Survey of Need of People with Dual Sensory Loss in Northern Ireland

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CONTENTS

Introduction

This report summarises the results of a survey of need of people with acquired dual sensory loss carried out in Northern Ireland in summer 2004. The objectives of the survey were:

1. to carry out research into living conditions of people in Northern Ireland with dual sensory impairment;
2. to examine services currently available in Northern Ireland for people with dual sensory impairment and establish any health and social needs they may have.

The role of ARK

ARK, the Northern Ireland Social and Political Archive is dedicated to making social and political information available to all. ARK runs a contemporary website (www.ark.ac.uk) holding a vast amount of information on a wide range of social and political topics. ARK also provides a number of services, including technical support for people who want to carry out analyses of large scale datasets, but do not have the resources or expertise to do this themselves.

Each year, the ARK Research Centre carries out a set amount of work for voluntary and community sector organisations that is free of charge. This will facilitate access to the most up-to-date social and political information by organisations, which are not in the position to pay for such work. The current project with Deafblind UK has been made possible with funding from the Office of the First Minister and Deputy First Minister (OFMDFM) in Northern Ireland and with the support of the Science Shop.

The Northern Ireland Region

Deafblind UK extended its services and support in 2001 to reach out to dual sensory impaired people living in Northern Ireland. To date, numbers are much lower than anticipated and for those who have become known to the organisation, very few services could be offered locally. With this in mind, Deafblind UK initiated a piece of research to identify gaps in services for dual sensory impaired people in Northern Ireland.

This report is also available on Deafblind UK's website at www.deafblind.org.uk.

Methodology

A survey questionnaire was developed and structured interviews were conducted in a purposive sample of people that were registered members of Deafbllind UK in Northern Ireland. All interviews were conducted by the Deafblind UK representative for Northern Ireland in the homes of the respondents.

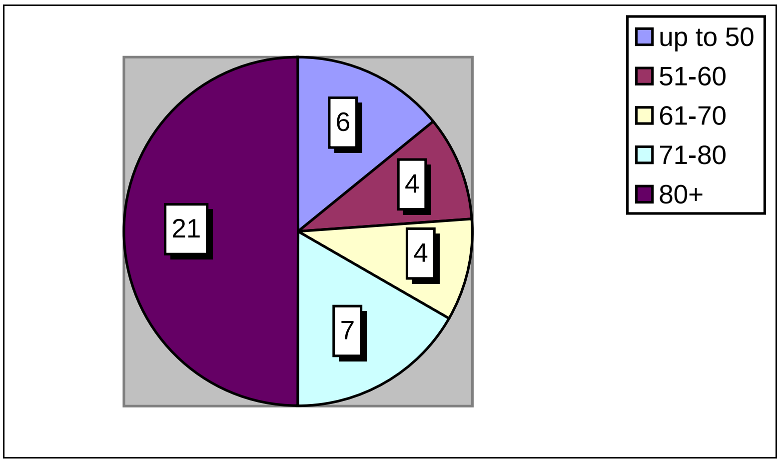
The data collected were analysed using SPSS and Microsoft Excel.

Results

Background and Communication

In total 42 respondents completed the survey. This represents around 70% of all known people with dual sensory loss in Northern Ireland. As Figure 1 shows, three quarters of those taking part in the survey were aged over 60 years, and half of all respondents were over 80 years of age. The average age of respondents was 74 years.

Figure 1: Age group of respondents



Over two thirds of all respondents (69%) were female. The majority of respondents (83%, n=35) were living in private homes, just under half of whom (n=13) lived with their partner, spouse or a relative in a private house. The remaining 17% lived either in nursing homes or in sheltered accommodation.

95% of all respondents were registered blind with the remaining respondents being registered partially sighted. One fifth of respondents (19%) said that their hearing loss was profound, 69% said it was severe and 12% described their hearing loss as moderate. 88% of all respondents used a hearing aid. In terms of their visual impairment, 57% of all respondents used some form of visual aid to access written information. Audiotapes were the most commonly used aid (52%), followed by large or extra-large print (29% each). One third of all respondents (33%) said they did not read at all. Male respondents were much more likely than females to say that they did not read at all (46% compared to 28%). Respondents over 70 years of age were also much more likely than younger respondents not to read at all (43% compared to 14%).

Most respondents communicated through their voice (93%). Only two respondents said they did not use their voice to communicate. A small number also used other forms of communication, such as lip read (12%, n=5), sign language or the deaf-blind manual alphabet (2 respondents each) or ‘hands on’ (1 respondent).

Most respondents used some form of special piece of equipment to assist them with their communication. In most cases these were provided by the NHS or Social Services. Most commonly used were low vision magnifiers (60%), followed by portable loop systems and wireless for the blind (36% each). Respondents rarely bought their own pieces of specialist equipment, as Table 1 illustrates. Among the other pieces of equipment, listed under the 'something else' category, a big button telephone and a loud ringing door bell were by far the most commonly used pieces of equipment (60% and 26% of respondents), followed by care line systems and an intercom for the entrance door. Most 'other' pieces of equipment were purchased privately by the respondents.

Table 1: Respondents using specialist pieces of equipment to assist them with communicating or accessing information. Source of this equipment*

	Users		Equipment provided by ...*			
	%	n	Social Services	NHS	A charity	Bought privately
Low vision magnifiers(s)	60	25	1	22	-	2
Portable loop systems	36	15	14	-	-	1
Wireless for the blind	36	15	5	-	9	1
Digital hearing aids	29	12	-	10	-	1
CCTV or Easi Reader Scanner	5	2	2	-	-	-
Something else	86	36	18%	1%	-	80%

*** Total numbers are given here because of low cell count, except for 'something else' category.**

Other Health Issues

Over three quarters of respondents (79%) said that they also suffered from another health problem or disability aside from loss of hearing and sight. There was a wide range of health problems mentioned, with the three most common problems mentioned being arthritis (18%), depression (14%) and heart conditions (8%). Whilst arthritis and heart conditions may be linked to the old age of most respondents, the findings from the survey would indicate that the high level of depression among respondents could be directly linked to their dual sensory loss and its consequences, such as loneliness, high dependency on other people and an almost complete exclusion from social life. The following comments from respondents are representative for this:

> **'I would like a volunteer to take me for a wee walk to help give me confidence and help me not feel so depressed.'**
>
> **'I would wish for my hearing back. If I could only hear, life would be so much easier. It is such a long day. I have lots of bad days and some good days.'**
>
> **'So used to just staying on my own. If I go anywhere I can't see a thing. I can't hear others talking. Very little I can do.'**
>
> **'As regards activities, if I go anywhere, I can't hear or see so what is the point?'**
>
> **'I am not content at all. If only I could read. I loved it and miss it badly. I wish I could just sit here all day and read. The staff here organise trips and activities but I do not go. What is the point as I can't hear anything people say or see things.'**
>
> **'I personally feel I do not want to go anywhere, even to dinner on Sundays with my family. I can't hear or see. I get embarrassed. I have a garden and I just potter about it. I really miss reading. I loved it. I feel I am passed my 'sell by date' or waiting in the 'departure lounge!'**

> **‘Get depressed with my own poor health and disabilities. My young married daughter died suddenly and I find it hard to come to terms with that.’**

Apart from hearing and visual aids, around three quarters of respondents also used other mobility aids, the most commonly used aids were walking sticks (35% of all respondents), Zimmer frames (12%) and red-white canes (8%).

Because of their poor health most respondents attended a GP or their health centre on a regular basis. Whereas one third of respondents said they had not visited their GP or a health centre in the past 12 months, 45% had seen their GP between one and six times, and over one fifth (21%) had attended their GP or health centre more often than this. Over one third of respondents (38%) had also been visited by their GP in their own house in the past 12 months. For example, over half of those (8 out of 14) respondents who said they did not visit their GP in the past 12 months received home visits from their GP, presumably because they were either too sick or too immobile to visit their GP themselves. Among those who did attend their GP or a health centre, 87% of all respondents reported that they had experienced difficulties. The most important ones were:

- the need to always bring someone with them if they wanted to attend a surgery or visit a doctor;
- the anxiety that they cannot communicate with the medical staff;
- the embarrassment of not being able to communicate with other patients.

One respondent reported for example:

> **‘I find it quite embarrassing going into a waiting room and not being able to communicate with people I know, but do not recognise because of my poor vision. When they are near enough for me to recognise them it is difficult to communicate because of poor hearing especially where there is background noise, e.g. others talking.’**

Others said that they felt anxious to miss their turn because they could not hear when their name was called or could not see when their name appeared on the screen. Any change in the organisation or the clinic routine was felt to be particularly stressful by the respondents. Simple changes such as the GP not practising in his or her usual room would mean difficult adjustments for people with dual sensory loss. The need to rely on a family member, a neighbour or a social worker for transportation to and from the clinic and for the exchange of information with regard to medical treatment made a number of respondents feel uncomfortable.

Of all respondents, 17% said that they had avoided visiting their GP because of communication difficulties. Again, this figure was much higher among those who had not attended the GP in the past 12 months themselves (36%, 5 out of 14 respondents). Only one quarter of respondents (27%) attended the GP or the health centre on their own. Most relied on support, in most cases (55%) provided by a member of their immediate family (spouse, partner, son, daughter or other relative). Only 13% of respondents were accompanied by someone else.

Nearly nine out of ten respondents (88%) had also attended the Outpatients’ Department in a hospital at least once over the past 12 months and 17% had done so between 7 and 12 times. One out of three (33%) respondents had stayed in the hospital in the past year. Over three quarters of respondents reported that they experienced difficulties when they attended the Outpatients’ Department, and nearly two third (64%) said they experienced difficulties when they stayed in hospital. As with visits at GP’s practices and surgeries, the main problems were related to:

- a lack of independence when attending an Outpatients' Department or staying in hospital;
- the need to be accompanied by someone else all the time;
- any unfamiliarity in the environment;
- the difficulties in communication with medical staff.

Furthermore, hospitals were seen by respondents as an even less familiar environment, which made it particularly hard to adjust.

One respondent said that the hospital staff did not know about the dual sensory loss and therefore lacked the appropriate knowledge and sensitivity to deal with the respondent's needs. Another respondent who reported similar difficulties said that half of the time she did not know what was wrong with her.

Social Life and Interaction

Because of their often quite poor general health and their old age, the social life of people with dual sensory loss and their interaction with others were relatively limited. Among respondents, 79% said they stayed at home every day. Two respondents said they were in full time employment and one respondent worked part time. Eight respondents (19%) attended day centres and four (10%) volunteered.

Only two (5%) of respondents were completely housebound and said they never left their house. 43% of respondents said they left their house every day or nearly every day. At the same time, many respondents were dependent on others to help them leave their house - over half (55%) said they never left their house alone. One quarter (26%) of people with dual sensory loss said they left their house every day or nearly every day on their own.

Almost half of all respondents (48%) were not involved in any leisure time activities. Among those who did attend social events, most attended special clubs for deaf or blind people (32%) or church activities (22%). A small number of those taking part in the survey went for walks, went swimming, worked as volunteers or took part in art classes.

One third (14%) of respondents said that they would like to take part in social events and activities, but that these were not organised nearby. Over half of the activities mentioned (12 out of 22 activities) were related to physical exercise and recreation. Most popular was swimming and walking. Three respondents would have liked the opportunity to learn IT skills nearby. Interestingly, the proportion of those who wanted more activities organised nearby was much higher among those who did already take part in activities among those who were more likely to go out, as Table 2 shows.

Table 2: Respondents who said they would like to take part in activities if they were organised nearby (in %)*

	%
Those who stay home every day	24 (8)
Those who *don't* stay home every day	66 (6)
Those who go out	
… every day or nearly every day	39 (7)
… once or twice per week or less	29 (7)
Those who go out alone	
… every day or nearly every day	36 (4)
… once or twice per week or less	32 (10)
Those already involved in activities	50 (11)
Those *not* involved in activities	15 (3)

*** Due to the low number of responses, total cell counts are given in brackets.**

Table 3 summarises to what extent people with dual sensory loss use services provided in the community and to what extent they said they would use them if they were available. A club for people who are dual sensory impaired was the service that a majority of respondents would have liked to use. Yet, such club was not available for any of the respondents. The most commonly available service available to respondents was a volunteer. Over three quarters (85%) of those who had a volunteer available did also make use of this service. Over half of those who did not have a volunteer available said they would take advantage of this service if it were available.

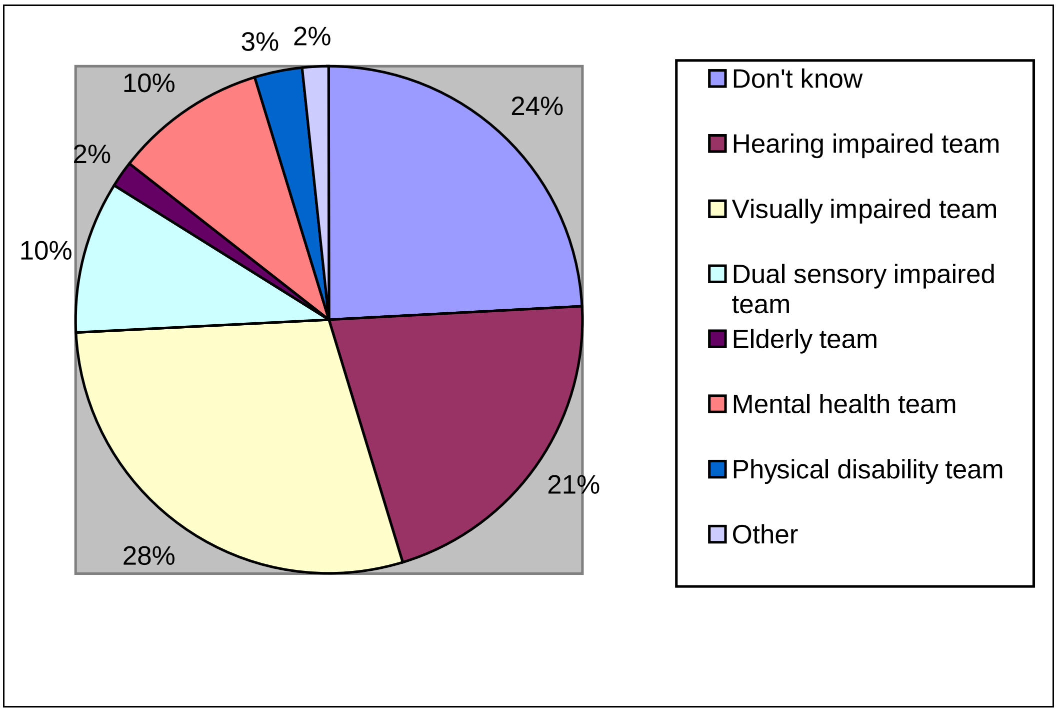
Table 3: Services in the community: available to respondents, used by respondents, used by respondents if available (total numbers)

	Available to respondents	**Used by respondents**	**Would use *if* available**
A club for dual sensory impaired people	0	0	25
Volunteers	7	6	18
One to one support from Communicator Guides	2	2	14
Respite for respondent and/or carers	2	1	15
Any other services	7	1	3

In many cases, immediate family members act as carers for people with poor health and for older people. The next section shows that this is also the case for the respondents of this survey, who were in most cases both pensioners and in need of almost complete care. Whether they are carers or not, the support of immediate family members can be regarded as crucial for people with dual sensory loss. The survey results show that nearly three quarters of respondents (74%) regarded their families as very supportive. A further 15% said that their family was supportive. Only 10% felt that their families were neither supportive nor unsupportive. Crucially, no respondent at all said that their family was unsupportive.

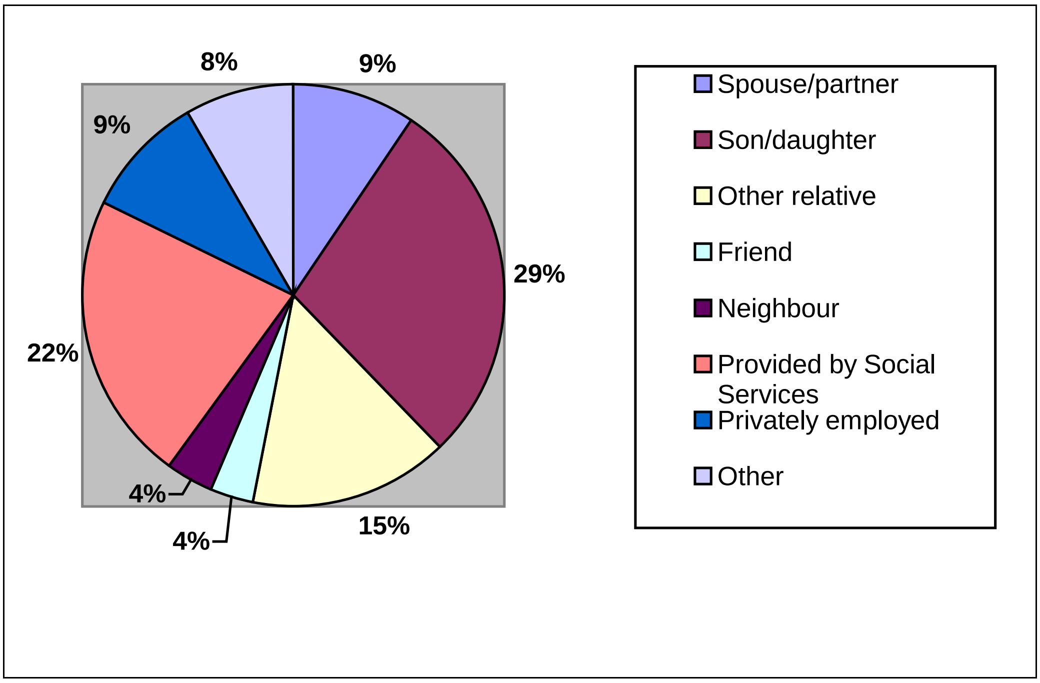
Because of their old age and their disabilities and health problems, the large majority of people with dual sensory loss have a social worker and had had an assessment of need carried out (93% each). As Figure 2 shows, there is no consistency in the organisational background of social workers. While, only 10% of social workers came from dual sensory impaired teams, nearly half (49%) came from either visually impaired or hearing impaired teams. The team affiliation of almost one quarter of the social workers is unknown to respondents.

Figure 2: Organisational Background of Social Workers Responsible for People with Dual Sensory Loss



95% of respondents had carers. Figure 4 shows that over half of the carers (57%) for people with dual sensory loss were family members. Less than one quarter of carers were provided by Social Services, and 9% were privately employed by the respondents themselves.

Figure 4: Relationship of People with Dual Sensory Loss and Their Carers (in %)



Carers provided support in a range of day-to-day activities:

- 97% of respondents received practical care support (e.g. cooking, cleaning, shopping);
- 72% of respondents were supported in their day-to-day communication, ie. by making phone calls and writing letters;
- 68% of respondents received support in relation to transport;
- 63% of respondents received advice and information from their carers;
- 38% of respondents received personal care support, such as personal hygiene;
- and 74% of respondents said they received care and support, for example in gardening, DIY, the collection of benefits, holidays and when going out for walks or exercises.

Policy Implications

It is difficult at this point to suggest comprehensively how the situation of people with dual sensory loss could be improved. However, a number of key issues have been highlighted through the survey, which should be addressed in relation to the service provision for people with dual sensory loss. The first policy implication is:

Regardless of their age, people with dual sensory loss experience a very high degree of dependence on other people and are particularly sensitive to any changes in their environment.

The survey showed that this dependence was even more manifested through the high age of most respondents and through a low mobility, which was diminished through further health problems or disabilities. Although the sample size of this survey was very small, it was noticeable how many respondents (14%) said they suffered from depression. A larger sample would allow an investigation of a possible link between the high degree of dependence and the reported depression, but some comments indicated that respondents felt excluded and lonely due to their dual sensory loss:

> **‘The way I am now - not seeing, not hearing well in company - what can I ask for? Everything is very limited and very difficult. I would really like someone to come and read a book to me in person.’**
>
> **‘Trying to cope with the loss of my wife a few years ago. Very difficult at times. I want to stay in my own home. Want to be independent but have to call on my daughter for so much.’**
>
> **‘I have no family left. I would love someone to take me out in the bus if I wanted some messages or a wee trip out from the house.’**
>
> **‘My mother has looked after me totally whilst trying to allow me to go out to deaf clubs etc without her. I get very anxious when she is ill for fear something happens to her. What would happen to me if I did not have?’**
>
> **‘I want to be as independent as possible but always have to call on my son or daughter to take me or get me things. I would rather have someone else I could call upon. Not fair on my family as they have family and jobs of their own.’**
>
> **‘Without the support and care provided by my family I would be very isolated and unable to go out and enjoy outings and family visits etc.’**
>
> **‘More people should know about deaf-blindness. My daughter had to sell her home and move her family to look after me and my son with Down Syndrome. She works full time and it is all very stressful.’**

Other respondents, however, expressed their satisfaction with the support they received and said that they were content with their lives:

> **‘I have no regrets. I have had a great life but feel I am here too long but I have to wait until I am called. Everyone has been so good and kind to me.’**
>
> **‘Content enough at 93 to be supported by my family. Used to be involved in other things like bowling but too old now and physically can't.’**
>
> **‘At 96 I am pleased to have my family and carers support and look after me. There is very little that I am able to do what with old age and deaf-blindness.’**
>
> **‘I feel that I have a very active busy life. Things are not always easy. I have full support from my wife I am fully employed at present and we like a holiday away just ourselves. We also are fully involved with local deaf club. Activities and holidays are organised through the club also.’**

The second policy implication that the survey has highlighted is:

There is a lack of awareness of the needs of people with dual sensory loss among the general public, but also within the medical profession and among public service providers.

Many respondents commented that they felt that there was a lack of awareness of their special and very particular needs. This also applied to hospitals and surgeries. The survey showed that social workers assigned to people with dual sensory loss came from a variety of teams. It could be suggested that the coordination between the different teams of social workers, possibly even the arrangement of specific training, would enable a better exchange and a greater awareness of the special needs of people with dual sensory loss. The following comments from respondents would support this recommendation.

> **‘More public awareness of deaf-blindness. More training for public services staff, e.g. banks, shops, hospitals etc. More government funding for services and support for DSI [dual sensory impaired] people here in Northern Ireland. More activities and clubs for DSI.’**

> **'I wish there was more awareness of deaf-blindness. Not a lot of people know about it.'**

The third policy implication highlighted by the survey is:

Access to public spaces is particularly difficult for people with dual sensory loss. This has adverse affects on the already limited independence that people with dual sensory loss have.

Although many respondents indicated that they received help and support for every-day activities, there were also comments highlighting that the independence of people with dual sensory loss could be improved by means of improved disability access in public spaces, as the following examples show:

> **'Wish that in my area in and around the town, white lines would be painted on the edge of steps. This would make it so much easier and safer for me to get around. Have these lines already at my local bus station and it is great!'**
>
> **'Definitions on the kerbs or roads would make things easier. Glass doors are literally a big headache! Pricing in shops and size of labels. Awareness of staff.'**
>
> **'Afraid of steps. No demarcation and have to guided everywhere.'**
>
> **'Gadgetry available would need to be reviewed especially as much improved equipment is becoming available as a result of technological advances, e.g. electronic pocket readers might take the place of ordinary magnifiers, digital hearing aids will be improved upon in time and a dual sensory impaired person should be given some priority if any relevant products become available.'**
>
> **'More specialist equipment in public places to assist communication and access. I have really valued the support from my communicator /guide at hospital appointments. Very essential and should be made available to other DSI people.'**

Finally, the results showed that those respondents who did feel that they wanted to be active found means of getting involved in clubs or of attending events. Other respondents also felt that their health did not permit them to be socially involved a lot anymore. However, for some respondents it was important to maintain a degree of independence and social life, despite their difficulties to communicate or their high age. Some of these respondents felt that the opportunities for people with dual sensory loss were very limited:

> **'I want to stay as independent as possible for as long as possible, in my own house. I am a very determined person. I try to keep active and would like to be part of a rambling club but feel at 96 I am too old and would not be welcome or able to walk miles and miles, but I still would like to get out!'**
>
> **'It would be lovely if we could all get together in N Ireland as a type of support group for one another, just for a social outing and chat. I am housebound and hardly ever get out.'**
>
> **'I pay a lady to look after the house and she is great. My daughter runs after all my other needs but I feel I would like someone like the lady from the Blind Centre to take me places and appointments instead of having to call on my daughter all the time.'**

The final policy implication from the survey is therefore that**:**

A centre for people with dual sensory for Northern Ireland, which could co-ordinate specific activities, provide advice, educational material and training could potentially improve the quality of life for people with dual sensory loss considerably.

The way forward: Concluding remarks from DeafBlind UK

Deafblindness is a distinct impairment that is more than simply a loss of sight and hearing. It is a unique impairment with specific effects on the lives of individuals. The difficulties created in communication, in mobility and in access to information are vast. The impact of a dual sensory loss is significantly different from a single loss as the individual's ability to compensate with the remaining sense is reduced. Many people will not be totally deaf and totally blind, but will have some remaining use of one or both senses. Others, as our research shows, will also have additional physical disabilities. The coping strategies and skills required change in their nature as do the support services required.

How then, can the situation be improved for people with a dual sensory loss in Northern Ireland?

One can only adopt the example being set by the on-going work of Deafblind UK within the English, Scottish and Welsh regions. Following the conclusions of the 'Who Cares' report 2001 with SENSE, Deafblind UK and over 2,500 dual sensory impaired people, the Department of Health in GB recognised that 'more has to be done to identify, correctly assess and provide appropriate services for people with dual sensory impairment'. They stated that 'deafblind people are a unique group who cannot always benefit from mainstream services for people who are either blind or deaf'

In conclusion, using the results from our own local research, Deafblind UK would ask the Department of Health in Northern Ireland to consider the enclosed report and make a commitment to improve services for deafblind people. We would strongly encourage the Department to endorse the Section 7 Guidance Social Care for Deafblind Adults and Children so that people in Northern Ireland with a Dual Sensory loss would be placed on an equal footing with their counterparts in Great Britain where Local Authorities are already following guidance set by Government: i.e.

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

Finally, Deafblind UK hopes that the report convinces those with the authority to implement change to do so now. There is no doubt that deafblind people with this unique disability will regain their right to choice, access, good health care, build relationships, participate equally within the community and be as independent as possible if Section 7 Guidance is used.

Appendices

1. Survey Questionnaire
2. Case Study
3. *Section 7 Guide of the Local Authorities Social Services Act (1970)*
4. European declaration of the rights of deafblind people
5. Contact Details

Appendix 1: Questionnaire

Survey of Need - Dual Sensory Loss

CONFIDENTIAL

This survey is being carried out by Deafblind UK in order to find out what services are available for people with an acquired dual sensory loss. We also wish to find out what other services people feel that they need.

A report of the survey findings will be available by the end of 2004, which will outline the needs identified in the survey. These findings will be used to support an application for funding from the Department of Health. A summary of the report will be sent to every survey participant in the Northern Ireland Region in the appropriate format.

However, I would like to stress that information provided in these reports will be completely anonymous, and will not identify you in any way. Your responses will not be used for any other purpose.

Section 1: Background information
(to be completed by interviewer before the interview)

ID number ☐

1 Date ________________________

2 Health Board area

Eastern	☐	1
Northern	☐	2
Southern	☐	3
Western	☐	4

3 Gender

Male	☐	1
Female	☐	2

4 Age (in years) ☐☐

5 Does the respondent live

In a residential or nursing home	☐	1
Alone in sheltered accommodation	☐	2
Alone in a private house	☐	3
With spouse/partner/relatives in sheltered accommodation	☐	4
With spouse/partner/relatives in a private house	☐	5
Other	☐	6

What other living situation? ________________________________

6 Is the respondent Registered Blind? Yes ☐ 1 No ☐ 2

7 Is the respondent Registered Partially Sighted? Yes ☐ 1 No ☐ 2

Section 2: Communication
(to be completed by interviewer during the interview)

8 Would you describe your hearing loss as …

Profound	☐	1
Severe	☐	2
Moderate	☐	3
Mild	☐	4

9 Do you wear a hearing aid(s)? Yes ☐ 1 No ☐ 2

10 Do you communicate using any of the following ways? (tick all that apply)

	Yes		No	
Deafblind Manual Alphabet	☐	1	☐	2
Block Alphabet	☐	1	☐	2
British/Irish Sign Language	☐	1	☐	2
Hands-on	☐	1	☐	2
Lip read	☐	1	☐	2
Voice	☐	1	☐	2
Other forms of communication	☐	1	☐	2

What other forms of communication do you use? ____

11 Do you use any of the following to access printed information? (tick all that apply)

	Yes		No	
Braille	☐	1	☐	2
Moon	☐	1	☐	2
Large print	☐	1	☐	2
Extra large print	☐	1	☐	2
Audiotapes	☐	1	☐	2
Cannot read at all	☐	1	☐	2

12 Do you have any of these specialist pieces of equipment to assist you with communicating or accessing information?

					Was this provided by ...			
	Yes		No		Social Services	NHS	A charity	Bought privately
Low vision magnifiers(s)	☐	1	☐	2	1	2	3	4
Digital hearing aids	☐	1	☐	2	1	2	3	4
Portable loop systems	☐	1	☐	2	1	2	3	4
CCTV or Easi Reader scanner	☐	1	☐	2	1	2	3	4
Wireless for the blind	☐	1	☐	2	1	2	3	4
Something else ____________________					1	2	3	4
Something else ____________________					1	2	3	4

Section 3: Lifestyle

13 Which of these describes your daily activities? (tick all that apply)

	Yes		No	
I stay at home every day	☐	1	☐	2
I attend a day centre	☐	1	☐	2
I am employed full time	☐	1	☐	2
I am employed part time	☐	1	☐	2
I am self employed and work full time	☐	1	☐	2
I am self employed and work part time	☐	1	☐	2
I am a volunteer	☐	1	☐	2
I do something else	☐	1	☐	2

13a What other things do you do?

____

14 How often do you go out of your home for any reason?

Every day ☐ 1
Nearly every day ☐ 2
1-2 times per week ☐ 3
Less than once a week ☐ 4
Never ☐ 5

15 How often do you go out of your home **on your own**?

Every day ☐ 1
Nearly every day ☐ 2
1-2 times per week ☐ 3
Less than once a week ☐ 4
Never ☐ 5

16 Are you involved in any activities, for example, sports, craft or church activities and so on?

Yes ☐ 1 No ☐ 2

16a If yes, please tell me what they are

____

17 Are there any (other) activities that you would like to take part in if they were organised near you? Yes ☐ 1 No ☐ 2

17a If yes, please tell me what they are

18 Are any of the following services provided in your community? (tick all that apply)

	Yes	No
A club for dual sensory impaired people	☐ 1	☐ 2
Volunteers	☐ 1	☐ 2
One to one support from Communicator Guides	☐ 1	☐ 2
Respite for you and/or your carers	☐ 1	☐ 2
Any other services you would like provided	☐ 1	☐ 2

18a What other services?

18b Of the services that **are** available, do you use any of them? (tick all that apply)

	Yes	No
A club for dual sensory impaired people	☐ 1	☐ 2
Volunteers	☐ 1	☐ 2
One to one support from Communicator Guides	☐ 1	☐ 2
Respite for you and/or your carers	☐ 1	☐ 2
Any other services you would like provided	☐ 1	☐ 2

18c What other services?

18d Of the services that **aren't** available, are there any that you would like to be provided? (tick all that apply)

	Yes	No
A club for dual sensory impaired people	☐ 1	☐ 2
Volunteers	☐ 1	☐ 2
One to one support from Communicator Guides	☐ 1	☐ 2
Respite for you and/or your carers	☐ 1	☐ 2
Any other services you would like provided	☐ 1	☐ 2

18e What other services?

Section 4: Health issues

19 How often do you take exercise, either indoors or out?

Every day ☐ 1
Nearly every day ☐ 2
1-2 times per week ☐ 3
Less than once a week ☐ 4
Never ☐ 5

20 Apart from loss of hearing and vision, do you have any problem or disability that substantially affects your health or wellbeing? Yes ☐ 1 No ☐ 2

20a If yes, can you please tell me about these problems?

21 Do have any specialist pieces of equipment or aids to assist you with mobility on a daily basis? Yes ☐ 1 No ☐ 2

21a If yes, please tell me what they are

22 How many times have you attended the Health Centre or your GP's surgery in the last 12 months? This could be to see the GP or someone else, for example, the practice nurse.

Never ☐ 1
1-6 times ☐ 2
7-12 times ☐ 3
13 or more times ☐ 4

23 Did you experience any difficulties when you attended the Health Centre or surgery? Yes ☐ 1 No ☐ 2

23a If yes, can you please tell me about these difficulties?

24 Have you ever avoided attending the Health Centre or your GP’s surgery because communication is too difficult? Yes ☐ 1 No ☐ 2

25 When you visit the Health Centre or your GP’s surgery, do you **usually** go on your own, or with someone else?

On my own ☐ 1
With my spouse/partner ☐ 2
With my son/daughter ☐ 3
With another relative ☐ 4
With a friend ☐ 5
With a carer ☐ 6
It depends ☐ 7
Someone else ☐ 8

Who else usually goes with you? ____________________

26 How many times have you had to call your GP out to your home in the last 12 months?

Never ☐ 1
1-6 times ☐ 2
7-12 times ☐ 3
13 or more times ☐ 4

27 How many times have you attended the hospital as an outpatient in the last 12 months?

Never ☐ 1
1-6 times ☐ 2
7-12 times ☐ 3
13 or more times ☐ 4

28 Did you experience any difficulties when you attended the outpatient clinic?

Yes ☐ 1 No ☐ 2

28a If yes, can you please tell me about these difficulties?

____

____

29 How many times have you stayed in hospital in the last 12 months?

Never	☐	1
1-6 times	☐	2
7-12 times	☐	3
13 or more times	☐	4

30 Did you experience any difficulties when you stayed in hospital?

Yes ☐ 1 No ☐ 2

30a If yes, can you please tell me about these difficulties?

____

____

Section 5: Social Services

31 Do you have a social worker(s)? Yes ☐ 1 No ☐ 2

31a If yes, are they based in any of the following teams?

	Yes		No	
I don’t know what team they are from	☐	1	☐	2
Hearing Impaired team	☐	1	☐	2
Visually Impaired team	☐	1	☐	2
Dual Sensory Impaired team	☐	1	☐	2
Elderly team	☐	1	☐	2
Mental health team	☐	1	☐	2
Physically Disabled team	☐	1	☐	2
Other team	☐	1	☐	2

What other team? ______________________________

32 Have you had an assessment of need carried out by a Social Worker? Yes ☐ 1 No ☐ 2

Section 6: Carers

33 Do you have a carer(s)? Yes ☐ 1 No ☐ 2

33a If yes, what relationship is/are this carer(s) to you?

	Yes	No
Spouse/partner	☐ 1	☐ 2
Son/daughter	☐ 1	☐ 2
Other relative	☐ 1	☐ 2
Friend	☐ 1	☐ 2
Neighbour	☐ 1	☐ 2
Provided by Social Services	☐ 1	☐ 2
They are privately employed	☐ 1	☐ 2
Other	☐ 1	☐ 2

What other kind of relationship?

____

34 Does your carer(s) provide any of the following support for you?

	Yes	No
Personal care support, for example, bathing, personal hygiene	☐ 1	☐ 2
Practical care support, for example, cooking, cleaning, shopping	☐ 1	☐ 2
Takes me everywhere	☐ 1	☐ 2
Communicates for me, for example, writes letters, makes phone calls	☐ 1	☐ 2
Provides advice and information	☐ 1	☐ 2
Some other kind of support	☐ 1	☐ 2

What other kind of support?

____

35 How supportive is your immediate family?

Very supportive	☐	1
Supportive	☐	2
Neither supportive nor unsupportive	☐	3
Unsupportive	☐	4
Very unsupportive	☐	5
Don’t know	☐	6

36 Finally, is there anything else that you would like to add, for example, about services for you and/or other dual sensory impaired people?

____

____

Thank you for taking the time to answer these questions.

Appendix 2: Case Study

Service User – Mrs X: Assessment completed by Hazel Wilson, Regional Development Officer for Deafblind UK in Northern Ireland

First visit to Mrs X in August 2002. She was 82. Since that time I have been involved in offering regular support to Mrs X to reduce social isolation and to enable her to access information. Also to deal with support needs relating to problems with her hearing aids, hospital appointments and trying to source a suitable volunteer.

Mrs X has 2 remaining relatives, her 76 year old recently widowed sister and her niece. They visit her as often as they can. Mrs X had a regular arrangement until early 2004, whereby a taxi would collect her and bring her to her sister's home for Sunday dinner. On the last occasion, the regular taxi driver who knew her well, was off ill and the replacement did not call back for her at her normal booked time. She returned to her own home at 5pm one hour later than usual and found herself totally disorientated and frightened in the pitch dark. This episode caused Mrs X to lose all confidence and she no longer continued her only weekly outing.

Mrs X has, in the past, attended a local day centre, but decided in the end that even this was futile, as she could no longer hear well enough in a group setting. The outing made her feel even more depressed and isolated.

Mrs X spends the entire day at her home totally alone except for the numerous swift visits from her carers provided by social services All she sees is a cracked-ice image, some shadows but absolutely no detail. With a hearing aid to assist her residual hearing she can communicate on a one to one basis only. Her days are very long and her nights filled with waking hours and intense pain brought on by Padgett's Disease which severely affects her pelvis and back.

Mrs X attended hospital visits with her sister but only if her sister was well enough to do so. They would travel by taxi and she would be guided to the appropriate department by her sister. Her sister would assist with communication. There is a possibility that appointments could have been missed and that a care package including a communicator guide would have ensured Mrs X's attendance at appointments and also promote essential one to one social contact so necessary for mental and physical well being.

Sadly Mrs X's health and well-being have taken a downward plunge and at present she is in a Mental Health Complex for the long term care of the elderly. There is no prognosis.

It was suggested that Mrs X had been so long on her own, within the same four walls that she had lost her will to go anywhere or do anything. In August 2003 Mrs X was taken for a drive to a local seaside town and she was able to feel the wind blow and smell the sea air. It was the first time she had been anywhere for 5 years…

Considerations

A communicator guide spending a few hours each week with Mrs X would have -

- Supported independence;
- Improved quality of life;
- Facilitated inclusion in the community;
- Reduced social isolation;
- Facilitated best use of residual sight and hearing.

In assessing Mrs X’s need for a communicator guide issues to be included are:

- She lived alone;
- She had additional impairments or disabilities;
- She was isolated for most of the day;
- She did not go out for a week or more;
- She may have missed appointments because there was no support;
- She had lack of access to activities, walks, visits, shops;
- She was only able to go out to or with carers;
- She demonstrated stress factors such as frustration, anger or depression.

Appendix 3: Section 7 Guidance

In April 2001 the Government issued new guidelines under Section 7 of the Local Authorities Social Services Act 1970. It clearly states that deafblind people should have access to specialist assessment, and where the need is identified, to specialist services, including one to one support services such as communicator-guide, interveners, and qualified support workers, within their everyday lives. The guidelines do not only cover deafblind people, it also encompasses all those with a dual sensory impairment.

Appendix 4: The European Deafblind Network

Tuesday, 20 April 2004

"Europe recognises deafblindness as a separate disability"

The campaign run by the European Deafblind Network (EdbN) has been successful in getting deafblindness recognized as a separate disability within the European Parliament as of Thursday 1st April.

Written Declaration by Richard Howitt, Mario Mantovani, Elizabeth Lynne, Patricia McKenna and Ilda Figueiredo on the rights of deafblind people.

The European Parliament

- having regard to Rule 51 of its Rules of Procedure,

- having regard to Article 13 of the Treaty on European Union and the principle of human dignity,

A. whereas deafblindness is a distinct disability that is a combination of both sight and hearing impairments, which results in difficulties having access to information, communication and mobility,

B. whereas there are about 150 000 people in the European Union who are deafblind,

C. whereas some of these people are completely deaf and blind, but most have some remaining use of one or both senses,

D. whereas, having a distinct disability, deafblind people need specific support provided by people with specialist knowledge,

1. Calls on the institutions of the European Union and the Member States to recognise and implement the rights of people who are deafblind;

2. Declares that deafblind people should have the same rights as are enjoyed by all EU citizens; these should be enforced by appropriate legislation in each Member State and should include:

- the right to participate in the democratic life of the European Union;
- the right to work and access training, with appropriate lighting, contrast and adaptations;
- the right to person-centred health and social care;
- the right to lifelong learning;
- the right to receive one-to-one support where appropriate from communicator-guides, deafblind interpreters and/or intervenors;

3. Instructs its President to forward this declaration to the Commission, the Council, and the governments of the Member States.

Appendix 5: Contact Details

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