



# Northern Health and Social Services Board Sensory Impairment Needs Assessment

October 2004

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## Background

The overall aim for the needs assessment of services for people with sensory impairment in the Northern Health and Social Services Board (NHSSB) area was to assess how well the level and range of services currently available is matched to the needs of the local sensory impaired population, and to assist local services in identifying priorities for future service development. The main focus of the needs assessment was on community-based services, including the interface between health and social care in both Homefirst Community Trust (Homefirst) and Causeway Health and Social Services Trust (Causeway). The review was intended to explicitly focus on user perspectives, both in terms of users views on existing services and the kind of service provision they would like to see developed. However, service providers' views were also sought in terms of statutory and voluntary providers and also sensory impairment advocacy groups. While this was an explorative and descriptive study based on a relatively small sample, it nevertheless provides significant data which will help the Board commission future services.

## Literature Review

The literature outlines the problem areas of service provision and development as well as examining areas of best practice. What is clear is that the way in which services are delivered often does not facilitate the people with sensory impairment particularly in relation to location and access. Availability of information in appropriate formats, specialist support services and awareness training were deemed to be area that made a difference in the quality of care received. The skill mix and complement of teams is also another key feature in best practice as well as regular consultation especially in planning services.

## Sampling

Three approaches were adopted in carrying out the Needs Assessment. Firstly, a sample was taken of a range of people with sensory impairments from each of the Physical Disability and Sensory

Impairment Teams. They are Antrim/Ballymena, Causeway, East Antrim and Mid-Ulster. In addition, a sample was taken of carers/support persons of people with a sensory impairment, again based on information provided by each of the Teams. Letters of explanation and consent forms were sent to these people by the staff in order to ensure informed consent for participation in the study. Secondly, key voluntary organizations (i.e. British Deaf Association (BDA) and Royal National Institute for the Blind (RNID) were asked to nominate additional profoundly deaf people in the Antrim/Ballymena/East Antrim Area and in the Causeway/Mid-Ulster Area for attendance at focus groups. The Blind Centre for Northern Ireland was requested to nominate centers in the same locations where focus groups could be held with blind/partially sighted people. In total 102 people were consulted, 9 profoundly deaf, 12 with partial hearing, 24 blind or partially sighted and 57 carers/support persons. The areas covered in these interviews were:-

- Range of available services.
- Accessing services.
- Use of specialised services.
- Monitoring and evaluation of services.
- Satisfaction with service provision.
- Areas of good practice.
- Services that are under-utilised.
- Unmet need.
- Recommendations for improvement.

Thirdly, 22 key stakeholders from the Physical Disability and Sensory Impairment teams, the voluntary and private sector service providers, service commissioners and voluntary organisations were identified for interview. The information sought from the key stakeholders was as follows:-

- Range of available services.
- Accessing services.
- Use of specialised services.
- Monitoring and evaluation of services.
- Services that are under-utilised.
- Unmet need.
- Budgets.
- Service level agreements.
- Contract types.
- Recommendations for improvement.

## Findings

- Social work time is mainly dedicated to physical disability.
- When the social workers are specialising in the area, the work is time consuming and involves a lot of co-working and counselling.
- While the numbers are low in terms of referrals to Social Workers, this does not adequately reflect the needs of people and their carers, in terms of support and care requirements from services.
- Not all specialist staff within the Physical Disability and Sensory Impairment teams have British Sign Language (BSL) level II or Level III and this is resulting in communication problems with people who are profoundly deaf.
- The majority of referrals are for Environmental Technical Officers (ETOs) and Rehabilitation workers in the sensory impairment area and this is reflected in the long waiting lists for services and a lack of monitoring and review. Both of these disciplines are under resourced. Difficulty in recruiting these staff is also causing problems.
- The Fieldworker for the blind, employed through the 'Homecall' scheme (Blind Centre for Northern Ireland) and attached to the Physical Disability teams, has been praised as a very positive development by both staff and people with visual impairment. This is facilitating befriending, practical support and advice.
- 'A service that is under resourced' is a theme presenting throughout the needs analysis. This is in terms of staff, equipment, partnership development and practical care and support.
- There is a general lack of information right across the Board area and complaints that the information that is provided is usually lacking sufficient detail and is not presented in the correct format.
- Outside of the Physical Disability and Sensory Impairment Teams, there are major gaps in awareness within health and social service departments. This is causing problems for the sensory impaired in terms of communicating with frontline staff, arranging appointments and attending appointments.

## Recommendations

### *Sensory Impairment Teams*

- There is a need to look at the development of locality-based dedicated staff delivering sensory impairment services.
- There should be a minimum requirement regarding the number of specialist staff trained to BSL Level II and III. A programme of training should be developed to ensure the agreed standard is met.
- A deaf advocate/support worker should be employed within each team to assist with communication difficulties and to ensure people with profound hearing impairments have their needs reported to professional staff.
- There is a need to increase the numbers of ETOs and rehabilitation workers in order to reduce waiting time and to enable at least annual reviews of existing clients with sensory impairment.
- There is the need for the development of a career structure for trainees who will eventually become Rehabilitation workers. Sensory Support Workers who could provide more direct support to people with sensory impairments could also be beneficial.
- The 'Homecall' service should be continued and developed with the Blind Centre for Northern Ireland. This service could also be extended to assist and facilitate carers' needs in terms of support and advice.
- Services should be resourced sufficiently to provide adequate, up-to-date equipment and home-help support for people with sensory impairment in order to enable independence and a satisfactory quality of life.
- Multi disciplinary working, and clarity in the inputs re older people (over 65) must be addressed. While specialist input from the Sensory Impairment team is essential in Older People's services, the assessment of need and allocation of resources needs to be understood by all staff, by the person with the sensory impairment and by their carer.
- The provision of clerical support to the teams needs to be addressed as a matter of urgency. There is also need to review office equipment in terms of computers, telephones, fax machines etc. There will also be a need for sensory impairment training for front-line clerical staff.

## ***Information***

- Information in terms of a 'directory of services' needs to be developed and made available in different formats on request.
- Better use of Trust and Board websites in giving information in available formats would be beneficial. All information must be jargon free and the website must also be presented in suitably contrasting colours.
- There is a distinct need to inform people as to whom they are dealing with (ETO, Social Worker or Rehabilitation officer) and what the role of the named officer is.
- Information should be made available to people with hearing impairment and their families regarding the interpreting service.

## ***Awareness***

- The promotion of awareness in sensory impairment is essential for all frontline staff, and access to services must be reviewed to enable appropriate communication channels for people with a sensory impairment.
- There is a need for partnership working with other agencies, and creation of awareness of the needs of people with a sensory impairment.
- As specialist Sensory Impairment Teams develop, they should become involved in delivering sensory awareness training to schools with the aim of providing to children and young people a sense of what it means to be deaf or blind and to promote an understanding of the issues faced by deaf and blind people.
- As part of a Quality Assurance method of measuring the quality of services delivered, it is recommended that Consumer Panels be developed as a forum where deficits in services can be highlighted and action plans developed to tackle these problems.
- An Audit of GP surgeries with independent assessment of the positive and negative aspect of service delivery is needed. This should be followed with a report of the findings to GPs, Local Health and Social Care Groups and Practice Managers. This could be part of the further development of the 'Getting There' initiative.
- Recommendations for improvement of awareness in Primary Care should form part of each Local Health and Social Care Groups strategy for Primary Care.

- The creation/development of sensory impairment support groups within local areas and associated transport provision would facilitate the development of local initiatives in creating awareness.

### ***Development***

- The development of a Sensory and Disability Database, similar to that in use in the Republic of Ireland, would be an invaluable asset in capturing detailed information on sensory impaired people within the Board area and assist with planning. More in-depth assessment of contact activities within teams would assist in workforce planning.
- The specialist Teams should develop services that are evidence based, using the most up to date research findings. A mechanism should be established for the dissemination of research findings and a research culture developed within the teams.
- The specialist Teams should co-ordinate service delivery and explore mechanisms for developing easy access to multiple services and supports. These would preferable be located in one centre similar to the concept of the 'one stop shop'.
- It is proposed that a short life working group be set up to produce common sensory impairment service standards, to be completed for implementation.

## About the Needs Assessment

The overall aim for the needs assessment of services for people with sensory impairment in the NHSSB area was to assess how well the level and range of services currently available is matched to the needs of the local sensory impaired population, and to assist local services in identifying priorities for future service development.

Within this overall aim, the needs assessment set out to meet the following specific objectives:-

- Comparative analysis of current service provision with other similar populations.
- Capture information on the range of specialist services in the voluntary and statutory sector and demographic details of those people who are accessing them.
- Evaluate the balance between demand and supply led service provision in NHSSB.
- The extent to which existing services promote choice and independence for local sensory impaired people and their carer/support person.
- To make recommendations from the analysis.

The main focus of the needs assessment was on community-based services, including the interface between health and social care. The review was intended to explicitly focus on user perspectives, both in terms of users' views on existing services and the kinds of service provision they would like to see developed. However, service providers' views were also sought in terms of statutory and voluntary providers and also sensory impairment advocacy groups. This was included in order to capture a holistic approach to needs-led development and to ensure that there was added value to previous Needs Analysis and research conducted in this area.

The outputs from the needs assessment are therefore intended to provide a basis for developing services, which are both feasible for commissioners and providers (i.e. developments which would be practical within the parameters of available resources), as well as empowering for local sensory impaired people. The research is also intended to have a strategic focus where attention is paid towards longer-term goals for service development.

## **Profile of the NHSSB Area**

The Northern Health and Social Services Board is the second largest of the four Health and Social Services Boards in Northern Ireland. 426,969 people live within the Board's area<sup>1</sup>, which covers the District Council boundaries of Antrim, Ballymena, Ballymoney, Carrickfergus, Coleraine, Cookstown, Larne, Magherafelt, Moyle and Newtownabbey.

The 3 local Trusts from which the Northern Board commissions many services are:-

- **Causeway Health and Social Services Trust**, which provides both health and social care services and covers the Council areas of Ballymoney, Coleraine and Moyle.
- **Homefirst Community Trust**, which provides community health, mental health and social care services and covers the Council areas of Antrim, Ballymena, Carrickfergus, Cookstown, Larne, Magherafelt and Newtownabbey.
- **United Hospitals Trust**, which provides acute hospital services at Antrim, Braid Valley, Mid-Ulster, Moyle and Whiteabbey Hospitals. The localities covered by United Trust are Antrim, Ballymena, Carrickfergus, Cookstown, Larne, Magherafelt, Moyle and Newtownabbey.

## **Sensory Impairment within the NHSSB Area**

The estimated prevalence of Hearing and Visual Impairment in the NHSSB by Trust area and age band is depicted in Table1.

**Table 1: Estimated Prevalence of Sensory Impairment NHSSB Area**

Age Band	Hearing Impairment			Visual Impairment		
	Causeway HSST	Homefirst HSST	NHSSB Area	Causeway HSST	Homefirst HSST	NHSSB Area
<b>0-4</b>	12	37	<b>49</b>	12	37	<b>49</b>
<b>5-9</b>	61	212	<b>273</b>	39	135	<b>174</b>
<b>10-15</b>	75	245	<b>320</b>	40	132	<b>172</b>
<b>16-59</b>	1,222	4,123	<b>5,345</b>	756	2,553	<b>3,309</b>
<b>60-74</b>	1,952	6,123	<b>8,075</b>	1,008	3,160	<b>4,168</b>
<b>75+</b>	2,223	6,516	<b>8,739</b>	1,777	5,211	<b>6,988</b>
<b>Total</b>	<b>5,545</b>	<b>17,256</b>	<b>22,801</b>	<b>3,632</b>	<b>11,228</b>	<b>14,860</b>

SOURCE: PPRU Surveys Of Disability<sup>2</sup>

These figures, which are updated and taken as a percentage of the 2001 population for the area, are in line with the Northern Ireland average prevalence rates of 3.5% of the population for visual impairment and 5.3% of the population for hearing impairment, with slight variations at District Council level.

In relation to Trust areas, Causeway has a slightly higher level of visual and hearing sensory impairment than the Northern Ireland average (3.6% and 5.5% respectively), whilst Homefirst is marginally lower (3.4% and 5.2%).

While the prevalence rate for hearing impairment is 53% higher than that of visual impairment within the NHSSB region, the Department of Health, Social Services and Public Safety (DHSSPS) Community Statistics 2002/03<sup>3</sup> show that there are more people with a visual impairment as opposed to those with a hearing impairment in contact with Health and Social Services in the area – 9.1% of the visually impaired and 5.9% of the hearing impaired population. When taken against those accessing the *Physical & Sensory Disability Programme of Care* this figure falls further – 2.3% of the visually impaired population as opposed to 1.6% of those with a hearing impairment.

Based on the DHSSPS Community Statistics 2002/03 for *all Programmes of Care*, a total of 2,700 people with a sensory impairment had contact with service providers in the NHSSB region. Of the Northern Ireland total for people in contact with Health and Social Services the NHSSB had 21% for deaf/hearing impairment and 25% for blind/partially sighted.

People over the age of 65 comprised almost three-quarters of all those with a sensory impairment having had contact with providers in the Board area during the period. This applies to both hearing and visual impairments.

Of this total, those with sensory impairments accessing the Physical and Sensory Disability Programme of Care within the Causeway and Homefirst Trusts are detailed as follows:-

### **Causeway**

- 3 deaf with speech; 12 deaf without speech; and 43 hard of hearing.
- *4% of hearing impaired population aged under 60.*
- 22 blind; and 23 partially sighted.
- *5% of visually impaired population aged under 60.*

### **Homefirst**

- 32 deaf with speech; 44 deaf without speech; and 142 hard of hearing.
- *5% of hearing impaired population aged under 60.*
- 112 blind; and 121 partially sighted.
- *8% of visually impaired population aged under 60.*

These, by all accounts, would appear to be quite low numbers. However, in the absence of a database to capture the comprehensive details on sensory impaired people in the Board area or Northern Ireland as a whole, it is difficult to assess precise numbers and real need. Nevertheless, it would appear that a gap does exist between the high number of people with a sensory impairment and the low number of people in contact with services.

The approach employed within this Needs Assessment consisted of both quantitative and qualitative measures. The methodology was programmed into 3 phases:-

## **Phase One - Desk Based Research and Literature Review**

Phase One involved desk research to gather together background information from local studies on the needs and circumstances of people with sensory impairments and to summarise existing best practice in relevant service areas. This information was used to help identify particular service development issues, which needed to be investigated further in subsequent stages of the review.

This part of the research included a review of existing policy and planning documents produced over the last three years such as local Community Care Plans, Health Board Commissioning Plans, local NHS Trust Business Plans, and the major local reviews which have already been carried out on the needs of people with sensory impairments, including those covering housing services and transport. Similar Needs Analysis from elsewhere was also explored in the literature together with their findings and references to best practice. Prevalence rates and service provider contact statistics were also examined.

## **Phase Two - Study Design**

### ***Ethical Clearance and Confidentiality***

Ethical clearance was not considered necessary for this Needs Analysis, as there were no direct effects to people in terms of experimental procedures, physical or psychological harm. Confidentiality was guaranteed by the anonymity of the questionnaires. Each interviewee and attendees of the focus groups were allocated a number, which was recorded on the questionnaire or transcript and the only person aware of the details is the researcher.

## ***Sampling***

Because of the short time-span in which the Needs Analysis had to be completed, it was decided that the best methodology would be the selection of a number of people with a range of sensory impairments from each of the physical and sensory disability teams in the 4 geographical areas within the NHSSB. They are, Antrim/Ballymena, Causeway, East Antrim and Mid-Ulster.

Staff were asked to identify 2 profoundly deaf people, 4 partially deaf people and 6 blind/partially-sighted people for individual interview. Because of confidentiality issues, letters of explanation and consent forms were sent to these people by the staff in order to ensure informed consent for participation in the study. The teams also identified 25 carers/support workers to which postal surveys were sent. Copies of the consent form, letters and questionnaire's are shown in Appendices I and II. In addition to this the voluntary sector i.e. BDA and RNID were asked to nominate an additional 10 profoundly deaf people in the Antrim/Ballymena/East Antrim Area and 10 profoundly deaf people in the Causeway/Mid-Ulster Area for attendance at focus groups in Antrim and Coleraine. The Blind Centre for Northern Ireland was requested to nominate centres in the same locations where focus groups could be held with approximately 10 blind/partially sighted people.

This meant the needs assessment involved 28 profoundly deaf, 16 partial hearing, and 36 blind/partially sighted people and 100 carers/support persons.

In addition 25 key stakeholders were identified for interview. They consisted of 20 staff, 5 from each of the individual physical disability and sensory impairment teams for round table workshops. Five telephone interviews with the voluntary and private sector services, service commissioners and voluntary organisations which act as advocates for the various sensory impairments e.g. BDA, RNID, Deafblind UK, and the Blind Centre for Northern Ireland were included as part of this consultation process.

## Sample Population

From the possible sample frame of 28 profoundly deaf people, 9 were interviewed - 6 via focus group and 3 via individual interview. From the 16 people who had partial hearing, 12 had individual interviews. For the blind/partially sighted group of 44 people, 24 were interviewed, 9 via focus group and 15 individual interviews. Responses were received from 57 of the 100 carers/support persons. The breakdown by nature of impairment and location is shown in Table 2:-

**Table 2: Breakdown of Interviews<sup>Sample</sup>**

Nature of Impairment	Mid-Ulster	Antrim/Ballymena	Causeway	East Antrim	TOTAL
Profoundly/Registered Deaf	1	6*	1**	1	9
Partial Hearing	2	3	2	5	12
Visually Impaired/Registered Blind	4	5	4	11***	24
Carer/Support Person	12	14	16	15	57
<b>Totals</b>	<b>19</b>	<b>28</b>	<b>23</b>	<b>32</b>	<b>102</b>

\* Focus Group held in Antrim: \*\* No focus Group in Causeway due to insufficient numbers: \*\*\*Due to time restraints only able to arrange focus group in East Antrim

In total 102 people were consulted, which represents 54% of the target sample population of 188.

## Individual Interviews

The information sought in these interviews was similar to that which was requested of the care/support person, with the pro-forma used included as Appendix III. The key areas covered were:-

- Range of available services.
- Accessing services.
- Use of specialised services.

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### Sample

The sample of 45 sensory impaired clients represents 10% of the sample population based DHSSPS Community Statistics 2002/03 for all Programmes of Care.

- Monitoring and evaluation of services.
- Satisfaction with service provision.
- Areas of good practice.
- Services that are under-utilised.
- Unmet need.
- Recommendations for improvement.

### ***Focus Groups***

Due to lack of availability of people, the number of focus groups was reduced to 2. One in Antrim for the profoundly deaf attended by 6 people, and 1 in Antrim/Ballymena area for the blind and partially sighted attended by 9 people (1 of which had dual sensory impairment). The topic guide for these group discussions covered the following areas:-

- The range of social and community support services which local sensory impaired people use, or might want to use.
- How easy/difficult is it for people to access the kind of support they need from local services?
- What do people think about the quality of support provided by these local services?
- Examples of ways in which services might be improved.
- Use of specialist services.
- Particular services which sensory impaired people need but which are not generally available locally.
- Views on GP services.
- Views on other local community health services.
- Views on local hospital services.
- Access to information.
- Specific examples of ways in which local health services might be improved.
- Transport services.
- Action on raising awareness of sensory impairment.

### ***Key Stakeholders***

Three round table workshops were held with the staff of the individual physical disability and sensory impairment teams. All 4 team leaders and individual staff who work with people with sensory impairment were in attendance. The staff included social workers, ETOs and

rehabilitation workers. Fourteen staff in total were consulted. Three additional stakeholders were added to the consultation list on the advice of other stakeholders interviewed. Eight telephone interviews were also conducted with voluntary and private sector services, service commissioners and voluntary organisations, which act as advocates for the various sensory impairments. The names and positions of those consulted are shown in Appendix IV. Thus 22 key stakeholders in total were consulted. The information sought from the key stakeholders was as follows:-

- Range of available services.
- Accessing services.
- Use of Specialised services.
- Monitoring and evaluation of services.
- Services that are under-utilised.
- Unmet need.
- Budgets.
- Service level agreements.
- Contract types.
- Recommendations for improvement.

### **Phase Three - Data Analysis**

Data was analyzed using the SPSS System with any emerging thematics reported on from the open-ended qualitative section of the questionnaire. The data collected via focus groups and key stakeholders was mostly qualitative and was analysed accordingly. Full transcriptions of individual interviews were analysed and coded into categories, which describe the specific content in as much detail as required. Finally, each of the extracts from the interviews was labeled with an individual ID number. Combining these with short profiles of each of the people providing the information helps to provide further contextual information, which can be useful in interpreting the significance of particular comments.

The report is descriptive in nature and highlights the defined prevalence rates for sensory impairment in the Northern Board area. It also describes the current level and range of service provision and draws comparisons with other regions. Locality based provision, is detailed together with areas of service deficits and unmet need. The range of specialist services provided by both the voluntary and statutory sectors and a profile of their users' is also reported.

## Introduction

The review will begin by defining 'sensory impairment' because in a study of this nature it is important to have clarity of terms in order to place the needs assessment in context. An exploration of the different legislation and policy documents in order to set the strategic context of the review will follow together with examination of local policy documents and reviews. Finally, best practice from other jurisdictions will be explored.

## Definition of 'Sensory Impairment'

In order to clarify the population sample the following definition of sensory impairment was adopted in this study:-

***“All those people who are blind or partially sighted, hearing impaired, deaf, hard of hearing, partially hearing, deafened, deafblindness or dual sensory impaired.”***

## Definition of Terms

- ***Sensory Impairment***  
This is the broad term used to cover visual impairment, deafness, being hard of hearing and deafblindness.
- ***Visual Impairment***  
This is a term used to cover the spectrum of those who have some residual vision to those who have no sight at all. The terms blind and partially sighted are also frequently used in the report. Blind in the context of a person being registrable has a specific meaning, being so blind as to be unable to perform any work for which eyesight is essential. It does not necessarily mean that the person concerned will have no vision at all.

- ***Deaf People and those who are Hard of Hearing***

The Deaf Community is generally used to describe those Deaf people who use British Sign Language and who feel they share a culture with other Deaf people. There is a larger number of people who are also profoundly deaf, many of who will have become deaf during the course of their lives and who will acquire a variety of new communication skills. The largest group are those who are hard of hearing, many of whom acquire hearing loss as they become older.

- ***Dual Sensory Impairment***

Dual sensory impairment refers to people with a combination of sight and hearing losses, which can cause difficulties with communication, access to information and mobility.

## **Policy and Legislation**

Over the past number of years there has been significant changes in both policy and legislation, which have influenced how services are shaped and developed. These include:-

### **Legislation**

- Disability Discrimination Act 1995<sup>4</sup>
- Carers Recognition and Services Act 1995<sup>5</sup>
- Children (NI) Order 1995<sup>6</sup>
- Direct Payments Act 1998<sup>7</sup>
- Northern Ireland Act 1998<sup>8</sup>
- Human Rights Act 1999<sup>9</sup>

### **Policy**

- Regional Strategy 1997-2002<sup>10</sup>
- New TSN (Targeting Social Need)<sup>11</sup>
- Investing for Health<sup>12</sup>
- Inspection of Services for Young People (aged 16-25) with a Physical Disability and/or Sensory Impairment<sup>13</sup>
- Review of Services for People Aged 16-25 with a Visual Impairment<sup>14</sup>
- Section 7 Policy Guidelines on Deafblindness 2000 (England & Wales)<sup>15</sup>

## **Disability Discrimination Act 1995**

The Disability Discrimination Act (DDA) is due to come into force in September 2004 and as such it is pertinent that Boards, Trusts and the Primary Care Sector are aware of the implications and what their responsibilities are under the Act. However, it is important to highlight that most of the legislation relevant to the sensory impaired is already in force. The following is a Disability Rights Commission Summary Extract.

**“For a deaf person who uses British Sign Language as his or her main form of communication, having a qualified BSL interpreter is the most effective method of communication. This is because for people whose first language is BSL (rather than spoken or written English) exchange of written notes or lip-reading can be an uncertain means of communication. British Sign Language Interpretation may not be easily available and should be arranged in advance wherever possible.**

**If an interpreter is not available, the service provider should consider an alternative method of communication, in consultation with the deaf person.”**

The Act leaves open what particular auxiliary aids or services might be provided in specific circumstances. Disabled people may be able to help the service provider to identify difficulties in accessing the service and what kind of auxiliary aid or service will overcome them. It is good practice to include disabled people in the process of considering what reasonable adjustments should be made. However, the duty remains on the service provider to determine what steps it needs to take.

The type of auxiliary aid or service will vary according to the importance, length, complexity or frequency of the communication involved. In some cases, more than one type of auxiliary aid or service might be appropriate, as different people have different communication requirements. Account should also be taken of people with multiple communication disabilities, such as deafblindness or combined speech and hearing disabilities.

## ***Provision for People with a Hearing Disability***

For people with hearing disabilities, the range of auxiliary aids or services, which it might be reasonable to provide to ensure that services are accessible, may include one or more of the following:-

- Written information (such as a leaflet or guide).
- A facility for taking and exchanging written notes.
- A verbatim speech-to-text transcription service.
- Induction loop systems.
- Subtitles.
- Videos with BSL interpretation.
- Information displayed on a computer screen.
- Accessible websites.
- Text phones, telephone amplifiers and inductive couplers.
- Teletext displays.
- Audio-visual telephones.
- Audio-visual fire alarms.
- Qualified BSL interpreters or lip speakers.

Where sign language interpretation is used as an auxiliary service the interpreter should be capable of communicating accurately and efficiently with both the disabled person and the other parties involved. Other interpretation services such as lipspeakers and Makaton communicators should similarly be capable of communicating accurately and effectively.

Service providers should bear in mind that hearing impairments take many forms and are of varying degrees. What might be a reasonable auxiliary aid or service for a person with tinnitus or reduced hearing might not be a reasonable adjustment for someone who is profoundly deaf.

## ***Provision for People with a Visual Impairment***

For people with visual impairments, the range of auxiliary aids or services, which it might be reasonable to provide to ensure that services are accessible, may include one or more of the following:-

- Readers.
- Documents in large or clear print or Braille.
- Information on computer disk or e-mail.
- Information on audiotape.
- Telephone services to supplement other information.
- Spoken announcements or verbal communication.
- Accessible websites.
- Assistance with guiding.
- Audio description services.
- Large print or tactile maps/plans and 3-dimensional models.

## ***Provision for Deafblind People***

Deafblind people are not necessarily assisted in accessing services by the simple provision of communication aids designed for people with hearing disabilities or visual impairments. Such aids could assist deafblind people if appropriately used e.g. information leaflets produced in Braille or acoustics, induction loop systems etc. However, what is appropriate will depend on the nature and extent of the individual's sensory impairment and the method used to access information.

Adjustments, which may be of use to a deafblind person, might include engaging a deafblind manual interpreter for important meetings or having a member of staff trained in specific ways to help a deafblind person. Where service providers give their staff disability awareness training, this should be accessible to all staff including clerical staff and could include safe guiding and tracing capital letters and numbers on the palm of the hand.

## **RNID Report 2004**

From a recent report published by RNID entitled “A Simple Cure: A Report into Deaf and Hard of Hearing People’s Experiences of the NHS”,<sup>16</sup> it would appear that **despite** the frequency with which deaf and hard of hearing people use the NHS, the level of service they receive, in both GP surgeries and hospitals, often falls short of what they could reasonably expect.

A number of reports from within the NHS have already recognised some of the problems faced by disabled people. The NHS in England found that “disabled people often face unacceptable difficulties when they try to use NHS services.” The NHS in Scotland has also acknowledged this problem and stated that these difficulties “may make it difficult or, at worst, impossible for disabled people to access the services they are entitled to, find their way around premises and communicate with staff.” The Welsh Assembly Review of Health and Social Care recognised that while there was some good and excellent practice in Health and Social Care, there was also widespread under-performance associated with systemic defects. Those defects are presenting real and serious barriers for deaf and hard of hearing patients.

The research found that of the 866 people surveyed the following percentages highlight the problem areas:-

### ***GP Surgeries***

- 35% of deaf and hard of hearing people had experienced difficulty communicating with their GP or nurse.
- 32% found it difficult to explain their health problems to their GP.
- 15% of deaf and hard of hearing people said they avoid going to see their GP because of communication problems; this proportion doubles among BSL users’.
- 28% of deaf and hard of hearing people found it difficult to contact their GP surgery to get an appointment because of their hearing loss.
- 35% of deaf and hard of hearing people had been left unclear about their condition because of communication problems with their GP or nurse.

- 33% of BSL users' were either unsure about instructions for medication, or had taken too much or too little of a medication because of communication problems.
- 24% of patients had missed an appointment because of poor communication – such as not being able to hear staff calling out their name – 19% of people missed more than five appointments.

### **Hospitals**

- 42% of deaf and hard of hearing people who had visited hospital (non emergency) had found it difficult to communicate with NHS staff. This increased to 66% amongst BSL users'.
- 77% of BSL users' who had visited hospital could not easily communicate with NHS staff. The proportion that had experienced difficulty was the same for both emergency visits and non-emergency overnight stays.
- 70% of BSL users' admitted to Accident and Emergency (A&E) Units were not provided with a BSL/English interpreter to enable them to communicate.

It would appear from these findings that lack of communication skills, basic equipment and general awareness is causing major problems for this group of people as well as the cost to the NHS of missed appointments. Some solutions proposed by RNID were:-

- Video telephones to support remote interpreting, thus making more intensive use of a resource and tailoring support to the people's needs.
- Improve basic communication of staff in BSL.
- Better written information in plain English.
- For many hard of hearing people, installation of a loop system at the reception to allow them to make full use of their hearing aid in noisy GP practices and hospital situations is essential.
- The use of visual displays can also ensure that deaf and hard of hearing patients can clearly see when they are being called for appointments.
- Provision of trained lipspeakers can also make a fundamental difference for some groups of hard of hearing people.
- Adequate lighting.
- Clear appointment systems and information.
- Good disability awareness.

## Visual Impairment and Access to Services

“Unseen, Neglect, Isolation and Household Poverty amongst Older People with Sight Loss” is a recent report published by RNIB (March 2004), which states that:-

***“Hundreds of thousands of older blind and partially sighted people are living in isolation and poverty. They have little or no regular contact with care services and go without vital but inexpensive equipment, which could help them live independently. Services for people in Britain who have lost their sight are not sufficient and do not reach most of the people in need of help. Many people are surviving hand to mouth outside of a system that is supposedly designed to support them.”***

The report, based on a major survey of 588 blind and partially sighted adults in England, Scotland and Wales highlights the alarmingly sparse nature of support for a growing older population encountering sight problems in later years. The research findings raise grave concerns about the level of social exclusion. Three out of 4 blind and partially sighted people were found to be living in or on the margins of poverty as measured by a recognised yardstick (living on less than half of the mean national household income). Three out of 5 live alone and only 1 in 3 has daily contact with someone from the outside world. This is of special concern given the difficulties of getting out and about.

Seven out of 8 people surveyed were "registered" with their local authority as blind or partially sighted. Registration ought to provide a gateway to support services and yet less than half of the people surveyed had ever received an assessment from care services and as many as 7 out of 10 had never even heard of mobility training, let alone received it. Changes regarding the process of registration and certification of blindness and partial sight in Northern Ireland that will include high street optometrists are underway with the establishment of a working party. Currently many ophthalmologists are not referring people for a social care assessment at the earliest possible time, but instead wait until medical intervention has been completely exhausted. During this time some people's independence has been entirely eroded. Indeed only a small minority of people receive the rehabilitation and

mobility training they need to maintain their independence. There are estimated to be fewer than 800 rehabilitation officers for a population of nearly 2 million people with sight loss in Great Britain.<sup>17</sup>

Various items of equipment have been designed specifically to help people with sight loss undertake everyday tasks. White canes for walking safely, magnifiers and task lamps for reading and close work, talking kitchen appliances to help cook safely and many other products have been demonstrated to be extremely useful and cost effective. Yet, despite the fact that these pieces of equipment have been shown to prevent accidents and injuries and premature dependence, they are still not offered with appropriate training as a matter of course by local authorities.

Blind and partially sighted people have a variety of basic daily needs as a result of their sight loss. The ability to perform these tasks will clearly vary from individual to individual, depending on a number of factors including confidence, age, training, other disabling conditions, presence of a carer and accessibility of their environment. Information and advice about support and services that would help older blind and partially sighted people keep their independence is often dispersed across a number of agencies and difficult to access.

Loneliness, isolation, fear of crime and lack of confidence are all extremely common amongst older people with sight loss, and given that so many live alone it would be hoped that people would be receiving visits on a daily basis. Yet only 36% said that they have people who they can rely on and trust to visit them daily, 18% have a visit less than once a week and 11% less than once a month or never.

## **Recommendations for Improvement**

The following recommendations are made in the report:-

- Every person with sight loss to be offered an assessment of needs and suitable services and tools to make the most of their remaining sight, so that they can live independently and with dignity.
- Ensure every person with sight loss receives a prompt assessment and needs based rehabilitation services, and that people with significant sight loss are not "rationed out" of care services by new eligibility criteria.

- Every blind or partially sighted person to have the maximum opportunity to retain his or her independence. This will mean everyone receiving equipment and appropriate training.
- Ensure that every Community Equipment Store stocks and provides equipment for blind and partially sighted people free at the point of need to every person assessed as being eligible for care and visually impaired.
- Assessments are carried out by professionals trained in sight loss issues.

## **Dual Sensory Impairment**

Deafblind people use different communication methods. The type of communication method used by a deafblind person will be dependent on the deafblind person's needs. Deafblind people may use one or more of the following types of communication:-

- Braille.
- Clear Speech.
- Block Alphabet.
- Manual Alphabet.
- BSL.
- Visual Frame Signing.
- Hands-on Signing.

## **Section 7 Policy Guidance**

Section 7 of the new policy guidance applicable in England and Wales, means that returns must be made to Government in which Local Authorities show that deafblind people have been identified, their needs assessed and that there is provision of trained 1:1 support workers. The SENSE document 'Standards of Services for Adults who are Deafblind or have a Dual Sensory Impairment' 2001; <sup>18</sup> outlines areas of good practice for those working with dual-sensory impaired people. An assessment has to be carried out by a specifically trained person. Information must be available on services in different formats. There must be one senior member of staff who is responsible for services to deafblind people. Local Authorities must have access to training for working with deafblind people.

## ***Prevalence of Dual Sensory Impairment in Northern Ireland***

A survey commissioned by SENSE in 1991<sup>19</sup> showed that 480 people with Dual Sensory Impairment (DSI), who were identified, lead to a prevalence rate of 30.8 per 100,000 population. Due to the variance in numbers returned by different Area Boards, it is likely that this is an underestimation. Significantly, 48.6% of these people had additional physical disabilities and 22.8% had severe learning difficulties. Within the Board's returns, 114 children aged 19 or under were identified (24%); 57% of these had an additional physical handicap and 72% were thought to be mentally handicapped. Less than 1 in 3 children had no speech and 40% had no communication method at all. One out of every 666 people aged 65 or over had a DSI; 291 (61%) of deafblind people were over 65. The survey also found that a multi-disciplinary approach to improvement in assessment procedures was needed, involving contributions from parents and other professional staff. A regional assessment centre specialising in sensory handicaps would bring this about effectively. Current clinical audiology and ophthalmology services in the Province were possibly inadequate for effective assessments.

It was also established that approximately 63% of deafblind people lived in the community, with 36% living in residential establishments. Only 9% received respite care; present facilities for this were considered inadequate. In turn, 7% had access to a rehabilitation officer in the capacity of a key worker. There was a clear need for greater input from specialist support staff in the areas of communication, mobility and rehabilitation.

## **Promotion of 'Principles of Good Practice'**

There were numerous areas of Good Practice highlighted in the literature and what is reported here is the amalgamation of the different aspects of best practice into an overall profile of what is entailed. These areas can be applied to all aspects of sensory impairment and are intended to be beneficial in the planning and delivery of sensory impairment services. Where areas of good practice were identified these tended to be developed by specialist teams in partnership with the voluntary sector and with consumer panel input. They are the combined result of multi-disciplinary and multi-agency partnership collaboration.

## ***Information***

Leaflets and other printed forms of communication designed for the public should contain the following statement in font size 14 and in an Ariel font:-

**‘If you would like this (leaflet/report/document) in large print, audio, Braille, alternative format or in a different language please contact (name) on (number) (minicom), and we will do our best to help.’**

Detailed information is given on:-

- Local translation and interpretation and communication services with advice on commissioning these services.
- Advice on cultural diversity with advice on language use and disability etiquette.
- Sensory disability, (including sections on conversation, plain language, print guidelines for leaflets and promotional materials, display boards and posters, making standard letters accessible, fax and photocopying).
- Comprehensive guidance on other forms of communication.
- Leaflets, forms and reports in a variety of large print formats.

As information is quickly out of date, it is not cost effective to have large stocks of literature. Staff from the specialist teams should carry an example of a leaflet in a variety of print sizes to ascertain a people's preference and thereafter all subsequent information, including assessment literature, can be produced in the appropriate format. Many sensory visually impaired people express a preference for brief summary information (e.g. of services to be provided) in large print and the full information in standard format for relatives or carers to read. A range of transcription services, BSL video tapes and audiocassettes are all commissioned from organisations within the local Trust areas.

## ***Assessment***

This involves a 3-stage assessment process for sensory impaired adults.

**Stage One:** Over a 4 to 8 week period a member of the specialist team who has the necessary training and skills to communicate effectively with the sensory impaired people conducts an assessment. The purpose of this is to clarify the support requirements. An in-depth report is then written under the following headings:-

- Vision.
- Hearing.
- Communication.
- Mobility.
- Interaction with others.
- Best practice.
- Behaviour/emotional.
- Any religious or cultural issue.
- Employment
- Education
- Daily Living Skills

The report also includes:-

- A daily record of activities undertaken.
- Recommendations and costs of external service providers (e.g. RNID, RNIB, DBA, Blind Centre for Northern Ireland, Sense and Deafblind UK) compared with internal provision from Social Services.

This report is then forwarded to the individual, the social worker and the chosen provider by the fourth week of the assessment. This skilled worker will continue to provide skilled follow-up support for another 4 weeks to ensure continuity before the new support arrangements are made.

**Stage 2:** A meeting or meetings where the evidence previously gathered is used to decide the level and type of support needed thereafter. At the meeting the following points are covered:-

- Is an assessment needed for any carer?
- Have any risks been identified?
- Sight - details. Does visual impairment restrict or cause difficulty in completing daily activities such as personal care, preparing food, getting around, reading and writing?

- Does the person agree to a visual impairment assessment?
- Hearing - details. Does the hearing impairment restrict any daily activities including the use of telephone, doorbell, alarms, TV, radio?
- Does the person agree to hearing impairment assessment?
- Effects of combined loss - does the combined loss result in difficulties with:-
  - Social interaction/isolation?
  - Mobility?
  - Communication?
  - Accessing leisure activities?
  - Accessing information?
  - Human contact?
  - Reading?
  - Keeping appointments?
  - Agree to Registration?
  - Communication needs/preferred formats?
  - Receptive communication?
  - Expressive communication
  - Current Support Services?
  - Other assessments required from?

**Stage 3:** This is completed jointly with the person's care manager/social worker when the need for one-to-one support has been established. This includes:-

- Medical conditions.
- People's view of needs/problems.
- Carer's view of needs/problems.
- Assessor's view of situation and recommendations/appropriateness of existing services.
- Line manager's comments/actions.
- A copy of the assessment goes to the people along with a comments, compliments and complaints booklet.

### ***Accessing and Promoting Services***

These activities are usually co-ordinated by the Team Leader. They involve social evenings where an educational topic or new information sharing is built into the event. These prove popular and are well attended. They are joint venture with the voluntary sector and transport

is provided. Drop in surgeries have also been established where sensory impaired people, their carers and families are given the opportunity to consult specialist staff on any aspect of the services provided.

### ***Capturing Data : Disability Database***

In 2001 the Republic of Ireland developed the Physical and Sensory Disability Database.<sup>20</sup> The overall objective was described as providing a picture of the specialised health and personal social service needs of people with a physical or sensory disability by monitoring current service provision and future service requirements over a five-year period. Individuals who currently received services and/or required services within a five-year period would be included on the database. The database would allow:-

- The planning of appropriate service developments.
- The prioritisation of service needs.
- Assistance in resource allocation decisions at national, regional and local level.
- The facilitation of research.

Initial information on the outcomes of the project is very positive with relevant up to date information easily accessible and is proving an asset in planning and development.

### **Sensory Impairment Services within the NHSSB**

The Board has outlined its vision for the future development of sensory impairment services in its latest Strategy entitled, 'New Directions: New Opportunities', 2002<sup>21</sup>. Widespread consultation has taken place in the form of audit, (1998 Review of Expenditure),<sup>22</sup> and surveys based on evidence from work undertaken by the Northern Health and Social Services Council, (2000)<sup>23</sup> and an access survey in 1998<sup>24</sup>. What is apparent from these findings is:-

- A general lack of awareness by staff of the needs of people with a disability/impairment.
- Need provision of staff training in using specialist equipment.
- Limited use of the equipment by people with a physical disability and/or sensory impairment.
- Difficulties for staff in retaining skills.

In 1999, the Northern Health and Social Services Board provided over £140,000 to ensure that all Health and Social Care facilities, where there was public access, had basic equipment to assist people with a visual or hearing impairment. The Board will continue to monitor Trusts to ensure that this specialist equipment is provided and that staff are appropriately trained.

The principle underlying the strategy was that of person centred care and support. Through this fact finding process a number of general issues were highlighted and if addressed would greatly improve the quality of life and independence of the person. These included:-

- Awareness amongst staff in Health and Social Services and the public regarding the needs of people with a physical disability and/or sensory impairment.
- Access to information at the point of diagnosis or immediately afterwards that needs to be understandable, in an appropriate format and in a sensitive way.
- Support in maintaining their general health and well being.
- Physical access to public facilities (particularly parking, signage and physical obstacles) and a lack of specialist and technical support.
- The need for greater interagency co-ordination, in particular, between housing, health, education and training and employment.

Some of these issues could be dealt with through current initiatives e.g. Northern Target by having disability awareness training as part of the pilot primary care programme. There is also scope for increasing the Disability Development Forum similar to the pilot project in Ballymoney.

Other areas relating to sensory impairment have been implemented e.g. Low Vision Clinics in Coleraine and Ballymena together with the Eye Help Desks, an initiative involving the Blind Centre for Northern Ireland. Training in deaf awareness for all staff in Causeway has also begun and is viewed as a positive step forward by the deaf community. The Board together with the other 3 Health and Social Services Boards is commissioning specialist psychiatric hospital services from the John Denmark Unit in Salford near Manchester. This Unit also provides an outpatient service every two months at clinics usually held in Belfast. Currently, no one from the Northern Board area is accessing this service.

The strategy also acknowledges that due to financial restraints the Board is only able to target available resources to carers where arrangements have reached crisis point and they are no longer able to cope. The Board is however currently funding an information and development worker through the Carers National Association to raise awareness and encourage the development of support groups for carers across its area. The Board proposes to evaluate this pilot exercise and consider how best future support in this area can be shaped.

The conclusion from the strategy is that there are gaps in service provision, some of which require changes that do not necessarily require additional resources but could have a big impact on the responsiveness and quality of the services available. There are also opportunities where minimal additional investment could have a positive impact in improving a person's quality of life, for example, in making information on services and activities more accessible. At the same time, gaps in essential services are evident, such as speech and language therapy and domiciliary support and these will require the provision of additional investment over the coming years if they are to be addressed.

## **Conclusion**

This review has attempted to outline the problem areas of service provision and development as well as examining the areas of best practice. These have been presented in such a way as to provide a blue print for service development and a sign-posting for the way forward in the future of sensory impairment services. What is clear is that the way in which services are delivered often do not facilitate the people and with more lateral thinking applied to location and access many of the issues can be resolved.

The skill mix and complement of teams is also another key feature in best practice as well as regular consultation especially in planning services.

## Introduction

The following section will amalgamate and explore the issues and discussions which formed the needs assessment process, and will look at the feedback from each of the four key groups as set out in the Methodology as follows:-

- People with Sensory Impairment(s).
- Carers for People with Sensory Impairment(s).
- NHSSB Staff in the Physical Disability and Sensory Impairment Care Teams.
- Additional Stakeholders.

## People with Sensory Impairments

This section of the report details the perceptions and experiences of people within the NHSSB area with a sensory impairment. They are the amalgamation of focus groups and individual interviews as detailed in the Methodology.

Fifteen people participated in focus groups. Nine people attended the focus group for people with a visual impairment. The secretary of the local blind club and the Blind Centre for Northern Ireland field worker also attended. The groups' age-band was from mid-30s to late 70s. Six people, aged from early 30s to late 40s, attended the focus group for people who are profoundly deaf which, was facilitated by 2 interpreters from RNID. Thirty people were interviewed on an individual basis using the questionnaire attached in the Appendices of this document. Where numerical data is provided, this is the quantitative analysis of these questionnaires. Qualitative feedback is the combination of opinions and experiences expressed both through interviews and focus group participation.

**Table 3: People Participating by Area<sup>Numbers</sup>**

	Antrim Ballymena	East Antrim	Causeway	Mid-Ulster	TOTAL
Profoundly/Registered Deaf	1	6	1	1	9
Hearing Impaired	2	3	2	5	12
Visually Impaired	4	5	4	11	24

**Demographic Data of Interviewees**

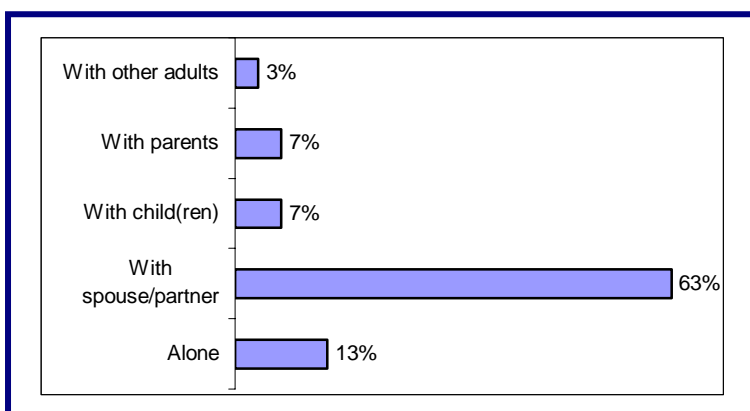
People were wide ranging in age – from 26 to 86 years of age, with over half (57%) aged over 60 years. Over half were female, and almost two-thirds married, as detailed in Table 4:-

**Table 4: Demographic Details of Interviewee’s**

Age:	% of Total	Gender	% of Total
Under 30	3%	Male	43%
31 – 40	13%	Female	57%
41 – 50	10%	Marital Status	% of Total*
51 – 60	17%	Married	63%
61 – 70	17%	Widowed	10%
71 +	40%	Single/Separated	20%

\*Where figures do not tally to 100%, this is due to missing responses

**Figure 1: Living Arrangements**



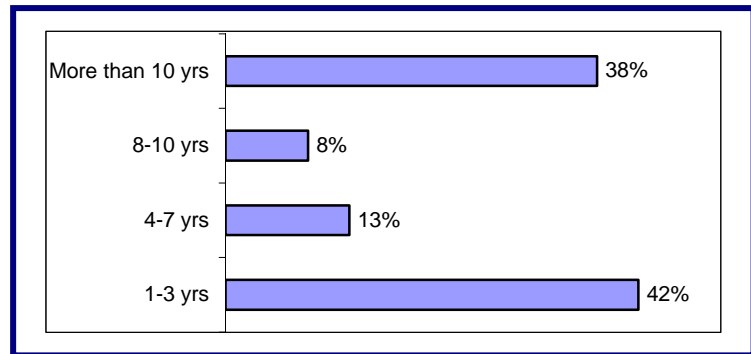
Just over 1 in 10 people with a sensory impairment lives alone; the remainder are living with their spouse or other family members.

Of those interviewed 13% are in current employment, with a further 3% on benefits and seeking work. Less than half are retired (47%), with almost 2 in 5 (37%) on permanent disability benefits.

<sup>Numbers</sup>: While 20 profoundly/registered deaf people were invited to attend focus groups only six attended. Eight people were offered individual interviews but only three attended for interview. (See Limitations of the Study)

**Figure 2: Length of Time with Acquired Impairment**

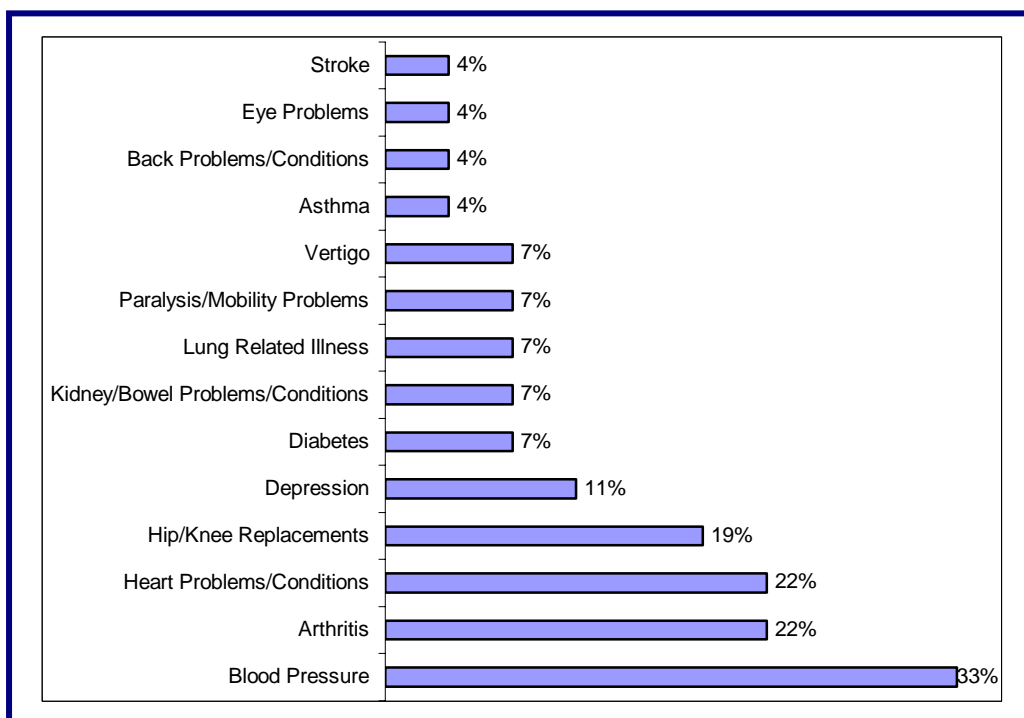
Over 4 in every 5 people interviewed acquired their sensory impairment (83%), the remainder having had their sensory impairment from birth. As illustrated (right), in 2 in 5 cases this impairment is relatively recent –



occurring within the last 3 years. Over half (54%) stated their impairment was a result of a medical condition – two-thirds of which were directly related to the impairment (e.g. macular degeneration, diabetes related blindness, perforated eardrums), the remainder indirect (problems at birth, pregnancy illnesses, cancer).

Three-quarters of those interviewed stated their condition was likely to deteriorate, many expecting total sensory loss within the coming years. Much treatment received was that of ‘damage limitation’ – protecting what sight/hearing was left.

**Figure 3: Additional Disabilities/Ongoing Health Problems**



Only 1 in 10 reported having no other ongoing health difficulties other than their sensory impairment. Of those that did refer to additional ailments, the most common was that of blood pressure (33%), followed by heart problems and arthritis (22%). Many people who were interviewed with additional ailments reported more than 1 health problem in addition to their sensory impairment.

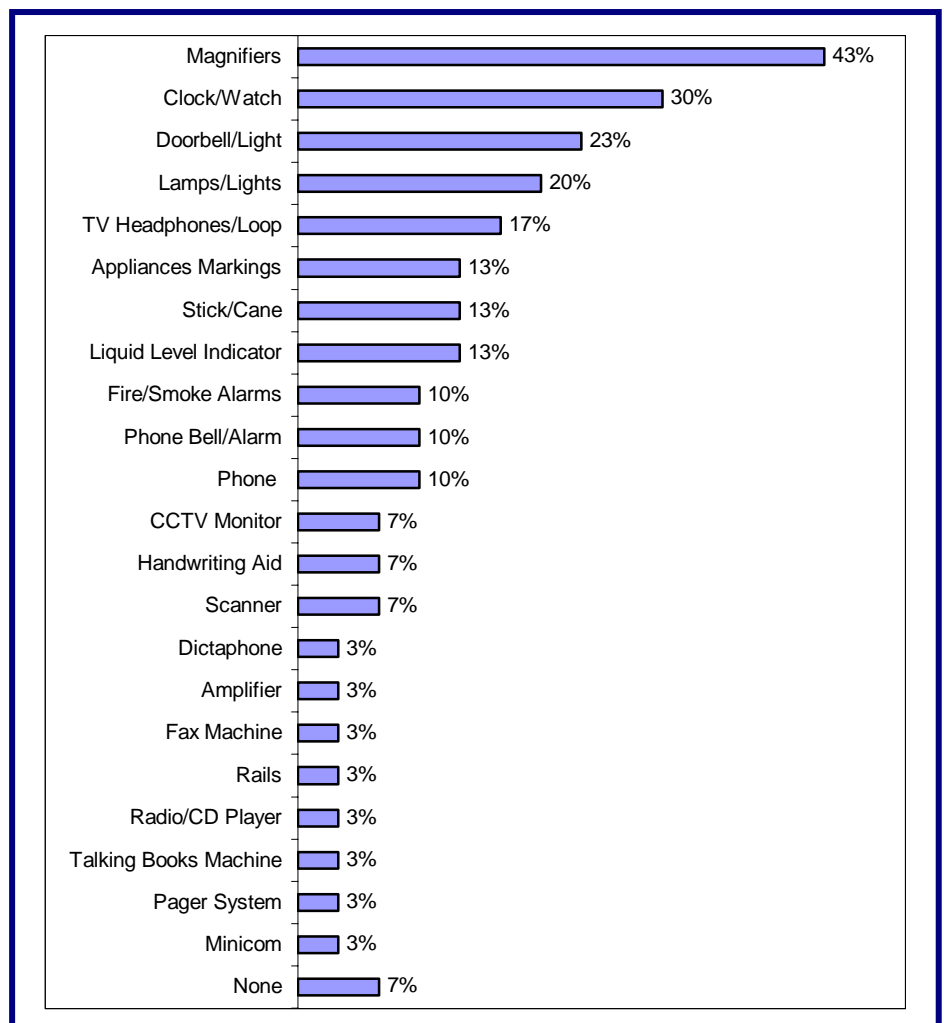
### ***Support for People with Sensory Impairment(s)***

Two-thirds of those interviewed reported needing home care – many describing increasing levels of dependency on family members. In half of cases where home care is needed, the primary source of care/support is the person’s spouse (52%), with over a third relying on other family members or friends. Only 1 in 10 of the people with sensory impairment interviewed received Home Help services, reporting a heavy reliance on family and friends to supplement this.

### ***Trust Support***

The Trust is generally identified as a provider of equipment/aids, with a wide-ranging and expansive list of various aids forwarded as illustrated. Services, however, are perceived as limited, with a third of people attending a low vision clinic or hard of hearing club (attended by Trust staff), and occasional staff visits from either a social worker or rehabilitation officer.

**Figure 4: Equipment Received From Trust**



There is much confusion across all those interviewed (individually and through focus groups) as to the role of Social Services, and social workers. In many cases, the people had limited understanding of the different roles of the staff i.e. they didn't understand the difference between the social worker and the rehabilitation officer. They believed they were all social workers. There is also a feeling of a lack of standardisation throughout the Board area in relation to provision of support services and equipment.

There is a heavy reliance on the voluntary sector for social interaction with others having a similar sensory impairment.

***"I'd got to the point where I wasn't going out the door until I joined the Hard of Hearing Club. It really brought me out of myself"***

Those attending hearing impaired clubs or the blind club commented that it was the only social outing they had where they could meet others and share their problems and concerns. It was a source of support and many felt the only real support they had outside of family. For those people with an acquired hearing impairment this support is of particular importance, as many reported a growing sense of isolation and increasing withdrawal from social interaction.

The people had all been visited by at least one member of Trust staff who supplied them with equipment. However, some felt that the equipment they had been provided with did not meet their needs and required review. The people who are profoundly deaf, in particular, expressed a high level of discontent with equipment provided, and there

***"They've put flashing lights in – I don't know if it's the phone or the door that's going and have to run all over the house to find out"***

was a general perception that people have to suit available equipment, rather than aids meeting individual needs. Some people were more informed about

available equipment than others. There was also a high level of confusion as to what people are entitled to, what they had to pay for and why some people had to pay for equipment and others didn't. Some people complained about having to purchase equipment themselves from limited personal finances due to unavailability or lengthy waiting lists. They felt they were not being kept up to date on the latest aids available, or basic entitlements.

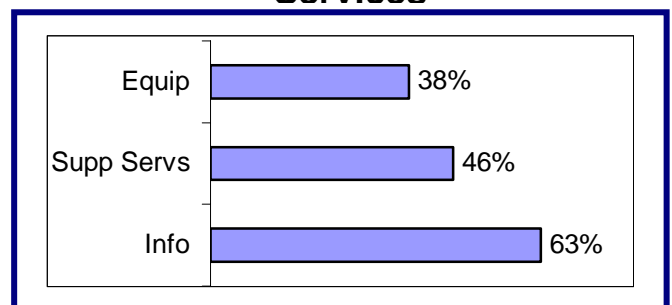
Those attending vision or hearing impaired clubs rely on these, as a vital source of information on what is available, having not received such information from members of staff in their Trust. They reported that equipment was not being reviewed and they felt this should be done on a regular basis – one person had not had equipment reviewed in 16 years. There were also issues raised regarding the quality of workmanship in installation of equipment, and prolonged periods of having no equipment due to time taken for repairs/replacements with no substitute in the interim period. Virtually all reported there had been no review of their circumstances by social services, despite deteriorating impairments.

***“They came in and put up lights and alarms, but left wires hanging out all over the place or only half finished the job. My house is a mess”***

### **Accessing HSST Supports**

The people interviewed reported lack of information as the most common difficulty that they experience in accessing support services from the Trust. Many felt they had no information as to available services, how to contact people where to go for help and support and how to get assistance with filling in forms. They felt there should be an available directory in appropriate format which gives details of all services, who to contact, contact details and how to access

**Figure 5: Difficulties in Accessing Services**



***“No-one tells you what you’re entitled to. If it wasn’t for the club I wouldn’t have half the aids I do now – I’d still be suffering in the dark”***

services. They would also like to know what the different staff roles are and what they provide.

People with a visual impairment in general reported no real difficulties in accessing local health services, their GPs surgeries were familiar to them and when they attended a hospital or other Trust setting they were always accompanied by a friend or relative as they were unsure if they could get around these buildings on their own. Many issues highlighted related to areas outside of the local Trust’s jurisdiction. Many people had difficulty with

***“I’ve had a lot of bad knocks with those bollards – they should put a yellow line or something on them for people like me. Shopkeepers putting shop signs and stock out on the street is a major problem for me”***

pavements, bollards, shop access, billboards and the lack of pedestrian crossings. Crossing the street for these people is a major ordeal and highlights the need for partnership working between the Trust, the Council, the Department of the Environment (DoE) and the voluntary sector so as these issues can be resolved. Some people highlighted that there were no real aids e.g. well-lit entrance, handrails on each side of the entrance, contrasting colours in the interior of the building, or tactile signage. It was also highlighted that not all prescriptions/labels were in large print or Braille, creating a reliance on external support in taking prescribed medication. Overall however, people felt staff at reception, GPs and other staff they encountered treated them very well.

People who are deaf or have a hearing impairment have the highest

***“I’ve been deaf all my life, and last week I had to take my nine-year old into hospital for an appointment – would you believe that’s the first time I’ve ever had an interpreter provided for me in my life?”***

level of difficulty in accessing Trust services. The lack of interpreters is a major problem for people who rely on Sign Language as their primary communication method, and find visits to GP’s, hospitals or

dealing with Trust staff across the board very frustrating. There were a number of incidences of having to wait up to a week for an interpreter to be arranged, only to have the interpreter cancel prior to the appointment. The lack of social workers trained in Sign Language is also a major problem for people who are deaf. One person reported having been assigned 4 different social workers in the last 3 years, none of who were able to communicate through Signing. Another stated their interaction with their social worker

consisted of an occasional text message to their mobile phone asking if everything was okay. It was felt by some people that social workers could come across as patronising in their attitude, which they attributed to lack of awareness on the staff’s behalf.

***“They have fire alarms in health centres and hospitals, but what happens if you’re deaf? Are we supposed to wait there until we see a fireman?! You could say to follow everyone else, but people are moving around us all the time – how are we supposed to know the difference? Or what if we’re in the toilet when the alarm goes off?”***

It was reported that social services have no textphone number for Out of Hours contact, and it is impossible to contact GPs Out of Hours in an emergency. There were also incidences of people attending A&E to be presented with an intercom to gain access with no other way of

communicating with staff/security. Also, whilst many reception areas have minicomms, it was reported that staff are unable to use the equipment, and there is a general lack of awareness among staff of the needs of people with a hearing impairment. Where Trust locations in the NHSSB area are generally perceived as physically accessible to people with a visual impairment, people with a hearing impairment – particularly those who are completely deaf – questioned what facilities there were in an emergency (fire alarms, for example), phones not being looped for use with a hearing aid, and television sets within hospitals or residential homes without teletext.

***“I was working but had to go off sick because of the harassment. I sit at home now and I’ve no-one I can talk to about how I’m feeling”  
(person who is profoundly deaf )***

Half of the people who were interviewed felt they had support needs that weren’t being addressed. There is a major gap in relation to mental health services – several people (both in interview and focus groups) pointed to feelings of isolation and loneliness. No-one was aware of the mental health service available for deaf people as highlighted in the literature. This may account for no one from the Northern Board using the service. They also described increasing withdrawal from outside social interaction, confirmed by their spouses who felt increasingly depended on for accompanying to appointments, etc. Transport is another area of concern, particularly for people in rural areas who require regular hospital treatment.

People were asked to identify their level of agreement to a series of statements designed to assess satisfaction levels around five key factors as highlighted below:-

**Table 5: Satisfaction Statements**

Area	Statement
Choice	The Trust gives me choice in terms of care
Consultation	The Trust consults with me and my family in the best options available
Information	I feel very well informed on what is available to me in health services
Independence	I feel that I am in control of my own care and treatment
Adequacy	The care I receive from the Trust is more than adequate for my needs

People were asked to rank these statements as to whether they totally agreed, agreed, disagreed or totally disagreed – ratings were then allocated on a scale of 1 to 4 against increasing satisfaction levels (i.e. rising levels of agreement). The results of this assessment are detailed as follows:-

**Table 6: Satisfaction Levels**

Area	
Choice	68%
Consultation	65%
Information	66%
Independence	59%
Adequacy	61%

The lowest level of satisfaction is in relation to independence – many people feeling that they are ‘at the

***“Once they give you a bit of equipment that’s it. I haven’t seen anyone from the Trust in years – my social worker texts me occasionally to see if I’m okay and that’s it”***

mercy’ of the Trust in relation

to what they are entitled to or receive. Also, many expressed the view that the supports they had in place were

adequate at that point in time, but questioned whether they would accommodate deterioration in their sensory impairment.

A third of the people praised the considerate and responsive nature of staff, and the advice staff provide in terms of equipment and aids. The issue is not one of staff as such, rather information and awareness on what the Trust has to offer. Follow up is an issue, with people emphasising the need for continuation of support, rather than addressing initial needs and ‘closing the book’. It was also stated on a number of occasions that other Boards treated people who are deaf better, however, the introduction of deaf awareness training for all staff in the Causeway area was highlighted as positive.

The issue of information, or lack of, was at the fore when people were asked to suggest ways in which the Trusts could improve their service to people with a sensory impairment, as was the provision of a counselling/advice service. Some people pointed to improvements based on perceived good practice in other Board areas. Suggestions for improvement are summarised as follows:-

- Information in the form of a directory in appropriate format.
- Counselling/advice service.
- Follow up/home visits and reviews on suitability of existing supports to changing needs.
- Improved and updated equipment provision and quicker contact/turnaround in dealing with people’s needs.
- Travel/transport for people with sensory impairment.
- Increased Home Help provision to increase independence.
- Staff training in awareness of sensory impairment.
- Recruitment of specialist social workers.

- Recruitment of deaf people within Trust areas to facilitate in supporting/visiting people who are deaf.
- Promotion of sensory impairment issues, and partnership working with other agencies.
- Improve communication methods for hearing impaired.
- Standardisation of services throughout the Board area.

## Carers of People with Sensory Impairments

As stated previously in this report, 100 questionnaires were sent out - 25 carers in each of the four geographical areas covered by physical disability and sensory impairment teams within the NHSSB (by which the term 'care' is used to mean **any** support, service or assistance provided to someone with a sensory impairment on a regular basis). Fifty-seven completed surveys were returned, the breakdown by area is detailed in Table 7.

**Table 7: Carer Responses Received by Area**

	Antrim Ballymena	East Antrim	Causeway	Mid-Ulster
<b>Number of Responses</b>	<b>14</b>	<b>15</b>	<b>16</b>	<b>12</b>
<i>Response Rate</i>	<i>56%</i>	<i>60%</i>	<i>64%</i>	<i>48%</i>

### ***Demographic Data***

Carers were wide ranging in age – from 30 to 87 years of age, with the average age of carer being 56 years old. Two in 5 people caring for a person with a sensory impairment are aged over 60, with the primary caring relationship being that of supporting/looking after a spouse (46%). Over two-thirds of those surveyed were female. This is shown in table 8.

**Table 8: Demographic Details of Carers**

<b>Age:</b>	<b>% of Total</b>	<b>Gender</b>	<b>% of Total</b>
Under 30	2%	Male	30%
31 - 40	14%	Female	68%
41 - 50	19%	<b>Marital Status</b>	<b>% of Total</b>
51 - 60	21%	Married	70%
61 - 70	25%	Widowed	14%
71 +	16%	Single/Separated	10%

A third of those carers surveyed work either on a full or part-time basis in addition to their caring role, with 2 in 5 (42%) retired from active employment, and 1 in 4 (25%) having no paid employment. The majority of those in employment are in a management or administrative role, with additional professions including teaching, nursing, retail and catering.

As stated previously, the majority of those surveyed, care for a spouse. This is highest in the Causeway and East Antrim areas. A third of those in East Antrim are parents of a person with a sensory impairment, whilst a sibling cares for almost a third of those in Antrim/Ballymena. Overall 60% of those with a sensory impairment are a spouse or child of the carer, 80% live with their carer. The highest degree of independence in relation to a person with a sensory impairment living alone is in Antrim/Ballymena (36%). Hearing impairment accounts for 40% of those with a sensory impairment with (24% registered deaf and 16% hard of hearing), with another 40% visually impaired (24% registered blind and 16% partially sighted). The remaining 20% were classified as having a dual sensory impairment. Causeway had the highest incidence of dual impairment (almost a third), whilst in Antrim/Ballymena hearing impairment was most prevalent as detailed in Table 9.

**Table 9: Prevalence of Sensory Impairment by Area**

<b>Nature of Impairment</b>	<b>Antrim Ballymena</b>	<b>East Antrim</b>	<b>Causeway</b>	<b>Mid-Ulster</b>
Hearing	43%	47%	31%	45%
Visual	29%	47%	44%	45%
Dual	29%	7%	31%	9%

In 3 in 4 cases, the impairment was acquired – only 25% having had a sensory impairment since birth. A third of carers stated the impairment was the result of a medical condition, the most common being diabetes, cerebral palsy and macular degeneration. Over two-thirds (70%) expect that the level of impairment will deteriorate.

The carers reported that less than 1 in 6 of the people they care for with a sensory impairment (16%) were stated as having no other disability or ongoing health problem, with the majority having a number of additional ailments likely to contribute to dependency. Those affecting at least 5% or more of all responses are listed in Table 10.

**Table 10: Additional Disabilities/Ongoing Health Complaints**

<b>Health Problem</b>	<b>% of Total</b>
Arthritis	25%
Heart Problems/Conditions	21%
Blood Pressure	13%
Diabetes	8%
Eye Problems	8%
Paralysis/Mobility Problems	8%
Back Problems/Conditions	6%
Kidney/Bowel Problems/Conditions	6%
Skin Problems/Conditions	6%
Stroke	6%

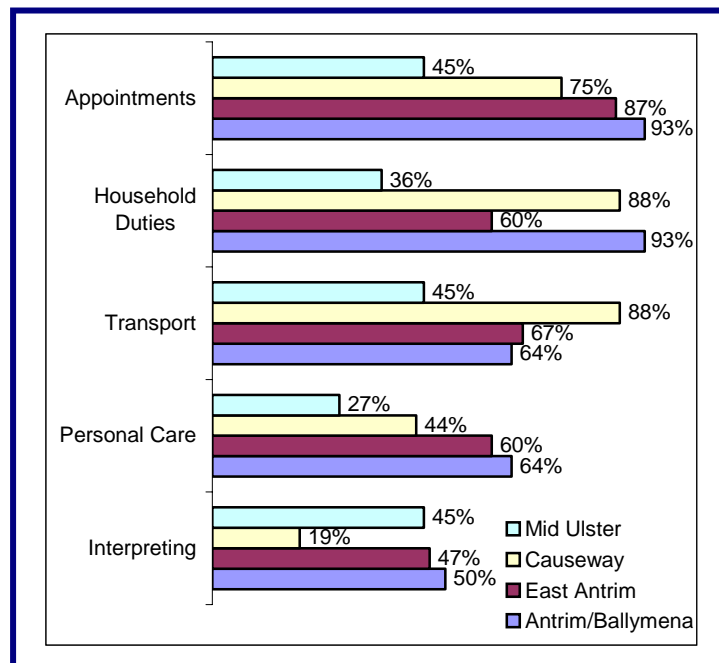
### ***Support for People with Sensory Impairment(s)***

The level of support provided by carers is significant, and reflects a high level of dependency on the carer by the person with sensory impairment. Over two-thirds require assistance in attending appointments, everyday household tasks, and transport. The lowest level of support based on responses given was found in Mid-Ulster, whilst almost all people in Antrim/Ballymena and Causeway have high support needs. Almost all those with a hearing problem need their carer to provide interpreting support, including all of those registered deaf.

Additional care supports included:-

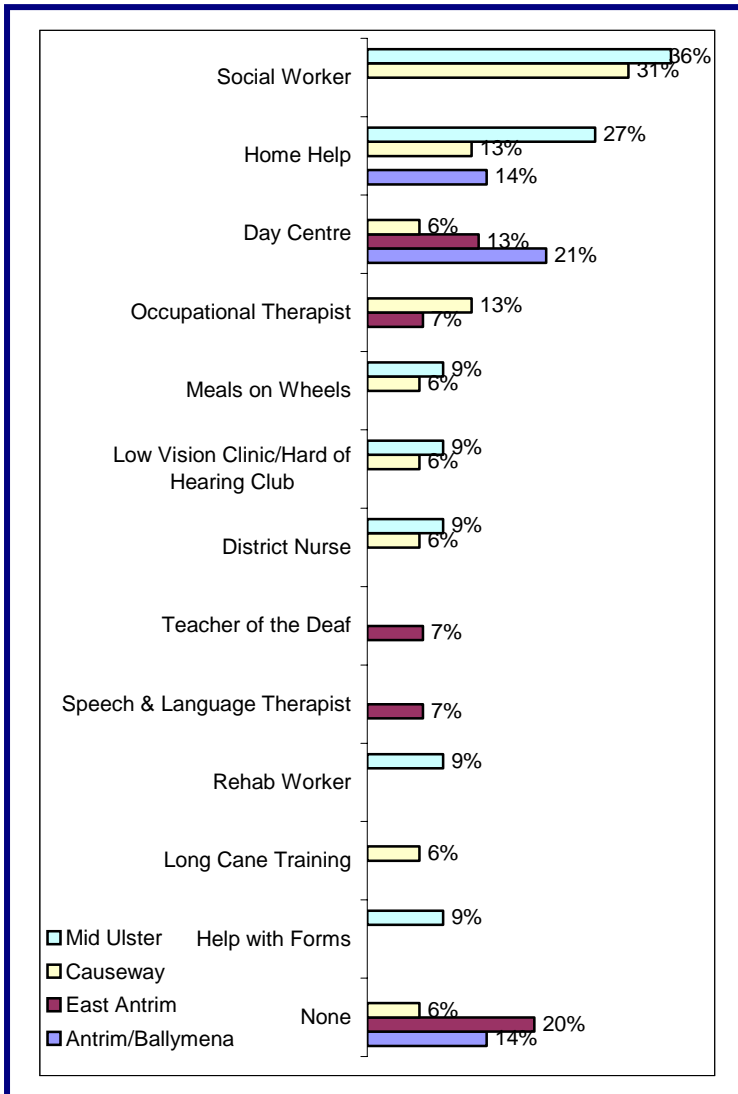
- Help with Shopping/Going to the Bank, Post Office, etc.
- Dealing with Letters and Correspondence.
- 24 hour care and supervision.
- Cooking/Meals.
- Medication.
- Childcare.
- DIY and gardening.

**Figure 6: Caring/Support Activities by Carer Provided by Area**



## Trust Support

**Figure 7: Client Support Services Received from Trust by Area**



Support services from Health and Social Services tend to be perceived largely in relation to contact with/from professional staff – social worker, district nurse, occupational therapist, etc. One in 10 carers feel the person they care for receives no support service from the Trust, as illustrated.

Voluntary organisations are generally perceived as providing more in terms of social supports – support groups, social outings, respite care/breaks, and Home Help in the form of befriending services (20% of all carers reported supports of these types being received from the voluntary sector). Another main source of support

service from the voluntary sector is in the form of talking books/newspapers (12%).

## Equipment

The Trust is generally identified as a provider of equipment/aids, with a wide-ranging and expansive list of various aids supplied. The voluntary sector has very little input here, providing support to 1 in 10 people and only in the areas of Causeway and Mid-Ulster.

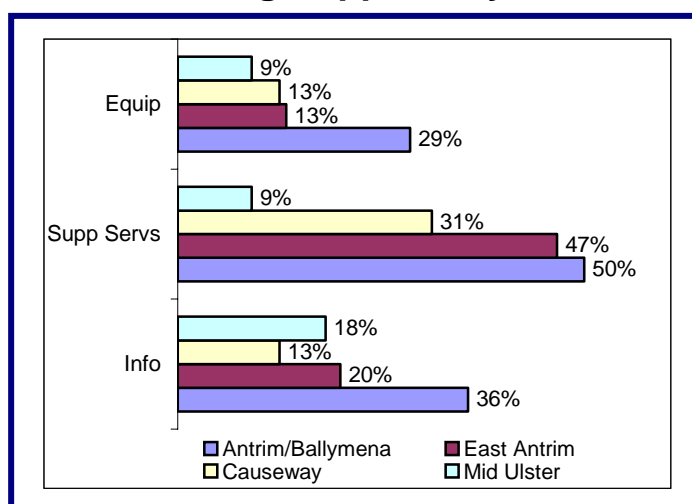
**Table 11: Equipment**

<b>Trust Equipment</b>		Phone	10%	Rails	3%
None	7%	Phone Bell/Alarm	10%	Talking Book Machine	3%
Magnifiers	43%	CCTV Monitor	7%	<b>Voluntary Equipment</b>	
Clock/Watch	30%	Handwriting Aid	7%	Phone Alarm	11%
Doorbell/Light	23%	Scanner	7%	<b>Provided by Self</b>	
Lamps/Lights	20%	Amplifier	3%	Visual Aids	11%
TV Headphones/Loop	17%	Dictaphone	3%	Phone	11%
Appliances Markings	13%	Fax Machine	3%	Doorbell	4%
Liquid Level Indicator	13%	Minicom	3%	Home Help	4%
Stick/Cane	13%	Pager System	3%	Stick/Cane	4%
Fire/Smoke Alarms	10%	Radio/CD Player	3%	TV	4%

### **Accessing HSST Supports**

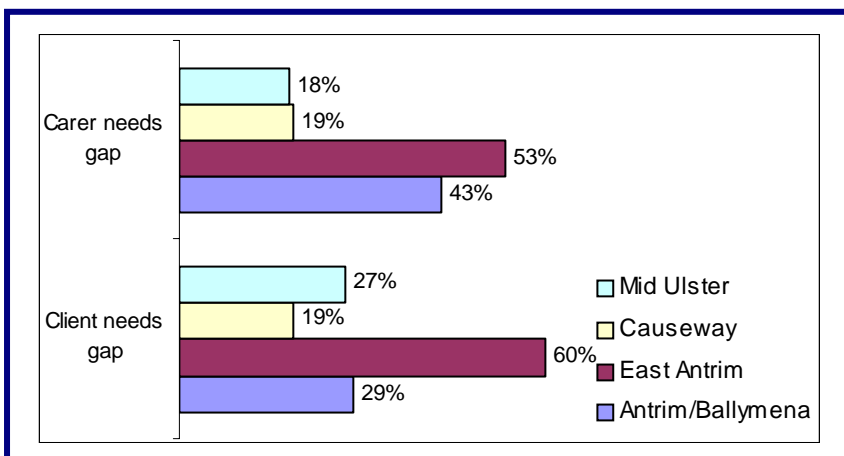
Whilst the majority of carers experience no difficulties in accessing supports from their local physical disability and sensory impairment team, 35% of all carers have had difficulties in accessing support services, with 21% finding difficulties in attaining equipment/aids, and 16% finding it difficult to get information.

**Figure 8: Difficulties in Accessing Supports by Area**



Information is the principal difficulty – in relation to what services and equipment are available to people, and what they are entitled to. The second most frequent criticism is that of contact - it can be very difficult for people/carers to get hold of staff, and visits to people are irregular and infrequent. Waiting lists for getting equipment was also quoted.

**Figure 9: Gaps in Addressing Needs by Area**



Overall, a third of people feel that they and the person they care for have support requirements that are not being addressed. This is felt most noticeably in the East Antrim and Ballymena areas as shown.

In relation to carers, those surveyed who feel dissatisfied primarily refer to the need for support/back-up on a personal level in their caring role, and the lack of information available. In relation to person with the sensory disability, the carers pointed out that there was little independence, few visits/contact

***“I don’t feel they [the Trust] are aware that we exist apart from the occasional input from the ETO”***

with Trust staff, difficulties in getting suitable equipment for their needs, and having to rely more and more on carers.

***“No social worker that has ever visited has ever had sign language”***

Carers were asked to identify their level of agreement to a series of statements designed to assess satisfaction levels around 5 key factors as highlighted:-

**Table 12: Satisfaction Statements**

Satisfaction Issue	Statement
Choice	“The Trust gives the person I care for choice in terms of care”
Consultation	“The Trust consults with the person I care for and me in the best options available”
Information	“I feel very well informed on what is available to the person I care for in health services”
Independence	“I feel that the person I care for is in control of their own care and treatment”
Adequacy	“The care received from the Trust is more than adequate for the needs of the person I care for”

Carers were asked to rank these statements as to whether they totally agreed, agreed, disagreed or totally disagreed – ratings were then allocated on a scale of 1 to 4 against increasing satisfaction levels (i.e. rising levels of agreement). The results of this assessment are detailed as follows:-

**Table 13: Satisfaction Levels**

Satisfaction Issue	Antrim/Ballymena	East Antrim	Causeway	Mid-Ulster	NHSSB
Choice	66%	65%	78%	80%	70%
Consultation	70%	62%	75%	80%	71%
Information	55%	54%	74%	78%	65%
Independence	58%	50%	75%	65%	63%
Adequacy	56%	58%	69%	65%	62%

Whilst there appears to be a general consensus that the Trusts provides choice in terms of care for sensory impairment, with a high level of satisfaction, there is less so in terms of information available and the level of independence/meeting of people needs. Consultation is high, but sufficiency of support delivery not so evident.

***“There are absolutely no facilities for deaf people in this area”***

***“Deaf people are very isolated”***

Over a quarter of carers praised the considerate and responsive nature of staff, and the advice staff provide in terms of equipment and aids. The issue is not one of staff as such, rather information and awareness on what the Trust has to offer. Follow up is an issue, with one in ten carers emphasising the need for continuation of support, rather than addressing initial needs and ‘closing the book’.

The issue of information, or lack of, was at the fore when carers were asked to suggest ways in which the Trusts could improve their service to people with a sensory impairment, as detailed below, as was the level of contact between Trusts and people with sensory impairment and their carers.

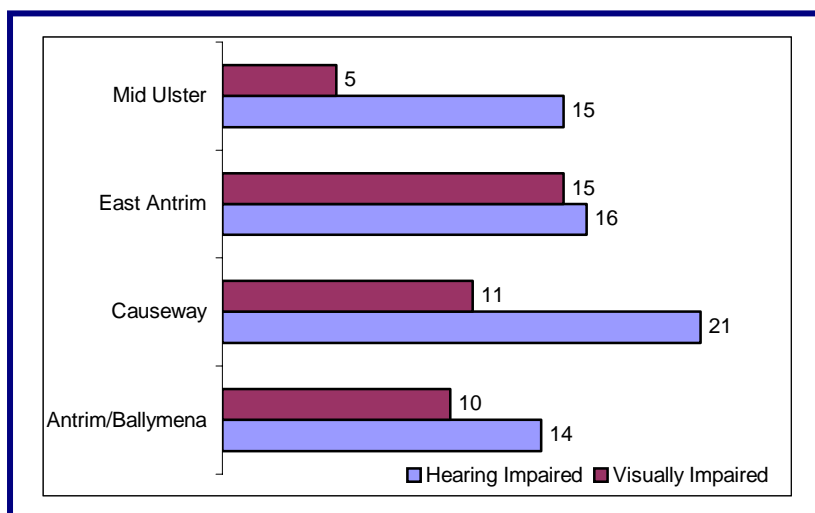
**Table 14: Suggested Improvements by Area**

Improvements	Antrim/ Ballymena	East Antrim	Causeway	Mid-Ulster	NHSSB
Better Information on Services	43%	33%	38%	9%	32%
More Time/Visits with People	43%	33%	6%	18%	25%
Social Support Groups/Networks	21%		13%	27%	14%
Practical Home Support	29%				7%
Better Training for Staff			13%	9%	5%
Respite Care	14%				4%
Quicker Response Times	14%				4%
More Staff		7%	6%		4%
Better Care Packages		7%			2%
Reduce Waiting Lists			6%		2%
Local Outreach			6%		2%

Within the Mid-Ulster area, carers advocated the need for social networking/support with others facing similar issues, as was the case in Antrim/Ballymena (where practical home support was also proposed). It was felt that better training for staff would be an improvement within the Causeway and Mid-Ulster areas, whilst suggestions specific to the East Antrim area focussed on the need for increased staffing levels and integrated care packages.

### Staff in the Sensory Impairment Programme of Care

**Figure 10: Average Monthly Referrals by Area**



Referral figures were provided by each of the 4 teams for the period 1 September 2002 through to the end of February 2004. From these figures, average monthly referrals were calculated as illustrated (left), to provide an indication as to the level of referral activity throughout the Board area.

Based on additional information provided by 2 teams, less than 2% of referrals are passed to social workers, with ETOs and rehabilitation officers the primary source of contact with new referrals.

Focussing specifically on the 2002/03 period, there were a total of 1,213 referrals to sensory impairment teams in the NHSSB area (745 hearing impaired and 468 visually impaired). Community Statistics for the period (as detailed in Section 1 of this report) documented a total of 554 people with a sensory impairment having had contact with the Physical Disability and Sensory Impairment Programme of Care (276 hearing impaired and 278 visually impaired).

**Table 15: Correlation of Referrals in Contact with Provider**

	Hearing Impaired	Visually Impaired	Total
Total Referrals based on HSST Data	745	468	1213
People having Contact with SI Teams based on Community Statistics	276	278	554
	37%	59%	46%

On the unlikely assumption that these people were solely new referrals, this would suggest a turnover rate of only 46% overall (37% for hearing impaired and 59% for visually impaired), implying a significant resource issue in providing services to sensory impaired people.

### Round Table Discussion

Staff within the 4 physical disability and sensory impairment teams were interviewed via round table discussion, the focus of which was to examine current processes and issues facing delivery of care and support services to people with a sensory impairment in the area. Key feedback is summarised in the areas of visually impaired, Hearing Impaired and general issues as follows:-

## Visual Impairment

- It can take up to 2 years from a GP referral until people seen by a Consultant Ophthalmologist, and during this time there is no contact with the Social Services team, with an additional current waiting list for one team of up to a year from referral to the team until the people are assessed.
- There are differences across hospitals and other services in information giving and not all will inform people about the Social Care team. There is also no clear system/structure for referrals. Not all visually impaired people are referred – low vision are not registered.
- The Eye Help Desk, which is a voluntary operated service that is one year in operation and is a valuable support to the Causeway team, in giving the person with the visual impairment timely and accurate information. The Eye Help Desk is now also available at Braid Valley Hospital.
- The most appropriate staff member based on information supplied on the referral undertakes the assessment. Referrals are mostly assessed for equipment and rehabilitation work i.e. lighting, magnification, mobility, communication, reading, banking and day to day activities, with requests for assistance with form filling.
- There is an issue with age limits – physical disability is served by the team up to the age of 65, with visual impairment there is no upper age limit. A lot of work is being done with children in the area, even though the teams are not resourced to provide services to children and their parents in relation to independent living skills. There is also a high level of referrals of over 65's.
- The average time spent with a person varies, rehabilitation work with the visually impaired can take up to 6 months with regular, persistent work required
- The social workers provide support and counselling and this can range from visits of 1 hour up to 3 hours. Also staff have quite a lot of travelling to do because of the rural geographical area, and transport is a significant issue for people

- Occasionally an Assessment Unit is operated within the Causeway area – this operates on a Friday and invites people/referrals to come into the centre for assessment. This is offered ad-hoc depending on staff and resources.
- One afternoon per week in the day centres in Larne, Carrickfergus, and Newtownabbey are dedicated to the visually impaired. The day centre staff, Blind Centre field worker and the rehabilitation worker are involved in these. They involve information sharing, teaching in use of aids, and the promotion of social interaction. Social activity groups, such as blind clubs or hard of hearing clubs, also provide a valuable forum for staff to carry out rehabilitation work and information giving. Venues and transport are provided by the Trust for all these clubs.
- Once equipment is in place and rehabilitation complete there is no mechanism in place for follow-up, plus it is difficult to undertake monitoring and review work due to the number of new referrals
- Recruitment of staff is a major issue. It is difficult to recruit rehabilitation workers, once these staff are in post there is no incentive to transfer to other areas as there is no career structure and professional recognition is needed. Role accountability regarding management and supervision areas are blurred. In Antrim/Ballymena the Rehabilitation Worker is provided through a partnership with Guide Dogs for the Blind Association. This was in part due to difficulties in recruiting a Rehabilitation Worker. In Mid-Ulster, the Blind Centre Field Worker, attached to the team left a number of months ago but has yet to be replaced

## **Hearing Impairment**

- The process for referral operates similar to that of visually impaired referrals come from audiology, carers and voluntary agencies, but it is the person's choice whether they want a social worker to call with them or not, and many often accept a hearing aid and leave it at that. Eighty percent of the people base would be classed as hard of hearing.
- There is a difficulty with referrals from audiology, insufficient information make ETOs work more time consuming. Also audiology clinics operate differently in terms of referrals, information on referrals etc. All referrals to ETOs are for equipment with the majority of people also seeking advice on Hearing Aids.

- Staff suggested that an ETO attending Audiology Clinics would be more beneficial in terms of improving the service to the people and a more effective and efficient use of staff resources.
- Majority of work is with partial hearing, and a high number of referrals are over the 65 years age bracket. Only 21 profoundly deaf people are known to the team in the Mid-Ulster area, with only 5 - 6 currently receiving ongoing support. The teams have also to deal with requests from the over 65 population in terms of basic support with form filling.
- There should be a facility for people to text into the office rather than having to fax or phone.
- Employment of a deaf support worker similar to that provided in other dedicated sensory impairment teams in other Boards would be beneficial.
- The ETO and social worker for the deaf in Antrim/Ballymena have BSL Level I; both are studying for BSL Level II. Two staff in Causeway are currently studying BSL Stage I. In East Antrim 1 ETO has BSL Level I and the other has BSL Level II. One social Worker has BSL Level I and the other is studying for BSL Level II. The team leader has BSL Level I. In Mid-Ulster the social worker has BSL Level II and the ETO has BSL Level I.
- The Trusts currently purchase a service from RNID for interpreters which have to be booked two weeks in advance. This service is currently under review by the NHSSB.
- The focus on hearing impaired is equipment oriented - “adapting the environment to meet needs and adjust to hearing loss”, with some counselling input. Staff felt there is an element of mental health difficulties in terms of isolation and depression and the mechanism for working with the mental health team in relation to these problems is unclear.
- There is a lot of co-working done within the team and also with staff from other teams. In Antrim/Ballymena the part-time staff are carrying caseloads of 30 people.
- Staff report that, because of the demands on their time with new referrals, paperwork, liaising with the voluntary sector and attending courses and training, they do not have time to review people or to read files. Long-term follow-up and review is not possible because of insufficient staff, and there is a need to increase the complement of ETOs to meet demand.

- As with visually impaired, social clubs provide a valuable method in contact with people. There is currently 1 hard of hearing club, and 1 tinnitus support group in the Magherafelt Area, and 2 hearing impaired clubs in East Antrim (for which venue and transport is provided by the Trust). There is a hard of hearing club in Ballymena and the social worker and ETO in Antrim/Ballymena facilitate the tinnitus club in the evenings. Staff would like time to develop more support services and to work more closely with the voluntary sector.
- Lack of awareness re available equipment and its use by staff in GP practices and nursing homes is causing under usage of supplied equipment. There is a need for ETOs to become proactive in awareness raising amongst other professionals and nursing home staff in available equipment and its use. However, it is not the remit of the ETO to provide awareness raising in GP Practices.

## **General Issues**

- The sensory impairment team covers all age bands and as such requests are made from other teams for specialist input.
- There is a need for dedicated social work staff who are properly trained in BSL and visual impairment to specialise in this work and develop the social work role.
- More staff training needed, skill mix and staff ratios of teams need to be addressed as a workforce planning exercise.
- Staff recruitment of rehabilitation workers can be difficult as there are few trained in this area.
- Need for staff to be more proactive rather than reactive.
- Some of the team leaders felt that there was not sufficient time to dedicate to sensory impairment. ETO and rehabilitation staff are left to get on with the work as team leaders and social workers are very busy dealing with physical disability and the pressure of the workload in that area.
- Staff believe that the designated team is the best option for developing expertise and delivering a more streamlined service. If a dedicated team is to be established then staff should be locality based with floating team leader.

- A lack of adequate clerical support is creating unnecessary tasks for the professional and technical staff to complete. Staff are typing their own reports, filing, answering phones, dealing with mail and correspondence. In Antrim/Ballymena there are no computers or access to email, internet or a fax machine within the department. This is a very unsatisfactory situation and is neither an effective or efficient use of professional staff time.
- Resources are stretched in terms of day care, staffing, and budgets for services and equipment.
- Home Helps for the over 65's is provided by the elderly care team and some staff perceived that this can be confusing for clients because they are dealing with different staff and perhaps different allocation criteria.
- In relation to equipment, there is no review of equipment as they don't have the staff, or provision to update equipment that people have. Some staff felt bulk purchasing of equipment would be more cost effective, and a central store base would also be helpful. Other staff however, felt that they can order equipment that addresses an individual's specific need when smaller stocks are maintained.
- Need to develop better information directories in appropriate formats.
- Consultation meetings with the voluntary sector need agreed agendas for discussion.
- There is a need for promotion of sensory impairment awareness with all other public sector agencies/services (Department of Social Security (DSS), Northern Ireland Housing Executive (NIHE), etc) – a lot of time is taken up with trying to sort out benefits, and publicising what the team actually does.

## **Key Stakeholder Interviews**

The following outlines the main findings from a series of interviews with key stakeholders. The interviews concentrated on extracting information on activity levels, unmet need, partnership working and recommendations for service delivery and improvement. Their views are reported under the sub-headings of visual impairment, hearing impairment and dual sensory impairment.

## Visual Impairment

### Strengths

- Provision of 2 low vision clinics
- Eye Help Desk in Ballymena and Coleraine positive step forward
- Blind Centre in Coleraine and specialist co-working in Homefirst day centres
- Blind clubs
- Blind Centre field workers attached to the teams
- Increased consultation with users'
- Better environmental improvements in Trust facilities

### Opportunities

- Develop better networking between teams
- Develop partnership working with other statutory groups
- Strengthen partnership working between the voluntary sector and the Trusts
- Develop dedicated specialist workers within teams
- Increase training opportunities for staff
- Increase the staff complements of teams
- Reduce waiting lists
- Increase multi-disciplinary working

### Weaknesses

- Lack of resources
- Long waiting lists
- Lack of dedicated specialised social workers
- Long waiting list for Ophthalmology
- Difficulty in recruiting rehabilitation workers
- Not enough promotional work being done
- Lack of transport
- Poor capturing of detailed reliable data

### Threats

- Lack of funding
- Staff burnout
- Failure to recruit, train and retain specialist staff
- Failure to develop upon the work already undertaken with the Voluntary Sector

## Hearing Impairment

### **Strengths**

- Consultation with the Voluntary Sector and services users'
- Causeway to initiate deaf awareness training for all staff
- Introduction of digital hearing aids
- Supply of sensors
- Supply of equipment to GP surgeries
- Co working of complex cases
- Support provided by sensory impairment teams to other teams
- Dedication of staff

### **Opportunities**

- Develop training programme for all staff in Deaf Awareness
- Develop dedicated team with trained staff and staff complement
- Independently audit GP surgeries in relation to service delivery, followed with dissemination of findings
- Inclusion of recommendations for improvements set with targets as part of contractual agreement for Primary Care Services with Board
- Strengthen partnership working between the voluntary sector and the Trusts
- Multi-disciplinary approach to delivery
- Developing multi-partnership services

### **Weaknesses**

- Lack of specialist staff
- Lack of co-ordination of services across the various departments
- Lack of staff with BSL Level I, II and III.
- Difficulty in recruiting suitable trained staff
- Need for input at planning stage of services with Voluntary Sector
- Despite consultation, little in the way of action
- Lengthy waiting list for services
- Out dated equipment
- Lack of appropriate skill mix in teams
- Service under resourced
- Managers have high staff numbers to manage and supervise
- Physical disability occupies the majority of social work hours
- Not the time or staff to promote service development and create innovation

### **Threats**

- Failure to secure funding for dedicated specialist teams
- Failure to take on board the findings of various consultations
- Failure to embrace partnership working

## Dual Sensory Impairment

### Strengths

- Disability Forum, which gave opportunity to highlight the major deficits in services for the sensory impaired
- Section 7 in UK and Wales Policy Guidelines
- Provision of equipment
- Co-working of cases with in the teams

### Opportunities

- Meaningful consultation with the deafblind community
- Training of more specialist staff
- Adopt the principles of Section 7
- Address the mental health needs of the sensory impaired
- Incorporate dual sensory impairment into planning of service development

### Weaknesses

- Lack of skilled staff to communicate and assess the needs of this group
- Voluntary sector unable to get access to people base by postal information
- No clear departmental direction on the implications of Section 7
- NHSSB not taking on board the efforts of the voluntary sector
- Not enough consultation with dual impairment advocacy services
- No assessment or treatment of people's mental health problems

### Threats

- Lack of commitment to address the needs
- Failure to work in partnership with voluntary sector
- Develop specialist training for staff in dedicated teams
- Failure to acknowledge the specialism of dual-sensory impairment

## Conclusions

From this needs analysis it is clear that the social work time is mainly dedicated to the physical disability area of the work due to the complexity of the cases, their acting as care managers and the high level of care packages, which require close monitoring and review. This is with the exception of Antrim/Ballymena who has dedicated social workers but with insufficient social work hours to meet the demand. When the social workers are specialising in the area, the work is time consuming and involves a lot of co-working and counselling. While the numbers are low in terms of referrals to social workers this does not adequately reflect the needs of people and their carers, in terms of support requirements such as counselling, personal support and advice.

Not all specialist staff in Homefirst and Causeway have BSL Level II or Level III and this is resulting in communication problems with people who are profoundly deaf. The volume of referrals to the ETOs and Rehabilitation workers is leading to long waiting lists for services and lack of follow-up, monitoring and review. Both of these disciplines are under resourced. Difficulty in recruiting these staff is also causing problems. The fieldworker for the blind employed through the 'Homecall' scheme and attached to the teams has been praised as a very positive development by both staff and people with visual impairment. This is facilitating befriending, practical support and advice and is a good practical approach to partnership working.

A service that is under resourced is a theme presenting throughout the needs analysis. This is in terms of staff, equipment, partnership development and practical care and support. Another particular area that has shown a consistent deficit throughout the analysis is that of information. There is a general lack of information right across the Board area and complaints that the information that is provided is usually lacking sufficient detail and not presented in the correct format.

Another area where, despite the number of awareness campaigns and consultations, the general consensus from this analysis is that there is major gaps in awareness within Health and Social Service departments. This is causing problems for the sensory impaired in terms of communicating with frontline staff, arranging appointments and attending appointments. The need to develop and create innovation in sensory impairment services was advocated through the needs analysis.

## Sensory Impairment Teams

1. There is clearly the need to look at the development of locality-based dedicated staff delivering sensory impairment services. The system and structures of dedicated teams may mean that the team leader will have split-sites. It is recommended that in Homefirst there should be 2 sensory impairment teams due to the geographical spread and nature of demand.
2. In Causeway the number of referrals would indicate a high demand for sensory impairment services but again referrals to social workers is low. However feedback from people with sensory impairment and their carers would indicate that social work services are needed and as such specialist social workers should be available to meet this need.
3. There should be a minimum requirement regarding the number of staff training to BSL Level II and Level III standard. A programme of training should be developed to ensure these standards are met. All new staff will also need to be trained to this level. A programme of ongoing training would increase the number of available staff who are BSL trained.
4. It is recommended that a deaf advocate/support worker be employed within each team to assist with communication difficulties and to ensure the people with sensory impairments have their needs reported to the professional staff.
5. There is a need to increase the numbers of ETOs and rehabilitation workers in order to reduce waiting time and to enable at least annual reviews of existing people with sensory impairment. There is the need for the development of a career structure with adequate training provided. The introduction of a sensory support worker who could undertake some of the training and support work should be considered.
6. This 'Homecall' service should be continued and developed with the Blind Centre. This service could also be extended to assist and facilitate carers' needs in terms of support and advice.

7. Additional resources must be made available to ensure an acceptable level of care and contact with existing people with sensory impairment and enable annual reviews of people who have deteriorating sensory impairments.
8. Support services should be resourced sufficiently to provide up to date equipment and home help support for people with a sensory impairment to enable independence and satisfactory quality of life.
9. Multi disciplinary working, and clarity in the inputs re older people (over 65) much be addressed. While the specialist input from the sensory impairment team is essential in older people's services, the assessment of need and allocation of resources in terms of home support needs to be understood by all staff and by the person with the sensory impairment and their carer.
10. The provision of clerical support to the teams needs to be addressed as a matter of urgency. There is also need to review office equipment in terms of computers, telephones, fax machines etc.

## **Information**

1. Information in terms of a 'directory of services' needs to be developed and made available in different formats. This should outline available services, the different staff roles, information on referral and assessment and an outline of other appropriate avenues of help and support. A clear signposting outline to facilitate easy access to a variety of services should be included. Better use of Trust and Board websites in giving information in available formats would be beneficial. All information must be jargon free.
2. There is a distinct need to inform clients and carers as to whom they are dealing with (ETO, social worker or rehabilitation officer) and what exactly that role entails.
3. Information should be made available to people with hearing impairment and their families regarding the interpreting service. There are differences in practice in accessing the service in different teams within the one Trust. Clear guidelines should be drawn up regarding accessing the service; monitoring and evaluation should be incorporated.

## **Awareness**

1. Promotion of awareness in sensory impairment is essential for all frontline staff, and access to services must be reviewed to enable appropriate communication channels for people with a sensory impairment.
2. As part of a proactive service there is a need for to further develop partnership working with other agencies, and creation of awareness of the needs of people with a sensory impairment. Sensory impairment team specialists should be involved in delivering sensory awareness training to schools and the voluntary sector with the aim of providing children and young people with a sense of what it means to be deaf or blind and promote an understanding of the issues faced by deaf and blind people.
3. As part of a Quality Assurance method of measuring the quality of services delivered, it is recommended that Consumer Panels be developed as a forum in which deficits in services can be highlighted, and action plans developed to tackle the problem areas.
4. An Audit of GP surgeries with independent assessment of the positive and negative aspect of service delivery is needed. This should be followed with a report of the findings to GPs, Local Health and Social Care Councils and Practice Managers. This could be part of the further development of the 'Getting There' initiative. Inclusion of recommendations for improvement set with targets should be part of the primary care services with the Board.
5. Creation/development of sensory impairment groups within areas, and transport for people with sensory impairment, would facilitate the development of local initiatives in creating awareness.

## **Development**

1. The development of a Sensory and Disability Database, similar to the one in use in the Republic of Ireland, would be an invaluable asset in capturing detailed information on sensory impaired people within the Board area and assist with planning. This is particularly important bearing in mind that there is a great discrepancy between the number of referrals recorded by the teams for the period 2002/2003 and of those recorded in the community statistics. It would appear that the teams are having much higher contact activity than that which is being recorded in the community statistics. More in-depth assessment of contact activities within teams would assist in workforce planning.

2. A dedicated team with a team leader who can focus on research and development of services would be beneficial. The specialist team could begin to co-ordinate the service delivery and explore mechanisms for developing easy access to multiple services and supports. These would preferably be located in one centre similar to the concept of the one stop shop. For example a major problem for people with hearing aids was obtaining batteries. These people have to go to audiology departments between certain hours during the working day, having to wait for lengthy periods just to obtain batteries. This would not reflect a user-friendly service.
3. It is proposed that a short life working group be set up to produce common sensory impairment service standards, to be completed for implementation.

# Limitations of the Study

## 8

This was a small-scale explorative and descriptive study with 45 and 57 clients and carers consulted respectively and 22 key stakeholders. The number of sensory impaired clients and level of service provision is different in each area, therefore it would be inappropriate to generalise the findings to other areas. However, it should be noted that the results of the study largely corroborate the results of other studies as demonstrated in the literature review. To that extent, it is appropriate to draw wider inferences from the study.

The fact that the timescale of the study was 6 weeks from commencement to completion did not allow time to increase participant numbers through rescheduling of interview appointments or focus groups. If the study were to be repeated, the timeframe would need to be much longer to allow for more qualitative individual interviews and more focus groups. While the focus groups were scheduled for mid-week morning and afternoon sessions in hindsight it would have been more appropriate to have scheduled these for evenings or weekends. It would also be important to factor in transport costs for those people attending for individual interview and focus groups, as this was problematic for some people.

In conclusion the results obtained were valuable in identifying the various characteristics of the sensory impaired in the NHSSB area. They were also useful in identifying client and carer perceptions of the services provided. Obtaining service users' opinions has to be seen as a powerful tool for change, one that will benefit client, carer, staff and the statutory organisations as a whole. The implementation of findings will ultimately demonstrate the integration of research and practice, and demonstrate that the services delivered are evidence based.

Overall, this study has provided findings, which should result in significant improvements in service provision, and in innovative practice. It should also provide an impetus for further research and development into partnership working in sensory impairment services.

## Appendix I

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QE5 Limited is a company which has been chosen by the Northern Health and Social Services Board to do a Needs Assessment of People With a Sensory Disability in the area. They have been asked to look at what services are available to you, how easily you can get services, how good the services are, and how **you** would improve what is there.

Eileen and Fiona at QE5 would like to talk to you about your experiences at an informal workshop on DATE in VENUE from 10 o'clock to midday.

Can you please sign the consent form attached to this letter if you would like to take part in the study, and return it to them by **Friday 20<sup>th</sup> February 2004**.

The Northern Health and Social Services Board covers Causeway Health and Social Services Trust, Homefirst Community Trust and United Hospital Trust.

# Consent Form




187 Killyclogher Road, On  
Co Tyrone BT79 7PN


Name: \_\_\_\_\_


Address: \_\_\_\_\_

\_\_\_\_\_

Telephone Number: \_\_\_\_\_

 028 8077 1212

 028 8077 1692

 info@qe5.co.uk

I have read the letter explaining the Needs Assessment and am happy for my details to be given to QE5 Ltd, and to take part in the Study.

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Please tick the box or boxes that apply to you:

I am partially sighted.....

I am registered blind.....

I have partial hearing.....

I am registered deaf.....  BSL  ISL

I have other disabilities \_\_\_\_\_

\_\_\_\_\_

## Appendix II

# Sensory Impairment Needs Assessment Client Questionnaire

### Demographic Information – About You

1. Age \_\_\_\_\_
2. Gender Male  Female
3. Marital Status Married  Single   
Widowed  Separated/Divorced
4. Do you live ... Alone   
With Spouse/Partner   
With Spouse/Partner and Children   
With Parents  With Other Adults
5. Are you ... Working full or part time   
On benefits and looking for work   
Permanently sick or disabled   
Temporarily sick or disabled   
Looking after home or family   
In training or education   
Retired   
b.If employed, what is your occupation?  
\_\_\_\_\_

### Information on your Sensory Impairment

6. Are you ... (tick all that apply)
- Hearing impaired
- Deaf
- Visually Impaired
- Blind
- b. Have you had this impairment(s)...
- From birth  Acquired
- If acquired, how long have you had your impairment?
- Since birth  5 to 10 years
- Less than 5 years  More than 10 years

**c. Is your impairment(s) likely to deteriorate?**

Yes  No

**d. Is your impairment due to a medical condition (eg Downs Syndrome, Macular Degeneration)?**

Yes  No

If Yes, what is the name of this condition?

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**7. Do you have any other disabilities/ongoing illnesses?**

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**8. Do you need home care?** Yes  No

a. If yes, do you need this care:

Full-time  Part-time

b. Who provides you with this care?

Spouse/Partner

Parent

Sibling

Other Relative

Other

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(Please specify)

**9. What services do you receive:**

<b>From the Trust</b>	<b>From Voluntary Agencies</b>

**10. What equipment do you receive (on loan/permanent):**

<b>From the Trust</b>	<b>From Voluntary Agencies</b>

**11. Have you had difficulties in obtaining any of the following from the Trust?**

**a. Information**      Yes            No     

**If Yes, please tell us about this**

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**b. Support Services**    Yes        No      
If Yes, please tell us about this

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**c. Equipment**    Yes        No      
If Yes, please tell us about this

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**12. Do you have support requirements that are not being addressed?**

Yes        No   

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**13. Have you ever been visited by any of the following:**

ETO     Social Worker     Rehabilitation Officer   
If yes, what areas did you discuss?

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**14. Please tell us how you feel about the following:**

	Totally Agree	Agree	Disagree	Totally Disagree
The Trust gives me choice in terms of care				
The Trust consults with me and my family in the best options available				
I feel very well informed on what is available to me in health services				
I feel that I am in control of my own care and treatment				
The care I receive from the Trust is more than adequate for my needs				

**15. What is the Trust best at in terms of meeting the needs of sensory impairment?**

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**16. What is the Trust not so good at in terms of meeting the needs of sensory impairment?**

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**17. How would you suggest improving current services?**

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**\*\*\* Thank you very much for your help \*\*\***

## Appendix III

### Sensory Impairment Needs Assessment Carer Questionnaire

Please note: We use the term 'care' to mean any support, service or assistance you may provide to someone with a sensory impairment

#### Demographic Information – About You

1. Age \_\_\_\_\_
2. Gender Male  Female
3. Marital Status Married  Single   
Widowed  Separated/Divorced
4. What is your relationship to the person you care for?  
Spouse/Partner   
Parent   
Sibling   
Other Relative   
Other \_\_\_\_\_  
(Please specify)
5. Are you in paid employment additional to this?  
Employed Full time  No other paid employment   
Employed Part time  Retired   
b.If employed, what is your occupation?  
\_\_\_\_\_
6. Does the person you care for with a sensory impairment live  
...  
Alone  With you   
With Spouse/Partner   
With Spouse/Partner and Children   
With Parents  With Other Adults

#### Information on Sensory Impairment – the person you care for

7. Is the person you care for ... (tick all that apply)  
Hearing impaired   
Deaf   
Visually Impaired   
Blind

**b. Is their impairment(s)...**

From birth  Acquired

**c. Is their impairment(s) likely to deteriorate?**

Yes  No

**d. Is their impairment due to a medical condition (eg Downs Syndrome, Macular Degeneration)?**

Yes  No

If Yes, what is the name of this condition?

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**8. Do they have any other disabilities/ongoing illnesses?**

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**9. What activities do you carry out as part of your caring role?**

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**Health & Social Services Support**

10. What services does the person you care for receive:

From the Trust	From Voluntary Agencies

11. What equipment does the person you care for receive (on loan/permanent):

From the Trust	From Voluntary Agencies

12. Have you or the person you care for had difficulties in obtaining any of the following from the Trust?

a. Information      Yes            No     

If Yes, please tell us about this

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**b. Support Services**    Yes        No      
**If Yes, please tell us about this**

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**c. Equipment**    Yes        No      
**If Yes, please tell us about this**

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**13. Does the person you care for have support requirements that are not being addressed?**

Yes        No   

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**14. Do you have support requirements that are not being addressed?**

Yes        No   

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**15. Please tell us how you feel about the following:**

	Totally Agree	Agree	Disagree	Totally Disagree
The Trust gives the person I care for choice in terms of care				
The Trust consults with the person I care for and me in the best options available				
I feel very well informed on what is available to the person I care for in health services				
I feel that the person I care for is in control of their own care and treatment				
The care received from the Trust is more than adequate for the needs of the person I care for				

**16. What is the Trust best at in terms of meeting the needs of sensory impairment?**

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**17. What is the Trust not so good at in terms of meeting the needs of sensory impairment?**

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**18. How would you suggest improving current services?**

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**\*\*\* Thank you very much for your help \*\*\***

## Appendix IV

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### **Key Stakeholders Consulted**

Mr Dean Houston, Blind Centre, Northern Ireland

Mrs Elizabeth Simpson, Physical and Sensory Disability Services, Homefirst Community Trust

Dr Denis Boyd, Family Practitioner Unit, Northern Health & Social Services Board

Mr Sam Valleley, Causeway Health & Social Services Trust

Ms Janet Purcell, Blind Centre, Coleraine.

Mr Michael Mulvaney, Project Worker, Blind Deaf Association

Mr Don Johnston, Physical & Sensory Disability Services, Causeway Health & Social Services Trust.

Ms Hazel Wilson, Project Worker, Deafblind Northern Ireland

## References

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- <sup>2</sup> Policy, Planning and Research Unit (PPRU) 1992 The Prevalence of Disability Among Adults in NI
- <sup>3</sup> DHSSP Community Statistics 2003
- <sup>4</sup> HMSO Disability Discrimination Act 1995 Stationery Office London
- <sup>5</sup> HMSO Carers Recognition and Services Act 1995 Stationery Office London
- <sup>6</sup> HMSO The Children (Northern Ireland) Order 1995 Stationery Office London
- <sup>7</sup> HMSO Direct Payments Act 1998 Stationery Office London
- <sup>8</sup> HMSO Northern Ireland Act 1998 Stationery Office London
- <sup>9</sup> HMSO Human Rights Act 1999 Stationery Office London
- <sup>10</sup> DHSS 1997 Health and wellbeing into the next millennium. Regional strategy for health and social wellbeing 1997-2002.
- <sup>11</sup> CCRU, 1998 New TSN: an agenda for Targeting Social Need and Social Exclusion in Northern Ireland,
- <sup>12</sup> DHSSNI 2002 Investing for Health
- <sup>13</sup> Social Service Inspectorate 2002 "From Dependence to Independence Agenda for Action: Inspection of Services for Young People (aged 16-25) with a Physical Disability and/or Sensory Impairment"
- <sup>14</sup> DHSSPS 1999, review of Services for People Aged 16-25 with a Visual Impairment
- <sup>15</sup> DHSS 2000 Section 7 Guidance of the Local Authority Social Services Act 1970
- <sup>16</sup> RNID 2004 "A Simple Cure: A Report into Deaf and Hard of Hearing People's Experiences of the NHS"
- <sup>17</sup> RNIB 2004 "Unseen, Neglect, Isolation and Household Poverty amongst Older People with Sight Loss"
- <sup>18</sup> SENSE 2001 'Standards of Services for Adults who are Deafblind or have a Dual Sensory Impairment'
- <sup>19</sup> SENSE 1991, Report on Dual & Multiple Sensory Handicapped People in Northern Ireland
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- <sup>21</sup> NHSSB 2002 New Directions: New Opportunities – A Strategy for promoting the Well-Being and Independence of People with a Physical Disability and/or Sensory Impairment
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- <sup>23</sup> NHSSC 2000 “ Breaking the Silence – A Study of the Needs and Experiences of those who are Deaf or Hard of Hearing in the Northern Area”.
- <sup>24</sup> NHSSB 1998 “ Getting There – A survey of Standards of Accessibility to Health and Social Care Facilities for People with a Sensory Impairment”.