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*PROMOTING AND MAINTAINING HEALTH
OF PEOPLE WITH SIGHT LOSS:
A SCOPING STUDY*

Prepared for the Thomas Pocklington Trust

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Executive summary

This study was undertaken in response to a request by the Thomas Pocklington Trust to identify and explore the following issues:

- The needs and concerns regarding immediate risks to health and safety related to sight loss;
- Additional risks arising from sight loss for those who are also managing a long term disease;
- The difficulties in maintaining and promoting health;
- Whether or not health promotion activities and policies sufficiently address perceived needs.

Findings pertaining to these objectives have been generated from data collected in Leeds, UK, a city where innovative programming for sight loss has either been planned or is being incorporated into health planning and a review of the literature. Findings related to the last two issues indicate that gaps exist in service provision for maintaining health and emphasise the need for more explicitly targeted health promotion initiatives that could address current weaknesses.

Four qualitative methods were adopted to explore the issues:
- A review of the literature;
- Focus group discussions with a range of people who had experienced sight loss;
- Interviews with professional practitioners engaged in service provision to this population;
- An expert hearing with four professional practitioners, one of whom had sight loss, and two service users with sight loss. Most participants were from the West Yorkshire region and the services described in the study are largely located in Leeds.

Evidence from the literature review suggests that people with visual impairment have increased risk of accidents within the home and that ensuing consequences include injuries incurred and decreased confidence. Rates of depression among people who are blind or partially sighted are far higher than in the wider population and the likelihood of depression increases with age, although psycho-social interventions and technological assistance can be successfully implemented to improve quality of life. Sight loss together with other long term health conditions exacerbates the impact of other health conditions and has particularly severe impact on the wellbeing of older people insofar as it may affect their mobility, which in turn increases their risk of falls and depression. The nature and level of support available to people is variable but it is clear that access both to the right information at the right time and to appropriate services is a critical issue.

Focus group discussions, interviews and the expert hearing corroborated and extended the themes noted in the literature and discuss the differential impact of different risks to health and the difficulties of coping with these at different times in a person's life. A simple typology was defined using two dimensions of experience ('stage of life' and 'early/late onset of sight loss') as a means of organizing findings and providing a means of making further distinctions in interpreting the data. Potentially, this scheme can allow health promotion initiatives to be targeted more effectively to stages at which people with sight loss are more likely to encounter specific difficulties in managing and maintaining their health.

There was a clear consensus throughout the study that interventions to meet the needs of people with sight loss must be tailored to meet the specific needs of individuals: people with sight loss

are not a homogeneous group and the way in which each person experiences the challenges of sight loss and of managing their health will inevitably vary from person to person.

Recommendations generated by this study include:

- The scope for more pro-active services and need for closer collaboration between service providers;

- The need for provision and promotion of targeted information;

- The need for greater awareness of the needs of people with visual impairments among generic service providers; and

- Further research that explores the usefulness of the typology with a larger sample more representative of population demographics such as BME communities that are more likely to slip through the cracks of service provision.

1. Literature review

The purpose of this rapid review of the literature was to generate a clearer understanding of the following four areas of enquiry:

- Health & safety issues affecting people with sight loss;

- Sight loss and co-morbid conditions;

- Difficulties in maintaining and promoting health; and

- Health promotion and sight loss.

Bibliographic databases were accessed to identify studies for inclusion in the rapid review; of an initial 1,300 identified references, 68 are cited in the report.

1.1 Health & safety issues and sight loss

Some of the most commonly-occurring challenges / risks to the safety of people with sight loss have been identified in research (Pey *et al*, 2007; Green *et al*, 2002; Nelson & Barrack, 2001), including reading labels (e.g. food / medication); setting controls on appliances; making a hot meal / drink; going to the doctor / dentist. Participants who live with family / friends appear to be more likely to have difficulty with preparing hot meals, organising possessions and setting controls on appliances. Increased age adds to the challenges because age is associated with other long term conditions; twice as many older people attributed their difficulties with maintaining safety to these additional conditions (op cit, 2007).

The increased likelihood of people with sight loss falling and suffering an injury or reduction in their confidence was identified (Campbell, 2005; Jutai, *et al*, 2005; DoH, 2001; Lord & Dayhew, 2001; Legood *et al*, 1980), with older people with sight loss being more prone to falls than their sighted counterparts (Crews & Campbell, 2001). The reasons for the increased incidence of falls among people with sight loss include: their failure to see obstacles; their tendency to over-correct in anticipation of encountering obstacles; and their lack of strength / balance. People with sight loss also appear more likely to cause or sustain an injury from a fire (USFA, 1999).

The emotional impact of sight loss has been highlighted in a number of studies (e.g. LVSCG, 1999; Dale, 2008), with rates of depression among people who are blind or partially sighted being far higher than in the wider population (Burmedi *et al*, 2002). The risk of people with sight loss experiencing depression increases with age (Evans *et al*, 2007; Verstraten *et al*, 2006), although a range of psychosocial interventions have been shown to improve the quality of life of older people suffering from sight loss (Birk *et al*, 2004; Horowitz *et al*, 2006). Crucially, it has been found that it is necessary to support people with emotional issues relating to their sight loss

before condition-specific interventions (such as mobility training) are likely to work (Brouwer *et al*, 2008; Rovner & Casten, 2001). As with other risks, family and friends have been identified as a key source of support to minimise the emotional impact on people with sight loss (Rees *et al*, 2007).

1.2 Sight loss and co-morbid conditions

People with sight loss are more likely to have multiple types of disabilities and to have more severe conditions than the wider population; their ability to manage these conditions is impaired by the fact that they are more likely to live alone (Gold & Shaw, 2008; Pey *et al*, 2007). Consequently, they are more likely to require assistance with everyday activities than the overall population of people with other disabilities, and those with sight loss are also more likely to have their needs unmet (unless they live with other adult family members (op cit, 2007). Conditions found to have a higher incidence among people with sight loss (Crews & Campbell, 2001; Crews *et al*, 2006) include: strokes; diabetes; osteoporosis; depression; confusion, disorientation and forgetfulness. Older age is also associated with these co-morbidities and the impact of these conditions can be particularly severe (Riddering, 2008) particularly for those conditions that affect people's mobility, which in turn increases the risk of falls and depression. Dual sensory loss has been found to compromise not only communication but also other key aspects of functioning, impacting in particular on orientation and mobility, psychological wellbeing and social participation (Brennan & Bally, 2007). The impact of dual sensory loss is especially significant on independent navigation, although physical training programmes have been shown to reduce this in the short to medium term (Surakka & Kivela, 2008).

Sight loss has also been shown (Lawrence *et al*, 2008) to compound the symptoms of dementia and can affect all aspects of life including increasing disorientation and impaired judgement, increasing the loss of independence and risk of isolation, and resulting in a greater reliance on carers.

The incidence of sight loss among people with learning disabilities is higher than among the wider population. The additional impact of sight loss may result in people with learning disabilities becoming depressed and anxious, and exhibiting more challenging behaviour (Levy, 1984; Willetts *et al*, 2007). Appropriate vision screening and early interventions have been shown to be particularly important for these individuals (Owens *et al*, 2006; Ryan *et al*, 2007), because they are likely to need most help in devising coping strategies. As well as ensuring that low vision staff understand the needs of people with learning disabilities, it is important that the provision of support (including information, training and aids) is suited to their individual needs. The specific needs of children with sight loss and autism have also been explored (Kern *et al*, 2005) and staff are urged to persevere in offering assistance to them because they may be more prone to fear of failure, frustration and lack of control than other people with sight loss; children's general

inexperience makes this assistance even more vital.

1.3 Difficulties in maintaining and promoting health

Because of the greater prevalence of co-existing conditions among people with sight loss, for example diabetes and blindness, than in the general population – one study found that there are small but significant health differences across age groups among people with sight loss and that these people are liable to experience poorer overall physical health at all ages (Pey *et al*, 2007). But even for those without a co-condition, many of the difficulties in maintaining health can be inferred from previous sections. The health and safety issues noted previously imply for example that if reading medication and food labelling is challenging because of lack of accessible, appropriate information, then engaging in these activities is not only difficult but potentially dangerous. Difficulties in maintaining emotional health are equally significant because one's sense of self and identity are challenged in different ways over the course of having a sight loss condition. Being able to access information and support at critical times such as when a diagnosis of deteriorating sight is given and during the initial period of learning to adjust to sight loss is considered to be crucial (MIND, 1999). However, for those who do not receive a diagnosis early enough in their condition, coping with sight loss 'comes at a cost' in terms of its impact on health, work and relationships (Green *et al*, 2002). Particularly, although not exclusively among older people with sight loss, the increased potential for social isolation due to lack of mobility also threatens emotional health (FMR 2002, Or *et al*, 2006, Cook, 2006).

1.4 Health promotion and sight loss

The nature and level of support available to people with sight loss has been shown to be variable (Douglas *et al*, 2008; Jutai *et al*, 2005); with generic social welfare and specialist eye care professionals as well as volunteers identified among the sources of support. The key areas of support which can be provided can be grouped under the following headings:

- Low vision devices and aids, and assistive technology;

- Orientation and mobility training;

- Education, vocation and awareness programmes;

- 'Visual training' and general understanding of visual impairment;

- Counselling / emotional support;

- Direct and indirect support for family members; and

- General advice and financial support.

Issues around take-up of support have been identified, with very low uptake levels and a fall-off in access to services after initial registration. Satisfaction levels, however, appear to be high, which has been interpreted as suggesting that the expectation levels of people with sight loss are low

(Douglas et al, 2008). It is asserted by Percival (2007) that generic (and client-group-specific) support services need to be delivered in such a way that makes it easier for people with sight loss to access them.

The fact that people with sight loss are less active than their sighted counterparts has been highlighted (Crews & Campbell, 2001; Lamoreux *et al*, 2004; Brouwer *et al*, 2008). The areas of greatest restriction of participation by people with sight loss are associated with reading, outdoor mobility, participation in leisure activities, and shopping. Hence, the occupational choices, and independence of people with sight loss are affected negatively, as a result of which they attend fewer social activities and become more dependent on assistance. The impact of sight loss on participation / activity rates has been found to be compounded by the additional debilitating factors associated with older age and the experience of co-morbid conditions (Good *et al*, 2008; Crews & Campbell, 2004). Similarly, is has been found that children who are visually impaired have lower levels of health-related fitness than their sighted peers (Stuart *et al*, 2006), and that this is due in part to the limiting impact of parents' expectations or perceptions of barriers to their children's participation in physical activities.

Research into the mobility of people with sight loss (Kuyk & Elliot, 1999; Virgili & Rubin, 2009) indicates that it is inappropriate to draw generalisations about their mobility performance, and that interventions to facilitate the strategies they use to compensate for sight loss may need to be highly individualised. The use of tools such as the Independent Mobility Questionnaire (Turano *et al* , 2002) offers the potential to plan appropriate interventions.

Variations in the impact of sight loss on an individual's functioning have been found to depend on their age when the condition occurs (Monegato *et al*, 2007). People with congenital conditions have been found to perform better in visual-spatial tasks than similarly aged people who become visually impaired later, and it is suggested that the better performance of visual-spatial tasks in the former group is a function of stronger compensatory mechanisms. This implies that interventions (or degrees of intervention) may need to be tailored to the different ages at which people develop visual impairment in order to enable them to develop compensatory responses to their new condition. Other research (Dale & Salt, 2008; Andrews & Wyver, 2005) has identified the importance of early (health promotion) interventions for children diagnosed with sight loss to minimise the potential for the development of behaviours and other developmental problems that are similar to those in the Autism Spectrum Disorder.

The health information needs of visually impaired people have been highlighted (Beverley *et al*, 2004; Moore, 2000; BCA, 2006), and grouped under a number of themes, including: information for healthy living, information about visual impairment and coping strategies, information about accessing health services, and information about finances / benefits, housing and employment /

education / training. The impact of sight loss on an individual's ability to access health promotion information is emphasised in particular, and it is suggested that a more co-ordinated approach to the provision of information to people with sight loss is needed, especially between health, social care and information providers. While as individualised an approach as possible is recommended, differentiation between the likely requirements of different groups (with an emphasis on the needs of children, older people, newly-diagnosed people and carers) is also indicated. The importance of improving information on foodstuffs is also highlighted (Sokol-McKay & Michels, 1989), in order to enable people with sight loss to make informed choices about their diet.

Other references emphasise the importance of providing people with sight loss with the right information at the right time (HPE, 2001; Nzegwu, 2005; LVSCG, 1999; RNIB, 2008) in order to maximise independent living.

Making better use of existing service centres (such as GP's surgeries) and using a multi-disciplinary approach to providing support are ways which can maximize the impact of health promotion interventions, particularly when working with children to help them develop compensatory skills (Gold *et al*, 2005; Kern *et al,* 2005).

Good practice

The need for health promotion interventions targeted at people with sight loss to address clinical and psychological issues associated with patients' conditions and wider health needs is emphasised (Crews & Campbell, 2001; Lamoreux et al, 2004; Suttie, 2007; Cimarolli & Boerner, 2005; Crews et al, 2006; Riddering, 2008). Suggested activities that might usefully be incorporated into health promotion activities for people with sight loss include friendship enrichment programmes (to limit the effects of social isolation), memory training, information and services that contribute to a healthy lifestyle such as home safety assessments and exercise programmes.

Existing programmes which have been identified as offering the potential for refinement to better meet the specific needs of different people with sight loss, and which can be delivered to groups or individuals, include the Expert Patient Programme (EPP, 2008). This appears to offer the potential to support people with sight loss in developing a systematic approach to developing coping strategies to overcome the challenges associated with their condition (Wilson *et al*, 2007). Similarly, the Health Trainer Programme (HTP) offers the potential to provide targeted support to individuals with sight loss (Visram & Drinkwater, 2005). Both are described further in Section 6.2.

1.5 Conclusion

The literature reviewed illustrates a number of health-related challenges specific to people with

sight loss, and incorporates examples of ways in which health and social care practitioners can improve the support they provide to their clients. Crucially, while the research reviewed highlights ways in which the needs of people with sight loss are experienced, literature (and practice) are also prone to referring to persons with sight loss as if they were a homogenous group. In part this may be more characteristic of quantitative than qualitative studies but it is worth re-emphasizing the need for interventions to be tailored as much as possible to meet the specific needs of individuals who, despite some commonalities, are diverse and experience the challenges of sight loss in individual and varied ways. Clearly there *are* approaches that offer the potential for increasing the amount or quality of support provided to enable people with sight loss and other long term conditions to promote and maintain their health. The following discussion begins by identifying the health and safety issues that participants in the study encounter in daily life (Objectives 1 & 2) and explores the difficulties they have in maintaining their health (Objective 3). Health promotion activities and policies (Objective 4) intended to address these concerns are subsequently examined in the context of service provision in Leeds.

2. Methodology

The qualitative methodology used in the study involved three methods of data collection (in addition to the literature review): focus groups, professional practitioner interviews and an expert hearing conducted after the preliminary analysis had been undertaken. Each is described below followed by a summary of how methodological issues were addressed.

The study participants are primarily drawn from people living, working and studying in Leeds and nearby communities in West Yorkshire. Although service provision for people with sight loss is differently distributed throughout the country, Leeds has the benefit of an innovative community-based public health and prevention strategy delivered by Leeds Primary Care Trust in which three sub-groups of the Leeds Vision Programme Team - Ophthalmic Public Health, Community Eye Care and Sight loss Services - are leading on the key priority actions for Leeds including:

- establishing and evaluating a network of 'Community Eye Champions' ;
- commissioning and evaluating a new integrated community eye care service;
- mainstreaming the Eye Care Liaison Officer (ECLO) service; and
- a contract review of voluntary sector sight loss support provision (UK Vision Strategy, 2009, p 6).

As such, access to support in managing sight loss as well as access to services informed by good practice is assumed to be more likely to be the case in Leeds than in less well served regions in the UK and, conversely, identified gaps in service may apply to an even greater extent in some other parts of the UK.

As a scoping study primarily focused on health promotion for people with sight loss, it may be useful to consider this research in the context of other developing research and practice, especially that regarding emotional support.

2.1 Focus groups

The initial aim was to conduct two focus groups, each of approximately 8 adults with sight loss. In the event 4 groups and one individual interview were held with a total of 23 participants (14 women and 9 men). This allowed different age demographics to be included, ranging from college students to older people (18-90+ years). The objectives were to investigate:

- Their needs and concerns regarding immediate risks to health and safety related to sight loss;
- Additional risks arising from sight loss for those who are also managing a long term disease;

- The difficulties in maintaining and promoting health; and

- Whether or not health promotion activities and policies sufficiently address perceived needs.

Recruitment and demographics of focus group participants

Participants were recruited through networking with local and national blind / sight loss organisations and centres (See Appendix 1).

Focus group/ interview	Number of participants (m/f)	Approximate age	Sight loss situation	Any other info
Interview 1	1 female	40s	Total sight loss	Not working, living independently
FOCUS GROUP1	9 participants – 6 women, 3 men	Older people – 60 – 90+	Ranged from some sight loss to total sight loss	Also had hearing problems. Majority lived independently.
FOCUS GROUP2	4 participants – all women	Middle aged	Ranged from some to total sight loss	3 were married, 1 not. All lived with family.
FOCUS GROUP3	6 participants – 2 women, 4 men	Late teens / early 20s	All had some or total sight loss	College students. All lived with parents / family
FOCUS GROUP4	3 participants – 2 male, 1 female	From mid 20s to mid 40s	All had some or total sight loss	Two married, one living with parents

All participants at the focus group discussions were read an information sheet (previously sent to them) detailing the project and their rights to withdraw from it. Each participant was asked for their consent prior to the discussion.[1] A small reward was subsequently provided to thank them for their participation.

Focus group schedule development

The Focus Group Discussion schedule (FGD) was circulated to Pocklington for comments and feedback prior to the focus group discussion being held. Questions focused on 4 key areas:

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[1] This study complies fully with recognised ethical practice in terms of informed consent, confidentiality, security of information, right to withdraw, and to Leeds Metropolitan University standards regarding the involvement of human participants in research; it received approval from the Faculty Research Ethics Committee prior to being undertaken.

- Information regarding personal circumstances (who they lived with – if anyone) and what they did with their time (work / study / volunteering etc);
- Health and safety issues they perceived for people with sight loss, where these issues tended to occur; whether they had any experiences they would like to share; coping mechanisms they used to address these issues; and what they thought could be done to improve their safety;
- Long term health conditions (to explore how people with sight loss manage when they also have other health conditions);
- Improving health (how sight loss affected their ability to live healthily in terms of diet, exercise; how sight loss affected how easy it was to live healthily; what initiatives would make it easier to live healthily and any health promotion or maintenance programmes of which they had experience).

Three of the four focus groups were electronically recorded[2]; detailed notes and quotes were written up immediately after. The data were subsequently analysed using thematic analysis, the results of which are reported in section 3.

2.2 Professional practitioner interviews

The aim of these interviews was to gain the perspective of professionals involved in service provision. The interview schedule covered similar areas to the focus group schedule but was adapted to focus on eliciting professional perspectives rather than personal experiences. Participants were also asked to discuss their role and its perceived impact on issues raised in the focus group discussions, and were asked about services available in the local area in terms of what their organisations provided, how services were accessed, barriers to use and potential improvements they felt were needed.

The interview schedule was developed by the research team and sent to Pocklington for feedback prior to the interviews being conducted.

Recruitment of practitioners

A snowball strategy was used to recruit potential interviewees who were initially selected from the networking process developed in the course of focus group recruitment. In total 6 interviews were undertaken[3]. A sample of respondents was compiled to reflect the variety of agencies providing support to people with sight loss in the city. Respondents included the

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[2] Recording problems made audio quality inaudible in one group.
[3] Although 8 interviews had initially been planned, an initial review of adult social services found that some of the intended interviewees faced the threat of redundancy and the decision was made not to add to their stress by asking them to participate.

following:

Interviewees	Role
Interview 1	Further Education College Visual Impairment Support Co-ordinator - RNIB
Interview 2	Hospital-based Eye Care Liaison & Information Officer – NHS Trust
Interviews 3+ 4	Senior Rehabilitation Officers – City Council
Interview 5	Resource Centre Manager – voluntary organisation
Interview 6	Health Promotion Strategic Manager - PCT

All interviews were recorded, transcribed and analyzed through thematic analysis the results of which are discussed below in section 4.

2.3 Expert hearing

The expert hearing was held after the preliminary analysis of data themes collected in the Focus Group Discussions and practitioner interviews. The aim was to extend the analytic and data collection process through an interactive method which could triangulate and refine the preliminary findings. In advance of the hearing, all participants were provided with a summary of key issues and questions which had arisen from the focus groups and interviews and were asked to reflect on these prior to the hearing. The hearing was recorded, transcribed and analysed in conjunction with the other primary data.

Expert participants were recruited to represent key stakeholders in the research, one on a recommendation from the Pocklington Trust, the others through purposive sampling.

Participant	Organizational Affiliation	Position
JP	Leeds Society for Deaf and Blind People	Specialist Worker
MF	Leeds City Council	Senior Rehabilitation Officer
JT	consultant	Occupational Therapist
GM	Kirklees	Rehabilitation Officer for Visual Impairment /user*
NR	Shireview Centre	Homemaker/user*
C	Park Lane College	Student/user*

*user of services/person with sight loss

2.4 Methodological issues

Sampling

As a qualitative study, the aim was not to create statistically significant findings about the

wider populations of people with sight loss. Therefore sampling was less about numbers of participants and geographical spread and more about the experience and meaning of sight loss and about participant's access to external services. In this regard, every effort was made to include a wide range of experiences, gender, age, ethnicity, extent of sight loss and/or role in providing services. This appeared to be successful in that one of the first comments made at the expert hearing was that "findings are typical of people across the country although carried out in Leeds".

Validity and reliability

Qualitative research has often been criticised for lack of reliability and validity. Validity was addressed by piloting the interview schedules, and through the analysis process. Reliability was addressed by recording all data collected. Research observations were recorded systematically during and after data collection and team meetings were held routinely to discuss emerging findings and their interpretation. Two researchers independently coded and identified initial themes in the analysis of the data to establish inter-rater reliability. Analysis and interpretation of the material used Framework Analysis, a case by theme method that uses a matrix to order, synthesise and summarise data for the purpose of abstraction and interpretation (Ritchie and Lewis, 2003).

3. Focus group findings

This section presents the findings from the four focus groups and the one interview conducted with adults with sight loss. Section 3.1 discusses the health and safety issues faced by people with sight loss/visual impairment. How participants manage long term conditions is discussed briefly in section 3.2 since most participants largely did not feel longer term conditions applied to them. Section 3.3 presents the participants' difficulties in maintaining health and their strategies for managing these challenges while Section 3.4 outlines suggested improvements to services, and by implication, the extent to which current health promotion activities address perceived needs.

The participants covered a wide age range with a bias towards women; seven lived independently and the balance with either parents or their own families as noted above. The majority of participants were either in full time education, retired or did not work. Most of the young and mid-aged participants had severe or total sight loss, generally since birth or early childhood. Most of the older participants had previously been sighted and experienced a range of degrees and forms of sight loss. Health status varied. Many of the older participants had hearing loss and other age-related conditions; some of the mid aged participants had a variety of health conditions; younger participants described themselves as fit and healthy.

Many issues of interest were raised, some directly related to the project's objectives, others less so. The emphasis of this section is on the most relevant themes to the project objectives. Other points of interest raised are outlined briefly but not discussed in detail.

3.1 Immediate health needs and concerns faced by people with sight loss

Trips / falls

All participants had experienced trips or falls caused by their sight loss. This was most commonly a problem outside their home or in unfamiliar environments. Inside their own home tripping or falling was less of an issue, unless visitors disturbed the normal layout.

The impact of such trips and falls varied. For some it was annoyance but was accepted as part of everyday life. For others it seriously affected their quality of life and health. How it affected participants' confidence appeared to relate to their previous experiences of falls and to their physical robustness.

For many participants the impact of tripping or falling had been substantial. One described damaging her spine from falling down the stairs. For another three very bad falls had required

medical attention and one had been left with reduced mobility in his left arm (critical given that he uses a guide dog). Most of the older participants described curtailing their activities due to a fear of falling. They talked about not going to a particular destination if it was unfamiliar or if it meant they had to go down steps, for example.

For many of the younger participants tripping or falling was treated as merely an annoyance; *"I'm not fussed, you just get used to it"*, minor cuts and bruising seemed to be perceived as inevitable. Their main concern was how they appeared to other people and the social implications. One young woman talked about the embarrassment of bumping into others *"they might think you are an idiot … if I walk into something I just think, god, I hope no-one saw"*. The young men were worried about getting into fights if the person they bumped into did not realise they were blind, *"if the person is bigger than you and you don't have any aids like a cane … then they are just going to kick your butt"*.

Common outdoor hazards leading to tripping or falling included:
- Steps (especially descending);
- Slippery surfaces, often caused by ice. Many participants described slipping on untreated pavements. One interview was repeatedly delayed because the interviewee was unable to leave her house due to icy pavements. Others had previously slipped on ice and some had required medical attention;
- Holes in the pavement, particularly because canes do not detect them.
- Unexpected items on the pavement (e.g. bins, parked cars). This was a particular issue in familiar areas where participants felt more at ease walking and then faced unexpected items;
- Street furniture e.g. bollards, "wet surface" signs;
- Items left by others on routes in shops e.g. baskets in aisles or half filled clothes rails;
- Other people. This was more of an issue if the participants did not have a cane or a guide dog which acted as overt signals of their blindness.

The most common reason given for tripping inside the home was other people leaving objects in the wrong place. Rugs and steps were also identified as potential trip hazards.

Food preparation

Food preparation was associated by most participants with a number of health and safety issues. Nearly all of those who cooked talked about burning themselves on the hob or being scalded by steam or boiling water. One participant talked about scalding himself with water from the kettle whilst others described the complexity of making a hot drink:

> *"when you're making a drink and it's sometimes near the end of the unit, and you've lost the ratio of where things are, and you're pouring boiling water from the kettle, and your liquid level indicator goes kaput and you keep pouring…"*

Chopping vegetables was also a potential hazard with participants aware of the possibility of cutting themselves.

Fire emerged as a major concern for some. One participant had set fire to the kitchen whilst making toast; she couldn't shut the oven door and, even though she couldn't see the flames, kept throwing wet towels on them to keep the fire under control whilst waiting for the fire brigade. For another participant's friend (who has sight loss) the front of a cooker had melted. Many participants talked about having smoke alarms installed.

The impact of these issues affected participants differently. Many of the younger participants rarely cooked, or only prepared simple items such as sandwiches. Whilst they were grateful for their parents' assistance (who generally cooked for them) they were aware that without learning to cook themselves they would not be able to live independently, *"I want a house at the end of the day, but I'm not allowed to cook!"*.

Many of the participants who did cook mostly used microwaves, often equipped with tactile dots or stickers to help them find the buttons. This meant they did not have to use a hob or an oven. Most participants were unable to use sight to tell when food was cooked or to read cooking instructions. They would therefore set the microwave at the same number of minutes for everything; this avoided the danger of eating under-cooked food but meant that much of what they ate was overcooked.

Others saw the kitchen as an area presenting particular challenges but felt capable of using the kitchen without causing harm to themselves or others. To do this they described needing to concentrate, "*I have to make sure when I am doing it (cooking) and say if the phone rings and if I am in the middle of something, I won't answer it because it's not safe … concentration has to be there*". They also used some adapted equipment; this is discussed in more detail in section 3.3.1.

One participant raised the issue of hygiene. He had not realised mice had been in his cupboards and in his pans until his daughter noticed.

Healthcare
Taking medication, particularly if that involved a number of different tablets through the course

of the day, was raised as an issue by some participants; *"pills are a nightmare"*. Most said the doctors and pharmacists were helpful and pills in different sizes and shapes reduced the chances of taking incorrect medication. Ways of managing medication included transferring all the tablets into daily pill boxes, "marking" the packets with tears or nicks or getting family to arrange medication for them. No one mentioned the role pharmacists can play in dispensing medication into boxes although this service avoids the dangers of significant error. One participant used an insulin injection pen and also had an audio blood sugar monitor but did not feel it necessary to use it, relying instead on experience to judge blood sugar levels.

Perhaps surprisingly, participants talked about how hospitals and staff working in them often seemed unable or unwilling to acknowledge or accommodate the additional demands of people with sight loss. For example, more than one participant recalled having been told to 'follow the black/yellow/etc. line/footprints on the floor', even though this was patently inappropriate. (It was acknowledged that reception staff might not always know they are talking to a blind person).

The communication of health related information emerged consistently as a concern. Particular issues included:

- Information leaflets accompanying medication being unreadable for people with sight loss. This meant that information about potential side effects was inaccessible;

- Medical appointment letters being sent in inappropriate fonts and formats. This included correspondence about appointments from eye clinics. Some patients were also given insufficient time between the letter arriving and the date of the appointment to obtain help to 'read' the letters, meaning they missed appointments; and

- Health related information leaflets not being easily available in suitable formats. It was noted that no central point existed locally for information about, for example exercise classes suitable for people with sight loss. (While this may not be the case, because Shire View[4] provides many information resources, that participants *felt* it was, suggests a lack of accessible information).

Some participants were dismissive of the nature and level of information that had been made available to them as a result of their diagnoses. It was noted that it was very important for people with sight loss to be told how to expect their condition to develop.

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[4] Appendix 1

There was a sense that the information provided by statutory and voluntary organisations was often inconsistent, and many participants agreed that "word of mouth is much better". For example, it was felt to be unhelpful that individuals were dealt with by more than one Rehabilitation Officer, and that the information provided was sometimes contradictory. The only organisation praised for the clarity and sensitivity of its information was Guide Dogs.

3.2 Additional risks in managing long term health conditions

Participants were asked what extra problems people with long term health conditions may have if they also have sight loss. Many participants found this difficult to answer. In some cases, this was because they had no direct experience of a long term health condition. Others indicated they didn't believe there was any necessary link between sight loss and other health conditions. The older participants pointed out that doctors were always helpful and explained things well and their families were willing to help. Two of the participants with diabetes felt capable of managing their conditions (perhaps because both had been diabetic before they lost their sight).

In Focus Group 1 one participant noted that everyone develops their own ways of coping. She felt however, that having two or more conditions would make it much more difficult to cope. This was re-inforced in another focus group where one participant had experienced a serious viral illness. This combination of conditions had made her increasingly dependent upon others and made her re-think her ability to live independently.

Some participants suffered from inherited conditions (that led to sight loss), and had passed them onto their children. One talked about how guilty she felt, even though she recognised this was "wrongly so". Another spoke of how resentful her son was of her for having him.

3.3 The difficulties in maintaining and promoting health

Exercise

Having a visual impairment or sight loss presented a barrier to taking exercise. Many stressed that whilst they wished to exercise they were unable to do this independently; they were either reliant on others to accompany them or on formal facilities to enable access. One participant who had recently lost his sight had put on 1 ½ stone and felt this was because he could no longer play football. He felt his choice of exercise was now very limited. Others emphasised how informal, impromptu, exercise was not possible for them;

> *"because you're blind and you've learnt the bus route you can't just randomly walk miles and miles if you don't know where you are going"*

"I like to do a lot of walking, if I know the place inside out, then I will walk for ever and a day. If I don't know it, difficult, very difficult"

Some participants talked about going walking as part of organised groups e.g. once a month in the Yorkshire Dales or even around Mont Blanc. These groups tended to be comprised of people with a range of disabilities.

Perhaps the most popular form of exercise discussed was visiting gyms. Most participants saw gyms as potentially a practical way for those with sight loss to be active. One participant talked about how much she had enjoyed her gym sessions *"I enjoyed it, I used to look forward to it"* before they were stopped. Significant barriers to using gyms however emerged. In the case of one woman the instructor who used to guide her had left and no-one had replaced him. Another had tried to join a gym and her mother had volunteered to guide her. However, the gym had insisted that her mother must pay as well, despite not wanting to use the equipment. Other participants talked about how gyms had imposed restrictions on what equipment they could use (e.g. weights) due to safety fears and the requirements of their insurers for people with sight loss to be accompanied. Such barriers created great annoyance: *"I'm blind, not stupid"*.

It was felt by many of the more confident participants that they were able to use gyms competently and safely if they were given some extra help at the beginning *"once you've been shown how to use gym equipment it's fairly easy"*. They pointed out that gym equipment tended to stay in the same place as it was so heavy. It was felt that if staff were given some training they would be able to help those with sight loss fairly easily. Other less confident participants did want more help in gyms but again thought this could be provided by their existing instructors with some extra training.

Other forms of exercise mentioned included tandem bicycle riding but this required a sighted person to assist. A few participants had swum but this required special sessions so they did not drift into other swimmers. Exercise classes had been held at Shire View (a local specialist facility), but it was felt these were only appropriate for older people as they were "seated" classes. One participant intended to join a local exercise class and would go with her sighted friend if the instructor was happy to have a person with sight loss attend.

Eating healthily
Most participants felt that sight loss did make it more difficult to eat healthily. Difficulties preparing food (see earlier section) meant that there was a tendency to eat more processed ready meals or to have a more repetitive diet. However, it was emphasised by some that they

did try to eat healthy, fresh food as often as possible.

Inability to read nutritional labels meant people were often unable to assess the healthiness or otherwise of particular foods.

Emotional issues

A number of emotional issues arising from participants' sight loss emerged.

Some participants talked about how they could find themselves getting depressed. This was particularly associated with not being able to get out;

"you can go down-hill, you do have days that you don't feel, you know… you don't want to do anything, you get depressed, especially with weather like this, when you can't get out. Because I like to get out."

Another participant talked about how the weekly group at the local Deaf and Blind centre was a "life-saver" *"otherwise I'd be sat at home crying and I'm a man".*

One participant described a number of negative emotions experienced since his recent sight-loss including anger, frustration and depression. Indeed, he suggested that he had felt the emotional impact of his diagnosis more significantly than the practical impact. The other participants in this focus group had been visually impaired since birth and as such felt it did not have as much emotional impact as sight loss had always been part of their experience.

Being reliant on family provided a particular challenge for many participants. They felt the emotional impact of their condition on family members was more significant than on themselves:

"… my disabilities have had a bigger effect on mum, dad (when he was alive) and my brother, really than me … I feel it's harder on the ones you love"

"It's been hardest on the family, because – whatever's been thrown at me – I've no option but to live with it, medically, visually, physically. Moaning isn't going to improve things is it? You've just got to get on with our life"

Reliance on other people also meant many participants experienced a lack of freedom. This was particularly evident amongst the younger participants who, whilst being grateful and appreciative of their families, also resented their inability to be spontaneous and carefree. For example, one participant talked about how she would like to be able to visit a club but felt she couldn't because she would not know how to get to the bar when the club was full of

strangers.

Reliance on strangers

The perceptions of strangers and the associated need to rely on their cooperativeness under some circumstances presented challenges for the participants. How these challenges were managed when out and about varied but it was generally agreed that there was considerable ignorance and naiveté exhibited by the everyday public. When asked what would most help participants be safer, one participant replied;

> "…apart from the public not being as ignorant .. they just stand there and you think, look there's a blind person coming towards you, it would be really useful if you would move".

There was a general feeling that strangers often felt there was 'nothing wrong' with the person with sight loss as they had no external signs of disability and comments had been received such as *"you can't be blind – your eyes moved".* Having a more aware public was felt to be very important; *"The key thing is awareness … and [they] have no perception of what being 'blind' means … especially as everybody is different."*

Many participants commented that members of the public were more accepting and happier to help when they had a guide dog or were using a cane. One participant had even made a badge with "person with limited vision" written on to ensure strangers modified their response. Others were happy to ask for assistance from strangers when needed.

This need to identify themselves as "blind" was a dilemma for some participants. They recognised the advantages but did not like being categorised; *"I want to be accepted as a person first, and somebody with a disability second".*

The issue of trust emerged as important as participants often found themselves in unfamiliar surroundings not knowing if the person with whom they are dealing is trustworthy. While all agreed that the vast majority of strangers are only too happy to help when asked, there remained certain situations where the element of trust was more significant; for example, when shopping in unfamiliar retail outlets, passing cash notes to strangers at the tills and hoping they would receive the correct change. The issue of needing to trust strangers at least occasionally also arose in the following section on coping strategies where it continued to elicit differences of opinions among the participants.

3.3.1 Coping strategies used by people with sight loss

This section discusses how participants try to keep themselves safe and healthy.

A: Behavioural changes

All participants talked about the importance of learned routes. This included learning how to walk from their home to the bus stop, to local shops or to college. They were generally assisted in this by a Rehabilitation Officer. One participant described how it had taken her half a day to learn a route from her new home to the bus stop; it was *"quite tricky"* because it involved lots of turns and going up and down pavements. Having to learn routes limited participants' ability to visit new places without assistance. As one participant pointed out, having more rehab officers would *"make us more mobile outside".* Another younger participant talked about how he was *"always keen to learn new places and new areas"* but found it more difficult if he had not been trained in the area.

Limiting where they travelled emerged as a key coping strategy. Some of the older participants were very constrained in where they would go – only going out locally or with a friend or family member. This related not only to their sight loss but also to general health problems and mobility issues. The young and middle aged participants were more mobile. Whilst one spoke about having *"no limits, as long as I know where the bus stop is and the bus is, I can go anywhere"*, most said they stayed in familiar areas but would have travelled more widely if sighted.

Limiting when they went out was also an issue. Some participants talked of adjusting their travel patterns depending upon daylight (one participant had albinism so preferred to travel at night) or how their sight was on a given occasion (one participant's sight varied from day to day). Weather also had an impact - icy pavements forced many participants to stay indoors during the study period.

Pace emerged as a key theme, with participants emphasising that they had to walk slowly in order to avoid accidents; *"you have to walk at a slow pace, which is annoying."* Similarly, the importance of *concentration* for keeping safe was emphasised. This related to such activities as cooking, taking the bus and navigating.

"Orderliness" was vital for those with sight loss. Nearly all the participants talked about the importance of having an organised living space to prevent falls and trips and to assist with daily living. When asked how she kept safe, one participant replied; *"make sure that everything is tidy, don't have things in the way".* Many participants had examples of occasions when the way in which they organised their living space was disrupted by visitors or family. The consequences had been at best disruptive / irritating, and at worst potentially dangerous; *"if they have left a chair or something that they have not put back, that's a hazard".* One participant's son had moved her ashtray and mobile phone away from their normal place,

as she pointed out; *"two feet might as well be two miles when you're not right good at seeing"*.

Participants talked about how they had developed their own methods for keeping themselves safe whilst performing everyday tasks. For example, most had developed their own ways of organising their medication (using pill boxes or marking packs). Similarly, participants talked about chopping vegetables in a certain way; one participant did not use a chopping board but instead held the vegetables as she chopped them as she felt less likely to cut herself this way.

B: Help from others

Having access to support from others clearly assisted participants in keeping safe and healthy. This support was provided from a range of family members, professionals and other members of the public.

Family

Family members provided a great deal of assistance to many participants. Those with the greatest level of support tended to be the younger participants, all of whom still lived with their parents. A number of the older participants lived with (or near) their children and were supported, to a greater or lesser extent, by them. At the other end of the spectrum, some participants had no family living locally. Participants tended to be appreciative of the support provided by their family. However, it was clear that some felt over-protected. One participant described a recent trip to stay with her brother in London where he would not let her travel alone on a bus: she *"couldn't wait to get home".* Younger participants talked about not being allowed to cook.

Professionals / specialist facilities

The support provided by professionals and local specialist facilities was discussed. The majority of participants were very positive about how such facilities provided opportunities for social interaction, a place to volunteer and to learn about new products or relevant services. Participants' requirements from the facilities varied. Older participants described them as a *"life-line"* as they were an opportunity to get out of the house and meet others in similar circumstances. Some of the younger participants however felt more emphasis was needed on "life-skills" than on socialising through day-trips or organised groups.

Some participants had had access to Rehabilitation Officers (ROs) to help them learn routes and gain information on types of equipment. It was noted however that the number of ROs had been reduced and as a consequence the quality of people's experiences varied, with some feeling rushed and others having the impression that staff were overworked.

Groups

Organised groups were mentioned by some. These were either social groups or based around an activity e.g. walking. Most were happy to participate but there were some reservations about mixing entirely with people with sight loss. It was recognised that whilst this was more comfortable for them it was preferable to also integrate with sighted people. This was not only better for them but also helped educate sighted people about the issues they faced.

Other working people

Bus drivers, gym instructors and shop staff all emerged as people that can significantly improve (or detract) from participants' attempts to keep safe and healthy.

Bus drivers were critical to participants' ability to be mobile. At times, they were mentioned positively but negative comments were common. This related to, for example, not being dropped off in the right place or not having their disability acknowledged. Positive examples of gym instructors were given – one had enabled a participant to be physically active and it was clear that her weekly session had been a highlight of her week. It was emphasised that gyms needed to be more accessible and basic staff training would assist in this. Helpful shop staff were critical as they had to be trusted with money and were needed for their assistance in finding products and negotiating their way around the store. Participants felt more at ease in shops and with staff that they were familiar with – either in local shops or using the access bus shopping scheme available locally.

Strangers

The issue of asking for assistance from strangers separated the participants. Some of the younger participants were clearly reluctant to do so. One talked about how he would not ask other bus passengers for help: *"they stare at you weirdly, thinking what the hell*." Many clearly felt embarrassed asking for help and wanted to be independent. Others actively sought help from strangers with one handing out cards saying he had a visual impairment. Another participant felt that trusting strangers was critical to her ability to get out, she was happy asking for help if she got stuck and that meant she was not afraid to go out.

Equipment

Participants described a range of equipment that helped keep them safe and healthy.

Mobility equipment used by participants included canes and guide dogs. Most participants used canes although some of the younger adults did not like to use them all the time. It was also pointed out that canes did not pick out everything (e.g. pot-holes). Sonar canes had been

used by two participants and were very enthusiastically received by one. One participant currently had a guide dog, another had previously owned one. It was noted that a major advantage of both canes and dogs was that they ensured other people knew the person using them was blind.

Adapted kitchen equipment such as talking microwaves, scales, liquid level indicators, special enclosed choppers and kettles in cradles were used by some participants. Levels of use and knowledge of them varied greatly.

"High tech" equipment such as the internet equipped with speech recognition was enthusiastically used by some participants. Others, however, emphasised that they were not "techy" and had not yet come to grips with their use.

Other equipment mentioned included: reading lights and magnifiers, audio blood sugar monitors and smoke / fire alarms.

The issue of cost arose in most of the focus groups. Many participants resented the high prices charged by manufacturers / retailers for adapted equipment and the fact that the information provided by for example the RNIB failed to take cost into account. An observation that it feels like you are "penalised for being blind" was agreed with by many.

3.3.2 Other themes

- A lack of money emerged as an issue for some. One participant, for example, was reluctant to put the heating on because of the cost. Others brought up the issue of the expense of adapted items (for example specialised cooking equipment);

- Issues of personal security arose. One participant had been burgled because since he had lost his sight he was unable to operate his door-locks. Older participants talked about being scared of being out due to their lack of sight and hearing. Younger participants were worried about becoming involved in fights when they bumped into other people who did not realise they were visually impaired;

- Many participants found using public transport (particularly buses) difficult. This tended to revolve around the refusal of bus drivers to acknowledge either that they were blind, or that they were entitled to free use of the service, or to accommodate their needs. Participants were fearful of mistakenly being dropped off in a strange area with no way of knowing how to get back;

- Shops were identified as a location that presented particular challenges. Other people and obstacles such as baskets and hanging rails were potential trip or bump hazards. In addition, participants described how irritating it was when shops changed their layouts *"you get used to a shop, your route around the shop and then they change it";*

- Bringing up children was discussed in one focus group. One participant with two children focused mainly on the positive aspects, identifying ways in which her children had helped her to overcome challenges associated with her deteriorating vision. For example, guiding her to places with better lighting or helping her to cross the road (from aged 3). Children were also felt to be more accepting generally.

3.4 Participants' suggested improvements to services

Improvements were suggested that would improve the ability of participants to live healthily and safely. These included:

Health and safety
- First aid courses to improve their ability to deal with cuts and burns;
- Improved knowledge and availability of specialist kitchen equipment; and
- Increased public education on sight loss/visual impairment.

Information provision
- Use of formats tailored to the individual (particularly for healthcare). Preferred formats include the telephone (particularly for appointments), Braille and electronic information;
- Improved consistency of information from service providers. The preferred sources for provision of information for specialist equipment matters were the Rehabilitation Officers. It was noted however that more ROs were needed for this to be effective; and
- A central point for information on local health promotion and maintenance resources. Shire View Centre and Centenary House[5] were identified as the best places for this.

Specialist facilities
- To provide both practical support (e.g. advice on equipment and teaching life-skills) and emotional support (e.g. groups, social interaction opportunities); and
- Consistent support and information from Rehabilitation Officers are needed.

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[5] See Appendix 1

Health improvement

Eating healthily
- Equipment to be more accessible (cost and knowledge);
- Access to classes to learn how to cook safely; and
- Better labelling of products.

Exercise
- Improve accessibility to gyms and leisure facilities – including staff training;
- More walking groups: for people with sight loss, people with other disabilities and people with no disabilities;
- Improved information about available exercise classes that are suitable for those with sight loss; and
- More Rehabilitation Officers in order to aid walking as exercise.

3.5 Summary of key themes
- The impact of health and safety issues encountered by people with sight loss is considerable ranging from social embarrassment to major injury; all participants felt that sight loss had a significant impact on their ability to live independently;
- The emotional impact of sight loss is substantial with depression, anger and frustration common, particularly in relation to lack of social contact;
- Improving health was felt to be particularly related to access to exercise and the difficulties experienced in shopping for and preparing food;
- Appropriately formatted information and training related to practical living need to be more available. Accessibly priced assistive equipment and opportunities for social interaction would also improve quality of life.

4. Practitioner interviews

This section presents the findings from six interviews conducted with practitioners employed by local agencies that provide services for people with sight loss. As with other areas of the research, various issues were raised; the emphasis of this section is on the most relevant themes to the project objectives. Other points of interest raised are outlined briefly but not discussed in detail.

Stakeholders' views were sought to investigate their professional opinions on:

- the immediate health and safety risks for people with sight loss;
- the additional risks arising from sight loss for those who also have a long term health condition;
- the difficulties in maintaining and promoting health for people with sight loss; and
- whether or not health promotion activities and policies sufficiently address the needs of those with sight loss.

In addition, the interviews were used to investigate services in the local area that aim to promote and maintain the health of people with sight loss, detailing current provision and identifying any gaps.

4.1 Health and safety issues

Respondents identified a number of factors contributing to the heightened risk of accidents experienced by people with sight loss, including the lack of information / visual cues (e.g. "*basic stuff*" focused on the public environment, such as things like low fences, unmarked steps, street furniture). The kinds of potential hazards identified by respondents as being likely to be encountered by people with sight loss were broadly similar to those identified by participants in the focus groups, and included the following:

- Kitchen ("knowing the 'on-off' or heat level on the cooker"; pouring hot drinks; preparing meals / chopping food);
- Mobility at home (getting round the house; using stairs; getting in/out of the bath);
- Mobility outside the home (judging where / when to cross the road safely; route planning; becoming familiar with using mobility aids; negotiating obstacles).

There was general agreement that there are often differences in the perceptions that people with sight loss have of their level of risk of accident, and that this is often age-based. For instance, it was felt that younger people can worry more about embarrassment than physical injury, whereas older people tend to worry more about hurting themselves.

Other issues identified by respondents as having the potential to make accidents more likely for people with sight loss included the following:

- An individual's lack of awareness of the danger(s) they face in any given situation, due to more limited visual stimuli; and

- People rushing as a result of feeling under pressure to perform a particular task (associated with an individual's sense of independence and/or frustration at their impairment).

Respondents provided examples of situations in which people with sight loss might be particularly **vulnerable**, including the following:

- Doorstep crime (especially for older people, who are already at heightened risk of this);

- Responding (in)appropriately in an emergency situation (increasing the need for people with sight loss to have fire safety checks in their homes); and

- Issues to do with trusting strangers. " … *if you get thrown off a bus at the wrong place [you] can end up having to ask people where you are …* " .

One respondent commented on the different experiences / vulnerabilities of people who have always been blind compared to those for whom sight loss occurs later in life, suggesting that someone who acquires sight loss in later life is "*going to be aware of the dangers out there but worse at avoiding them*". Similarly, it was suggested that someone blind since birth will "*have been taught since you were small*", whereas those experiencing sight loss in later life will have to *"learn blind skills".* Other respondents concurred with this analysis, with one highlighting the additional challenges faced by people experiencing sudden sight loss, and suggesting that they *"find it harder to re-train themselves".*

Health and safety: place
Most respondents felt that people with sight loss are less likely to have an accident in places familiar to them, with one suggesting that *"people tend to be more comfortable in their home environment … the anxiety starts when they go out".* On the whole, this was taken to mean that accidents are less likely to occur in the home or in other places frequented by the individual (such as: work, college, "the pub", regularly used shops; etc.).

However, it was acknowledged that sight loss heightens the risk of accidents in all settings, as the following examples identified by respondents illustrate:

- Public highways – traffic; kerbs; bollards; uneven surface; etc. create trip and bump hazards; (N.B. All exacerbated by distractions caused by noise and variations in individuals' depth of perception / sensitivity to light);

- Buildings – stairs; can be crowded and noisy, making navigation difficult if an individual is using sound stimuli;

- Home – cooking using gas / live flames; over-filling cups / pans; scalding; trips on stairs; slipping on bathroom floors, taking medication; and

- Workplaces – where modifications may not have been implemented to meet the individual's needs).

Health and safety: strategies to maintain personal safety

Practitioners identified a number of approaches to ensuring personal safety taken by people with sight loss with whom they have come into contact. These can be grouped into the following four categories:

1. Risk avoidance (e.g. not going out of the home at all; not going out unaccompanied; relying on family members / friends to carry out 'dangerous' or mundane tasks on their behalf);

2. Increasing confidence (e.g. by taking part in mobility training; learning how to make hot drinks);

3. Using specialist equipment / services (such as mobility aids, kitchen modifications, Braille readers, accessible transport); and

4. Accessing information or advice (although it was acknowledged that there is a lack of clarity about useful sources, and that this could be better co-ordinated locally).

Respondents suggested that people with sight loss tend to memorise routes and go to the same places, rather than explore new surroundings. It seems that this approach minimises potential risk to people with sight loss. Noting that this is not always the case with younger people, one respondent said she was, however, *"unsure whether they adapted where they want to be or really do exercise free choice".*

Practitioners felt there is an issue around the use of canes and other mobility aids, especially (but not exclusively) among younger people. One respondent emphasised that some people with sight loss "*are reluctant to highlight their condition",* as a result of which they don't use canes and other devices in public. Other respondents agreed, suggesting that people with sight loss "*don't want to draw attention to themselves",* some went further, suggesting that

carrying symbols of their impairment may make people feel more vulnerable rather than more secure. It was also suggested by one practitioner that young people are less likely to employ the services of a guide dog. This was felt to reflect the same issue (not wanting to appear to be different), as well as practicalities associated with keeping a dog (the need for space, time and a 'settled life').

It was suggested that this attitude presents people with sight loss with additional challenges. For instance, it was felt that – as people with sight loss often find themselves in situations where they need to rely on the support of strangers (such as shop-keepers, bus drivers, bouncers) – there is a potential problem in accessing the necessary help if they do not carry a form of identification such as a health card). When it is difficult for a stranger to know whether someone is blind or not, people might not necessarily realise they have a sight problem: *"people don't believe they are blind and this makes life difficult for them"*.

Another issue identified was the impact sight loss has on an individual's degree of independence, and their ability to make informed decisions. In particular, reference was made to the potential for family members to become *"over-protective … they worry and intervene too quickly"*. As a result, respondents felt that it can prove difficult for people with sight loss to develop their own capabilities to deal with the challenges they face. One respondent commented that some people are *"so fiercely independent … that they refuse to accept help"*, which they felt also has the potential to undermine the ability to learn coping strategies. These two perspectives suggest that practitioners need to be particularly sensitive to this issue, and approach their work with clients and their families in such a way that people feel able to accept the support offered and to allow the space necessary for the individual to develop their own skills and strategies.

Different perspectives were offered on the nature and value of assistance from members of the general public / third parties. Highlighting the fact that this requires individuals to *"rely on unknown quantities (i.e. other people)"*, one respondent captured the essence of what the other practitioners were articulating by saying that it is *"terribly dodgy"* for someone with sight loss to have to rely on a complete stranger for help.

Several practitioners emphasised the importance of experiential learning, with one commenting that *"making the odd mistake is how people learn"*. They emphasised the need for services to allow people with sight loss to work their own way around problems, and to encourage them to be less risk averse because it is through taking / accommodating risks in a supportive environment that people learn to deal with the risks they encounter

4.2 Managing co-morbid conditions

Amongst practitioners there was varied experience of people with sight loss and other long

term health conditions, and practitioners emphasised that this reflected the mix of clients' conditions. Hence, some had more experience of the challenges faced by clients with co-morbid conditions than others. Whereas one respondent who worked with younger people had only had one client with an additional long term condition (diabetes – which was controlled adequately, with support in selecting food in cafes, etc. and the use of a 'clicking' insulin pen to ensure dose was administered correctly), others indicated that *"the majority of my clients have additional problems"*.

One respondent observed that, in her experience, most people with additional conditions *"just get on with it, and cope",* although she acknowledged that their ability to cope varied, depending on the extent to which they were able to access support. Another suggested that the diagnosis of sight loss on top of a pre-existing condition can be *"the final straw … as it takes away all the little things they previously enjoyed despite being incapacitated"* (such as reading or watching television)

Practitioners identified a range of conditions which, in their experience, presented people with sight loss with particular challenges (including genetic and lifestyle-related conditions), but highlighted age-related conditions as the most problematic, because clients were felt to be *"too accepting"* of those, and tended not to look for assistance. Respondents felt that the main challenges that people with co-morbid conditions were likely to face were similar to those identified elsewhere in this research, and can be summarised as follows:

- Difficulty in reading instructions on prescriptions;
- Problems with taking medication, applying eye drops, creams, etc.;
- Compounding physical challenges (such as getting in and out of the bath);
- Lack of awareness of / failure to access necessary support services early in their condition (with one respondent asserting that they would "*rather see someone while they're managing than when things become critical*").

The condition felt most likely by respondents to present the greatest challenges to people with sight loss was dual sensory loss, as it was felt *that "communication affects every part of life"*. The existence of a dedicated service (provided at Centenary House by Leeds Deaf Blind Society) was regarded as a major benefit for people experiencing this condition. One respondent noted that learning difficulties would also have the potential to affect significantly the ability of someone with sight loss to adopt coping strategies.

Some of the coping strategies discussed with practitioners are outlined below, and extend approaches described by participants in the focus groups:

- Use dossit boxes / pill delivery services;

- Take delivery of meals-on-wheels (when eligible) or cook using processed and pre-prepared food or 'ready meals' heated through microwaves.

4.3 The difficulties in maintaining and promoting health

Practitioners identified a number of factors that they believe present challenges to people with sight loss living healthily. The following section presents an illustration of the kinds of challenges they had observed.

- **Diets** - especially when people get older, sight loss means people are less able / willing to prepare fresh food. Going out to shop for high quality / fresh food can be difficult and expensive (especially relative to the low income of many people with sight loss). People's ability to judge the freshness of food is impaired; accessing / reading (healthy) recipes is hindered; reading packaging presents challenges; and the use of the kitchen presents safety hazards. One respondent indicated that her clients are *"as able to go into a shop and buy an apple as anybody else"*, suggesting it is *"not all about limitations – it is about motivation too"*.

- **Exercise** - one respondent asserted that the ability to *"just go to a park and run is just not there"* (citing examples of occasions when her clients have reported accidents, such as coming off the path and ending up in the duck pond). Emphasising that clients are likely to need a sighted person with them to facilitate exercise, the fact was emphasised that *"you can't run or sprint with a cane ... you can't just get off a bus and walk"*.

- **Mental health** and **emotional wellbeing** was acknowledged by all practitioners. In particular, people's confidence (rather than their ability to function / perform certain tasks) was emphasized in regard to how it may compound an individual's sense of loneliness. Although some felt that how an individual responds to sight loss *"depends on how they are as a person"* (implying that disposition may affect responses to the challenges of their condition), the potential for someone to go on a *"downward spiral emotionally"* was common in their experience. Respondents also supported the opinion expressed by one practitioner that the mental health dimension of sight loss appears *"not to be taken seriously by mental health professionals"*. It was a generally held view that services for people with sight loss tend to focus on functional aspects related to their condition as opposed to social, emotional and psychological aspects. A number of practitioners highlighted the difficulties experienced by newly diagnosed people who already had a mental health problem, or if their impairment led to the breakdown in a significant relationship, emphasising the potentially damaging

compounding effect in such circumstances.

A number of approaches to achieving healthy lifestyles were described by practitioners. Most of these focused on exercise, as illustrated by the following sample:

- Participating in exercise classes was noted; (although these classes are usually run by Neighbourhood Networks or local voluntary organisations, for people who have access to transport there are also a variety of other classes run by different groups or agencies);

- Visiting gyms (when possible, and usually accompanied);

- Some (usually younger) people access sports activities (mostly run by the RNIB's Leisure Services); and

- Meeting other people and mixing socially (both in networks of people with sight loss AND with sighted people) offers the potential to minimise mental health problems associated with an individual's condition. One respondent emphasised that most of her clients *"just want to be part of general society",* want to make sighted friends *"don't want to become a ghetto, they just want to make sure sighted people understand, because I think half of the problem is that they think the sighted world does not really get the problems that non-sighted people have".*

It was noted by one respondent that – like members of the sighted community – people with sight loss are *"unlikely to make any behavioural changes in relation to healthy lifestyles if they do not feel good about themselves, or are lacking in confidence or self esteem".* It may be necessary to implement targeted interventions (such as the one-to-one motivational interviewing element of the health trainer programme[6]) prior to trying to deliver any health promotion messages to enable recipients to respond positively.

4.4 Models of service delivery in Leeds

Practitioners provided information about a variety of services for people with sight loss in Leeds. The following is not intended to be an exhaustive description of these services. Rather, it provides a summary of some of the ways in which people with sight loss can access these services, and the kinds of support they can expect to access.

Social services rehabilitation officers (ROs)

Employed by the local authority's adult social services department, this team of practitioners provides a personalised support service to all adults with sight loss in the city. Access to the service is normally via a referral from a healthcare practitioner (including GPs or eye-care

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[6] Described further in Section 6.2

specialists, e.g. after the completion of a certificate of visual impairment). However, individuals may also self-refer at any point, and other professionals refer people to the ROs as needed.

Leeds City Council Adult Social Services has recently initiated a screening process for all clients coming into contact with the service for the first time, including people with sight loss. This ensures that individual clients' needs are identified at an early stage by an Assessment Officer and means that Rehabilitation Officers can target their support appropriately and spend more time with people in most need. Additionally, the provision / replacement of equipment is now dealt with by the administrative support section, freeing up more RO time to provide personalised support.

The support provided starts with a face-to-face interview, at which the RO discusses the client's needs and agrees with them a plan of the kinds of activities they will engage on together during the period of support (which varies from 6 weeks up to a year). These activities include: liaison with all advice / service providers the individual may need to access; delivery of training (including mobility training and the use of specialist equipment); and – if deemed necessary – work with family members and friends to provide them with the skills they may need to support the client. The focus of the RO's intervention is to meet the most urgent needs of the client, as a result of which no two plans are alike.

Eye Care Liaison and Information Officer (ECLIO)
Based at the eye clinic in the city's main hospital, this relatively new post has been mainstreamed in light of a successful pilot project managed jointly by the DoH and RNIB. The ECLIO is able to provide an *in situ* intervention for people at the point of diagnosis of sight loss and it is the immediate, personalised access to information, advice and guidance which has been found to be valuable. Each consultation is used to generate a pack of information for the client that is designed to support them in the independent self-management of their condition and to ensure that they are in possession of all the facts they need to understand their diagnosis.

Clients are said to be enthusiastic about the ability of the ECLIO to provide information specific to their condition through holistic face-to-face contact (i.e. not limited to their eye condition). As well as providing functional support, the ECLIO is able to make referrals to services identified with the client as likely to be helpful to them in accommodating the changes needed to help them manage their newly diagnosed condition. They are able to help individuals deal with some of the immediate emotional challenges of their diagnosis.

One of the other practitioners made the following comments about the value of the ECLIO service: *"NHS services tend to state the medical and ignore anything else which of course*

when [you've received] the news … your life is just at an end for some people … so they just need help to get them back on the road again."

Further Education (FE) college student support

This national partnership between RNIB and the FE sector has been established to develop a "hub and spoke" model that aims to provide high quality services to students with sight loss in the hub (one FE college), and then roll out best practice through spokes (other colleges in the region). The hub FE College in Leeds employs an officer whose work involves assessing students for courses to identify, plan and implement the support they will need to participate (e.g. having a guide / support in the classroom with the student, a guide to classrooms; providing technology). Each plan is individually tailored because of diverse individual needs.[7]

Gaps in provision

There appeared to be a lack of clarity among practitioners about the different routes into support for people with sight loss. For example, one respondent – when asked how they understood the referral process to further services worked for people once diagnosed – stated that she thinks "*the ophthalmologist fills in a form … that goes to social services … who post you a cane, and that is it*". When challenged about this, she reiterated her belief that the system for newly diagnosed people works on a purely reactive basis "… *unless you contact them and say you can't do anything, I need help*".

Respondents acknowledged that there are probably not enough proactive services, particularly in relation to health promotion. Similarly, some respondents expressed concern about the potential for some clients to 'get lost' during the transition from one service to another (such as from children's services to adult services, or clinical to social care services). It was felt that better record keeping and coordination on the part of all services might reduce the likelihood of this happening.

The importance of accessible and flexible transport services was highlighted by several respondents. Reference was made to the fact that the sub-regional passenger transport executive is working with public transport providers to improve the quality of the interaction between their public-facing staff and customers with sight loss. However, the effectiveness of driver training in generating more enlightened attitudes towards this group was felt to be questionable, and the need for different types of provision (such as taxi cards) was felt to be an equally important issue.

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[7] It was acknowledged that students have to be quite confident to get to FE in the first place. For those who have decided to carry on after compulsory education *"they've made a positive decision to move on with their lives … they do have a certain grit and determination".*

Future provision

Referring to the fact that the City Council's social services department was undergoing restructuring while this study was underway, one practitioner commented on potential future services: *"who knows? They may have a whole load of exciting things coming up"*. However at the time of the study it appeared that the local specialist facility for people with sight loss (Shire View) was likely to be closed and services would be provided from dispersed sites.

The work of the Low Vision Committee was referred to by two respondents, reference in particular being made to the recently-launched Leeds Vision Strategy & Charter. However, they felt that it remains unclear how effective this will be in light of recent change and development in adult social services and the fact that the strategy had not then been widely disseminated.

One final observation made by two respondents relates to the potential for Individual Budgets to make an impact on the way in which people with sight loss engage with services in the city. As with the Strategy, it is too early to say how this development may impact on service delivery but it was seen by practitioners as offering individuals with sight loss the opportunity to 'force' service providers to tailor their generic services to better meet their needs.

4.5 Practitioner's suggestions for improvement

Respondents offered a number of suggestions about the way in which people with sight loss might be better supported in managing their condition and in attempting to live safer lives and adopt more healthy lifestyles. These included the following:

- Professionals need to **respond to individual needs**, but be prepared to offer pointers based on their experience / knowledge of the condition. At the same time, they should be **raising the expectations** of people with sight loss, "*to dare to dream for more*";

- Individuals need to be provided with the "**the right information at the right time in the right format**". In particular, newly diagnosed people need to be made aware of the equipment and services available to them. Similarly, more needs to be done to provide information to people about the benefits to which they are entitled, as this might help increase their disposable income, making it possible for them to pay for additional services and transport to activities, shops, services, etc. The opportunity that assistive and information technology provides for enhancing access to information needs to be explored to the full and acted upon;

- There is a need to **raise the profile of sight loss** and to **raise awareness and understanding among the wider population** about the needs and challenges

faced by people with sight loss, so that others can be more responsive to issues that arise in interactions between the sighted and those with sight loss;

- Services need to **communicate more effectively** with each other (linking, for example, with community nurses) and look at different ways of bolstering the support they offer (e.g. considering appointing "community eye champions" from among the existing pool of community-based health professionals);

- The needs of people with sight loss need to be taken into account by providers of **generic services**. For example, schools might include children and young people with sight loss in games by using fluorescent balls, sound management or buddying schemes. Similarly, gyms could be run (or specific sessions could be run) in such a way that people with sight loss can make use of the facilities (e.g. by running a voluntary buddying scheme, either with paid support staff or with volunteers recruited from among their membership). Delivery of initiatives such as the Self Care Programme, Expert Patient Programme and Health Trainer Programme could be modified to ensure that people with sight loss can benefit from them. While the Disability Discrimination Act does require services to respond to the needs of disabled people, in practice, implementation may fall short of making services equally accessible;

- Transport service planners and providers need to be encouraged to devise a more **accessible integrated transport system** that better enables all people with sight loss to use facilities and services. This could be bolstered by providing a 'travel trainer' service to enable people to make the best use of the available transport services.

4.6 Summary of key themes

- The experience of practitioners suggests that people with sight loss face a range of challenges to their personal safety and in relation to attempts to live healthily and that these challenges are additional to those facing people without sight loss;

- Services need to recognise the individual needs / requirements of people with sight loss;

- The significance of the impact of diagnosis and of experience of sight loss on mental health and emotional wellbeing cannot be over-stated;

- There is a strong desire on the part of people with sight loss to be perceived as "normal" / independent;

- Accessing services requires the individual to actively seek help – not enough services are provided proactively;

- There is a need for the 'sighted world' to better understand the challenges faced by people with sight loss; and

- Health and social services need to recognise the importance of providing support at critical moments (e.g. when first diagnosed with sight loss).

5. Expert hearing

This section presents the findings from the expert hearing by a panel of four practitioners and three service users[8] to discuss the preliminary analysis of the focus groups' discussions and practitioner's interviews. The hearing aimed to assess, and where possible corroborate and extend, the main themes among the project findings. The main ideas arising from the hearing are summarised in the section below, followed by recommendations made with respect to public space as this issue was not picked up on in other methods of data collection.

5.1 Health related issues faced by people with sight loss

There was a consensus that coping with the practicalities of health related issues, such as the use of medications, poses ongoing challenges for people with sight loss; tablets get mixed up, packaging can be difficult to identify and the general possibility of things becoming misplaced (*"You only have to move a thing 6 inches and it's lost"*) require ongoing concentration. While private space within the household is easier to control, particularly if other family members are supportive, coping with the routines of running a household such as cooking or childcare always involve some potential for accidents and this can only be partially controlled through focused attention. Monitoring health is potentially difficult as physical symptoms may not be apparent, and distinguishing the severity of subtle bodily changes may be a problem without assistance. For those living alone, monitoring hazards in the physical environment may be exacerbated as exposed wires, water leaking or tea towels caught on the hob and potentially flammable, can go unnoticed.

Unsurprisingly, this potential for accidents is increased in public space. Even when mobility patterns are well established, encountering unexpected hazards such as misplaced wheelie bins, cars parked unexpectedly on the pavement, badly designed street furniture, or street layout (*"every single crossing is created differently"*), enhance the likelihood of social embarrassment if not genuine danger. The strain of having to focus and concentrate continually on the physical environment (*"stress levels are enormous"*) was agreed to be a defining characteristic for both those who had experienced early and late onset sight loss, and despite the development of their coping skills. The extent to which skills for coping with uncertainty in public space impeded willingness to venture into less well known situations varied between younger people and older or more vulnerable people with sight loss. For the latter group it was noted that *"One or two bad experiences and people won't even try again.* Feelings of increased vulnerability and the stress of having to concentrate continually were

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[8] One person was both a practitioner and a service user.

common to people in each stage of life. However one participant noted that: "*It can be easy when you are visually impaired to blame sight loss for any or all difficulties and it is important for service providers to remind clients that people without sight loss also have accidents".*

People's emotional responses to visual impairment are very much conditioned by the responses of others. Because "*everyday interaction is missing in public space, when you lose sensory input like body language",* people potentially become more isolated. The consequences of this social isolation differ: for young people anxious to emphasize their similarity to their sighted colleagues rather than to focus on differences, making new contacts in social situations becomes problematic and potentially misunderstood when one is unable to make initial eye contact. For older people, missing the commonplace interactions of community life on the street, such as neighbour's greetings, potentially diminishes significantly the quality of one's life-with-others. A commonly expressed statement was that losing sight means that *others* think you are lacking capability, and the consequences of this inevitably, and in complex ways, become part of one's identity despite individuals' resistance to this perception in specific instances – *"I want to be accepted as a person first, and somebody with a disability second".*

While various technological aids can be enormously liberating for those able to invest the time (and expense) involved in becoming proficient, it was acknowledged that technologies designed particularly to assist in acquiring information can be frustrating ("*technology can be really time consuming because e.g. if something doesn't scan [it] can take hours to do simple things")* or inappropriate for some ("*older people are not so interested in technology, they see loss of sight as part of getting older").* In any case technology is not a replacement for human contact. *"[There's] no ideal way of getting information if you are blind; really people want someone to talk to and get information from, therefore there's a need for sociability with people of various degrees of sight loss".*

To address the perceived needs, across different stages of life, for information, particularly with respect to service provision, the following suggestions were made:
- Early intervention was recommended to create and support a logical chain of referrals for those with sight loss and long term health conditions; and,
- Despite the push by the government for 'generic' assessment, "*the persons required to do assessments really need empathy and intuitiveness to be good at assessing those with sight loss. This suggests the need for a training programme and teams with expertise in counselling those with sight loss".*

5.2 Recommendations on public space

Key recommendations generated by the hearing focused on ways in which public space could be improved to enable those with sight loss to manage tasks outside the home more easily. Given that shopping is a routine use of public space outside the household it was noted again that information on product packaging should be made tactile in more instances in order to allow easier access to information about products. Improvements in the design of buildings and other public spaces generated an additional five recommendations:

- Risk assessments for public buildings should be undertaken and identify responses that address issues affecting people with sight loss such as: a buddy system; improved signage; access to a receptionist;
- Contrasting colours should be used to enhance visibility of doors, through routes and hazards;
- Edges of steps should be marked with colour or tactile surfaces;
- Handrails that extend for the length of steps should be provided; and
- Decorative surfaces should be used in ways that do not cause reflection, glare, or obscure routes or hazards.

6. The application of key findings

This section draws together the findings from the four stages of the research project (literature review, focus groups, stakeholder interviews and expert hearing). The key themes that have emerged are presented in brief lists, with some explanation for clarity where required. Because the primary focus of the report is on the ways in which health promotion activities can address perceived gaps in service, objective 3 (difficulties in maintaining and promoting health) has been subsumed in Section C below (those areas where health promotion can be focused more effectively).

It is important to recognise that the section of the population designated as having sight loss is not homogeneous. Consequently, it should not be inferred from the following summary that all people with sight loss experience all these challenges in precisely the same way, nor should any single response to these issues be devised or considered adequate for the range of people with sight loss. As participants in the research were at pains to point out: the experience of each individual is unique, as a result of (for example) their differing: personalities; personal circumstances; proximity to the support of family and friends; age; physical health; emotional wellbeing and mental health; and the age at which they experienced the onset of their sight loss. Thus, while all the issues described below may be faced to some degree or at some point in the lives of people with sight loss, not all people with sight loss will experience these all the time. Similarly, the approaches to health promotion summarised below may be effective for different individuals with sight loss at different times.

A   Immediate risks to health and safety

The research has highlighted that people with sight loss are exposed to heightened risk of accidents as a result of their condition. The risks specified occur in a wide range of contexts and have been grouped under a series of themes for ease of reference.

A1   Trips / falls / bumps in public and unfamiliar locations (including highways – e.g. traffic; kerbs; bollards; uneven surfaces – and public buildings – e.g. stairs);

A2   Trips / falls / bumps in the home / familiar locations (including home – e.g. stairs; bathroom – and work);

A3   Cuts / burns / scalding during preparation of food and drinks;

A4   Danger of death / serious injury as a consequence of increased likelihood of causing and / or reduced capability of avoiding, responding to or escaping from an emergency (such as a fire or road traffic incident); and

Potential to lose bearings / become dependent upon the help of (potentially unreliable) strangers, and the vulnerability to criminal activity (in particular mugging and doorstep crime).

B Living with a long term health condition

The research findings have emphasised the additional challenges faced by people with a long term health condition when they also experience sight loss. The challenges identified impact in a variety of ways, and have been grouped under the following themes:

B1 Access to healthcare provision;

B2 Recognising symptoms;

B3 Monitoring progression;

B4 Taking medication; and

B5 Access to information about health conditions and treatments.

C Health promotion

The research has identified a number of areas where it appears that health promotion activity could be focused more effectively to better meet the needs of people with sight loss. These have been grouped under the following themes:

C1 Exercise

a keeping fit (e.g. going to the gym, taking part in sports, attending exercise classes); Keeping fit subsumes keeping mobile which is a necessary but not sufficient condition for keeping fit, and

b keeping mobile (engaging in a level of activity to ensure mobility and balance are maintained, or to counter the limiting effects of age-related deterioration in physical condition).

C2 Diet (people with sight loss experience particular obstacles to preparing healthy meals, including the impact of their condition on their ability to prepare fresh food; go out to shop for high quality / fresh food; judge the freshness of food; access and read recipes; read packaging; and use the kitchen safely).

C3 Labelling (making it easier for people to identify foodstuffs and medication – both in shops and at home – and to enable them to better discriminate between

products [e.g. on the grounds of freshness] when assessing which ones to buy or use).

C4   Emotional and social wellbeing / mental health

a   reducing social isolation (e.g. supporting individuals with sight loss to make connections with / derive succour from others in a similar situation to themselves, AND to meet people from the sighted population);

b   alleviating social discomfort (e.g. helping individuals with sight loss to access settings on an equal footing to their sighted counterparts in such a way that they do not feel self-conscious about their sensory impairment);

c   enhancing an individual's confidence and combating their sense of frustration (e.g. providing opportunities for people with sight loss – especially those experiencing later onset of their condition – to address the limitations their condition imposes on their lives, both through emotional support and through practical suggestions to manage their condition); and

d   responding to the symptoms or diagnoses of depression by providing clinical and practical support to manage impacts.

C5   Information

a   for people with sight loss (about their condition and related issues / services they may access, as well as about other, general, issues and services);

b   for the family and / or carers of people with sight loss (to increase their understanding of the likely needs of the person with sight loss and raise their awareness of the sources of support available).

C6   Awareness-raising among the wider population, particularly among people providing a face-to-face service likely to be used by individuals with sight loss (such as: health care workers, public transport operatives, shop staff), and those planning / providing services to the wider public that will impact upon the lives of people with sight loss (e.g. town planners, architects, street cleaners, leisure services, etc.).

6.1 Typology of impact

To complement the foregoing summary of issues, a rudimentary typology is presented to illustrate one approach to defining the varying impact of these themes when considering the

interaction of two variables ('stage of life' and 'age at onset of sight loss'). This typology offers a framework for interventions targeted at small groups within the wider population of people with sight loss in order to address issues that are likely to be a more significant challenge to some people than to others.

The use of this typology allows the researchers to interpret and present findings in a way that allows subtle distinctions to be drawn between different sub-groups of the population of people with sight loss. Judgements have been informed by, and draw on, the qualitative data to identify which of the challenges identified in the research are likely to have most impact on different people with sight loss as a function of their age and the length of time they have had their condition.

For example, people who were diagnosed with sight loss early in life were found to be more likely to have more coping strategies than those affected at a later stage in their life, and that these were more 'embedded' in their routines. Similarly, younger people were more resilient to physical accidents than older people (whose frailties may make recovery more difficult), and their attitudes to personal risks made them less likely to be inhibited in potentially dangerous situations. Younger people may also be able to access the support and care of their parents, family and friends – support which older people may find less easy to access. In the 'middle stages' of life, people may find themselves responsible not only for more aspects of their own personal care and safety, but also for others, including their children and parents and this presents additional challenges. Finally, the challenges experienced by many people in the later stages of their lives – such as social isolation, deterioration in health, greater reliance on public transport, etc. – are likely to be compounded by sight loss.

Thus, while all the issues summarised above are likely to impact to some extent on the lives of all people with sight loss (irrespective of their age, or the point of onset of sight loss), some people are likely to experience more of these, and for some people (or at some times) some issues will have a greater impact. For example, if, as seems likely, the potential impact of a fall in public / unfamiliar settings is greater for people diagnosed with sight loss later in life and for older people in general, then it follows that there might be a greater need for the provision of mobility training for people in those circumstances than for younger people or those with long-standing sight loss. Similarly, as illustrated by the typology, the provision of training to help people develop their cooking skills might be better targeted at younger people and people diagnosed with sight loss in middle age.

Typology of Impact

S t a g e   o f   L i f e

Young

A: Cuts/burns during food preparation;

C: Keeping fit- gym; labelling; social discomfort; family awareness of sources of support; awareness among wider population

Middle

A: Cuts/burns during food preparation; danger of serious injury due to fire or road traffic accident;

B: Accessing healthcare provision; recognising symptoms; monitoring progression;

C: Keeping fit- gym; labelling; social isolation; info about condition & related access; awareness among wider population

Older

A: Tripping/falling in public places;

B: Accessing healthcare provision; recognizing symptoms; monitoring progression, taking medication, accessing info about condition & treatment;

C: Keeping mobile; social isolation; possible symptoms of depression; awareness among wider population

Middle

A: Tripping/falling in public places and/or in the home; cuts/burns during food preparation; danger of serious injury due to fire or road traffic accident;

B: Accessing healthcare provision; recognising symptoms; monitoring progression of chronic condition; taking medication; accessing info about conditions/treatment;

C: Keeping fit- gym; diet; labelling; social discomfort; diminished confidence; possible symptoms of depression; accessing info about condition; accessing info for family/carers; awareness among wider population

Older

A: Tripping/falling in public places;

B: Accessing healthcare provision; recognising symptoms; monitoring progression of chronic condition; taking medication; accessing info about conditions/treatment;

C: Keeping mobile; diet; labelling; reducing social isolation; diminished confidence; accessing info re condition and services; accessing info for family/carers re support available; awareness among wider population

A: Immediate Risks to Health & Safety   **B: Living with a Long Term Condition**   **C: Health Promotion**

6.2 Different approaches to maintaining and promoting health

The following programmes/activities each address one or more of the concerns raised by participants in the study. Some, such as Self Care Programme, The Expert Patient Program (EPP) and the Health Trainer programme are implemented by the NHS throughout the country and are underpinned by the philosophy that health interventions should facilitate active management by clients themselves. As such they address the need for individually targeted interventions recommended by participants in this study. Manchester Environmental Group of Blind and Partially-sighted People (MEGOBAPP) external safety checklist and the Westmead Home Safety checklist are also provided as examples of useful checklists that provide tools for assessing hazards in either public or private spaces respectively.

Self Care Programme

This programme aims to coordinate resources and support options for patients with long-term conditions. It is patient-centred and identifies people's individual needs using a health assessment. The Self Care programme targets key resources for patients about health and wellbeing and also provides self-care skills courses like the Expert Patient Programme. Specifically people are encouraged to:

- adopt healthy behaviours;
- actively manage conditions through problem solving, pacing and action planning;
- work with professionals to make decisions about their healthcare; and
- maintain an active lifestyle through work, leisure and the development of personal and social relationships.

Self Care Connect (http://www.selfcareconnect.co.uk/) provides a user driven information and networking resource for professionals interested in learning more about supporting self-care.

Expert Patient Programme

The Expert Patient Programme (EPP) is a set of self-management courses sponsored by the NHS which aims to give people the confidence, skills and knowledge to manage their condition better and be more in control of their lives. People are encouraged to take responsibility for their own health needs and are provided with the skills and knowledge to take control of their conditions(s), thus allowing resources to be better targeted.

EPP courses can support people to change behaviour and develop the ability to take more control of their health condition(s). The aim of EPP is to make self-management as accessible as possible for the 17 million people living with long-term conditions in England. (http://www.dh.gov.uk/)

Health Trainer Programme

The government's White Paper 'Choosing Health' indicated that from 2006, initially in the most deprived areas of 'spearhead' Primary Care Trusts, NHS accredited Health Trainers will

provide personal support to people who want it and from 2007 the Health Trainer programme will be available in all PCT areas. Health trainers are a new cadre of workers whose priorities include improving mental health and wellbeing. Characteristically they:

- Will come from local communities and have a stake in improving the health of their community;
- Will be accredited by the NHS, with a core set of skills;
- Will have skills to help people to make changes;
- Will be friendly, approachable, understanding and supportive;
- Will be in touch with the realities of people's lives;
- Will be available at the times of day people wish to access them;
- Will be accessible to those who do not speak or read English well;
- Will offer practical support and guidance;
- Will have good connections into local advice and support services;
- Will help people to assess their needs and motivations;
- Will help people set goals and plan how to achieve them, identifying and helping to overcome barriers;
- Will provide advice and practical support on what they can do, e.g. stop smoking, healthy eating, stress management, safer sex, tackling social isolation; and
- Will build people's confidence to make the changes they want.

(https://www.nelincs.gov.uk/NR/.../0/HealthTrainerLeafleta5.pdf) More information on the programme can be found at
(http://www.dh.gov.uk/en/Publichealth/Healthinequalities/HealthTrainersusefullinks/DH_6590)

Information Prescriptions for Sight Loss/ECLIOS model
RNIB, over the last year, has been working in partnership with Leeds Low Vision Service Committee on a Department of Health (DH) initiative to ensure that people with long term conditions get the right information at the right time. It includes five key elements:

- **Patient information form** – detailed, important, personal eye health information, such as diagnosis, visual acuity and follow up, act as the prescription for information by establishing critical stages of care and the information needs at each stage;
- **Set prescription pack** – key pieces of information people want including information about their eye condition and who can help;
- **Free phone information line –** a source of information that enables people to listen to the leaflets in the pack over the 'phone or to order copies in their preferred format;
- **Eye Care Liaison and Information Officer (ECLIO) –**the ECLIO is able to individualise prescriptions further according to the needs of the patient. The creation

of the post has also enabled the creation of an information resource within the eye clinic and community; and a

- **Database –** developed with guidance from the Department of Health, in order to support the programme by making it easy to print prescription information according to the needs of the client. (NHS, 2007)

Westmead Home Safety Assessment Checklist (WeHSA)
The WeHSA is a 72-item checklist widely used to assess the physical and environmental home hazards of people at risk of falling. Hazard information is recorded relating to external and internal traffic ways, the general environment, and specific rooms such as the bathroom. Other risks such as seating, footwear, medication and personal alarm systems are also targeted as part of the assessment. (Steultjens, E & L. Clemson, 2006)

MEGOBAPP external safety checklist
The aim of MEGOBAPP is to improve mobility, service provision and access to information for blind and partially-sighted people within the area controlled by Manchester City Council and, where appropriate, outside that area, their website includes a checklist of external hazards. (MEGOBAPP, 2005).

Visual awareness training
This may include orientation and mobility training, training in independent living skills and/or vision rehabilitation through the use of adaptive or assistive technology tools and training that improve people's ability to manage daily living tasks. See http://www.actionforblindpeople.org.uk/ for more information.

7. RECOMMENDATIONS

Participants in all areas of the research identified a number of ways in which they felt improvements could be implemented in the design, planning and delivery of services for people with sight loss in order to enable better promotion and maintenance of health among people with sight loss. The recommendations that follow reflect recurring themes emerging from the research and consideration of the typology of impact described above.

1. Since the needs of people with sight loss are as many and varied as the individuals themselves, the design of any service for people with sight loss should not be a one-size-fits-all prescriptive approach; rather, services should be designed in such a way that they can be **responsive to the needs of individuals**. The Information Prescriptions / ECLIOS model and the Health Trainer's programme are premised on personalised and holistic interventions that may potentially address varied and individual needs.

2. People with sight loss :(i) may prefer not to have to draw attention to their impairment; and (ii) all are entitled to the same access to, and standards of, service as members of the wider population. Although DDA requires that their needs be taken into account, the research findings reported here suggest that implementation could be improved and that providers of **generic services** (e.g. schools, gyms, public transport, general healthcare services, etc.), and front-line staff should receive explicit training to raise their awareness of, and ability to respond sensitively to, the needs of people with sight loss.

3. Although many people with sight loss have developed a range of effective strategies to enable them to overcome the challenges presented by their impairment, there is scope for the provision of **more pro-active services** (such as a personalised service at the point of diagnosis, and specialist health promotion work) to enable each person with sight loss to develop their own coping strategies. **Closer liaison and co-ordination** – both between providers of eye care services and between them and providers of generic services - would make it easier for people with sight loss to access services when needed, and to be better supported in devising appropriate coping strategies. Similarly, **generic health services** designed to help people manage long term conditions (such as the Self Care Programme and the Expert Patient Programme) could be explicitly modified to ensure that people with sight loss can benefit from them as part of a broader approach to health promotion.

4. The research identified examples of approaches to service delivery that offer significant potential for the improvement of **co-ordination between specialist**

providers and the **provision of better information** to people with sight loss. It is recommended that the potential for replicating and extending these (so that they incorporate wider messages about health promotion) be explored, with particular attention given to: Information Prescriptions for Sight Loss / ECLIO models; the Westmead Home Safety Assessment Checklist; and external safety checklists such as that used by MEGOBAPP.

5. To ensure that the needs of people with sight loss are addressed adequately by services targeted to them and by generic services which may be used by people with sight loss a range of actions should be undertaken including the following:

a) Within all services:
- Provision of 'Visual Training' and information to raise general understanding of sight loss;
- Recognition of both the functional and psychological impact of sight loss and the provision of appropriate support; and
- Direct and indirect support for family members, friends and other carers.

b) Within services targeted to people with sight loss:
- Provision of general information, as well as advice about financial support;
- Delivering health promotion campaigns and messages, tailored to people with sight loss; and
- Circulating home safety checklists and advising on their use.

c) In eye health services:
- The value of reaching people with sight loss early in their condition implies the importance of regular eye examinations to ensure early detection of eye disease and access to treatment must be promoted.

6. While the Health Trainer programme does not specifically target people with sight loss, it is sensitive to the health maintenance issues encountered by those who are trying to live healthier lives, particularly in relation to eating, exercise and mental health, and is well placed to address individual needs for accessing information, including through provision of local referrals. Since the programme has now been rolled out through PCTs, assessment of its potential contribution to health promotion activities among people with sight loss, particularly among marginalized communities is recommended.

7. Future studies might explore the usefulness of the typology in defining interventions appropriate to and enjoyed by people with sight loss who live in less 'resource rich' environments than Leeds and/or in minority communities who may access fewer services than participants in the study reported here. Exploring the typology with larger numbers of people could increase its usefulness in defining and targeting interventions and may allow further distinctions to be made.

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**In this publication, the terms 'visually impaired people', 'blind and partially sighted people' and 'people with sight loss' all refer to people who are blind or have partial sight.

Appendix 1

Shireview Centre

Shireview is a city-wide resource centre run by and for blind and partially sighted people. It comes under the umbrella of Leeds Society for Deaf and Blind People; a Blind Services Committee heads the Centre. Shireview aimis to provide services in one place that include:

- A display of daily living equipment;

- A display of low-vision aids and a low-vision service;

- Information and information packs in appropriate formats;

- Meeting space and the facilitating of meetings for groups, classes and activities; and

- An outreach service which includes the gathering and dissemination of information, supporting and facilitating community-based groups, and offering training to local groups and businesses on visual-impairment

Centenary House like Shireview is the second major centre of the Leeds Society for Deaf and Blind People a charity based in Leeds that provides practical services to deaf, hard of hearing, deafblind, blind and partially sighted people in the region. Catering for everyone, from young people (youth clubs and summer play schemes) to senior citizens groups, a wide range of social activities is provided. Professional social-work support, day-centre provision, rehabilitation services, equipment, and interpreting services are offered in partnership with Leeds' Social Services department.

www.leedsdeafandblind.org.uk/services/sv/services_sv.asp

Park Lane College, Leeds

Park Lane is a further education college offering a variety of courses. A learning partnership between Park Lane and the Royal National Institute of the Blind (RNIB) has enabled learning opportunities to open up for blind and partially sighted individuals in the region.

Park Lane College Leeds was one of the first Colleges in the country to be given a regional hub status to facilitate learning amongst individuals with sight problems. One-to-one professional support is available to any students with sight problems wishing to pursue ANY course at the College. http://www.parklane.ac.uk/