

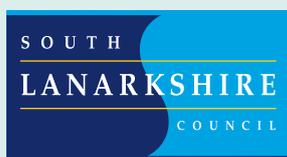


See Hear

an exploration of people's lived experience of having a sensory impairment in Lanarkshire



UWS UNIVERSITY OF THE WEST of SCOTLAND



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We would like to thank everyone who helped us gather information through participation in discussions or completion of questionnaires, thus contributing to the development of this report.

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About the project partners

University of the West of Scotland:

The study was undertaken by Principal Researchers Dr Helen Walker and Dr Mick Fleming, Researchers in the Institute of Healthcare Policy and Practice at the University of the West of Scotland. Bronagh Reynolds was employed as Research Assistant.

Representatives from South and North Lanarkshire contributed to the developmental and organisational process, see below.

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Terminology

The term 'dual sensory impairment' will be used throughout the report to define people with hearing and sight difficulties and Deafblind individuals that is, people with difficulties in both senses.

1. Executive summary

Introduction

Sensory impairment refers to people with hearing and sight difficulties. In the UK 11 million people will experience some form of hearing loss, two million people are living with sight loss and around 250, 000 people have a dual sensory impairment (Deafblind). Between 15, 000-24, 000 people use sign language as their first language. Demographic changes within the population mean that the number of people with hearing loss will rise to 15.6 million by 2035 and the number of people with sight loss will double by 2050.

In Scotland, sensory impairment affects 150, 000 (significant sight loss), 850, 000 (hearing loss) and 5,000 (Deafblind) people. It has been estimated that these numbers will double in the next 15 years for those with sight loss and by 50% for those with hearing loss in the next 20 years.

Sight and hearing (as well as dual sensory impairments) have been found to have an adverse effect on psychological well-being, self-esteem, interpersonal relationships and functioning, loneliness, mood, general well-being and quality of life, as well as other physical health issues.

Employment and participation in community activities such as social clubs and leisure activities helps to overcome feelings of social isolation, and improves quality of life, life satisfaction and the achievement of life goals.

When delivered in a way that is sensitive to the needs of people with sensory impairment, services such as health, leisure and transport can

make a significant contribution to the quality of life, physical health and psychosocial adaptation of people with a sensory impairment.

The See Hear Framework (Scottish Government 2013) is a strategic framework that promotes a seamless multi-agency provision of assessment, care and support to people with a sensory impairment.

North Lanarkshire Health and Social Care Partnership (HSCP) and South Lanarkshire HSCP, along with specific Third Sector organisations are in the process of planning how to take forward the recommendations made in See Hear. In order to facilitate this planning both HSCPs (together with other agencies) sought to gather information from people experiencing a sensory (or dual sensory) impairment relating to the lived experience of sensory loss. This was with a view to identifying gaps in service provision and areas of good practice. This information will be analysed and used to inform decisions regarding service developments and to prioritise service provision in relation to the See Hear Framework.

It was decided to carry out a small piece of independent research using a combination of interviews, focus groups and surveys to gain people's experience of living with a sensory impairment across Lanarkshire. This is briefly outlined below.

Research aims

- to develop an understanding of the lived experience of having a sensory impairment in relation to well-being and access to services
- identify gaps in service provision for people with a sensory impairment in North and South Lanarkshire

- to identify areas of helpful and effective practice and service provision for people with a sensory impairment
- to identify priority areas for service development regarding the See Hear Framework
- obtain a baseline measure of the well-being of people that experience a sensory impairment in North and South Lanarkshire.

Method

A project group was established to take forward the research, which comprised of representatives from the University of the West of Scotland and colleagues from both HSCPs.

A mixed methods approach (as detailed above) was used and included:

1. An on-line survey regarding demographic characteristics and well-being was conducted from the population of the people with a sensory impairment living within the boundaries of North and South Lanarkshire. The data provided a baseline measure of well-being and was used to determine the level of need within North and South Lanarkshire.
2. Six focus groups comprising of a maximum of six people were established and facilitated. Those people taking part all identified themselves as having a sensory impairment. A few were carers. Individual interviews were offered to those people who felt they could not attend the groups.

Semi-structured prompt questions based on the key themes that underpin the See Hear Framework and the aims of the study were used as an approach to generate discussion.

At the end of each focus group participants were asked to make a list of recommendations for service design, then prioritise five from the list. The group meetings were also audio-recorded on a laptop computer (encryption). The data was transcribed and analysed using thematic content analysis. Key themes were identified and used to form the basis of this report.

Findings

Results focus on mental well-being, gaps in services and good practice points. As with all research, there are limitations with what can be drawn from the findings and though a concerted effort was made to reach children and younger people experiencing a sensory impairment, it is acknowledged that further, dedicated research needs to be undertaken in this area.

The lived experience of sensory loss

A total of sixty three participants were involved in the study and five themes emerged from the data: awareness, communication, physical access, social isolation and adaptation to sensory impairment. Each theme was further divided into sub themes, for example, communication included external support, contact with local Council services, emergency services and information in appropriate formats.

Well-being

The majority of people completing the survey (71%) reported an average range of well-being, 14.5% reported lower than average well-being and the remaining 14.5% reported above average well-being. Women within the survey were more likely to report significantly higher levels of mental wellbeing than males and participants with mild to moderate hearing loss also reported significantly better mental wellbeing than those with severe or profound hearing loss. There were no significant differences in well-being between people with a hearing impairment, people with a visual impairment and people with a dual sensory impairment.

Gaps in service provision

The ability of front-line staff in Councils and NHS facilities to communicate appropriately with people with sensory impairment is limited. Receiving healthcare related information in inaccessible and inappropriate formats prevented people from accessing important results, for example, test results from health checks. The lack of working loop systems in public buildings as well as a lack of specialised accessible toilets for those with a sensory impairment and complex health needs were reported.

Good practice

A number of good practice examples are highlighted throughout the report. Visibility Scotland and PAMIS (an organisation supporting people with profound and multiple learning disabilities and their carers) were commended as being effective at promoting and facilitating leisure and support services, which impacted positively on people with a sensory impairment and carers who have had contact with them.

Twenty recommendations are listed at the end of the report offering a prioritised list of areas for service provision.

Key recommendations include awareness training for frontline staff, investment in training for Guides, increasing the flexibility of booking times for Guides, increasing the availability of on-call Interpreters in hospitals and the development of local activities and groups for sensory impaired children.

Concluding comments

The themes that emerged from focus groups and interviews are consistent with those found in the literature and are closely linked with awareness, communication, physical access, social isolation and adaptation to sensory impairment. If the proposed recommendations are enacted this will help to provide the necessary improvements in communication, access to services, overcoming social isolation and enhancing adaptation and awareness. Consequently, these improvements may improve the quality of life, physical and psychological well-being of people that experience sensory impairment.

2. Introduction and aims of research

The National Picture

Hearing, sight and combined sight and hearing difficulties (dual sensory loss) are worldwide public health issues that can lead to reduced quality of life, other health issues, isolation, increased dependence and frustration (Ciorba 2012, Zhang et al., 2012, Yang et al., 2013). In the UK, 11 million people will experience some form of hearing loss and it is estimated that this figure will rise to 15.6 million by 2035, nearly one million people experience profound hearing loss and 45, 000 children are deaf (Action on Hearing Loss, 2011).

Approximately 70% of blind and partially sighted children are educated in mainstream settings, with the remainder being educated in schools for children with additional support needs (Morris and Smith, 2008). Many (66%) registered blind and partially sighted people of working age are not in employment (Pavey et al., 2006). Age, additional disability or health problems, severity of sight loss, educational level and ethnicity are all factors that influence the employment status of blind and partially sighted people (Pavey et al., 2009).

It has been estimated that between 15, 000 and 24, 000 people use sign language as their main language (Action on Hearing Loss, 2011, Emond et al., 2015). In 2003, British Sign Language (BSL) was finally recognised by the British Government as being an independent language. Two million people in the UK are living with sight loss with 360, 000 registered as blind. The number of people with sight loss will rise to four million by 2050 and 25, 000 children are blind or partially sighted (Access Economics, 2009, Royal National Institute for the Blind, 2014).

Across the UK, 250, 000 people experience dual sensory loss (Action on Hearing Loss, 2011). The prevalence and severity of hearing, sight loss and dual sensory loss have been found to increase with age (Saunders and Echt 2007, Yang et al., 2013). As an example of the 250, 000 people with dual sensory loss 220, 000 of these are above the age of 70 years (Action on Hearing Loss, 2011, Smith et al., 2015).

Population estimates in Scotland

In Scotland sensory impairment (sight and hearing difficulty) affects between 150, 000 (significant sight loss) and 850, 000 (hearing loss) people. It has been estimated that these numbers will double in the next 15 years for those with sight loss and by 50% for those with hearing loss in the next 20 years (Royal National Hearing Institute for the Deaf/Action on Hearing Loss, 2011, Scottish Vision Advisory Group/Royal National Institute for the Blind, 2012).

There are around 5, 000 people that experience a combination of sensory impairment (Deafblind) in Scotland (Scottish Government, 2013).

Demographic changes and an ageing population mean that these figures will continue to rise in the future.

North and South Lanarkshire

In North Lanarkshire, 39,065 people (11.5% of the total population) consider their day-to-day activities to be seriously limited through either a long-term health problem or disability and of those, 19,989 (9%) are of working age (16-64). In addition 33,126 consider their day-to-day activities to be limited a little (2011 Census).

Of the 21,276 (6.3%) people in North Lanarkshire who have a hearing impairment, 7914 are Deaf and of working age and there are 828 British Sign Language (BSL) users. 7767 people (2.3%) have a visual impairment (2011 Census).

Following the Pupil Census conducted every year, the Scottish Government publishes data from each Council area. This contains information on children living with a sensory impairment. In North Lanarkshire, of the 1335 primary pupils who gave information on their additional support needs, 57 had a visual impairment and 35 reported a hearing impairment. In secondary schools, 1667 pupils reported reasons for additional support, of these 41 reported having a visual impairment and 54 having a hearing impairment. From the total of 928 pupils in schools for children with additional support needs, 49 had a visual impairment and 26 had a hearing impairment.

In South Lanarkshire 97,480 adults were recognised as living with a disability or a long term health problem in 2014, equating to 38.3% of the adult population. This is nearly a tenth higher than the Scottish average of 35%. Those with communication disabilities reported that it limited their abilities a lot (South Lanarkshire Council, 2014). Approximately 3.2% had a hearing impairment, and approximately 2% had a visual impairment.

From a total of 4,964 primary pupils for whom additional support needs was reported, 110 had a visual impairment and 71 had a hearing impairment. Amongst secondary school pupils, 109 reported a visual impairment and 73 reported having a hearing impairment. This is based on 3,803 pupils for whom additional support need was reported. Finally, of the 347 pupils in South Lanarkshire in additional support needs

schools, 46 reported a visual impairment and 25 reported a hearing impairment.

No pupils from either Council area reported a dual sensory impairment.

The projected number of population estimates for the next 15-20 years for deaf/ partially deaf and blind/partially blind people in North and South Lanarkshire can be seen in appendix 1.

Types of sensory impairment and impact

There are three main groups within the category of sensory impairment;

1. People with a recognised sensory impairment
2. People at risk of sensory impairment, and
3. People who are living with an untreated and unrecognised sensory impairment as a consequence of other factors such as stroke, dementia or learning disability.

A number of studies have reported on the influence of sight and hearing (as well as dual sensory) impairments on psychological well-being, self-esteem, interpersonal relationships and functioning, affect and quality of life, as well as other health issues (Dalton et al., 2003, Fellingner et al., 2005, Augustin et al., 2007, Hawkins et al., 2012, Wahl et al., 2013 and Kwon et al., 2015). In comparison to people with no sensory impairment those with a hearing impairment, sight impairment and dual impairment were more likely to experience falls, hypertension, stress, depression and suicidal thoughts.

Understanding sensory impairment in relation to wellbeing: evidence from the literature

Much of the literature in relation to the impact of living with a sensory impairment focuses on the day-to-day functioning of people with a sensory impairment; it is 'medicalised'. In addressing wellbeing it is important to note the difference between the medical model and the social model of disability (paraphrased here by Carson, 2017). Through the medical model, a disability is understood as an individual problem (for example, if somebody has a visual or hearing impairment their inability to see or hear is understood as their disability). This model regards the difficulties that people with a disability experience in society as being caused by the way in which their bodies are disabled.

Within the social model of disability, disability is understood as 'having an unequal relationship within a society'. The social model was created by people with disabilities. It was primarily a result of society's response to them but also of their experience of the health and social care system, which made them feel socially isolated and oppressed. The model suggests people with disabilities are disabled by the fact that they are excluded from participation within the mainstream of society as a result of barriers that prevent them from gaining equal access to information, education, employment, public transport, housing and social/recreational opportunities. It is within this context that wellbeing is explored.

From a review of the literature, those with dual sensory impairment reported a higher frequency of physical and psychological health issues. Participants reported a high level of mobility problems, pain and discomfort, and problems carrying out normal day-to-day activities (Kwon et al., 2015). A recent study has confirmed more health problems in the

deaf population with probable under-diagnosis and under-treatment of health conditions (Emond et al., 2015).

Under-diagnosis and under-treatment may be a consequence of difficulties with engagement and communication with health services (Bennet et al., 2016). The mechanisms are thought to be related to the effects of sight and hearing loss on interpersonal communication, behavioural functioning and the development and maintenance of relationships, which in turn leads to loneliness (Brennan and Bally 2007, Wahl et al., 2013).

It is by these mechanisms that the well-being of people with sensory loss is defined. The trends found in the literature are that the quality of life and well-being of people with sensory impairment is lower than those people within the general population (Fellinger et al., 2005, Hawkins et al., 2012). Over the last two decades policy makers and researchers have noted the increasing importance of measuring aspects of well-being in relation to health problems as outcome measures.

These types of outcomes provide more comprehensive, person-centred and relevant measures in comparison to symptomatic measures. Well-being measures are included in the Scottish Health Survey and used to develop a comprehensive picture of the health of the Scottish population and to aid on-going monitoring of the population's health.

Quality of life is a broad concept and an outcome measure that relates to all aspects of a person's existence and well-being, goals, expectations, functioning and standards (Oliver et al., 1996) and the perception of

position in life within the context of the person's culture and value system (World Health Organisation, 1997).

Quality of life is influenced by physical health, psychological well-being, environment and level of functioning. Studies that have investigated the health related quality of life in people with a visual impairment (average age of 79.3 years) found a lower health related quality of life. Factors that contributed to better health related quality of life included a greater level of participation and satisfaction in social roles, higher activity and use of a writing aid (Renaud et al., 2010).

Psychosocial adaptation (attitude, self-acceptance, self-esteem, anxiety/depression, sense of belonging, self-efficacy and self-control) has been found to influence the quality of life of people with visual impairments (Zhang et al., 2012). Factors that influence psychosocial adaptation such as everyday functioning were found to be lower in people with a dual sensory impairment (Wahl et al., 2013). Quality of life has also been found to be lower in people who experience deafness (Fellinger et al., 2005, Helvick et al., 2006).

Social isolation, reduced independence and engagement with the community and services are associated with sensory impairment (Smith et al., 2014, Cruddent et al., 2015; Bennet et al., 2016). Participation in community activities such as social clubs, lunch clubs, leisure, health, employment is fundamental to increasing feelings of independence, improved quality of life, life satisfaction, physical health and achievement of life goals.

Co-ordinated and seamless transport, leisure, housing, employment, health, social and education services can all support the engagement of people with a sensory impairment within their communities. When services are delivered in a way that is sensitive to the needs of people with a sensory impairment they can make a significant contribution to the quality of life, physical health and psychosocial adaptation of people with a sensory impairment.

Legislation and policy context

Several legislative and policy changes have emerged fairly recently, designed to protect, support and empower people with a sensory impairment. The Equality Act (2010) for example, defined disability as a protected characteristic and defined discrimination arising from disability. The British Sign Language (Scotland) Act was given Royal Assent in October 2015. The Act aims to promote the use and understanding of British Sign Language in Scotland.

In addition, two policies have been supported by the Scottish Government.

A Right to Speak

The first policy 'A Right to Speak' (Scottish Government, 2012) was introduced to pilot the development of 10 sensory impairment one-stop-shops across Scotland. The aim of these one-stop-shops was to move away from the traditional model of accessing support through hospitals and GP practices, towards a model which would allow services to be delivered locally with additional support, information and advice.

The policy recommends co-ordinating a wide range of rehabilitation, enablement, support and information services for people with a sensory impairment locally at a single point (Smith et al., 2015). Initial findings from one of these one-stop-shops indicate that interventions delivered have reduced the sense of isolation, which has impacted on self-confidence and self-esteem.

See Hear Framework

The second policy is the See Hear Framework, which was developed as a strategic framework for meeting the needs of people with a sensory impairment in Scotland (Scottish Government, 2013). It promotes a seamless multi-agency provision of assessment, care and support to people with a sensory impairment. There are a number of themes that underpin the strategy and these include: the importance of early diagnosis and detection, screening, information giving, focused and targeted resources towards preventative strategies, flexible delivery, effective integration of multi-agency working, a skilled and well-trained workforce and service-user involvement in defining outcomes. The development of an integrated care pathway is an objective that combines the aims, the underlying themes and the seven recommendations of the See Hear Framework into a workable plan of action.

North Lanarkshire HSCP and South Lanarkshire HSCP, along with specific Third Sector organisations are in the process of planning how to take forward the recommendations within the See Hear framework. In order to facilitate this planning both HSCPs, together with other agencies, have gathered information through this piece of independent research from people experiencing a sensory impairment. This relates to their 'lived experience', which also identifies gaps in service provision and

areas of good practice. The results of the research have been analysed and are presented here in this report. Findings will be used to inform service design for people experiencing sensory loss across Lanarkshire.

Aims of the research:

- to develop an understanding of the lived experience of having a sensory impairment in relation to well-being and access to services
- identify gaps in service provision for people with a sensory impairment in North and South Lanarkshire
- to identify areas of helpful and effective practice and service provision for people with a sensory impairment
- to identify priority areas for service development regarding the See Hear Framework
- obtain a baseline measure of the well-being of people that experience a sensory impairment in North and South Lanarkshire

3. Method

Research preparation

A project group was established to take forward the research, which comprised of representatives from both Councils and The University of the West of Scotland (UWS). The project group met at regular intervals to plan all aspects of the study and to co-ordinate specific technological, promotional and network support to facilitate the data collection.

Study methods used to build the evidence required

For this study, a mixed methods (qualitative and quantitative) approach was chosen in order to gain a representative profile of participants including demographic characteristics and measures of wellbeing (via the Well-being Scale described below) as well as gaining an in-depth

understanding of participants' needs regarding access (via focus group/interview).

Survey

1. An on-line survey was developed to capture responses from people with a sensory impairment living within the boundaries of North and South Lanarkshire. The sampling frame and initial contact were determined by snowball sampling strategies, where one person is known and they identify another, the new person identifies yet another and so on. Contact and promotion strategies were used to engage the general public, specific service-user groups, third party providers and carer/family groups using registers held by agencies within North and South Lanarkshire.

Participants that consented to the study were invited to complete a short 14 item well-being questionnaire (Edinburgh-Warwick Mental Well-being Scale). Permission was granted for on-line use.

Participants were also invited to complete a short number of demographic questions regarding age, gender and level of sensory impairment (appendix 2). The on-line version of the well-being questionnaire was available in formats that maximise the access and completion of the questionnaire by people with a sensory impairment (for example, SNAP survey that allows sound/audio and pictures to be embedded in on-line documents, signed, video/visual, British Sign Language (BSL), spoken word). The data provided a baseline measure of the well-being of people with a sensory impairment and was used to help determine the level of need within North and South Lanarkshire.

Focus groups

2. Six focus groups were facilitated at the University of the West of Scotland for people experiencing a sensory impairment. Groups were made up of a maximum of six people (participants); the composition of groups was planned to allow specific data to be collected from participants who have a sensory impairment and their carers. The sample of service-users and carers reflected, as far as was possible from those who came forward, the experiences of people with a sensory impairment. However, this research acknowledges that further, dedicated work with children and young people is a 'gap'; their experiences are not reflected despite efforts being made to reach this group.

In order to increase accessibility and opportunities for participation the group meetings took place at UWS Hamilton Campus. Prior to commencing the groupwork the Principal Researcher asked each participant to sign the consent form (audio/large print version, see appendix 3) and participants were all given an information leaflet (appendix 4). Focus groups offered the opportunity to facilitate discussion and interviews were also offered. Semi-structured prompt questions based on the key themes that underpin the See Hear strategy and the aims of the study were used (appendix 5). Effective facilitation of the group process promoted discussion and questioning between group participants, which provided a rich source of insights and interpretations regarding the local context for people with a sensory impairment. At the end of each focus group participants were asked to make a list of recommendations for service design, then prioritise five from the list. The group meetings were facilitated by the Principal Researcher and a Research Assistant was present at all

group meetings to take notes, summarising the discussion. The group meetings were also audio-recorded on a laptop computer (encryption).

Data collection

The data was transcribed and analysed using a 6 stage thematic analysis (Braun and Clarke, 2006). The stages include a familiarisation of the data, generating the initial codes, followed by the identification, review, defining of themes and concluding with the finalisation of the report. Key themes identified form the basis of this report for North and South Lanarkshire HSCPs and their partners. Where potential participants indicated that they would like to take part but would feel uncomfortable discussing issues in a focus group, an individual interview was offered to these people as stated. The same access support, interpreting and other help was offered and the same semi-structured prompt questions were used for these interviews.

Support

Loop system, BSL Interpreters, Palan Typists (with large screen visual presentation) and sensory impairment (technical and other) support was provided for all participants agreeing to be part of the focus groups and individual interviews. The facilitation of the focus groups was tailored to the needs of the participants and the practical arrangements were made by North and South Lanarkshire HSCPs. Each focus group meeting lasted approximately ninety minutes. Participant transport costs were reimbursed.

Ethical permission

Ethical permission was obtained from UWS and North and South Lanarkshire Councils' Ethics Committees. All participants were provided

with a suitable version of the information leaflet (audio/large print version) and were offered the opportunity to discuss the aims of the study and study requirements, the voluntary nature of the study, their rights and requirements in detail. There was the opportunity to ask questions and clarify any points.

A 'cooling off period' of one week was provided and after this, the Principal Researcher contacted the potential participant directly or organised another meeting through Deafblind Scotland to discuss any other clarification points or questions the potential participant had. The Principal Researcher checked the participants' understanding of the aims, requirements and rights to withdraw from the study. If the participant understood these points and agreed to be part of the study, the Principal Researcher then offered the details of the website survey, the venue and time of the focus group and the reimbursement of transport costs. Any access requirements were communicated to the teams at both HSCPs for these to be organised prior to the participant accessing the web-survey and the focus group.

Recruiting participants

North and South Lanarkshire HSCPs promoted the study to the general public via Lanarkshire TV, Royal National Institute for the Blind, Insight Radio, talking newspapers and their main websites. They also promoted the study to more specific groups such as South Lanarkshire Carers Network, Lanarkshire Carers Centre, North Lanarkshire Carers Together, Deaf Equality Access Forum, North Lanarkshire Disability Access Panel, South Lanarkshire Access Panel and Lanarkshire Deaf Club.

The project team had expected to adapt their approach in working with children and young people though as stated, this is a gap in the research findings. In order to reach out to children and young people, the opportunity to take part was followed up with Hamilton School for the Deaf, Calderside Academy, Uddingston Grammar and Hamilton Grammar.

The Principal Researcher recorded an audio-visual message outlining the aims of the study, the requirements of the study and the participants required. All promotional material included the Principal Researcher's name and contact details. Potential participants were asked to contact the Principal Researcher directly. The promotional material provided contact details for Third Sector organisations that could offer support to participants and in turn they were advised of the study. The Third Sector agencies acted as the initial contact for those potential participants that required assistance with communication. The Third Sector also provided Interpreters for each of the focus groups. The Interpreters facilitated communication between participants and the Principal Researcher to aid the data collection.

4. Profile of participants

A total of 63 people participated in the study. Thirty participants engaged in focus groups or one-to-one interviews. The remaining 33 participants took part by completing the on-line survey (Warwick-Edinburgh Mental-Wellbeing Scale and Equality Monitoring Information Form). Although, there was no direct representation from the 16-25 age group, parents of sensory impaired children/ young people did participate and relevant issues for this age group were explored as part of the wider discussion.

Table 1: Age and Gender of Participants

Gender	Age					Total
	25-34	35-44	45-54	55-64	65+	
Male	2	0	8	10	13	33
Female	3	3	11	9	4	30
Total	5	3	19	19	17	63

More information is provided in the tables below, on the age range and gender of those with sight, hearing and dual sensory impairments respectively.

Table 2: Gender, Age and Sight Impairment

Gender		Age					Total
		25-34	35-44	45-54	55-64	65+	
Male	Yes	0	0	4	5	2	11
	No	2	0	4	5	11	22
Total		2	0	8	10	13	33
Female	Yes	0	1	1	2	1	5
	No	3	2	10	7	3	25
Total		3	3	11	9	4	30

Table 3: Gender, Age and Hearing Impairment

Gender		Age					Total
		25-34	35-44	45-54	55-64	65+	
Male	Yes	2	0	6	6	12	26
	No	0	0	2	4	1	7
Total		2	0	8	10	13	33
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Female	Yes	2	1	9	9	4	25
	No	1	2	2	0	0	5
Total		3	3	11	9	4	30

Table 4: Gender, Age and Dual Sensory Impairment

Gender		Age					Total
		25-34	35-44	45-54	55-64	65+	
Male Dual	Yes	0	0	2	1	2	5
	No	2	0	6	9	11	28
Total		2	0	8	10	13	33
<hr/>							
Female	Yes	0	0	1	2	1	4
	No	3	3	10	7	3	26
Total		3	3	11	9	4	30

5. Findings

Five themes emerged from the discussions during the focus groups and one- to-one interviews. A summary of these themes and sub-themes is provided in Table 5 below. Themes are highlighted in bold and sub-themes in italics in the following pages.

Table 5: Summary of Themes

1) Awareness

- 1.1. Self-awareness
- 1.2. Frontline staff
- 1.3. Public servants

2) Communication

- 2.1. External support
- 2.2. Contact with local Council services
- 2.3. Emergency services
- 2.4. Information in appropriate formats

3) Physical Access

- 3.1. Safety
- 3.2. Transportation
- 3.3. Leisure facilities

4) Social Isolation

- 4.1. Personal relationships
- 4.2. Employment
- 4.3. Local community
- 4.4. Age-specific

5) Adaptation to Sensory Impairment

- 5.1. Self confidence
- 5.2. Stress/Worry
- 5.3. Rehabilitation

A brief discussion is included in this section associated with the key findings. The main discussion points are available in Chapter 7. Good practice points are highlighted in boxes.

Themes that emerged from interviews

(1) Awareness

Different levels of awareness emerged. Firstly, self-awareness, which changes over time, particularly for those who have become visually or hearing impaired later in life. Secondly, awareness of frontline staff regarding basic communication and their interaction with sensory impaired individuals. Thirdly, awareness of people working in other public services, including the Police, bus and taxi drivers.

1.1. Self-awareness

People born with a sensory impairment have differing experiences growing up. For some there is a normality associated with it as it is all they have ever known,

“It’s not something that I had to adjust to.” (Visually impaired participant).

Others were less accepting,

“I look fine, but it’s a hidden disability.” (Deafblind participant).

1.2. Frontline staff

A major part of living with a sensory impairment and adjusting to living with a sensory impairment depends on the awareness and knowledge of frontline staff. Lack of awareness causes frustration and culminates in negative experiences for people. This unfolded as a key issue for all participants during interviews,

“Simple things like going to the doctor, dentist, [reception], where they talk to the computer. People need training in general. Sitting with your back to the window, we can’t see your face, and it’s just through lack of understanding... Just to change front of house, that would be half the battle.” (Hearing impaired participant).

“Even in Audiology in Wishaw, somebody comes out and shouts your number. You think if the Audiology Department can’t get it right what chance do the others have?” (Hearing impaired participant).

“They are dealing with deafness every day and they don’t know the basics.” (Hearing impaired participant).

“He told me that next time I must phone for an appointment first. I told him I was deaf!” (Deafblind participant).

Frontline staff often mistakenly assume that people who are hearing impaired or deaf can lip-read in English, but this is their second language, whereas British Sign Language (BSL) is their first language.

These issues are not unique and raising awareness amongst frontline staff has been highlighted in previous research as an area requiring improvement, in order to provide the best care for sensory impaired patients (Smith et al., 2014).

Good practice point

One visually impaired participant delivered sensory impairment awareness training in her son's school in an attempt to raise awareness and understanding of basic issues.

"They loved it, seeing all the gadgets and talking watches".

1.3. Public Servants

Awareness training for other public servants was also recommended by participants, particularly bus and taxi drivers, Police and Fire services,

"You do rely on the bus drivers to tell you where to get off. It's just good customer service. But if they don't tell you, you could end up anywhere which happened one time." (Visually impaired participant).

"I find I don't even bother asking the driver where to get off anymore. I've had too many bad experiences of not being told so I use my GPS if I'm ever on the bus and look out for my stop." (Visually impaired participant).

Not every experience was negative, some participants indicated a gradual improvement in the awareness of bus drivers over the past few years,

“They [bus drivers] are having awareness training too. Nowadays the drivers wait for you to get to your seat before moving off.”

(Visually impaired participant).

There have also been issues with the Police and a lack of awareness when it comes to arresting an individual who is deaf or Deafblind,

“People trying to sign, the police think they’re going to get assaulted so they put their hands behind their back.” (Deafblind participant).

It has been suggested that due to a lack of knowledge and awareness, public servants may not be providing the best service possible for sensory impaired individuals (du Feu and Fergusson, 2003, Dobbie et al., 2010).

Good practice point

Good awareness is most commonly demonstrated by Network Rail staff .

“The train conductors and managers are brilliant, they keep an eye on you and you can give them a shout if you need anything.” (Visually impaired participant).

(2) Communication

Communication encompassed a range of sub-themes including: access to external support; contact with local Councils; emergency service access and information in appropriate formats. Participants believed that improvements to these areas could enhance their quality of life.

Difficulties with communication continues to feature as a prominent theme in the literature (du Feu and Fergusson, 2003, Heine and Browning, 2004, Pavey et al., 2008, Smith et al., 2015).

2.1 External support

In order to facilitate communication, Deafblind participants rely on Guides/Communicators and Interpreters. Lack of Interpreters and insufficient time from Guides were raised as issues by many participants.

A dilemma exists for participants reliant on Guides if they need healthcare assistance without having a pre-booked appointment with a Guide,

“I get a Guide for Tuesdays to go to Deaf Club Bingo, on a Wednesday to go shopping and on a Friday to go to the Hamilton Deaf Club, and Saturday, but these are all linked to an activity. So what happens if I need to go to the Doctor tomorrow?” (Deafblind participant).

Some participants do not use Guides on a regular basis but would find them useful in certain situations. When asked for priorities for future service development one participant said,

“I’d like help with hospital appointments. The thing is you’re not able to hear when they call your name. Deafblind people have a Guide, but I don’t go to those types of things” [activities for hearing impaired individuals]. (Hearing impaired participant).

Moreover, Guides, although essential for getting around and to and from Doctors’ appointments for some participants, do not always have the level of communication skills needed for sitting in on Doctors’ appointments when the medical terminology and instructions can be complex and information can get lost. The Guides were clear this was not their role.

This has also been reported as a serious issue in a neighbouring Council (NHS Greater Glasgow and Clyde, 2013).

A suggested solution was,

“We should have qualified interpreters going to the Doctor”.
(Deafblind participant).

Hospital appointments can be made even more challenging when, “Some [Interpreters] just don’t turn up.” (Deafblind participant).

Lack of availability of Interpreters in certain situations can make people feel like “second class citizens” (Deafblind participant). In an emergency medical situation, participants who require an interpreter could be waiting two to three hours before an interpreter can be there, leaving them waiting in the hospital while they see, “non-sensory impaired people with the same health needs as them getting seen right away.” (Deafblind participant).

This is a common occurrence, with many BSL users admitted to Accident and Emergency (A&E) not provided with an interpreter (NHS Greater Glasgow & Clyde, 2013). Such situations can be equally traumatic for family members, particularly if they themselves are sensory or dual sensory impaired (for example, having to act as interpreters in serious medical situations).

Similar situations occur when dealing with Police Scotland. They regularly rely on family members to interpret in highly emotive situations.

2.2 Contact with local Council services

Many participants were unhappy with the degree or level of contact with local Council services, in particular with Social Work and other statutory services. Lack of contact with the Social Work Department also came up as a key issue in a previous report carried out in relation to Scotland (Skellington Orr and Leven, 2006). The main issues related to: lengthy waiting times for assessments, lack of information given out by services such as Audiology and the desire for a Deaf Officer in the Council.

The transition process from Children to Adult Services can be a stressful time for families. One participant whose son is currently in the 'transitions process' from Children's into Adult Services commented on this:

“...The local authority has got timescales for transitions but my son doesn't fit into their timescales because he's so complicated. Where he would benefit or people like him would benefit hugely, life or death, is if a budget for him was in place an awful lot earlier which would allow him to then employ his own staff or to get a placement and for that placement to provide the staff...” (Carer).

Other participants also feel frustrated as they do not have regular communication with Social Work.

“There are a group of families being missed constantly... I would like them [referring to Social Workers] to come to me with information.” (Carer).

Good practice point

There are organisations who can help with information and advice, such as PAMIS, an organisation which supports families of those with profound multiple learning disabilities (PMLD).

“PAMIS have been brilliant.” (Carer).

However there are other participants who do not regularly use local services, as they do not have information about them. It is especially difficult for those who have acquired a sensory impairment and are having to find out information on different aspects of rehabilitation such as lip-reading classes by themselves,

“The Audiologist should signpost you to the local Social Work Department. The hearing aids have been around for 30 odd years. Audiology doesn’t refer you onto the local authority and the kids are not signposted to the Deaf Children’s Society.” (Hearing impaired participant).

Participants also supported the notion of more integrated healthcare and social work systems to provide holistic care for individuals with a sensory impairment. The integration of systems is now underpinned by legislation in Scotland with the establishment of Health and Social Care Partnerships,

“Get the word out there to people who need hearing aids and let them know this will be available. We bring people in to introduce them to different services and the Council needs to think more and not have departments only dealing with one thing.” (Hearing impaired participant).

When discussing contact with local councils, Deaf Officers were mentioned as possible sources of information for hearing impaired individuals. When the council areas were under Strathclyde Region there was a Deaf Officer that covered Lanarkshire. Since the councils have been split up and the Deaf Officers have been replaced with Sensory Impairment Officers, many participants feel that a designated Deaf Officer is needed in addition to Sensory Impairment Officers,

“People will travel out of their way to go and speak to a Deaf Officer if they are deaf themselves, as they are speaking to someone who understands.”(Carer).

The desire for a Deaf Officer in the local Council was also expressed by another participant,

“I’ve been registered partially sighted and hearing for ten to twelve years and you don’t get information or help from the Council. They don’t have a Deaf Officer. Something should be done, we need somebody in the building. I mean somebody who understands us.” (Hearing impaired participant).

2.3 Emergency services

Emergency service access emerged as an issue for many participants. How would they get in contact with relevant services in case of an emergency? “Chap a neighbour’s door” (Deafblind participant), was a common response among participants. This was also an issue in public facilities,

“The big thing for me, for Deaf BSL users and hard of hearing people, there is no emergency access, and that stops them going to sports centres, the main public area and in the toilets, there should be alarms. Deaf people are often stuck in the toilet during alarms.” (Carer).

2.4 Information in appropriate formats

Receiving personal information in the right format is important to people. One participant described her experience of not being able to access her personal information as it was not in an appropriate format,

“It most powerfully struck me when I first became pregnant for the first time and I couldn’t read any of my pregnancy notes or any of the information around my pregnancy. I had minimal contact with the NHS before my pregnancy. When you’re in the system, once you’re pregnant, you have a lot more contact and I realised how little I was able to access.” (Visually impaired participant).

This was echoed by another participant,

“It’s not much good sending a letter to a blind person in standard A4 print. Need to understand the best format, large print, Braille, email, text messaging. A lot of Deafblind people use the text service.” (Visually impaired participant).

The desire to receive important health information was echoed in a separate report which found that 91% (213/223) of visually impaired participants felt they had the right to receive information regarding their health in a format that they could read (NHS Greater Glasgow and Clyde, 2013).

Good practice point

Specialist departments [associated with research] in the NHS have communicated personal information to participants in the appropriate format using email.

“I was part of a genetics study and all of my summaries of my appointments came by email, and they’re part of the NHS as well and they were able to do that for me because they chose to do it because they looked into that and wanted to do that for me, so it is possible.” (Visually impaired participant).

Other participants such as those who are Deafblind, stated that they often rely on family members to read their letters because they cannot access that information otherwise.

(3) Physical access

Physical access emerged as a major theme throughout the focus groups. This was discussed by participants in relation to safety when ‘out and about’, as well as transportation and local facility access.

3.1. Safety

Some examples given by participants expressed the need for more amenable health and safety practices in local facilities, as they can be prohibitive rather than protective in certain contexts.

An example is given here by a Carer.

“I was at the swimming pool last week with my daughters and the policy is that you’re supposed to stay by the shower pool... it’s probably up to my knees, but I’m not allowed to go any further with my daughter who is visually impaired even though I still want to keep an eye on my older daughter who can swim really well. I’ve decided it’s not worth going back because it’s not working for me. We could access a private pool but you want to be able to access your own local service.”

Another participant mentioned the issue of pavement parking, which is a serious safety hazard,

“It’s a nightmare. As somebody in a wheelchair or with a guide dog, we have to come off the pavement onto the road, because somebody has parked their car on a dropped kerb.” (Visually impaired participant).

Other issues with safety on the roads came up with regards to children. Two visually impaired participants wanted a crossing installed on their road to improve safety while crossing,

“We had debates with the Head of Planning and Transport. We had two little babies at the time and they assessed the road and vulnerability and said that there wasn’t a need for the crossing because there weren’t enough people crossing the road.” (Visually impaired participants).

“..Eventually they came back and offered a zebra crossing and we weren’t as keen on that but thought it was an excellent compromise. What they ended up doing was putting in tactile paving for us...”

“I suppose we wouldn’t want them to go away with the message that for example, if you put in lots of crossings then you’ve done your duty, because although that is important in terms of safety, in terms of what we have spoken about, it’s the awareness of people and the flexibility of policy that really needs to be looked at as well if we’re going to improve quality of life.” (Visually impaired participants).

3.2 Transportation

Transportation was also noted as a key issue for participants during focus groups with many relying on taxis, buses and trains to get around. Many visually impaired participants have received cars through the Mobility Scheme, however, their family member is not always available to take them where they need to go,

“...Feeling like you’re quite limited in how you can get around. You’re having to pay for taxis when other people could just jump on a bus. It’s just the way our situation is, he’s [husband] not there all the time, and it’s just family life.” (Visually impaired participant).

Another visually impaired participant has also received a car from the Mobility Scheme, but like the participant above, relies on his wife to drive him places such as to work,

“Well I would say the biggest gap I’ve got if I’m by myself is the car. When I was going to University it wouldn’t always suit with the hours she worked so I had to get the train myself.”

This leads to the issue of the accessibility of public transportation for those with a sensory impairment,

“You can’t see the bus when the bus comes forward so there’s no facility for someone who’s blind waiting for the bus. That’s a huge disadvantage. It’s the same at Central Station in Glasgow. I can’t see the board. I have to constantly ask somebody.” (Visually impaired participant).

Other participants rely on their knowledge of the bus routes to get off at the right stop,

“Sometimes I can remember through the bumps in the road when to get off and you get used to the bends in the road, but you have to pay attention.” (Visually impaired participant).

Utilising public transportation such as bus services can often be off-putting for sensory impaired individuals, as they are uncertain of how informative the bus driver will be and if they will get off at the right stop (Dobbie et al., 2010).

3.3 Local facilities

Sometimes local amenities are unsuited to the needs of severely disabled people,

“Would you lie on the floor in a public toilet to get changed? Well my son – who has complex needs - is expected to.” (Carer).

The same participant also had issues with ramp access in and out of public leisure facilities. There were steps at the front of the building and so they had to access the facility through the back door, “I wouldn’t go in the back door so why should I expect my son to?”

Access to equipment at local gyms can also be reduced and people can find it difficult to move around the gyms safely unless there is someone available to show them around. Some participants acknowledged they could exercise safely at home but feel they are losing out on the social aspect of attending a gym. Participants spoke about their desire to be shown round a gym, to give them confidence in getting about and in using equipment.

Loop systems not being installed in public buildings seemed commonplace. This reduces the likelihood of access by people who are sensory impaired when the system is either unavailable or not maintained properly,

“Loop systems are notorious, everywhere you go, banks, theatres, all ticking the boxes, but none of them work. They lie and gather dust. People who are trained move on and the new people don’t get training [in how to operate loop systems]”. (Hearing impaired participant).

Good practice point

Local (and non-local) organisations can promote access to facilities.

“Visibility Scotland are good. They brought me around and showed me all of the equipment they had. They help me out with my golf and provide red golf balls so I can see them in the grass.” (Visually impaired participant).

Also mentioned by one participant was the Linburn Centre in West Lothian. This centre is specially designed for those who are visually impaired and it promotes independence and creativity, offering art, craftwork and other skilled workshops.

(4) Social isolation

Living with a sensory or dual sensory impairment can be challenging, particularly with regard to social functioning. Increased social engagement was desired by almost all participants. The primary issues discussed in relation to this were social isolation regarding friends, family, co-workers and local communities.

Social isolation amongst young sensory impaired people growing up was another important issue discussed. Some felt included in their community and were accepted as part of the social group,

“I grew up in quite a small town and went to a mainstream school, so I was very much a part of the community. I had lots of friends ‘from the word go’ really”. (Visually impaired participant).

For others, they were excluded from a lot of social contact and engagement whilst growing up as they did not have the ability to initiate eye contact and start a conversation,

“I was the child with the white hair and pink eye at primary school. Now I’m older there seems to be more albinos and people are much more aware. As a baby you pick up on expressions through eye contact but there was not much point for me. So trying to interact with others was difficult... Socially it was not so great at school.”
(Visually impaired participant).

A parent of a child who is visually impaired also noted this as a barrier for social engagement for her son at school.

“He engages with others, but he doesn’t see others, so if somebody waves to him, he doesn’t know. He misses out on the social engagement aspect. I think kids should be coached on how to meet people, sometimes he sees what others are doing but he goes off on his own. It’s not picked up on at nursery. It’s an additional support needs nursery but to me they need more awareness of how to be in the world. At his school there’s a whole unit dedicated to these kids, why not spread knowledge and awareness?”

Social isolation was a common finding in previous reports on sensory impairment (Skellington Orr and Leven, 2006) and is closely related to a range of physical outcomes such as mortality and health behaviours (Holt-Lundstad, Smith and Layton, 2010); hence the importance of acknowledging the issue.

4.1. Personal relationships

Personal relationships with family members and friends can suffer as a result of sensory impairment. Individuals can experience feelings of isolation, even when surrounded by family and friends. Feelings of isolation and detachment in personal relationships in individuals with a sensory impairment have also been found in recent research (Lehane et al., 2016),

“It’s isolating for people. My mum became deaf but was previously a gregarious person who became isolated. If somebody had an accent she would not get it or answer inappropriately and get embarrassed. She stopped going to family gatherings.” (Carer).

“I tend to withdraw from company as you can’t distinguish 2 or 3 people talking at the same time.” (Hearing impaired participant).

Becoming Deafblind later in life can have a profound effect on lifestyle.

“Friends often avoid you because they don’t know what to say, they treat you like a leper.” (Deafblind participant).

4.2. Employment

Lack of support and engagement at work, as well as reduced opportunities for employment, put sensory impaired individuals at risk of isolation. Social isolation can again become an issue for older individuals with a sensory impairment as they can no longer work,

“Where I don’t get enough support is work. It’s a killer. My degree is in Human Resource Management and you would think the natural

progression for me would have been Personnel Manager. So I went to the shop I work in and I asked about a job as a Personnel Manager. They said, "You've got a problem with your eyesight we're not interested." (Visually impaired participant).

"There is not a lot of opportunity these days, there was more before when there was sewing factories and all that. We have the skills, we just put our head down and get on with the work." (Deafblind participant).

One Carer also expressed concern that when her son leaves his course he will find it tough to gain employment,

"I'm worried that he won't get a job when he leaves because he is deaf and employers won't give him a chance." (Deafblind participant).

For those participants who work it can also be isolating not to be involved in daily conversations.

"I think people under-estimate how important casual conversation is. I can't always hear what is being said so you are not involved in that relaxed conversation which is different than talking about work. People think you are antisocial but I enjoy company." (Hearing impaired participant).

Another participant also suggested that having a visual impairment at working age does not impact greatly on her mood and wellbeing,

“...But I work with people who are visually impaired and as they get older, that becomes an issue again. It’s OK when you are working, but as you get older you might be more isolated and have other conditions, so it has a greater effect.” (Visually impaired participant).

4.3. Local community

Many participants also spoke about feeling isolated and detached from their local community.

“I feel like a ghost, most of the time you’re on your own and nobody speaks to you. It’s as if you’re not there.” (Deafblind participant).

This was highlighted by participants who stated that there were not enough facilities in their local areas for individuals with sensory impairments to attend,

“The deaf community has gone back years. No specialist services. We don’t provide social work services for deaf people where they could go and communicate in their first language. There are a lot of deaf people isolated out there and mental health issues have increased as a result of the isolation.” (Carer).

In South Lanarkshire, a support group for sensory impaired people was set up by two of the participants. Although it is not funded by the Council, they do offer a discount on the hall where the group meets,

“We’re the only group [for visually impaired]. We used to be able to fundraise more when we were younger but not now.” (Carer).

And in North Lanarkshire,

“There’s a book club at Cumbernauld Library which five or six of us go to, and listen to CDs and discuss it. But that’s the only club going.” (Visually impaired participant).

“..Burns suppers, Christmas dinners, a community of deaf and Deafblind people and it has disappeared as the facilities are not there.” (Deafblind participant).

“When there were group activities at Deafblind Scotland it was more of a social thing, more community; more group activities is what we need.” (Carer).

4.4. Age-specific

Lack of activities to attend for young people and children with a sensory and dual sensory impairment was highlighted. This reduces young people and children’s opportunities to engage with others their own age. A parent whose child has dual sensory impairment with complex needs explained that her son had only accessed one service in his local authority. This group-based activity is available for children with disabilities from 5-12 years old, but there is no follow-on service.

Another parent whose child has a visual impairment believes local sports services could be adapted in order to improve access for her son and to allow him to engage with his classmates,

“Council services are a bit of a disgrace. My son has 1:1 swimming lessons, but there will be a point when he realises he’s not the same. He’s a wee chatty boy. I hope he gets more opportunity”.

“As a society we mix a lot in sport. As a child in P.E that’s your free time to go and enjoy and play and learn how to interact.”

There is existing evidence to support these findings. Children with a visual impairment may be at greater risk of social isolation in school than their sighted counterparts and may have problems developing friendships (Cambra, 2005, Hodge and Eccles, 2014).

(5) Adaptation to sensory impairment

Throughout the interviews information was gathered in relation to how parents/carers adapt if their child has a sensory impairment or if as parents, they are living with a sensory impairment. The research focussed on participants’ psychosocial and physical adaptation to their sensory impairment and/or their child’s sensory impairment. Participants spoke about addressing the emotional and psychological issues such as self-confidence and stress/anxiety, which can act as barriers to ‘adapting’. This can result in reducing access to services. The process of rehabilitation was also raised as an issue that people feel needs greater attention.

5.1. Self-confidence

“Your self-confidence takes a knock. I was made redundant from Scottish Power having worked my way up to foreman, but since the deafness came on I could not come back to that environment, dealing with hundreds of guys.” (Hearing impaired participant).

It also inhibits participants from accessing local services,

“I would never step into a pool but that’s to do with my confidence. If the fire alarm goes off I won’t hear it. Some people are nervous because of the over-riding fear of not understanding and being able to participate. So that puts you off.” (Hearing impaired participant).

Research indicates that sensory impaired older individuals are at a higher risk of depression and decreased autonomy in carrying out day-to-day activities (Corrado et al., 1993).

5.2. Stress/Worry

Stressful thinking patterns and worrying are common in sensory impaired individuals, particularly those with a dual sensory impairment (Högner, 2015),

“I find it bad when I have to go somewhere I don’t know. I have a satnav but also go on the computer to look at the map first... Simple things that should not really worry us.” (Hearing impaired participant).

Trying to re-orientate yourself in the world again can be difficult and stressful,

“It’s a nightmare...it’s taken away my life.” (Deafblind participant).

“Cannae cope with all the noise around me. Can’t get over my fear.” (Deafblind participant).

Yet others demonstrated a strength and resilience,

“A disability is what you make it.” (Visually impaired participant).

5.3. Rehabilitation

Rehabilitation was the term used by participants to encompass ‘after care’, such as training on using hearing aids and the development of after-care facilities such as lip-reading classes,

“..When I first realised I had hearing loss at 32, they gave me hearing aids but no prep to go into the world. Audiology need to get on board with after-care. The softer side of giving out equipment is only part of the job. For those with no hearing, when you get hearing with equipment it can be quite scary.” (Hearing impaired participant).

“It was very difficult to find support in North Lanarkshire and I had to travel to lip-reading classes in Glasgow.” (Hearing impaired participant).

“For me it’s essential that local Councils support lip reading and classes, and promote them.” (Hearing impaired participant).

Good practice point

One visually impaired participant was offered support to use his cane.

“...this lady’s a Social Worker who helped me enormously. She worked for South Lanarkshire Council and she would give me white stick training. We’d go up steps and all that.”

6. Results of the on-line survey (Warwick-Edinburgh Mental Wellbeing Scale)

The Mental Wellbeing Scale was developed in 2005, funded by NHS Health Scotland. It was selected for use in this study as it represents positive qualities of wellbeing and covers both feeling and functioning in the general population. In addition, the Mental Wellbeing Scale is preferred by service-users and their carers, in comparison with other mental health measures (Crawford et al., 2011).

The mean (average) Mental Wellbeing score for all participants in this Lanarkshire study was 41 compared to an average Mental Wellbeing score of 50 for non-sensory impaired adults and adolescents. This was in a study, which used survey data in relation to over 4,000 individuals (Mitchell, 2013). Huppert and Johnson (2010) found an average Mental Wellbeing score of 49.5 in adolescents aged fourteen and fifteen years old.

These findings suggest that individuals with a sensory or dual sensory impairment rate their emotional wellbeing lower than adults and adolescents who do not have sensory impairment. Further details of the findings are provided here.

Interpretation of results

As the Wellbeing Scale is a relatively new measure, there are no validated cut-off points indicating positive or negative mental health and wellbeing (Mitchell, 2013). In order to be able to interpret the scores of participants, guidance was followed from the Fourth National Survey of Public Attitudes to Mental Wellbeing and Mental Health (Scottish

Government, 2008). They used standard deviations to create a three-fold classification tool for Mental Wellbeing. This was above average Mental Wellbeing, average Mental Wellbeing and below average Mental Wellbeing.

Standard deviation is the spread of scores around the mean (average). In this sample the mean score for all participants was 41. The standard deviation was 13.6, letting us know that participant scores were spread 13.6 points above or below the mean.

Above average Mental Wellbeing was a score of over one standard deviation above the mean. Average Mental Wellbeing was a score within one standard deviation of the mean and below average Mental Wellbeing was one standard deviation below the mean.

Therefore:

- above average mental wellbeing of this population = a score of 55+
- average mental wellbeing for this population = between 28-54
- below average mental wellbeing for this population = 27 or less.

Most participants (n=45, 71%) fell into the average Mental Wellbeing for the population. A total of (n=9, 14.5%) participants were below average Mental Wellbeing and (n=9, 14.5%) had above average Mental Wellbeing. Female participants had a higher mean score than males as displayed in the table below. Females had a mean score of 46 whilst males had a mean score of 37. In addition, the lowest possible scale score is 14, which 4 males scored. The lowest scale score obtained for females was 23, suggesting a higher level of mental health wellbeing for females, even when examining the lower scale scores.

Table 6: Mean Scale Scores for Males and Females

	Gender	Number	Mean	Standard Deviation
Wellbeing Scale	Male	33	36.18	14.25
	Female	30	46.37	9.78

An independent samples t-test was conducted to examine whether this difference in male and female mean scale scores reached a significant level. The results of the test confirmed that there is a significant difference between males' and females' scores in this sample, with females having a higher Mental Wellbeing score than males, ($n=63$, $t= -3.33$, $p=.002$).

The range of scores for those who were sight impaired was 41- 69, for hearing impaired, 14-70, and for dual sensory impaired participants the range of scores fell between 18-59. The lowest score on the Wellbeing Scale for a sight impaired participant was 41, higher than both hearing impaired and dual sensory impaired participants.

Mean scores for all three groups and their mean scale scores are given separately here in Table 7.

Table 7: Mean Scores and standard deviations for participants with hearing, sight and dual sensory impairment

		N	Mean Scale	Standard Deviation
Hearing Impairment	Yes	42	38.36	13.85
	No	12	49.67	7.73
Sight Impairment	Yes	7	51.57	9.79
	No	47	39.28	13.37
Dual Sensory Impairment	Yes	9	42.00	12.12
	No	54	40.87	13.54

Comparisons of well-being scores between those participants reporting specific sensory impairments and those reporting no specific sensory impairment showed no significant differences within groups with sight (n=63, t=1.94, p=.06) or dual sensory impairment (n=63, t=.25, p=.80), but there was a significant difference amongst those with a hearing impairment (n=63, t=-3.64, p=.01). From Table 7 above it can be seen that despite this significant difference, both groups remain within the average Mental Wellbeing classification.

Further exploration of hearing loss demonstrated a statistically significant difference in Mental Wellbeing between participants with a mild to moderate hearing loss versus those with a severe or profound hearing loss (n=52, t=4.24, p=.01). People with mild to moderate loss had a higher mean score in Mental Wellbeing (n=8, m=52, sd=8.6) by comparison to those with mild to moderate hearing loss (n=44, m=37, sd=13.1). Higher scores indicate better wellbeing.

7. Discussion

The five major themes generated through the focus groups and interviews were: awareness, communication, physical access, social isolation and adaptation to sensory impairment. All of these themes are interlinked with wellbeing and positive mental health, particularly social isolation which many sensory impaired individuals are at risk of (Skellington Orr and Leven, 2006, Hodge et al., 2012, Hodge and Eccles 2014, Cruddent et al., 2015). This is particularly true for older dual sensory impaired individuals who are more likely to have lower-self reported health and are also at an increased risk for depression and low levels of social engagement (Crews and Campbell, 2004, Capella-McDonnall, 2005). This appeared to be the case in our study, with older participants lamenting the lack of group activity available to them and a diminishment of a sense of community.

Awareness is also closely related to wellbeing and mental health. Not being able to read body language and engage in eye contact can negatively impact on an individual's sense of self (du Feu and Fergusson, 2003). In addition, a lack of awareness from others, such as frontline staff as well as public servants, as found in this report, can impede practice (Smith et al., 2014, du Feu and Fergusson, 2003), which has an impact on both psychological and physical wellbeing. The continued implementation of awareness training for frontline staff could have a positive effect on sensory impaired individuals' sense of self, as they become more aware of their own role for self-care and treatment through enhanced communication.

Communication was a major theme to emerge from the data which also has an impact on wellbeing and mental health (Tambs, 2004). Increasing communication can be implemented through different avenues, such as

information being distributed in an appropriate format. Actions such as this promote the inclusivity of sensory impaired individuals into society and may serve to ease the frustration felt by many participants in this study.

Gaining physical access to services emerged as a challenge. Disabling environments such as those discussed during the groups and interviews, can make it difficult for participants to engage with local services and use facilities. This negatively impacts on quality of life, wellbeing and mental health through reduced independence and the ability to socialise.

Physical activity in general is associated with increased health related quality of life, as well as improved functioning (Penedo and Dahn, 2005). Working to improve physical access to buildings and activities therefore can have a positive impact on participants' sense of wellbeing and quality of life.

Adaptation to sensory impairment proved to be more of a psychological challenge for participants. This was mainly an issue for individuals who had acquired a single or dual sensory impairment later in life, where they were having to go through a process of re-orientation in the world.

Everyday functioning (for example, leaving the house and going for a walk) was quite an issue some participants; this is recognised elsewhere as a key feature of psychosocial adaptation (Wahl et al., 2013), and can take some time depending on individual personalities and circumstances.

In order to provide a more holistic picture of participants and their wellbeing, all participants were invited to complete the Warwick-Edinburgh Mental Well-being Scale. Results indicated that the mean (average) score for participants in this project was below the mean score of other non-sensory impaired samples. This reduced Mental Wellbeing was also

demonstrated through expressions of stress and low self-confidence reported by many participants throughout the interviews. Other key findings emerging from the questionnaire included females having significantly higher average score than males and severely hearing impaired people having significantly lower mean scores than mildly hearing impaired participants.

In any study it is important to identify limitations. The sample selection process for this study was entirely dependent upon volunteers, consequently there is a likelihood for bias to occur in the results. There was, for example, an under representation of the younger sensory impaired population, despite repeated attempts to involve this group. This means we have to be cautious with the interpretation of results, because they may not be generalised to the wider population.

8. Conclusion

This joint project sought to explore the lived experience of people with a sensory impairment in North and South Lanarkshire. Although a number of gaps in service provision were identified good practice was also evident. Participants spoke about gaps in service provision but also more widely of their 'lived experience', of difficulties accessing private sector facilities, of issues in relation to their emotional wellbeing and how this impacts on their ability to be active citizens within their own communities and so on. Many of the findings do not relate to new issues, but they do provide up-to-date evidence on the current needs of sensory impaired individuals. The themes that emerged from focus groups and interviews are consistent with those found in the literature and are closely linked with awareness, communication, physical access, social isolation and adaptation to sensory impairment. If the proposed recommendations are

enacted this may help to provide the necessary improvements in communication, access to services, overcoming social isolation and enhancing adaptation and awareness. Consequently, these improvements will improve the quality of life, physical and psychological wellbeing of people that experience a sensory impairment across Lanarkshire.

9. Recommendations

Prioritised recommendations are listed below.

- provide basic sensory awareness training for public servants and frontline NHS and Council staff (eg: via LearnPro (online) modules). This could be further developed to include progressively more advanced awareness training for staff.
- invest in training for Guides and Interpreters to a minimum standard of Level 3.
- increase the flexibility of booking times for Guides, (eg: book same day).
- provide on-call Interpreters in hospitals, especially in Accident and Emergency.
- liaise with the NHS to consider the format of communication for people with a sensory or dual sensory impairment, when issuing appointments/results from tests.
- liaise with the NHS to introduce a password protected service to access personal information/results via phone.
- following assessment and upon initial diagnosis of sensory impairment, Audiologists and Doctors to signpost service-users to rehabilitation services.

- produce local newsletters as a way of delivering information to sensory impaired individuals' homes. A Sensory Impaired Consultation Group could ensure that only relevant information is included.
- utilise a text service for people who are deaf to alert them to local service works (for example, water being turned off in a certain Council area).
- consider provision of a designated Deaf Officer in the Council.
- consider how individuals with a dual sensory impairment contact services in an emergency situation.
- explore safety issues in public places (for example, swimming pools).
- improve audio-visual technology on buses and at bus stops in order to facilitate ease of access on public transport.
- introduce ramp access to all public buildings.
- introduce loop systems to all public buildings and ensure all are maintained at regular intervals.
- develop more local support groups/activities and support those already existing in North and South Lanarkshire, to promote social engagement and reduce isolation amongst adults/older adults.
- develop activities and groups specifically for sensory impaired children/young people (eg: sporting activity).
- improve communication with local services to streamline complex needs referrals, particularly in relation to young people at the transition stage.
- develop lip-reading classes in North and South Lanarkshire delivered by appropriate personnel.
- introduce a banner or ticket system in hospital waiting rooms.

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Appendix 1: Population estimates for North and South Lanarkshire

North Lanarkshire population estimates and projections

Age group	2019 projection	2024 projection	2029 projection	2034 projection
0 to 15	63382	61936	60312	59083
16 to 24	35345	34568	35309	34130
25 to 49	108297	103786	101019	98466
50 to 64	72441	73455	68504	63486
65 to 74	33981	35924	40398	44385
75 to 84	19882	22848	25162	27240
85 and over	6597	8456	10207	12790
Total	339925	340973	340911	339580

South Lanarkshire population estimates and projections

Age group	2019 projection	2024 projection	2029 projection	2034 projection
0 to 15	55,353	55,246	54,752	54,180
16 to 24	30,861	29,932	30,769	30,562
25 to 49	97,105	93,559	92,172	90,664
50 to 64	70,855	70,178	63,735	58,838
65 to 74	34,748	37,223	41,543	43,533
75 to 84	20,862	24,158	26,725	29,227
85 and over	8,330	10,170	12,223	15,137
Total	318,114	320,466	321,919	322,141

Projected number of deaf/partially deaf people in North Lanarkshire by broad age group

Age group	2019	2024	2029	2034
0 to 15	329	322	313	307
16 to 24	289	283	289	279
25 to 49	2263	2169	2111	1969
50 to 64	5730	5810	5411	5015
65 to 74	6116	6613	7271	7989
75 to 84	6362	7311	8051	8716
85 and over	3232	4143	5001	6267
Total	24321	26651	28447	30542

Projected number of deaf/partially deaf people in South Lanarkshire by broad age group

Age group	2019	2024	2029	2034
0 to 15	252	252	250	247
16 to 24	259	251	258	256
25 to 49	1,992	1,920	1,891	1,860
50 to 64	5,323	5,272	4,788	4,420
65 to 74	6,086	6,520	7,277	7,625
75 to 84	6,649	7,700	8,518	9,315
85 and over	4,010	4,896	5,884	7,287
Total	24,572	26,810	28,866	31,011

Projected number of blind/partially blind people in North Lanarkshire by broad age group

Age group	2019	2024	2029	2034
0 to 15	259	253	247	242
16 to 24	201	197	201	194
25 to 49	909	871	848	827
50 to 64	1666	1689	1575	1460
65 to 74	1733	1832	2060	2263
75 to 84	2385	2741	3019	3268
85 and over	1715	2198	2653	3325
Total	8868	9781	10603	11579

Projected number of blind/partially blind people in South Lanarkshire by broad age group

Age group	2019	2024	2029	2034
0 to 15	177	176	175	173
16 to 24	150	145	149	148
25 to 49	857	826	814	800
50 to 64	1,483	1,468	1,334	1,231
65 to 74	1,597	1,711	1,909	2,001
75 to 84	2,409	2,789	3,086	3,375
85 and over	2,185	2,668	3,206	3,971
Total	8,857	9,784	10,673	11,699

Appendix 2: The Warwick-Edinburgh Mental Well-being Scale.

Below are some statements about feelings and thoughts. Please tick the box that best describes your experience of each over the last two weeks.

Statements	None of the Time	Rarely	Some of the Time	Often	All of the Time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5

Statements	None of the Time	Rarely	Some of the Time	Often	All of the Time
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

Demographic questions

Age _____

Gender: Male/Female

Have you got a recognised hearing impairment?: Yes/No

If **yes** please tick the box that best describes your hearing loss:

<p>Mild hearing loss</p> <p>People with mild hearing loss can have some difficulty following speech, mainly in noisy situations. The quietest sounds they can hear average between 25 and 39 decibels.</p>	
<p>Moderate hearing loss</p> <p>People with moderate hearing loss may have difficulty following speech without hearing aids. The quietest sounds they can hear average between 40 and 69 decibels.</p>	
<p>Severe hearing loss</p> <p>People with severe hearing loss rely a lot on lip-reading, even with hearing aids. BSL may be their first or preferred language. The quietest sounds they can hear average between 70 and 94 decibels.</p>	
<p>Profound deafness</p> <p>British Sign Language may be the first or preferred language for people who are profoundly deaf, or they might communicate by lip-reading. The quietest sounds they can hear average 95 decibels or more.</p>	

Have you got a recognised sight impairment? Yes/No

If you have been certified as sight impaired please tick the box that best describes your level of certification:

<p>Sight Impaired-Partially Sighted</p> <p>Your sight falls into one of the following categories, while wearing any glasses or contact lenses:</p> <ul style="list-style-type: none">• visual acuity of 3 / 60 to 6 / 60 with a full field of vision• visual acuity of up to 6 / 24 with a moderate reduction of field of vision or with a central part of vision that is cloudy or blurry• visual acuity of 6 / 18 or even better if a large part of your field of vision, for example, a whole half of your vision, is missing or a lot of your peripheral vision is missing.	
<p>Sight Impaired-Blind</p> <p>Your sight falls into one of the following categories, while wearing any glasses or contact lenses:</p> <ul style="list-style-type: none">• visual acuity of less than 3 / 60 with a full visual field• visual acuity between 3 / 60 and 6 / 60 with a severe reduction of field of vision, such as tunnel vision• visual acuity of 6 / 60 or above but with a very reduced field of vision, especially if a lot of sight is missing in the lower part of the field.	

If you experience any other visual impairment please describe

Do you have dual sensory impairment? Yes/No

Many thanks for participating in this survey and answering these questions.

Appendix 3: Consent form



4.9.15 - Version 3

This form is also available in large print and with audio embedded

Consent Form

Title: An exploration of the provision of assessment, care and support to children and adults with a sensory impairment in North and South Lanarkshire, Scotland.

In signing this consent form

I confirm that I have read and understand the information sheet dated _____ for the above study and have had the opportunity to ask questions and to have these answered satisfactorily.

I will be invited to complete a short well-being questionnaire on a web-site and to attend and participate in a group meeting within my locality to discuss my experiences of sight/hearing difficulty and the services that I receive. This information will not require my name.

I understand that my involvement in the study is voluntary and that I am free to withdraw from the study at any time, without giving any reason, without any effect on the services I receive or legal rights being affected.

I understand that the principal investigator (Mick Fleming) will ask me to complete the web-based questionnaire and ask me some further open questions to generate discussion within a focus group.

I understand that the principal investigator (Mick Fleming) will ask me to complete the web-based questionnaire and ask me some further open questions to generate discussion within a focus group.

I agree to take part in the above study.

Participant signature _____

Date ___/___/_____

Principal Investigator signature _____

Date ___/___/_____

1 copy for participant; 1 copy for researcher

Appendix 4: Information leaflet



25.9.15 Version 7

Mick Fleming,
Institute of Healthcare Policy and Practice,
School of Health, Nursing and Midwifery,
Ayr campus, University Avenue,
Ayr.
KA8 0SX

Participant information leaflet - this is also available in large print and with audio embedded

You are being invited to take part in a research study about the provision of assessment, care and support to children and adults with sight and/or hearing difficulties in North and South Lanarkshire. This information sheet gives you the information that will help you decide if you would like to take part in the study.

Who is conducting the study?

- the study is being organised by Mick Fleming, Researcher in the Institute of Healthcare Policy and Practice at the University of the West of Scotland on behalf of North and South Lanarkshire Councils.

What is the study about?

- it is important to understand how having sight/hearing difficulties affect the feelings of people and the experiences of people regarding the provision of services. To do this I need to ask groups of people and parents of children what their experiences of receiving specific health, social and voluntary services have been. At the same time, it is

important to assess the feelings and well-being of people with sight and/or hearing difficulties so that it is possible to check on any future changes. North and South Lanarkshire Council are very also interested to learn more about people's experiences and their needs so that they can ensure their future health, social and voluntary services are designed to help people better than they do now.

If you agreed to help with the study, what would you be asked to do?

- if you are interested in helping with the study, you will be invited to complete a short well-being questionnaire on a website that will ask you about how you feel generally and some other general questions about how old you are, your sight and/or hearing difficulties and how these affect your lifestyle. There are no right or wrong answers and the information you provide is private and confidential. No one else can see how you have answered the questions and your name is not needed so your involvement is not known to anyone else. I will ask you if you require any help with access to the website and with adding your answers to the questions. Further help will be provided by North and South Lanarkshire councils such as having sound embedded into the questions to help you answer the questions.
- you will also be invited to attend one group meeting that will be held in the University of the West of Scotland, Hamilton Campus. The costs of transport to the meeting will be reimbursed. For people who feel that they are unable to communicate as well as they would like within a group a number of individual interviews will be offered. The required access support will be offered for these interviews.

- one of the group meetings will be held for you if you are 16-18 years of age. This particular group will only be for people of those ages. Therefore, if you are 16-18 years of age you will be in a group made up of people of the same age as yourself. This group meeting will be held within either North or South Lanarkshire, I will notify you of the actual venue when this is confirmed. The costs of transport will be reimbursed. If you are in this age range please feel free to discuss your interest in the study with your parents or the people that look after you.
- a different group will be held for parents or those people that look after children up to the age of 18 years with sight and/or hearing difficulties. This group will be held in your locality and the costs of transport will be reimbursed.
- each group will be made up of you and five or six other people that also have a sight and/or hearing difficulty or are parents or people that look after children with a sight and/or hearing difficulty. The group meeting will last about two hours and there will be comfort breaks every 40 minutes. As a group, you will be asked about your experiences of receiving services and the type and structure of services you would like to receive in the future. Prior to attending the group I will ask you if you will require help such as BSL, or Palan typist, to participate fully in the group discussion. This help can then be organised and provided for you by North and South Lanarkshire Councils.
- at the end of the group meeting, I will check to see if discussing your experiences has caused you to be distressed and I can offer emotional

support. You will be encouraged to contact me if I can offer further emotional support following the group meeting.

- the discussion will be audio-recorded and a research assistant will take notes of the discussion within the group meeting. The information you provide will be included in a report that will be presented to North and South Lanarkshire Councils to help them to plan future services and may be used for publication in a scientific journal.
- the audio recording will only be listened to by the research assistant and me. All the information that you provide will be held at the University and be encrypted and stored on a password-protected computer.
- you will not be referred to personally in any written document and so at all times your identity will be protected. There will be no detail that could identify you. Once the study has been completed, the information will be destroyed.

What if you want to withdraw from the study?

- the study is optional (voluntary) you do not have to be involved if you do not want to and you can withdraw from the study at any time. The study itself is separate from any services you receive and so if you do not wish to be involved in the study this will not affect any services you receive from the Council or other provider. If you do consent to participate in the study initially but decide to withdraw at a later date simply let me know. My contact details are at the address at the top of the information leaflet. Please contact me anyway if you have any questions about the study.

What will you gain from the helping out with this study?

- many thanks for considering helping out with this study. Letting me know about your experiences of sight/hearing difficulty, your specific needs and your views of the services you receive will be passed onto North and South Lanarkshire Councils in the form of a report. In this way, you can help to shape the future content and delivery of services for people with sight and/or hearing difficulties.

What happens after the study is completed?

- North and South Lanarkshire Council will use the information in the report to plan the delivery of future services in a way to ensure they satisfy the needs of people with sight/hearing difficulties more effectively. The information that comes from the study may be helpful for people outwith North and South Lanarkshire, publication in a scientific journal can help to convey this information to a wider range of people to help them to plan services in other parts of Scotland or in other countries.
- once I have completed these tasks, the information will be destroyed. If you thought it was appropriate I would like to come back to see you to tell you about the findings from the study and what they mean for the development of future services. This can be arranged through North and South Lanarkshire Councils.

Dr Mick Fleming

Appendix 5: Interview Schedule

A. Introductions

B. Confirmation of study aims, requirements, voluntary nature of the study and right to withdraw. Reminder of web-based survey

C. Formulation of ground rules

D. Semi-structured questions/prompts for focus groups

1. To develop an understanding of the lived experience of living with sensory impairment in relation to well-being and access to services.

What is it like living with a sight/hearing difficulty? How do you feel that you cope/how much does your sight/hearing difficulties influence?:

- your level of functioning, education, employment and leisure
- your feeling of happiness, positivity, feeling of security, overall health,
- your life satisfaction,
- your access to services

How does that make you feel?

How would you describe your access to services provided by local authority, health board and voluntary organisation?

2. Identify gaps and barriers in service provision for people with a sensory impairment in your local authority, health board and voluntary organisation.

- how would you rate/describe the quality and effectiveness of services provided by your local authority, health board and voluntary organisation?
- did you have any problems accessing any of these services/how would you describe access to these services/what factors influenced your access to these services?
- what gaps do you think there are within the services provided by your local authority, health board and voluntary organisation?
- what changes/improvements would you like to see to services for people with sight/hearing difficulties?
- what do you think the priorities are for future service development for people with sight/hearing difficulties?

3. To identify areas of helpful and effective practice and service provision for people with sensory impairment.

- can you describe examples of helpful and effective practice and/or service provision that you or someone you know has received?

E. Closure

- Summary of key points
- Process of analysing data
- Any questions

Many thanks for your help.

If you need this information in another format or language,
please contact us to discuss how we can best meet your needs.

Phone: 0303 123 1015

Email: equalities@southlanarkshire.gov.uk