a sensory loss and how they might be improved.**

**We would be grateful if you would take a few minutes to answer the following questions. Please use extra paper if you wish.**

**If you prefer to discuss this questionnaire over the phone, require further copies, large print or other formats please contact PFA on 01434 684944. Write to us at Chesterwood Grange, Haydon Bridge, Hexham, Northumberland NE47 6HW or email us at [info@peterfletcherassociates.co.uk](mailto:info@peterfletcherassociates.co.uk)**

**Please return by 13<sup>th</sup> December 2010 in the enclosed stamped addressed envelope.**

**1. How satisfied are you with the following aspects of the service you have received relating to your hearing/sight loss? (Please tick one box on each line)**

	Very satisfied	Fairly satisfied	Neither	Fairly dissatisfied	Very dissatisfied
Information provided by Health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services provided by Health e.g. audiology or eye clinics	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Information provided by Social Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Services provided by Social Services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support from Voluntary agencies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Understanding of your religious/ cultural needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**2. Please tell us what you have found helpful or unhelpful about any services you have received:**

---

---

---

---

---

---

---

**3. If you have received help with any of the following from Social Services, please tick the box that best describes your experience.**

	Very helpful	Fairly helpful	Neither	Fairly unhelpful	Very unhelpful
Assessment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rehabilitation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Registration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Equipment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If other - please specify

---

---

---

**4. What particular problems relating to your hearing/sight loss do you still experience in everyday life?**

---

---

---

---

---

---

---

**5. Tell us how services could better help people with a hearing/sight loss.**

---

---

---

---

---

---

---

## **Appendix 8: Summary of Feedback from Sensory Loss Workers in 28 April 2010**

### ***Shortfalls in Present Service***

The list produced was extensive. Rather than simply reproduce it, the following is a summary of what was recorded on the day.

Specialist workers clearly feel that there are conflicting pressures in their role between the generic and specialist work. This arises to some extent from the lack of specialist management and/or the lack of sensory awareness amongst some managers of Specialist workers. As a consequence, training is not given a high enough priority and workers do not always feel adequately skilled. Resources available and potential areas for service development can suffer e.g., links with clinics.

There are needs amongst people with a wide range of sensory loss in the community that specialist workers could go some way to meeting but are prevented from doing so by constraints placed upon them intentionally or otherwise. These constraints relate to lack of awareness, poor strategic planning, training, resources and service model.

### ***Unmet Needs***

Some duplication (inevitably) with “shortfalls” in this section with references to variations in service provision across the county and a lack of certain services e.g. emotional support.

In summary, the more universal needs of people with a sensory loss in the community are not being met e.g. suitable employment, isolation, transport, access including communication support and equipment availability.

Sensory loss awareness in the community is poor, affecting people’s access to wider community activities/facilities/health care, etc.

Additionally, though there are children and families with a sensory loss whose needs are not being (appropriately) met, if met at all, including those with additional disabilities.

### ***Positives of Present Service***

There is a strong belief that specialist workers in Somerset are dedicated and are able to make a real difference to people's lives by employing a range of skills and meeting needs however small.

Needs are also met by a spread of other Agencies, some of which are contracted to SCC. The range/amount of equipment provision is also reasonable despite reservations about Medequip.

Although things could be improved, this sense of working together is enhanced by having a county project/policy Post.

### ***Training/Career Progression***

Overall, comments on this subject were downbeat. Comments appear to suggest that career opportunities/pathway and training direction are very limited and not altogether coherent.

Comments also suggest there is room for roles within sensory service provision for posts that are not social work or OT related i.e. lower level, focused jobs with relevant NVQ (or other) training.

The availability of BSL training is clearly of concern.

### ***Transition/Children's Work***

Feedback on this subject suggests quite a lot of negativity or concern about the fact that specialist workers are expected, in some instances, to take on children's work when they are not suitably equipped to do so. There is a lack of clarity, policy and protocol both from within sensory loss services and children with disability services.

In some cases, families receive support, purely based on the goodwill of an individual worker.

This situation does not serve children with a sensory loss and their families well, compromises the role of specialist workers and there are inherent risks.

### ***MH/LD/BME Groups***

Responses to this section were not unlike those for children's work. There appears to be an awareness that the numbers of people with a sensory loss who also have MH issues, LD or are members of a BME group, are considerable. However, services/support are not consistent and it raises the issue of whether established services (LD for example) should have expertise in sensory loss or whether there should be expertise in LD within sensory loss services.

Currently, the level of sensory loss awareness amongst established services (e.g. LD, MH and wider) is quite low. Therefore, very often sensory loss needs are not recognised and go un-met.

A clearer working model that everyone understands appears to be needed.

### ***A Wider Vision for the Future***

There was no shortage of very constructive comments on this issue and they included the need to consider the more "universal" needs of people with a sensory loss.

There seems to be significant consistency that a more centralised, specialist sensory loss team with specialist management/supervision

would better serve everyone. This would lead to consistency (including use of resources) improve direction based on user involvement and relevant research. It would also be more likely to lead to necessary service developments e.g. one stop shop, co-operative/partnership working, possibly “under one roof”.

Such a specialist presence could also improve sensory loss awareness within the statutory sector and in the community.

## Appendix 9: Record of Phase 2 Consultation Meetings

### Sensory Review Record of Phase 2 Consultation Meetings.

<b>Date</b>	<b>Venue</b>	<b>Group/individual</b>	<b>Numbers</b>
27/10	Taunton	Stakeholder	12
29/10	Taunton	Low vision seminar	11
11/11	Taunton	GP/Wyvern Health	1
17/11	Ashcott	Sensory specialists	23
18/11	Taunton	Hard of hearing club	22
23/11	Yeovil	Public consultation mtg	15
23/11	Taunton	Deaf Club	29
26/11	Taunton	"	23
30/11	Taunton	Alison Houselander, SCC	1
1/12	Shepton Mallet	"	7
2/12	Taunton	Miriam Maddison/Clare Steel, SCC	2
9/12	Chard	Barrie Fitzpatrick, SCC	1
9/12	Norton Fitzwarren	Team Managers	20
15/12	Yeovil	Geoff Snell, SCC	1
15/12	T/C	Ann Anderson, NHS	1