

Loneliness, Social Isolation and Sight Loss

A literature review conducted for Thomas Pocklington Trust

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Executive Summary

This summary reports the findings of a literature review on loneliness, social isolation and sight loss commissioned by Thomas Pocklington Trust and conducted by Suzanne Hodge and Fiona Eccles from the University of Lancaster.

Aims and method

The aims were to review English-language research published since 1993 in order to:

- Establish the nature and extent of the ‘problem’ of loneliness and social isolation for people with visual impairment resulting from sight loss;
- Identify factors that may address loneliness and social isolation for this group of people;
- Make recommendations for policy, practice and future research based on the review findings.

Searches were conducted between May and July 2013 of the key academic databases and other web-based resources. Relevant papers identified from these searches formed the basis of the review.

Findings

Although the topic of loneliness and social isolation has been widely researched, especially as it affects older people, much less research has been conducted into the issue as it affects people with a visual impairment (VI). The majority of research that has been published relates to older people with VI, with a smaller body of research relating to children and young people. Thus the majority of the review findings reported here relate to research with general adult populations, but with a focus on older people. We also looked separately at research with children and young people.

Prevalence

There is some evidence that people with a VI are more at risk of loneliness and social isolation than those without, however, this evidence is modest. Two recent Dutch studies using the De Jong Gierveld loneliness scale, with people aged 55 plus reported rates of loneliness of 54% and 50% (Alma et al., 2011) in people with VI, compared with 44% of the general population. However, this must be set against research using the UCLA loneliness scale (Foxall et al., 1994, Foxall et al., 1993, Wahl et al., 2013) which shows no significant difference in the prevalence of loneliness in older people with and without a VI.

Relationships, social support and lone-living

Evidence for whether people with VI who live alone are more at risk of loneliness is mixed, with just one study identifying lone-living as a risk factor for loneliness in older people with a VI (Alma et al., 2011). Similarly, although there is some evidence that loneliness is linked to lower levels of social support, there is other evidence to suggest that there is no link between loneliness and the size of people's support networks. However, what emerged from several studies as important in understanding the link between social support and loneliness is the way people with VI feel about their relationships; if people are satisfied with the social support they receive they are less likely to feel lonely and isolated (Barron et al., 1994, Foxall et al., 1994, Bookwala, 2011, Weber and Wong, 2010). Worryingly, though, findings from the English Longitudinal Study of Ageing (Nazroo and Zimdars, 2010, Zimdars et al., 2012) suggest that older people with a VI are more likely to experience poor relationships than those without, suggesting that there may be additional stress factors relating to sight loss which lead to poorer relationships, which in turn may contribute to an increased risk of loneliness and social isolation.

Individual psychological factors

A number of studies have focused on the role of individual factors which affect whether people with a VI experience loneliness and social isolation. One study showed that older people with VI who were lonely also showed lower levels of adaptation to sight loss (Verstraten et al., 2005). Another study showed that self-efficacy was the most significant factor in determining whether or not people felt lonely (Alma et al., 2011). One of the few qualitative studies reviewed highlighted that older people with VI relied more on personal psychological resources than on social support to cope with sight loss (Lee and Brennan, 2006).

Gender

Within more general research into loneliness, loneliness has been found to affect women more than men. However, our review reveals a more complex picture, with two longitudinal studies with older people with VI showing that although there were higher rates of loneliness in women than in men at the first time point assessed, over time this difference reduced (Demakakos et al., 2006, Jacobs et al., 2005). These findings suggest that there may be differences in the way that men and women adapt to sight loss over time.

Visual and hearing impairments

Several studies had looked at both visual and hearing impairment, comparing the impacts of the two. In terms of general mental health and well-being, visual impairment was shown to have a greater negative impact than hearing impairment (Carabellese et al., 1993, Schneider et al., 2011, Wahl et al.,

2013). However, in relation to loneliness, although both types of impairment were found to represent a risk factor, hearing impairment was shown to represent a greater risk than VI (Foxall et al., 1992, Wallhagen et al., 2001).

Physical health, everyday functioning and psychosocial well-being

The review suggests that loneliness and social isolation themselves are not the most significant factors contributing to the decline in well-being associated with VI. However, they play a part in what is best understood as a reinforcing, interactive process (Bookwala and Lawson, 2011, Jacobs et al., 2005, Wallhagen et al., 2001). The research reviewed suggests the most significant factors in this process of decline to be the increasing functional difficulties associated with VI, including difficulties with reading, shopping, leisure activities, socialising and mobility (Cimarolli et al., 2012, Jones et al., 2009). Problems with mobility, in particular, have been shown to be linked to an increased risk of social isolation and loneliness (Gallagher et al., 2011, Grue et al., 2010, Weber and Wong, 2010). The decline in people's mobility and ability to carry out everyday activities contributes to a spiral of decline, as restrictions in everyday activities and mobility lead to a reduction in social interaction which can negatively affect people's psychological well-being. This can lead to a further reduction in mobility and physical well-being, which in turn can reduce the amount of social interaction people have, leading to loneliness and social isolation (Wallhagen et al., 2001). This reinforcing process has also been linked to higher mortality rates in people with VI (Jacobs et al., 2005, Wahl et al., 2013).

Communication and social interaction

A similar reinforcing process can be seen in relation to communication and social interaction. One qualitative study (Heine and Browning, 2002) showed that people with a VI often experience communication breakdown in conversational situations. This can lead to feelings of social isolation and low self-confidence, which in turn can lead to them withdrawing from social situations, which then increases the risk of social isolation and loneliness. Other research has found similar difficulties for people with VI engaging in social interaction more generally (Hersen et al., 1995, Naraine and Lindsay, 2011), which can lead to feelings of social exclusion and ultimately increase the risk of social isolation and loneliness.

Socio-economic factors

Very little research has been conducted into whether there is a direct, three-way link between loneliness, VI and socio-economic status. However, there is evidence to show that the socio-economic status of people with VI is considerably worse than that of the general population (Clements and Douglas, 2009, Gold and Simson, 2005, McManus and Lord, 2012, Vale, 2004). There is

also evidence of a link between economic status and loneliness, with the poorest older people being most at risk of loneliness (Demakakos et al., 2006).

Perceived versus 'objective' low vision

Two studies highlight a discrepancy between perceived, self-reported low vision and low vision as defined by the criteria used to assess visual acuity (Bookwala and Lawson, 2011, Zimdars et al., 2012). One of these studies specifically looked at the different impacts of self-reported and objective low vision on feelings of social isolation, finding that these were predicted by self-reported low vision, but not by objective low vision (Bookwala and Lawson, 2011). This highlights the importance of understanding the lived experience of loneliness for people who have a VI.

Charles Bonnet Syndrome

One paper looked specifically at the link between loneliness and Charles Bonnet Syndrome (CBS) (Teunisse et al., 1999). The authors found there was a strong link, with 64% of people with CBS reporting to feel lonely, compared to only 35% of a control group of people with VI. However, there was no difference in the quantity of social contacts between the groups. Mirroring the findings relating to the importance of the quality of relationships for people with VI, the authors identify the quality of people's social contacts as important.

Children and young people

Risk of social isolation in children and young people with a visual impairment

Research shows that children and young people with a VI may lag behind their sighted peers in developing social skills (Huurre and Aro, 1998). They may also have more limited opportunities to develop relationships and social networks (Pinquart and Pfeiffer, 2012). Both these factors may increase the risk of them becoming socially isolated (Douglas et al., 2009).

Prevalence of loneliness

There has been a limited amount of research looking directly at the prevalence of social isolation and loneliness in children and young people with a VI. The evidence that does exist is inconclusive, with two studies suggesting an increased risk of loneliness for children with VI compared to those without (Hadidi and Al Khateeb, 2011, Keil et al., 2001); one showing severe loneliness but no difference from the sighted control group (Kef et al., 2000); and one study showing that girls with VI were at increased risk of loneliness compared with their sighted peers, but boys with VI were actually at less risk (Huurre and Aro, 1998).

Social isolation and the education system

A number of studies have looked at children's experiences of the education system and how these affect their experiences of social isolation and loneliness. Overall, this research suggests that inclusive education may not necessarily lead to less social isolation and loneliness than segregated education. The distance of the child's school from their home is an important factor, irrespective of the type of school. Several studies highlighted bullying as a problem for children with VI in school (Gray, 2005, Rosenblum, 2000, Keil et al., 2001, Pilling et al., 2005). Another key issue reported in this literature was difficulties in making friends (Huurre and Aro, 1998, Keil et al., 2001).

Friendships and social networks

Children and young people with VI have been shown to have smaller social networks than their sighted peers, but it is unclear whether this increases their risk of social isolation. One study for the RNIB showed that children with VI were more likely to feel left out than their sighted peers, more likely to want more friends and more likely to describe themselves as "sometimes lonely" (Keil et al., 2001). These findings are important as research also shows a link between satisfaction with relationships with friends and psychological well-being (Huurre and Aro, 1998).

Participation in social activities

The evidence reviewed shows that children and young people with VI are less likely than their sighted peers to be involved in social activities outside school (Ghate and Daniels, 1997, Wolffe and Sacks, 1997), and more likely to spend time on their own (Keil et al., 2001, Kroksmark and Nordell, 2001). Studies have identified various barriers faced by young people with VI, including not being accepted by peers, negative reactions to their sight condition, problems with social skills and difficulties with access and mobility (Gold et al., 2010, Gray, 2005, Leyser and Heinze, 2001).

Dating and relationships

Young people with VI are less likely to have had dating experiences than those without, although they are just as likely to have fallen in love or experienced romantic relationships (Pinquart and Pfeiffer, 2012). They are also likely to be older when they have their first dating experience (Kef and Bos, 2006, Pinquart and Pfeiffer, 2012).

Social networking

Social networking is now a significant part of everyday life for most children and young people, and the evidence reviewed here suggests that this is also true for those with a VI, with two recent studies showing that three quarters of

young people with a VI used the internet regularly for social networking (Gold et al., 2010, Keil et al., 2001).

Discussion

Key findings

Prevalence

Loneliness and social isolation are recognised as important issues in VI policy and practice. However, evidence for a strong link between VI and increased risk of loneliness and social isolation is inconclusive, both for adults and children. Loneliness and social isolation should not be seen as an inevitable consequence of sight loss. However, where they do occur, in combination with other factors, they can have a major negative impact on people's quality of life and even on life expectancy. Thus it is most important that the links between loneliness and these other factors are better understood.

Loneliness as part of a reinforcing process

One of the key findings from this review is that, particularly for older adults with VI, loneliness and social isolation interact with other factors as part of a reinforcing process, resulting in a decline in psychosocial and physical well-being. Difficulty with functional activities such as shopping, cooking, mobility and leisure pursuits play a particular part in the process.

Relationships and social support

For adults with VI, the review provides mixed evidence for the relationship between level of social contact and loneliness. However, what the review shows clearly is that how people feel about their relationships is important in mitigating loneliness. For children and young people the key findings are that having good social networks and access to social activities is important.

Implications for policy and practice

Addressing individual psychosocial support needs

The review highlights the complex interaction of different factors which impact on the physical and psychological well-being of people with VI. This highlights the importance of low vision professionals and others involved in the health and social care of people with VI attending to the particular psychosocial support needs of each individual. The Adult UK Sight Loss Pathway provides a framework which identifies key points in people's pathway through services at which such support might be offered.

Peer support

Peer support is identified as a key way of addressing loneliness and social isolation in several of the papers reviewed. Peer support can help by

facilitating mutual understanding of the difficulties associated with VI, the sharing of practical advice and coping strategies, and increasing people's confidence.

Addressing functional support needs

Functional difficulties are shown to be one of the key factors that impact on physical and psychological well-being, leading to loneliness and social isolation. The review highlights the importance of attention being given to identifying and addressing those support needs, in particular, people's mobility outside the home.

Areas needing further research

Developing ways of addressing loneliness and social isolation

Research is needed which is aimed at developing ways of addressing loneliness and social isolation in people with a visual impairment that take account of the complexity of the issues as highlighted in this review.

What protects against loneliness?

Understanding what protects people with a visual impairment from loneliness may help in developing a better understanding of how to address the problem where it occurs.

Prevalence

The review highlights the need for more, robust, quantitative research into the prevalence of loneliness and social isolation in people with VI. This should be conducted using standardised measures to ensure comparability with other studies, and should consider prevalence in relation to specific demographic groups.

Relationships and social support

There is a need for in-depth, qualitative research into the link between loneliness and the quality of people's relationships.

Loneliness and social isolation as part of an interactive process

Research is needed into the reinforcing process of which loneliness and social isolation are just one part. In particular there is a need for a better understanding of the relationship between loneliness, social isolation and the increasing functional difficulties associated with VI.

Societal barriers

The majority of research in the VI field, including that relating to loneliness and social isolation, tends to adopt an individualised approach. There is a need for more social research focusing on the role of societal factors, and the ways

in which these interact with individual factors to increase the risk of people with VI becoming socially isolated and lonely.

Socio-economic status, visual impairment and loneliness

Investigation into the three-way link between socio-economic status, VI and loneliness is needed.

Younger people with a visual impairment

The vast majority of research into VI has been conducted with older people. The review highlights the need for more research to be conducted with younger adults and children. This might look at broader issues around the social integration of children and young people with VI, and around the role of social networking.

Charles Bonnet Syndrome

Quantitative research shows a clear increased risk of loneliness in people who experience CBS. In-depth qualitative research would help us to understand the nature of this link.

1 Introduction

This literature review has been conducted by Suzanne Hodge and Fiona Eccles on behalf of Thomas Pocklington Trust. Its aim is to review the research evidence relating to loneliness, social isolation and sight loss published within the past 20 years in order to inform the development of further research, policy and practice.

1.1 Why are loneliness and social isolation important?

Loneliness and social isolation have come to increasing prominence in the UK in recent years as social problems that need to be addressed. This is highlighted by the Campaign to End Loneliness, which has involved a range of organisations mobilising research evidence to raise the issue of loneliness in older people up the public policy agenda (Bolton, 2012, Local Government Association, 2012); whilst the RNIB's 'Facing Blindness Alone' campaign has highlighted the issue of social isolation in relation specifically to people with a visual impairment (Kaye and Connolly, 2013).

Although in relation to older people it has been argued that loneliness and social isolation have been core concerns since the birth of the welfare state (Victor et al., 2009), there are nonetheless compelling reasons for giving them increased attention at this time. There is now clear evidence that loneliness has a detrimental impact on both mental and physical health (Cacioppo and Hawkley, 2009, Hawkley and Cacioppo, 2003, Victor et al., 2009), and that both loneliness and social isolation are linked to increased death rates (Holt-Lunstad et al., 2010, Steptoe et al., 2013). Although the prevalence of loneliness amongst older people has not increased significantly over the last 60 years (Victor et al., 2005), social and demographic changes within developed countries such as increases in life expectancy and lone-living have led to growing numbers of people living more isolated lives. The ageing process brings a particularly increased risk of social isolation as people's social networks shrink due to loss of friends and family and declining physical health and mobility (Windle et al., 2011); factors which have been shown to impact on the levels of loneliness experienced over time (Victor and Bowling, 2012).

People with a visual impairment have been identified as a group who are at particular risk of social isolation and loneliness; partly because the majority are older and partly because of the additional risk which sight loss itself presents (Nazroo and Zimdars, 2010, O'Donnell, 2005). Sight loss is linked to an increased risk of depression (Brody et al., 2001, Burmedi et al., 2002b, Evans et al., 2007); reduced quality of life (Mitchell and Bradley, 2006); declining physical health and decreased mobility (Crews et al., 2006, Nazroo and Gjonca, 2005); and higher rates of poverty than in the general population (Vale, 2004,

Stone, 2012). All these factors may contribute to social isolation and loneliness.

1.2 What are loneliness and social isolation?

One of the first challenges in talking about loneliness and social isolation is defining terms for which there are no precise and agreed definitions and which refer to complex, interrelated phenomena. In his seminal text on loneliness, Weiss (1973) differentiates between two types of loneliness that can occur independently of each other, which he calls *social isolation* and *emotional isolation*. Social isolation results from a lack of connectedness with a social network of peers; whereas emotional isolation is associated with the lack of a meaningful intimate relationship e.g. with a partner, parent or child.

Developing Weiss's ideas, Cacioppo and Hawkley (2009; p.26) conceptualise loneliness as *perceived social isolation*, distinguishing it from *objective social isolation*, which refers to the observable absence of social contacts. Although objective social isolation can affect loneliness, it is perceived social isolation that constitutes it. De Jong Gierveld (De Jong Gierveld, 1998; p.73) defines loneliness as "an unwelcome feeling of lack or loss of companionship, the negative, unpleasant aspects of missing certain relationships as well as missing a certain level of quality in one's relationships". This highlights the important distinction between feeling lonely and being alone; although being alone and thus being in a state of 'objective social isolation' may contribute to feelings of loneliness and 'perceived social isolation', the two states are not one and the same. It is possible to be lonely in the company of other people; just as it is possible to live an apparently socially isolated life and not experience loneliness.

Thus, for the purposes of demarcating the two concepts, loneliness can be defined as a psychological state, in which the individual feels a lack of meaningful connectedness to other people; whereas social isolation can be understood as a more objectively observable state, in which the individual lacks opportunities for social contact and interaction. However, as is apparent from the discussion above, there is within the research literature on this topic some variation in the way in which the two terms are used and defined. Whilst in writing this review we have attempted to be clear when we are referring to loneliness and when to social isolation, it is important to acknowledge that this distinction between the two concepts is not always reflected in the research being discussed.

1.3 Visual impairment and sight loss: a note on terminology

In this report we use the term 'visual impairment' as a general term to refer to poor vision. The term sight loss is used more specifically to refer to having developed a visual impairment, having previously not had one. Other terms,

such as 'blind' and 'low vision' are used only when they have been used in the research we are reviewing and have specific meanings.

Although the term visual impairment is used here as a general term, it is used within some of the research discussed in the report to refer to specific levels of objectively defined impairment. The degree of impairment may be assessed according to visual acuity, that is the level of detail that an individual is able to see, as measured using standardised tests, usually the Snellen chart. It may also be assessed according to visual function, that is the extent to which an individual is able to carry out everyday activities for which sight is regarded as necessary, such as driving, reading and climbing up and down stairs.

1.4 Aims of the review

The overarching aim of this review is to develop an up-to-date understanding of the links between loneliness, social isolation and sight loss as reflected in research literature. Although the research reviewed includes studies undertaken in different countries, the primary focus is upon the UK context, particularly in terms of the 'grey' literature (that is research published in reports and practitioner journals, rather than in peer-reviewed academic journals). The primary focus is on literature published in the last 20 years (i.e. since 1993), although particularly salient research published before that has also been included. The review has a number of specific aims:

- To establish the nature of the 'problem(s)' of loneliness and social isolation for people with sight loss.
- To establish (as far as is possible) the extent of the 'problem' of loneliness and social isolation, particularly in the UK context.
- To identify factors that might prevent or address/reduce loneliness and social isolation and their related negative consequences.
- To make recommendations based on the findings of the review for addressing loneliness and social isolation in people with sight loss.
- To identify avenues for future research.

1.5 Method

Initially a systematic search for academic articles directly relevant to the topic of loneliness, social isolation and sight loss was conducted between May and July 2013 using the following databases: PsycINFO, Academic Search Complete, AMED (The Allied and Complementary Medicine Database), CINAHL, MEDLINE, and Web of Science. The searches were conducted using the following search terms: ("sight loss" OR "visual impairment" OR "low vision" OR blind*) AND (lonely OR loneliness OR "social isolation" OR "socially isolated"). Only papers in English were searched for.

In order to capture the 'grey' literature not published in academic journals, further searches were conducted using a number of electronic resources. These included Social Care Online, the database of social care resources hosted by SCIE (Social Care Institute for Excellence); and the websites of key organisations responsible for commissioning and conducting social research in the area of visual impairment.

The research and other literature derived from these initial searches and of direct relevance to the topic formed the main body of literature to be reviewed. As the papers and other material identified through this process were read, further papers relevant to the topic were identified and incorporated into the review.

2 Findings

2.1 Overview

The topic of loneliness and social isolation has been widely researched, especially as it affects older people, with a number of important studies and review articles published over the last few years (Cattan et al., 2005, Chen et al., 2013, Dickens et al., 2011, Masi et al., 2011, Victor et al., 2009, Victor et al., 2000). However, the body of research that has looked at the issue in relation to visual impairment is much smaller, and the majority of this has focused on older people, with loneliness in children and younger adults remaining relatively unexplored. Because of this weighting of the evidence base towards older people, we have structured this report primarily around topics rather than age groups. This means that a large part of the report discusses issues that relate particularly, but not exclusively, to older people. However, because there are particular issues affecting children and young people we have included this as a separate section.

Although there have been a small number of qualitative studies, the majority of research conducted in this field has been quantitative, using data collected from questionnaires and validated measures. A number of different validated scales have been developed for measuring loneliness (Victor et al., 2009, Ó Luanaigh and Lawlor, 2008). The two most widely used in research into visual impairment are the University of California Los Angeles (UCLA) Loneliness Scale (Russell and Cutrona, 1987) and the De Jong Gierveld scale (De Jong Gierveld and Van Tilburg, 1999). It is outside the scope of this review to look at these scales in detail, however, it is important to note that they each reflect different ideas about what constitutes loneliness. A key difference is that the UCLA scale treats loneliness as a single phenomenon, focusing on social loneliness, whereas the De Jong-Gierveld Scale attempts to measure both social and emotional loneliness. Caution therefore needs to be exercised when

interpreting findings from studies that have used different scales (Ó Luanaigh and Lawlor, 2008).

Furthermore, relatively few of the studies reviewed here have focused specifically on loneliness, and thus only a few have used one of the loneliness scales. More often the insights into loneliness and social isolation have been derived either from more generic validated questionnaires which tap into certain aspects of loneliness and social isolation, or from specially designed non-validated questionnaires.

2.2 The prevalence of loneliness

Loneliness is widely understood as being a particular problem for older people. Rates of severe loneliness (that is people who report themselves to be very, often or always lonely) amongst the general older population in the UK have been estimated to be 5 to 16% (Victor et al., 2000). In accord with these rates, in their study Victor et al. found 5% of older people to be always lonely; although if those who report feeling lonely sometimes are also included, this figure increases to 38% (Victor et al., 2005).

However, there is evidence to suggest that loneliness is just as much of a problem for younger people as for older people. A survey of 2,256 people aged 18 and over conducted for the Mental Health Foundation in 2010 (Griffin, 2010) showed that 11% of adults often feel lonely, with a further 24% sometimes feeling lonely. Interestingly, however, people aged 18-34 were significantly more likely to feel lonely than people aged 55 and over; 35% of people aged over 55 reported feeling lonely often or sometimes (similar to the Victor et al. figure of 38%), compared with 57% of 18-34 year olds.

2.2.1 Are people with a visual impairment more at risk of loneliness than those without?

The evidence for whether people with a visual impairment are more at risk of loneliness than those without is relatively limited. As part of their broader review of quantitative research into the emotional and social consequences of visual impairment in older people conducted over a decade ago, Burmedi and colleagues (2002b) looked at the small subsection of papers (n=7) that focused on loneliness, concluding that the literature on the topic was sparse and that the relationship between loneliness and “objective vision factors” remained unclear, particularly around the question of whether older people with a visual impairment were lonelier than those without. In their recent update of the Burmedi review, Nyman and colleagues concluded that the topic of loneliness still remained under-researched and that the evidence also remained inconclusive (Nyman et al., 2010a, Nyman et al., 2010b). The authors of another recent review were slightly less equivocal, reporting higher levels of loneliness in people with a visual impairment than in those without, although

this difference was only relatively small (Pinquart and Pfeiffer, 2011). However, again, the authors found only a small number of studies that had looked specifically at loneliness, and only one of these (Verstraten et al., 2005) had used a validated measure of loneliness.

Verstraten et al. (2005) report on one of two Dutch studies published in the last decade that has identified an association between loneliness and visual impairment. Verstraten and colleagues looked at the prevalence of loneliness, along with adaptation to sight loss and depression, amongst older people (55 plus) with a visual impairment. Using the De Jong Gierveld loneliness scale, they found a high rate of loneliness, with 54% scoring 3 or higher on the 11 point scale, the point at which loneliness is considered to be present (Alma et al., 2011). This compared with a rate of 44% found in a study conducted using the same scale with a general population of Dutch older people. The authors also found a strong link between loneliness and depression. More recently, another Dutch study looked at the prevalence of loneliness in older people (55 plus) with and without a visual impairment using the de Jong Gierveld scale (Alma et al., 2011). Again, the researchers found that older people with VI were significantly more at risk of loneliness than those without VI (50% of VI compared with 29% of non-VI). Another recent US study of loneliness and functional decline in older people looked at a range of demographic and health characteristics and found that those who self-reported as lonely were significantly more likely than those who were not lonely to have a visual impairment (24.6% of lonely people compared with 13.9% of non-lonely people) (Perissinotto et al., 2012). However, another recent German study conducted using the UCLA Loneliness Scale found that the prevalence of loneliness was no greater in older people with either a visual or a hearing impairment than in those without an impairment (Wahl et al., 2013).

So there is some recent evidence that, overall, people with a visual impairment have a greater risk of loneliness than those without. However, this must be set against earlier research (e.g. Foxall et al., 1994, Foxall et al., 1993) examined in previous reviews and the recent study by Wahl et al. (2013), conducted using the UCLA Loneliness Scale, which offers less conclusive evidence for the link. The equivocal nature of this evidence may in part be due to the different scales used. What is more important to understand, though, are the various factors at work that may contribute to loneliness and social isolation in people with a visual impairment; it is this which forms the focus of the following section of the report.

2.3 Factors that play a part in loneliness and social isolation

2.3.1 Living alone

Living alone does not necessarily lead to either social isolation or loneliness. However, it does represent a risk factor for loneliness (Savikko et al., 2005). In

their US study, Perrisinotto et al. (2012) found that 26.7% of lonely older people lived alone, compared with only 10.5% of non-lonely people. However, the corollary of this should be noted; that the majority of lonely people lived with other people. Rates of loneliness amongst older people who live alone in the UK are reported to be 17% compared to 2% amongst those living with others (Victor et al., 2009).

The Network 1000 Comparison study of people who are registered visually impaired found rates of living alone for people with a visual impairment aged 65 plus comparable with those for the general population (41% compared with 40%)¹ (Clements and Douglas, 2009). These figures compare favourably with the findings of another UK survey of 588 adults with a visual impairment who receive a large print fuel bill, 84% of whom were aged 65 or over (Vale, 2004). This found significantly higher rates of lone living than the Network 1000 survey, with 62% of all respondents living alone. The discrepancy between the rates of lone living reported in the two surveys could be explained by a bias in the Vale sample: people who choose to receive large print fuel bills may be more likely to live alone, as there will be no-one else in their household to take responsibility for bills.

Where the Network 1000 survey found a bigger difference between people with a visual impairment and the general population was in younger adults, with 24% of people with VI aged 18 to 65 living alone compared with only 10% of the general population in this age group. This, the authors suggest, is explained by the much lower rates of people with a visual impairment who were married or living as a couple, particularly in the younger age groups (Clements and Douglas, 2009). We go on to explore the link between relationship status and loneliness in the following section.

2.3.2 Relationships and social support

Various studies have looked at the links between the social support networks of people with a visual impairment, including marital/intimate partner relationships, and loneliness. However, it should be noted that all the studies found here looked only at older people. The picture that emerges is somewhat complex. Foxall and colleagues found no direct link between loneliness and living with a partner or other people (Barron et al., 1994, Foxall et al., 1994). By contrast, Alma et al. (2011) did find a direct link: whether or not people lived with a partner was one of the factors that helped to explain the increased rates of loneliness they found in older people with a visual impairment.

In terms of wider social support networks, Verstraten and colleagues (2005) found that those older visually impaired participants who were lonely showed

¹ General population figures for the Network 1000 survey were taken from the British Household Panel Survey 2005.

significantly lower levels of social support (as well as lower levels of adaption to sight loss and more feelings of depression) than those who were not lonely . Although their study did not look at causality they argue that it is likely that a low level of social support leads to loneliness, rather than the other way around.

However, it is important to look further than simply the amount of social support available to people. In a number of studies, no evidence of a link has been found between the *size* of people's wider support networks and loneliness (Foxall et al., 1994, Alma et al., 2011, Teunisse et al., 1999). However, Alma et al. only looked at the size of people's social networks, not how they felt about the support they received from them, which the researchers acknowledge may be an important factor. This is supported by the Foxall/Barron study, which showed that loneliness was linked to the *level of satisfaction* people felt with the support they received (Barron et al., 1994, Foxall et al., 1994). Supporting this finding, Weber and Wong found that participants in their study who were less isolated attributed this to having a good network of friends and family (Weber and Wong, 2010). In other words, satisfaction with support seems to be more important in determining whether or not older people with a visual impairment feel lonely than either whether they live alone, or the size of their support network (Foxall et al., 1994).

In terms of intimate relationships, Barron and colleagues also found that non-lonely married people identified their spouse as a source of support more frequently than lonely married people, suggesting that people who are married may experience loneliness because they do not receive the emotional support that they expect from their partner (Barron et al., 1994). Extending this finding still further, Bookwala (2011) found that, compared with people with poor quality marital relationships, those with good relationships reported less social isolation, as well as fewer depressive symptoms and functional limitations, suggesting that a good quality relationship acts as a buffer against some of the negative effects of visual impairment, including social isolation. However, the downside of this is that the impact of bereavement can be even greater for those with good relationships: one study with a general population of older people showed that people with the best relationships took longest to recover from the loss of their partner (Wortman et al., 1993).

Worryingly, what the English Longitudinal Study of Ageing (ELSA) (Zimdars et al., 2012, Nazroo and Zimdars, 2010) shows is that older people (aged 50 plus) with a visual impairment are more likely to experience poor relationships with spouses, children and friends than older people without a visual impairment, despite there being no difference in the amount of contact they have with them (Nazroo and Zimdars, 2010). This suggests that there may be additional stress factors related to visual impairment which contribute to poorer

relationships, which in turn may contribute to an increased risk of loneliness and social isolation in people with a visual impairment.

All this evidence highlights the importance of differentiating the objective elements associated with social isolation from the subjective experience of loneliness; what is key is how people experience and feel about their relationships and social contacts.

2.3.3 Individual psychological factors

In addition to the role of various social factors in determining whether or not people with a visual impairment are lonely or not, research has also looked at more individual psychological factors, the emphasis of much of this being on individual adaptation to sight loss (Hersen et al., 1995, Verstraten et al., 2005, Weber and Wong, 2010). Verstraten and colleagues (2005) found that those older visually impaired participants who were lonely showed significantly lower levels of adaptation to sight loss, as well as lower levels of social support and more feelings of depression (highlighting that there is an interaction between social and psychological factors). Reporting on an analysis of qualitative data from two studies of adaptation to age-related visual impairment, Lee and Brennan (2006) highlight the fact that the majority of older people with a visual impairment draw on personal resources to cope, rather than seeking external support from either formal or informal sources. From this they argue for the importance of mutual support from others who have developed coping strategies.

In their study Alma et al. (2011) found that the factors which played the biggest roles in determining whether or not people were lonely were having a sense of personal competence or control (“self-efficacy”); having a sense of self-esteem; being self-motivated rather than passive and fatalistic (“taking initiatives”); and partner status. Of these, self-efficacy was the most important factor; people with a stronger sense of personal competence and control are less likely to feel lonely.

In similar vein, Hersen and colleagues (1995) report findings from a study which shows a link between social support and assertiveness in older people with a visual impairment, leading them to argue that if individuals fail to be assertive (or are too assertive) they may fail to have their social needs met, which in turn may lead to social isolation, which in turn again may lead to depression.

2.3.4 Gender

Gender has been identified as a factor in loneliness, with research consistently showing that women report higher rates of loneliness than men, leading to the assumption that loneliness is a particular issue for women (Victor et al., 2009). However, it has been argued that the picture is more complex than this, and that there may be other factors at play which affect the ways in which

loneliness presents itself in men and women (ibid.). Certainly, findings from one study reviewed here which looked at gender differences suggest a more complex picture. In a longitudinal study of the impact of visual impairment on health, function and mortality in older people (70 plus) in Israel, Jacobs and colleagues (2005) found significantly higher rates of loneliness amongst women with a visual impairment surveyed at the first time point in their study, aged 70 (72% of VI women compared with a rate of 39% of non-VI women), whereas at the second data collection point, 7 years later, the difference in these rates for women had narrowed to a non-significant level (46% of VI women compared with 41% of non-VI women). For men, however, the picture was slightly different: aged 70 the VI men did not show significantly higher rates of loneliness (26% of VI men compared with 20% of non-VI men); whereas at age 77 they were significantly more lonely than the non-VI men (40% of VI men compared with 23% of non-VI men).

These findings accord with data from the ELSA, which showed that more women felt lonely than men, but that this difference reduced with age (Demakakos et al., 2006). This suggests that there may be differences in the ways that men and women adapt to visual impairment over time, perhaps in the way their experience of visual impairment interacts with other life changes such as increased physical ill-health, loss of mobility and bereavement.

2.3.5 Visual and hearing impairments

A small body of research relating to visual impairment has looked at both visual and hearing impairments, either in order to compare the impacts and experiences of the two sensory impairments, or to investigate the impact of dual sensory impairment (DSI), that is the experience of having both a visual and a hearing impairment.

In one recent German study, both types of impairment were linked to poorer subjective health, but with visual impairment having the strongest link (Wahl et al., 2013). Wallhagen et al (2001) found both types of impairment to have strong negative impacts on mental health. In a recent review of research into DSI in older people Schneider and colleagues (2011) concluded that it is the negative effects of visual impairment that dominate the impacts of DSI, with hearing impairment not significantly increasing the negative effects experienced. This supports findings from an Italian study which showed that both types of impairment were linked to an increased risk of depression, but with the risk being higher for visual impairment (Carabellese et al., 1993).

In relation to loneliness, however, the picture is somewhat different. Foxall et al.'s (1992) comparative study of loneliness in older people with and without a visual impairment found that visual impairment is not as significant a risk factor for loneliness in older people as hearing impairment. Wallhagen et al. (2001) found that both types of impairment were strongly linked to difficulties with

social functioning, including feeling lonely and socially isolated. However, they too found that the link was stronger with hearing impairment than with visual impairment.

2.3.6 Physical health, everyday functioning and psychosocial well-being

Visual impairment has been shown to be associated with a range of negative impacts, particularly on the lives of older people. This includes impacts on people's physical and mental health, their ability to carry out everyday activities such as reading, shopping, cooking, getting around both inside and outside the home, and taking part in social and leisure activities (Burmedi et al., 2002a, Burmedi et al., 2002b). Loneliness and social isolation form part of this complex picture of interacting factors that lead to a reduced quality of life for many people with a visual impairment.

The evidence reviewed here appears to suggest that loneliness and social isolation themselves may not be the most significant factors contributing to the decline in well-being associated with visual impairment, but they do play a part in what can best be understood as a reinforcing, interactive process. The evidence suggests that perhaps the most significant factors in this process are the increasing functional difficulties people face in carrying out everyday activities.

One American study (Cimarolli et al., 2012) which looked at changes in the functional, social and psychological challenges faced by 364 older people (65 plus) with recent visual decline over two years, found evidence that the psychological challenges people faced at first tended to decrease over time. These included feelings of depression and of loneliness (reported by only 1% of participants). However, 'functional challenges' such as reading, outdoor mobility, shopping and watching TV increased over time. Furthermore, the kind of social functioning challenges that may contribute directly to increasing social isolation were also a significant issue for people and remained so over time. These included taking part in social and leisure activities and visiting friends and family. Researchers in another US study of older people with a visual impairment (Jones et al., 2009) found a strong link between depressive symptoms and both poorer physical health and increased difficulties with activities of daily living, including socialising with friends and family as well as other functional tasks such as walking, mobility, shopping and personal care.

One of the key functional challenges highlighted repeatedly in the research is mobility, particularly outside the home. Analysis of the UK Life Opportunities Survey data (McManus and Lord, 2012) showed that people with a visual impairment were six times more likely than those with no impairment to face restrictions with access outside of the home (38% compared with 6%). For older people (aged 65 and over) with a visual impairment, the proportion

experiencing restrictions in access increased to 49%, whilst the proportion of those with no impairment experiencing restrictions in this age group remained at 6%.

In his survey of people with visual impairment in the UK Vale (2004) found that functional difficulties were the most often cited challenges for people, with getting out and about being the biggest challenge. Another large scale, cross-national study of older (65 plus) home care clients (Grue et al., 2010) found that people who had experienced recent visual decline were more likely to withdraw from social activities, have reduced social interactions and feel lonely than clients with stable visual impairment. They were also less likely than people with stable visual impairment to be able to get about outside the home and to travel by public transport.

Weber and Wong (2010) identify transport as a major barrier to social interaction and independence for older people with a visual impairment. A qualitative study of mobility and transport issues for people with a visual impairment identified lack of access to transport as a major contributory factor in the sense of isolation and loneliness experienced by many, particularly in rural areas (Gallagher et al., 2011). Findings from the analysis of Life Opportunities Survey data (McManus and Lord, 2012) showed restriction in the use of local buses to be a particular problem for older people with a visual impairment. Across all ages, people with a visual impairment were significantly more likely than the general population to experience restriction in accessing local buses (33% compared with 24%). However, the proportion of people aged 65 and over with a visual impairment experiencing restrictions increased to 44%, whereas for older people in the general population the proportion remained fairly static at 26%. Here we can see one way in which societal barriers serve to reinforce individual functional challenges to disable people with a visual impairment, in keeping with the social model of disability (Oliver, 1990).

The picture that emerges, then, is one of a reinforcing dynamic in which social isolation and loneliness play a part, but may not be the key contributory factors. Rather, people's declining ability to carry out everyday activities, and particularly their ability to get about, seems to be the crucial factor. When people develop a visual impairment, or when their degree of impairment worsens, they are likely to experience increasing restrictions in their ability to carry out everyday activities, particularly those that involve them travelling outside the home such as driving, shopping and taking part in social activities. This in turn can lead to a loss in confidence, increasing social isolation and feelings of loneliness, as well as feelings of depression, all of which can then lead to a further reduction in activity levels.

Jones et al. (Jones et al., 2009) argue that “many older adults experience vision loss, depression and functional limitations as a single syndrome - with each element exacerbating the other.” (p.170). A further important element in this process is declining physical health. Wallhagen et al. (2001) describe the “double effect” that the restrictions in mobility and activities of daily living (ADLs) associated with both visual and hearing impairments can have. The decrease in mobility and physical activity can lead to a reduction in social activities and interaction which can negatively affect people’s psychosocial well-being. This in turn can lead to further reductions in mobility and physical well-being which lead to further reductions in social interaction and an increase in feelings of loneliness and social isolation (Wallhagen et al., 2001). Bookwala and Lawson (2011) report a similar reinforcing effect; poor subjective (i.e. self-reported) vision not only has a direct negative impact on people’s psychological well-being, but it also has a further indirect negative effect in that it leads to greater physical limitations and social isolation, which in turn lead to more depressive symptoms.

This multi-factorial reinforcing process has major health implications, including higher mortality rates in older people with a visual impairment than in the general older population. In their longitudinal study, Jacobs et al. (2005) report higher death rates amongst people with a visual impairment than amongst those with good vision. They describe a complex set of interacting factors, amongst them loneliness, which they see as contributing to “a spiral of increasing frailty and vulnerability, themselves the harbingers of illness and death” (p.285). Wahl et al. (2013) also report higher death rates amongst older people with a visual impairment than in those without, linking this particularly with the reduction in out-of-home activities shown in this group.

In their large scale US study, Perissinotto et al. (2012) report findings which show that, in a general older population, loneliness is a risk factor for functional decline, poor health outcomes and death. Somewhat contrary to what the visual impairment specific research literature suggests, however, Perissinotto et al. suggest that loneliness itself is a predictive factor in functional decline, morbidity and mortality; although they highlight the need for further research to investigate the exact nature of the relationships between these factors.

A longitudinal study of changes in loneliness in older people showed that improved physical health was one of the factors that helped to reduce loneliness, highlighting the importance of treating long-term health conditions (Victor and Bowling, 2012). Extending this finding to people with a visual impairment, this means ensuring that people with treatable eye conditions receive any treatment that can improve their sight, including provision of spectacles and other low vision aids, and that those who are discharged by

their ophthalmologist continue to receive regular eye checks and referral back into secondary care where necessary (Hodge et al., 2012, Thetford et al., 2009).

2.3.7 Communication and social interaction

A similar reinforcing process involving loneliness and social isolation can also be seen in relation to communication and social interaction. This is described by Heine and Browning (2004) who conducted a qualitative study looking at the communication experiences of older people (60 plus) who had either a visual impairment or DSI. They found that social factors such as low lighting and poor awareness of the communication needs of people with sensory impairments interacted with participants' psychological responses to their sight loss to impact negatively on their ability to engage in communication. People with a visual impairment often experience communication breakdown in conversational situations and are required to use communication repair strategies (such as asking communication partners to repeat what they have said). Such experiences can lead to or exacerbate feelings of social isolation and low self-confidence, which in turn reduces the likelihood of them developing or using the repair strategies needed to engage in communication in future. This can lead to withdrawal from social situations and an increased risk of social isolation and loneliness (Heine and Browning, 2004). In an earlier qualitative study of the experiences of older people with recent sight loss, Ainlay (1989) observes that people with a visual impairment may find themselves marginalised in conversational settings with sighted people, partly because of the unease of sighted people around communicating with people with a visual impairment, and partly because they are unable to pick up on visual cues, which leads them to assume they are being excluded. This can eventually lead them to avoid interaction with others because of the strains involved in communication.

Similarly Hersen and colleagues (1995) identify a complex of factors which may impact negatively on the social interaction of people with a visual impairment, ultimately increasing the risk of social isolation. These include the tendency of others to exclude people with a visual impairment from social activities because of feelings of discomfort and uncertainty as to how to communicate with them; and the reduced capacity of individuals with a visual impairment to reciprocate e.g. taking turns in driving.

Looking more specifically at social interaction within the workplace, Naraine and Lindsay (2011) identify a number of barriers faced by employees with a visual impairment when interacting socially with colleagues which can contribute to them feeling excluded. These include difficulties relating to communication, such as the use of facial or other physical gestures by colleagues, background noise, and having to negotiate assistance with getting

to or from meetings or social events. The isolating effects of the barriers encountered by people with a visual impairment when using social spaces such as restaurants and tourist attractions have also been reported (Richards et al., 2010).

These findings provide one explanation for the reduced levels of participation in social and cultural activities, reported particularly amongst older people with a visual impairment (Campbell and Crews, 2001, cited in O'Donnell, 2005, Zimdars et al., 2012). Again, they also highlight the ways in which individual factors interact with societal barriers to disable people with a visual impairment.

2.3.8 Socio-economic factors

In considering the link between socio-economic factors, visual impairment and loneliness, it should first be noted that there is evidence for a link between loneliness and low socio-economic status; and also for a link between visual impairment and low socio-economic status. However, what there appears not to be is any research which explores the relationship between the three factors in any depth, with the majority of research in this area taking the form of surveys.

The Network 1000 survey of people with a registered visual impairment living in the UK shows the socio-economic status of people with a visual impairment to be considerably worse than that of the general population, particularly in relation to employment status (Clements and Douglas, 2009). Only one third of people with a visual impairment reported being in some form of employment, compared with three-quarters of the general population. This corresponds to findings from the analysis of data from the Life Opportunities Survey conducted for RNIB (McManus and Lord, 2012), which showed that two-thirds of working age or employed people (64%) with sight loss experienced restriction in being able to access and fully participate in employment. The long-term employment prospects of people with a visual impairment also seem to be worse than for the general population, the Network 1000 survey showing that 65% of unemployed people with a visual impairment had been unemployed for four years or more, compared with 21% of unemployed people in the general population (Clements and Douglas, 2009).

In terms of household income, people with a visual impairment have been shown to have lower than average incomes, compared with the general population. The Life Opportunities Survey analysis (McManus and Lord, 2012) shows that people with a visual impairment are more likely than those with no impairment to live in a household with an income of less than £300 a week across all age groups, but that the disparity is greatest amongst those aged 45-64 (43% of people with a visual impairment compared with 15% of those without an impairment). This can be explained by the higher levels of unemployment

amongst working age people with a visual impairment. For those of retirement age (i.e. 65 and over), although the disparity between those with a visual impairment and those without an impairment is less (59% compared with 43%), this is only because of the significant fall in income levels of the general population after retirement.

In his survey of the social and living conditions of people with a visual impairment for the RNIB, Vale draws a strong link between visual impairment, living alone and poverty; with 62% of respondents living alone and 82% living in poverty² (Vale, 2004). Further to this, only 15% of respondents reported that they were living comfortably and 28% reported having additional expenses because of their visual impairment such as taxis, home care costs, and equipment, whilst only 61% were aware of benefits advice (ibid.). A similar picture emerges from findings of a Canadian survey of 352 adults with a significant visual impairment (Gold and Simson, 2005). Levels of unemployment were found to be much higher than for the general population, and access to information, support and transport identified as barriers to greater inclusion of people with a visual impairment. The authors conclude, like Vale, that despite progressive social policy goals people with a visual impairment continue to live in poverty and social isolation.

In terms of the implications for loneliness and social isolation, the link between economic status and loneliness has been clearly demonstrated in the analysis of the ELSA data, which shows that for people aged 50 to 75, those who are poorest are most at risk of loneliness (Demakakos et al., 2006).

2.3.9 Perceived low vision versus 'objective' low vision

One interesting issue that is highlighted by this review is the discrepancy between perceived or 'subjective' low vision and 'objective' low vision as defined by the criteria used to assess people's visual acuity. This emerged from the analysis of the ELSA data (Nazroo and Zimdars, 2010, Zimdars et al., 2012), which were based on people's perceptions of their eyesight, not on objective measures of visual acuity. In order to gauge the level of fit between these self-reported levels of visual impairment and objectively measured levels of visual acuity, the researchers compared the data with those from two other studies which used both types of data. From this comparison they found that only about one third of participants in both studies who self-reported having a visual impairment actually met the criteria for severely impaired vision in a nurse assessment.

Similarly, a study of a large sample of older people with a visual impairment in the US (Bookwala, 2011) found a lack of fit between self-reported poor vision

² Poverty is defined by Vale as having a household income of less than 50% of mean income or less than 60% of median income.

and poor vision as assessed using an 'objective' measure of visual acuity for about one fifth of their sample. The researchers in this study explored the different impacts of self-reported and objectively-assessed poor vision on people's psychological, everyday functioning and feelings of social isolation (using the UCLA Loneliness Scale), and found that feelings of social isolation and depressive symptoms were predicted by self-reported poor vision, but not by objectively-assessed poor vision. Objectively assessed poor vision was only linked directly to functional limitations (Bookwala and Lawson, 2011). These findings all highlight the subjective dimension of both visual impairment and loneliness, and the importance of acknowledging and understanding people's lived experience of both phenomena.

2.3.10 Charles Bonnet Syndrome

Charles Bonnet Syndrome (CBS) is a syndrome which causes visual hallucinations and mainly affects older people with a visual impairment, particularly those with AMD (Berman and Brodaty, 2006). It is estimated to affect between 11 and 15% of people with a visual impairment (Menon et al., 2003). It is discussed here because the initial search undertaken for this review identified one study (Teunisse et al., 1999) which looked specifically at loneliness in relation to people with Charles Bonnet Syndrome (CBS). It should be noted that had other studies looked at the link between loneliness and specific sight-related conditions, these would probably also have been picked up through the search process.

Teunisse et al. (1999) recruited older people (64 plus) through a Dutch low vision clinic and found a strong link between CBS and loneliness; 64% of people with CBS reported feeling lonely, compared with 35% of a control group of people who attended the same clinic but did not report visual hallucinations. Interestingly, and in keeping with findings already reported above, the authors found that there was no significant difference between the CBS group and the control group in terms of the number of social contacts or whether people lived alone. However, research has shown that social isolation and sensory deprivation may play a role in the onset of the condition (Menon et al., 2003). Thus, Teunisse et al. argue that what may be important clinically is the quality of people's social contacts, as a lack of social stimuli may contribute to symptoms of CBS (Teunisse et al., 1999). It has also been suggested that support groups may be helpful in enabling people to share their experiences (Menon et al., 2003).

2.4 Children and young people

In this section we look specifically at loneliness and social isolation as they affect children and young people. For the purposes of this review, the term 'young people' is used to refer primarily to young people eligible to be in full-time secondary education. Whilst some of the research reviewed also includes

young adults older than this, the focus of this section of the review is limited mainly to issues relating to young people still in full-time education. Coverage of issues relating to young adults older than this is included in the previous section of the report.

Although some of the issues affecting children and young people are similar to those affecting adults, there are some differences in focus and emphasis within the research. One particular difference relates to the point of onset of visual impairment. As already discussed, the majority of research conducted into visual impairment with adult populations focuses on older people. With much of this research, the onset of participants' visual impairment has been later in life, often the result of age-related eye conditions. However, most research with children and younger people is conducted with participants who have had a visual impairment since birth or early childhood. This inevitably affects the issues that arise and that become the focus of research.

2.4.1 Why children and young people with a visual impairment may be at risk of social isolation

The early development of children with VI differs from their sighted peers as they have to rely partly or wholly on their other senses to learn and make sense of their environment. Skills that sighted peers learn incidentally through observing their environment have to be explicitly taught, with a result that children with a visual impairment often lag behind their peers in developing social skills (Hurre and Aro, 1998), and the degree of difficulty with social skills may increase with increasing visual impairment (Pilling et al., 2005). For example, children with VI find it much harder to read body language or facial cues or respond to visual invitations to play and this can impede social interaction, particularly for young children. In addition, when starting school, the social communication and social use of language of children with VI is behind that of their sighted classmates, even when intellectual or general language abilities are unaffected (Tadić et al., 2010).

As Pinquart and Pfeiffer (2012) highlight, adolescence is a time when young people start to explore their identity, become more independent, and when peer relationships become increasingly important, including potential intimate relationships. However, adolescents with VI face additional challenges compared with their sighted peers. Their VI may place restrictions on their ability to travel independently, particularly if parents worry about their safety, and options for accessible social activities may be limited. Furthermore, if social opportunities arise, it is often harder for adolescents with VI to seek out and approach potential partners at social occasions; and at a time when young people in particular are concerned with appearance, adolescents may become more self-conscious about physical idiosyncrasies associated with particular eye conditions.

Thus, as a result of having reduced levels of social skills, and possibly more limited opportunities, children and adolescents with a visual impairment may be at risk for becoming socially isolated, particularly when their vision worsens, they change school or when entering adolescence (Douglas et al., 2009).

2.4.2 Loneliness in children and young people with a visual impairment

There has been limited research into the prevalence of social isolation and loneliness in children and young people with a visual impairment. Hadidi and Khateeb (2011) compared blind and sighted adolescents in Jordan and found that blind young people were more lonely, but the differences were small. In another study, about 15% of a sample of Dutch children reported severe loneliness, but this did not differ from the sighted control group (Kef et al., 2000). Huurre & Aro (1998) found a more complex picture with a gender specific difference, reflecting findings reported from research with adult populations; 57% of girls with VI reported feelings of loneliness compared to 33% sighted, but only 20% of boys with VI reported loneliness compared to 24% of sighted boys. Interestingly, both Hadidi and Khateeb and Huurre and Aro found no difference in overall psychological wellbeing, suggesting the difficulties were around loneliness specifically.

The RNIB's survey of the experiences, aspirations and needs of nearly 1000 children and young people with VI in 1999, "Shaping the Future" (Keil et al., 2001), found that 31% of secondary school-aged children said they were "sometimes lonely" (30% of boys and 34% of girls). These findings were compared with those from an NSPCC survey of non-disabled children of the same age (Ghate and Daniels, 1997, cited in RNIB report) in which only 11% of children reported themselves in this category (9% of boys, 13% of girls). In addition, 37% of parents of primary school-aged children felt their children were "sometimes lonely". Loneliness was also an expressed concern of parents of primary-aged children, particularly when the children went to school some distance away.

2.4.3 Social isolation and the education system

A recent review of the education of blind and visually impaired children concluded that visual impairment could be associated with social isolation at school and problems in developing friendships (Douglas et al., 2009; p. 136). Gray (2005) interviewed a small sample of parents, professionals and children with a VI in Northern Ireland about their observations of children's experiences at school in the early years. Some participants described the isolation experienced by children when they were kept away from the other children at break times so that they did not get hurt. Being teased or bullied was a particular concern of the children who were interviewed (Gray, 2005), an issue

also highlighted in another qualitative study involving interviews with older children (Rosenblum, 2000).

Parents may not always be aware of the extent of their children's difficulties; in a survey of children with nystagmus and their parents, 26% of children reported being bullied, whereas only 11% of parents reported the same problem (Pilling et al., 2005). However in the RNIB Shaping the Future survey, 37% of parents of primary-aged children and 30% of secondary pupils reported "emotional bullying" which included being ignored or left out, and being bullied increased the likelihood that they would report being "sometimes lonely" (Keil et al., 2001). Analysis of data from the Millennium Cohort Survey, a longitudinal study of 19,000 children born in 2000, also showed that parents and teachers were more likely to report that children with a visual impairment were bullied at school (Harris et al., 2012).

In Rosenblum's (2000) study, young people with VI reported concerns that their sighted peers were not sure how to interact with them because of their impairment, mirroring the experiences of adults reported by Ainlay (1989). Rosenblum also found that the best friends of the young people with a visual impairment acknowledged that their friendship required extra effort because of their friend's impairment but that this was worth it (Rosenblum, 2000). However, making friends can remain a challenge, as one study found that adolescents with VI (especially girls) reported they had "many friends" less often than sighted adolescents; and more adolescents with VI (both genders) said they found it hard to make friends more frequently than their sighted counterparts (Huurre and Aro, 1998). In the UK RNIB survey (Keil et al., 2001), 21% of children under 16 said it was difficult to make friends and this increased to 33% in the 16-25 age group. Interestingly no relationship was found between endorsing this statement and type of school attended and the report concludes that making friendships may be a problem in both mainstream and special school settings. However, none of the (parents of) primary children at special schools endorsed the statement "I can always find a friend to talk to if I am worried or upset" compared to a third of mainstream-educated primary pupils with VI. In addition, the report suggests that children with complex needs in mainstream education or in a specialist school for children with VI (as opposed to a generic special school) were more likely to develop special friendships. Nonetheless, it is not clear to what extent these findings are due to the school attended or whether they reflect the types of difficulties experienced by children with more complex needs.

The location of the child's school has also been shown to be a factor affecting their socialisation; the RNIB survey (ibid.) showed that children educated outside their home area, irrespective of type of school, were more likely to experience isolation as a result of not being able to meet up with school friends

outside school hours. Furthermore, young visually impaired people may not have been able to develop good independent mobility skills, which may reduce their ability to socialise with friends (Wright et al., 2011).

2.4.4 Friendships and social networks

In general, adolescents with VI have been shown to have smaller social networks than sighted adolescents (Kef et al., 2000), mirroring the findings of research with adults with a visual impairment reported earlier. Whether or not having smaller social networks puts them at increased risk of social isolation is unclear: in Kef's study 58% of young people were satisfied or extremely satisfied with the level of social support they had. The Shaping the Future report (Keil et al., 2001) compared their results for secondary school children with VI with the NSPCC findings for non-disabled children and found more young people with VI had special friends (77% compared with 68%), but more children with VI endorsed the statement that they sometimes felt left out (34% compared with 21%) or wanted more friends (30% compared to 11%). The children with VI who described themselves as "sometimes lonely" were also less likely to have a large group of friends either at school or locally. In addition, 38% of parents of primary-aged children and 23% of parents of secondary aged children felt life would be improved if their children had more friends, or more friends living locally. Similarly, over a third of the 16-24 year olds felt more friends would improve their social life. Unsurprisingly, Keil et al. (2001) also found that those who went to a mainstream school were more likely to have a group of friends living locally than those within more specialist provision.

When considering the relationship between friendships and wellbeing, Huurre et al. (1998) found that a higher score on relationship with friends predicted lower depression and this was mediated via self-esteem. From the RNIB survey, primary-aged children who described themselves as "sometimes sad" were more likely to feel left out, wish they had more friends and find it difficult to make friends. These relationships were not seen for the older children; instead a positive relationship was seen in that those who were "cheerful" were more likely to have special friends and friends they could talk to.

2.4.5 Participation in social activities

When outside school, engaging in social activities can prove problematic for young people with a visual impairment. Forty-two percent of children with VI in the Shaping the Future survey were not involved in any club or activity outside school, which the authors contrast with the value of 25% reported for sighted children in the NSPCC study (Ghate and Daniels, 1997). Comparing the social activities of blind, low vision and sighted adolescents, Wolffe and Sacks (1997) found that sighted young people spent more time with friends and did more interactive "high level" social activities (such as going out or belonging to social groups such as scouts or a choir) than did their blind or low vision peers.

Interestingly, however, they also found that young people with low vision participated in fewer social activities and spent more time on their own than either blind or sighted peers. Kroksmark and Nordell (2001) similarly found that adolescents with low vision appeared to spend more time on their own (and in more structured activities) than sighted adolescents. In a later study comparing young people who were blind and those with low vision (Gold et al., 2010), no differences were found in the amount of passive activity, or high level social activity, but this study suggested the young people with low vision took part in more moderately social activity than the blind young people. There were no differences in the number of close friends or the social support reported by blind young people compared with those with low vision. The Shaping the Future study (Keil et al., 2001) found that watching TV or videos was the most frequent activity for under 16s, followed by playing on computers. Only 35% of secondary school children reported socialising with friends as one of their three main activities and the authors compare that finding with the NSPCC survey (Ghate and Daniels, 1997) of non-disabled children in which 61% of 12-15 year olds spent time with friends every day. Thus overall, it appears that visually impaired young people may spend more time doing less interactive social activities than their sighted peers, but the differences between blind adolescents and those with low vision varies between studies.

In the study by Gold et al. (2010), 50% of the young people (who were either blind or had low vision) reported barriers to their social life including not being accepted by peers, negative reaction of people to their blindness or unusual eye movements, problems with social skills and difficulties with access including not seeing as well at night and transportation difficulties. Similar difficulties have also been reported by the parents of young people with VI (Gray, 2005, Leyser and Heinze, 2001). The Shaping the Future report found that 26% of parents of under 16s and 12% of 16-25 year olds wanted more structured activities provided for young people and 11% of parents of under 16s thought that specialist activities for children with VI were needed (Keil et al., 2001).

2.4.6 Dating and relationships

Another significant feature of the lives of young people that may impact on their risk of social isolation and loneliness, both as young people and, potentially, later in life, is their experience of intimate, romantic relationships. However, the research evidence available only provides quantitative insights into the dating experiences of young people with a visual impairment; it does not explore any link with loneliness and social isolation. Huurre and Aro (1998) report no difference in the percentage of teenagers with and without a visual impairment currently dating, but those with a visual impairment had had fewer previous dating experiences. Pinqart and Pfeiffer (2012) found that young

people with a visual impairment were less likely to have had dating experiences than those without a visual impairment. However, they found no difference in the percentages that had fallen in love or experienced romantic relationships, although the young people with visual impairment were older when they first dated or had their first romantic relationship, a finding also reported in another study (Kef and Bos, 2006). Comparing the experiences of Canadian young people who are blind with those with low vision, Gold et al. (2010) found no difference in whether they had had a romantic relationship. However by age 25-29 only 16% were married, compared with the national figure of 27%. Interestingly, a somewhat different picture emerges from the Network 1000 study of adults in the UK (Clements and Douglas, 2009). Similar to the Canadian statistics, by age 18-29, the UK study shows 17% of people with a visual impairment to be married; however this compares with only 12% of the general population. However, what the UK figures show is that people with a visual impairment in this age group are much less likely than the general population to be living as a couple but unmarried; only 10% of people with a visual impairment were living together, compared with 21% of the general population.

2.4.7 Social networking

Social networking is a part of everyday life for most older children and adolescents. In a study of visually impaired children in the USA, Kelly and Smith (2008) suggested that only 23% of children aged 6-12 and 38% of children aged 13-16 used email or chat rooms at least once a week. While their study did not include a control group, they comment that this is far below that usually quoted for sighted children and suggest this may lead to children being excluded from this form of social interaction. However, a recent study for the RNIB (Hewett et al., 2012) indicated a much higher percentage of children accessing social interaction online. The authors found 76% of children and young people aged 14-17 accessed the internet every day, mainly to use social networking sites. Furthermore 91% had a profile on a social networking site and 25% used this to keep in touch with friends. In addition, 75% had smart phones and 93% used their mobile everyday for keeping in touch with friends and family. A few children were found to have some accessibility problems and could benefit from further advice on using assistive technology, but on the whole most children were interacting socially online. Gold et al.(2010) had similar figures to the RNIB study for their Canadian sample; three quarters of their sample of young people socialised or stayed in touch via online venues and 26% said they had met new people through electronic means. This suggests that the internet may prove a useful forum for young people with VI to meet others.

3 Discussion

In this section we draw together the key findings from the review, considering together both the research relating to a general/older population, and that relating to children and young people. We also reflect on some of the limitations arising from this review; both in terms of the review itself and in terms of the research reviewed. We then move on to make some recommendations for policy and practice arising from the review, before going on to identify some ideas for further research that would help to develop greater understanding in this complex area.

3.1 Key findings

3.1.1 Prevalence

Within the field of visual impairment policy and practice, loneliness and social isolation are widely understood as being important issues that play a significant part in the experience of sight loss for many people. They are also recognised as being major issues for older people, as reflected in the Campaign to End Loneliness. However, the evidence for a link between loneliness and visual impairment is somewhat mixed, and based on a limited amount of research; with recent Dutch studies conducted using the De Jong Gierveld loneliness scale suggesting a clear link (Alma et al., 2011, Verstraten et al., 2005), but other studies conducted using the UCLA scale finding a much weaker association (Barron et al., 1992, Foxall et al., 1993, Wahl et al., 2013). The evidence relating specifically to children and young people is similarly inconclusive.

The less than overwhelming nature of this quantitative evidence is also reflected in the link between ageing and loneliness, with the evidence suggesting that whilst loneliness is a significant issue for some people, it is not for others, and should not therefore be seen as a normal part of the ageing process (Victor et al., 2009). Indeed there is evidence to suggest that younger people may be more at risk of loneliness than older people (Griffin, 2010). Similarly, the evidence found here would suggest that loneliness and social isolation are not an inevitable consequence of having a visual impairment. Taking the broader evidence base reviewed here into account, however, it is clear that where loneliness and social isolation do occur, in combination with other factors, they can have a major negative impact on people's quality of life and even on life expectancy. Thus, whilst the issue of prevalence is still one that requires attention in terms of research, it is perhaps more important to understand the interaction between loneliness, social isolation and these other factors.

3.1.2 Loneliness as part of a reinforcing, multi-factorial process

Perhaps the single most important finding to emerge from this review is that loneliness and social isolation form part of a reinforcing, dynamic process in

which they interact with other factors to produce a decline in psychosocial and physical well-being in people with a visual impairment. This finding is at least partially reflected in the wider literature on loneliness in older people, where a reciprocal relationship between loneliness and depression has been observed such that it has been suggested that the two phenomena “act in a synergistic way to diminish well being in older adults” (Ó Luanaigh and Lawlor, 2008; p.1217).

For people with a visual impairment who are older, this reinforcing process can be seen to be more complex and thus perhaps stronger, due to the particular negative impact that visual impairment has on people’s ability to undertake functional activities such as shopping, cooking, getting about outside the house, and engaging in social and leisure activities. These functional limitations impact on people’s physical and psychological well-being, as both their physical activity levels and their contact with other people is reduced, leading to greater risk of social isolation and loneliness, which in turn further impact negatively on both physical and psychological well-being. This reinforcing process is reported in a number of studies reviewed here (Bookwala and Lawson, 2011, Jacobs et al., 2005, Jones et al., 2009, Wallhagen et al., 2001). Reduced mobility appears to be a key factor in this process, and one that can be seen to be directly linked to increased social isolation (Gallagher et al., 2011, Grue et al., 2010, McManus and Lord, 2012, Weber and Wong, 2010, Vale, 2004).

One particular aspect of this reinforcing process involves the difficulties that people with a visual impairment experience in everyday communication and social interaction. These difficulties, which include not recognising people in social situations, not being able to pick up on non-verbal cues, having to negotiate assistance (Naraine and Lindsay, 2011), and experiencing communication breakdown (Heine and Browning, 2004), can lead to people feeling socially marginalised (Naraine and Lindsay, 2011, Richards et al., 2010). These are issues that affect people of all ages, including children and young people (Gold et al., 2010). However, in older people, particularly, there is a concern that these difficulties can lead to feelings of social isolation and low self-confidence, reinforcing other factors and reducing the likelihood of them engaging in social interaction in future, leading to a greater risk of social isolation and loneliness (Heine and Browning, 2004).

Individual psychological factors also need to be understood as playing a part in this dynamic reinforcing process, with evidence suggesting that self-efficacy is the most important factor in determining whether or not people with a visual impairment experience loneliness (Alma et al., 2011); and further evidence that people who show lower levels of adaptation to sight loss are more likely to experience feelings of loneliness and poorer psychological well-being more

generally (Verstraten et al., 2005). Furthermore, findings from a number of studies reviewed (Bookwala, 2011, Bookwala and Lawson, 2011, Jacobs et al., 2005, Zimdars et al., 2012) highlight the importance of taking into account people's *perception* of their level of visual impairment, in understanding how the impact of sight loss can vary from one person to another.

Another factor that may be important in understanding how individuals experience social isolation and loneliness is gender; research with both adults and children (Huurte and Aro, 1998) suggests that females are more likely to experience loneliness than males. However, at least in terms of older people, the evidence reviewed here suggests that men's and women's experiences of loneliness in relation to sight loss change over time; with the difference between the genders flattening out (Demakakos et al., 2006, Jacobs et al., 2005). Thus in understanding how the various factors involved in the decline in well-being associated with sight loss interact, it may also be important to give greater consideration to the role of gender.

Considered overall, this finding reinforces the need for support to people with a visual impairment, and particularly for those who experience the onset of sight loss as adults, to be provided in a way that is co-ordinated and tailored to address people's individual support needs, but which also acknowledges that those support needs are likely to change over time (Cooper, 2013, Thetford et al., 2009a, Thetford et al., 2009b). The Adult UK Sight Loss Pathway, developed as part of the UK Vision Strategy (UK Vision Strategy, 2013a), maps out the pathway of care and support that should be available from health and social care agencies to people in the UK who experience sight loss. Although the ways in which provision is organised across the UK vary, the pathway represents the essential elements that should ideally be in place. It encompasses people's clinical, functional and emotional support needs, and emphasises the importance of early intervention, but also of enabling people to join or rejoin the pathway at different points.

3.1.3 Relationships and social support

Another crucial set of factors in understanding how loneliness and social isolation affect people with a visual impairment is the role of relationships and social support. With older adults, although there is some evidence to suggest that people with a visual impairment who live alone (Alma et al., 2011) or have lower levels of social support (Verstraten et al., 2005) are more likely to be lonely, this evidence is limited. What this review does show very clearly is that it is not the quantity of people's relationships that is most important in mitigating loneliness, but how people feel about those relationships; whether they feel cared about, and feel that they receive the support that they need and expect. It is when people's expectations of their relationships are not met that loneliness is likely to occur. This emerges from several studies reviewed

here (Barron et al., 1994, Bookwala, 2011, Foxall et al., 1994, Weber and Wong, 2010).

For children and young people, the core message in terms of understanding the link between relationships, social isolation and sight loss is somewhat different; the research reviewed here reflects a clear emphasis on the importance of making friends and developing social networks, with an emphasis on the size of children's networks that perhaps reflects the nature of social interaction at that stage in life. So for young people, having a good network of friends and access to social activities that can facilitate the development of those networks, seems to be important in preventing them from feeling left out and lonely. Factors that can impact on this include the location of the child's school, their distance from school friends, and the degree of independent mobility the child has been enabled to develop.

3.2 Limitations

3.2.1 Limitations of the review

As this is a narrative rather than a systematic review, no formal appraisal of quality has been applied in deciding which studies to include. Rather, an inclusive approach has been adopted in order to provide as comprehensive an overview of the evidence base as possible. Furthermore, because the amount of research focusing specifically on loneliness and social isolation as they affect people with a visual impairment is relatively limited, this review has been fairly wide-ranging in scope, including some studies which have looked at the issue in relation to a specific aspect of the issue e.g. as it affects people with Charles Bonnet Syndrome, and others which have looked at loneliness and social isolation only as part of broader projects. The relative lack of depth in much of this research has also meant that in places we have had to draw on a wider pool of literature on loneliness as it affects general populations. However, the use of this wider literature has necessarily had to be selective due to the limitations of time and space; for more in-depth reviews of this wider literature we would direct the reader to other recent reviews (Cattan et al., 2005, Chen et al., 2013, Dickens et al., 2011, Masi et al., 2011).

3.2.2 Limitations of the evidence base

Measures used

One limitation of the quantitative research reviewed here is that most of the studies have used single question measures of loneliness, with only a relatively small number of studies using validated measures of loneliness. This raises issues about the comparability of findings from different studies conducted using very different approaches, particularly when comparing prevalence.

Sampling techniques

Another limitation relating to the quantitative research reviewed is the use of different sampling techniques. In particular, much research conducted with people with a visual impairment uses convenience samples (e.g. recruited through low vision services) rather than community based samples which may be more representative; people recruited through low vision and other health and social care settings may be more likely to report feelings of low psychological well-being, including feelings of social isolation and loneliness, than general population samples (Pinquart and Pfeiffer, 2011).

Research across the age spectrum

As has become clear, the majority of research into social isolation and loneliness as it affects people with a visual impairment has focused on older adults. And because the prevalence of visual impairment increases significantly with age, even those studies which have looked at general adult populations have used study samples with an average age of 60 plus. Yet, as pointed out by Nyman and colleagues in their review, working age adults live with visual impairment for longer, and their risk of exclusion from employment and other social roles may be much greater than for the sighted population (Nyman et al., 2010a). However, the issue of loneliness as it relates specifically to working age adults remains unexplored (ibid.).

Qualitative research

In general, there is a lack of good quality qualitative research looking at the experiences of people with a visual impairment, and this absence is particularly noticeable in the area of research into loneliness and social isolation. This would have been helpful in interpreting some of the quantitative findings reported. Where good quality qualitative research has been available this has provided particularly useful insights e.g. Heine and Browning's (2004) study of communication breakdown.

Lack of a social perspective

Finally, it should be said that although there is an acknowledgement in some of the research reviewed of the inadequacy of societal responses to people with a visual impairment, the general tendency is to locate the 'problem' within the individual with the impairment and thus to focus on addressing the problem by developing interventions that enable people with a visual impairment to adapt to life in a sighted society. So, for example, based on the findings of their study of people's experiences of communication breakdown, Heine and Browning (2004) argue for the incorporation of communication skills training, especially the use of repair strategies, into rehabilitation. They also make the case for mutual support groups, through which people with sensory impairments can gain confidence and learn skills from others with direct experience. Similarly, Weber and Wong (2010) highlight the role of peer

support in helping people to develop coping strategies. Whilst such interventions are undoubtedly invaluable, it is also important to acknowledge that the need for them is at least partly created by social attitudes and responses to people with sensory impairments.

3.3 Implications for policy and practice

3.3.1 Addressing individual psychosocial support needs

One of the themes highlighted by this review is the complex way in which, particularly for older people, visual impairment interacts with other factors such as physical and functional decline, individual psychological factors and social circumstances to impact on people's well-being in different ways and to different degrees. So whilst there is some evidence for the greater prevalence of loneliness and social isolation amongst people with a visual impairment, it is not overwhelming, and it is certainly the case that some people are more likely to experience it than others. This underlines the need for services to attend to the particular psychosocial support needs of each individual. As O'Donnell (2005) argues, those working with people with a visual impairment need to take the time to listen to and understand the individual's circumstances, personal characteristics, interaction styles and concerns. This includes professionals working in specialist eye clinics, low vision services, and general health and social care services.

The Adult UK sight loss pathway, developed as part of the UK Vision Strategy, provides a framework which identifies key points at which emotional support might be offered. These are specifically at the point of early intervention when advice and information are provided by Eye Clinic Liaison Officers (ECLOs) or similar professionals; and at the point of registration and assessment by a Rehabilitation Officer for Visual Impairment (UK Vision Strategy, 2013a). However, evidence reported elsewhere in the UK Vision Strategy suggests that only about half of UK eye clinics provide early intervention support, and that there has been a decline in the numbers of rehabilitation officers (UK Vision Strategy, 2013b).

In terms of loneliness and social isolation specifically, very few studies have looked at the impact of low vision services on loneliness and social isolation. The one UK study found as part of this review looked at the impact of such a service on the quality of life of people with visual impairment and found that six months after their low vision appointment participants were less concerned about all aspects of their vision-related quality of life except for feelings of isolation and loneliness and not being able to carry out preferred activities (Hinds et al., 2003). This highlights the need for low vision services to continue to focus attention on developing ways to address loneliness and social isolation.

In relation to children and young people with a visual impairment, Roe (2008) has highlighted the importance of those working with them to provide a facilitating environment in which children are given the opportunity to develop social skills and to become socially included. Schools also need to be aware of the risk of children with a visual impairment becoming socially isolated. In particular, there is a need to be alert to the possibilities of children being excluded or even bullied by their peers. More attention should be paid to ensuring that pupils with a visual impairment within mainstream schools are enabled to access social activities that provide them with opportunities to develop their social networks; and that those whose school or college is some distance from their home are enabled to build a network of friends living locally to them.

3.3.2 Peer support

One key way of addressing social isolation and loneliness to emerge from this review is through peer support. Peer support, often through organised groups, is an approach that is already widely used, with groups often facilitated by local voluntary organisations. Given the finding that the majority of people with a visual impairment rely primarily on their own personal resources rather than on external support to cope with sight loss, peer support can serve a vital function in helping to develop and reinforce those resources (Lee and Brennan, 2006). They can do this by enabling people to meet others who have had similar experiences; developing mutual understanding of some of the difficulties resulting from living with a visual impairment; and sharing practical advice and strategies for coping (Byers-Lang and McCall, 1993). This includes the development of specific skills around communication e.g. communication repair strategies, and increasing people's sense of empowerment in communication situations (Heine and Browning, 2004). Peer support may also be particularly helpful for people experiencing specific conditions e.g. AMD and Charles Bonnet Syndrome (Menon et al., 2003).

Peer support services have the advantage of being relatively cheap to run. Provided alongside other specialist low vision services they may also help to reinforce the positive effects of other more expensive services, such as rehabilitation and counselling. Peer support "buddy" schemes are also suggested by parents as a way of improving the social lives of children with a visual impairment (Keil et al., 2001).

In terms of evidence for the effectiveness of peer support, one small scale UK pilot study of a programme of peer support for people with macular disease involving weekly discussion groups led by people with experience of living with MD showed promising results, with those with poorest well-being at the start of the programme showing the most significant improvement by the end (Bradley et al., 2005).

3.3.3 Addressing functional support needs

Functional difficulties emerge from this review as one of the key factors that impact on both physical and psychological well-being, leading to social isolation and loneliness. Thus, continued attention needs to be given to identifying and addressing those support needs at an early stage, as highlighted in the Adult UK sight loss pathway (UK Vision Strategy, 2013a). The pathway identifies Rehabilitation Officers for Visual Impairment as the key professional involved in providing this support at the early intervention stage, alongside a range of other professionals such as access technology trainers, occupational therapists, and dual sensory and complex needs specialists.

In particular, this review highlights the need to improve people's mobility outside the home. At an individual level there is a need to ensure people are supported to access and use services that will improve their mobility such as specialist and public transport, and training and support to use symbol canes. People may also need support to improve their confidence in getting about, which may come either through rehabilitation officers or other low vision professionals, through peer support or through one to one emotional support or counselling.

3.4 Suggestions for further research

3.4.1 Developing ways of addressing loneliness and social isolation

The review has highlighted the complexity of the problems associated with loneliness and social isolation, and in the process has also highlighted numerous gaps in our understanding of the issues involved, which we go on to discuss in the rest of this section. However, it needs to be acknowledged that loneliness and social isolation are real and pressing problems for people living with a visual impairment as well as for those professionals working with them to address their needs. There is currently a lack of effective, evidence-based ways of addressing these problems. Thus a first topic for further research is the identification and development of workable solutions to the problems of loneliness and social isolation that take account of the complexity of those problems as outlined in this review.

3.4.2 Prevalence

In terms of further research, this review highlights the very limited nature of the current evidence base for the prevalence of loneliness in people with a visual impairment. There is, therefore, a need for more quantitative research conducted in different national settings, and exploring the prevalence of the phenomenon in relation to different groups of people with a visual impairment; that is by age, gender, socio-economic status, ethnicity, urban versus rural living, levels of visual impairment etc. In relation to children, particularly, there is also a need for more research comparing the prevalence of loneliness

and social isolation in children in mainstream settings compared to those in specialist schools. Prevalence research should use standardised measures to allow the development of a more robust and comparative evidence base, with careful consideration given to the available measures and a clear rationale for their use.

3.4.3 What protects against loneliness?

The review highlights that although where it does occur loneliness can be a significant and complex problem, the majority of people with a visual impairment *do not* experience loneliness. Understanding what protects people from experiencing loneliness may be of great help in developing a better understanding of how to address the problem where it does occur.

3.4.4 Relationships and social support

The findings relating to the importance of people's perceptions of the quality of their relationships highlight the need for more research into the expectations that people with a visual impairment have of their support networks and how these relate to loneliness. This has been identified as an avenue for further investigation particularly with older people (Barron et al., 1994). However, this review highlights the need for a better understanding of the role of social support and relationships in mediating loneliness and social isolation amongst different groups across the age spectrum, including children and young people. It is suggested that whilst quantitative methods may be useful in investigating this area further, what is needed is good quality research conducted using qualitative methods, possibly used in combination with quantitative methods. Key questions that need to be addressed include: How do people's relationships change as a result of sight loss? How do people's expectations of their relationships affect their sense of social connectedness or isolation?

3.4.5 Loneliness and social isolation as part of an interactive process

It is clear that loneliness and social isolation are phenomena which affect different people in different ways, and which interact with many other individual and social factors. What is not clear from the current evidence base is how these factors interact e.g. whether there are particular causal relationships that can be identified. Thus, more research is needed which takes these different factors into account; which explores the experience of loneliness and social isolation in a multi-dimensional way; and which looks at the way in which these different factors interact. In particular, we suggest that more research is needed into the relationship between the increasing functional difficulties associated with visual impairment and loneliness and social isolation.

3.4.6 Societal barriers

The majority of research so far conducted in the field of visual impairment has tended to adopt an individualised approach to the disability associated with visual impairment, and thus seeks to identify solutions to the ‘problem’ through interventions aimed at changing the individual’s circumstances, behaviour or thinking. Whilst there is clearly value in such research, there is also a need for social research which adopts a more critical perspective, building particularly on research conducted within the disability studies field, which has built upon and developed a social model of disability perspective. Such an approach would focus attention more upon the societal barriers that people with a visual impairment face, and explore ways in which existing policy responses might be adapted to take account of this broader perspective. Areas highlighted by this review that lend themselves to such an approach include issues around communication, social interaction and mobility, where societal responses clearly interact with individual factors to produce barriers to the full inclusion within society of people with a visual impairment.

3.4.7 Socio-economic status, visual impairment and loneliness

This review highlights that there is a clear link between socio-economic status and visual impairment, and a similar link between socio-economic status and loneliness. Recent analysis conducted as part of the ELSA has been of particular value in exploring these links (Nazroo and Zimdars, 2010), with further analysis currently underway. However, there appears as yet to be very little evidence for how the three factors are related.

3.4.8 Research with younger people with a visual impairment

As highlighted in previous reviews (Nyman et al., 2010a), there is a general lack of research into visual impairment specifically as it affects working age adults, with most research being conducted with older populations, either intentionally or as a result of the sampling techniques used. In conducting this review no research was found which looked specifically at loneliness and social isolation amongst younger adults, with relatively little looking at the issue in relation to children and adolescents. Yet it is clear that people in these age groups are affected by social isolation and loneliness (Griffin, 2010), and certainly by experiences which could be regarded as risk factors or precursors, such as exclusion from social networks. One particular topic identified in research conducted for RNIB (Keil et al., 2001) is to understand the social processes that lead some children and young people to successfully integrate with their peers and others not. Another topic that it would be useful to explore further would be the role of social networking in mediating the social connectedness/social isolation of people with a visual impairment. This emerges particularly in relation to children and young people, but would be relevant to all age groups, as advances in technology and the increasing use of social networking creates

opportunities for social contact and communication that potentially reduce the advantages of sightedness.

3.4.9 Charles Bonnet Syndrome

One specific issue highlighted by this review is the link between loneliness and Charles Bonnet Syndrome. Quantitative research has shown clearly that there is a higher prevalence of loneliness in people with a visual impairment who also experience Charles Bonnet Syndrome. What this research does not do is explore why this link exists. In-depth qualitative research with people who experience CBS would be helpful in developing a fuller understanding of the link, and indeed of the wider psychosocial impacts of CBS.

3.5 Conclusion

This has been a wide-ranging review, looking at research published in the last 20 years which either focuses on, or has produced insights into, the interaction between loneliness, social isolation and sight loss. What emerges is a somewhat complex picture.

As previous reviews have concluded, evidence for the prevalence of loneliness in people with a VI is inconclusive, with very few published studies; lack of consistency in the measures used; and research limited mainly to older populations. Evidence from the most recent studies suggests that about half of older people with VI experience loneliness, compared with only about one third of the general population of older people. Combined with the fact that loneliness is associated with various negative impacts on health and well-being, including increased death rates, this clearly makes it an issue that warrants greater attention, both in terms of policy and research. However, it is also clear that loneliness and social isolation are not inevitable consequences of sight loss and that there are a wide range of factors that may influence whether or not people experience loneliness or social isolation.

Two key findings emerge from the review in terms of understanding the relationship between loneliness and visual impairment and which point the way to further research. One is that loneliness and social isolation occur as part of a complex, reinforcing process involving other factors, notably functional difficulties and mobility problems, which can combine to lead to a decline in psychosocial and physical well-being. The second key finding is that relationships and social support are important in mitigating the negative impacts of visual impairment, including loneliness and social isolation. However, the crucial factor in this is how people feel about their relationships; whether they receive the support they need and expect.

The review also highlights a number of limitations with the existing evidence base. These include the very limited amount of robust quantitative research into the prevalence of visual impairment and the lack of good quality, in-depth

qualitative research. It also highlights the lack of research into the experiences of children and younger adults with a visual impairment.

In terms of implications for policy and practice, the review highlights the need for services to attend to the individual psychosocial support needs of people with a visual impairment, taking into account the particular circumstances and needs of each individual.

Another vital resource in addressing loneliness and social isolation is peer support. This can provide an invaluable source of emotional and practical support by providing an opportunity for social contact focused around mutuality and shared experience. This can help to bolster people's confidence and reduce the feelings of isolation associated with visual impairment. It also enables the sharing of practical advice and coping strategies, and helps to raise awareness of the societal barriers that contribute to the disability associated with visual impairment.

In terms of the implications for future research in this area, firstly, there is a need for more robust quantitative research studies to investigate the prevalence of loneliness and social isolation in relation to different demographic groups. Just as importantly, there is also a need for good quality qualitative research into the lived experience of loneliness and social isolation in people with a visual impairment. Building on the key findings from this review, two key lines of further inquiry using qualitative methods can be identified. Firstly, there is a need for research into the role of relationships in mediating social isolation and loneliness. This should focus on understanding how people's relationships are affected by sight loss, and on how their expectations of the support they need and expect from those relationships are related to feelings of loneliness and social isolation. Secondly, there is a need for research which seeks to understand the nature of the relationship between loneliness and social isolation and other factors associated with sight loss, particularly functional difficulties and mobility.

In addition to these two key lines of inquiry a number of other areas for research are identified including the role of societal barriers in shaping experiences of loneliness and social isolation; and the interaction between visual impairment, loneliness and socio-economic status. Finally, the review highlights the need for more research into the experiences of visual impairment for people across the age spectrum.

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