



SOCIAL ISOLATION AND PHYSICAL AND SENSORY IMPAIRMENT

Research Findings Report

"Individuals who are socially isolated are between two and five times more likely than those who have strong social ties to die prematurely. Social networks have a larger impact on the risk of mortality than on the risk of developing disease, that is, it is not so much that social networks stop you from getting ill, but that they help you to recover when you do get ill."

Marmot (2010) Fair Society Healthy Lives Final Report.

Table of Contents	Page
Executive Summary	2
What is social isolation?	4
What factors contribute to social isolation?	4
Why is tackling social isolation important?	5
Social Isolation and Physical and Sensory Impairment	7
Life Opportunities Survey	7
Disabled Children and their Families	7
Disabled Refugee and Asylum Seekers	9
Visual Impairment	10
Hearing Impairment	13
Dual Sensory Impairment	14
Impaired Mobility, Transport and the Local	15
Environment	
Bristol Statistics	17
Limiting Illness or Disability	17
Physical Disability	17
Sensory Impairment	18
Disabled Children	19
<u>Harassment</u>	20
Key Points to Consider	21



Social Isolation and Physical and Sensory Deprivation – Executive Summary

Bristol is a member of the English Partnership of 6 local authorities who are working with the Marmot team to address health inequalities. Bristol's Marmot project is about tackling social isolation. Social isolation has been included as one of ten key priorities in Bristol's Health and Wellbeing Strategy. As part of this commitment, some research was undertaken looking at social isolation within the city (Social Isolation in Bristol 2013: Initial Findings – available on request). This briefing update looks in more detail at some of the research available examining social isolation as a particular issue for those with a physical and/or sensory impairment. First however, it will look at the concept of social isolation in more detail.

- The 2010 Life Opportunities survey asked 18,000 people about the "social barriers" they faced in eight key areas of life and found many disabled people in Britain are living socially isolated, cash-strapped lives and struggling to participate in normal activities. A disproportionately high number of disabled adults said they had limited engagement with the modern world and were unable to move freely, work or enjoy leisure pursuits.
- A UK study entitled 'On Holiday' investigated the experiences of disabled children and their families outside school time and especially during the school holidays. It found that that many young people often felt bored and missed their friends during the holidays. They wanted more opportunities for seeing their friends and more activities in mainstream leisure environments. The lack of out-of-school support for young people over the age of 12 or 13 was striking. There was little youth provision and young people's access to mainstream leisure leisure opportunities was often dependent on their parents.
- A Canadian study in 2012 illustrated how children with cerebral palsy are ostracized and bullied at school. A follow up study asked the same group of youths how school life could be improved. They identified three key strategies:
 - learn how to explain your disability to peers and teachers, rather than trying to hide it;
 - improve disability and bullying awareness so students are more comfortable seeking help; and
 - o develop friendships by engaging in extracurricular activities.
- According to research conducted by Contact a Family (2011) nearly three quarters of families with disabled children have experienced anxiety, depression, isolation or family breakdown. The survey, found that almost half had asked their GP for medication or counselling, while 65% said they felt isolated frequently or all of the time. One in five said feelings of isolation had even destroyed their family or marriage. Over half (56%) said their feelings of isolation were due to a lack of support from social services and the education system, while 57% believed it was because they could not work as much as they wanted to and 54% blamed a lack of time and money.
- University of York research into the presence of disabled people in refugee and asylumseeking communities in Britain noted that unmet personal care needs, unsuitable housing and a lack of aids and equipment were common issues, along with: a lack of knowledge about their entitlements or how to get a community care assessment, communication difficulties and extreme isolation.

- A 2003 study by the Thomas Pocklington Trust examined the needs of older people with visual impairment. The research identified a significant need for greater social contact. Over a quarter of interviewees said that they were not sufficiently in touch with other people and as many as a half wanted to go out more. Six out of ten acknowledged that they did not feel engaged with their local community. The Pocklington Trust research indicated four significant initiatives that would improve social care and inclusion of older people with visual impairment:
 - Peer support groups
 - o Resource centres
 - o Befriending services
 - o Community guides
- A 2012 study found that between 40 to 50 percent of older adults with visually impairing eye disease limited their activities due to a fear of falling. It was noted that this protective strategy puts seniors at potential risk for social isolation and disability. The research noted that continued social support may be an effective buffer against the consequences of vision loss and the negative effects of stress caused by visual impairment. It is important for family members and communities to understand eye disease and eliminate any associated stigma that can further worsen social isolation.
- A 1999 US survey of 2,300 hearing impaired adults age 50 and older found that those with untreated hearing loss were more likely to report depression, anxiety, and paranoia and were less likely to participate in organized social activities, compared to those who wear hearing aids. Because social isolation is a serious problem for some older people, the study also examined social behaviour and found that people who don't use hearing aids are considerably less likely to participate in social activities. A similar UK survey conducted by Specsavers in 2009 found that nearly two out of three Britons with hearing loss feel socially isolated because of their condition, yet one in ten of the 700 people surveyed said they would not wear a hearing aid due to the stigma attached to it.
- Many studies show that the combined loss of vision and hearing has a greater impact than that of either impairment alone, since the person affected cannot use one or other sense to compensate for the loss. People who have adjusted to hearing impairment, for example, may lose the ability to lip-read as their sight fails, and individuals with visual impairment may lose the ability to hear clearly. In both cases, there is likely to be increased isolation arising from the loss of not only essential information and interactive routes like conversation, but also more solitary leisure activities such as reading, listening to the radio or watching television.
- The 2012 report of the English Longitudinal Study of Ageing (ELSA)suggested that focussing public health intervention efforts on less wealthy, less healthy older people and on improving access to public and private transport for the over-50's is likely to have the greatest impact in alleviating what they termed as 'social detachment'.
- Community transport schemes are of vital importance where the public transport system does not fully serve the needs of older or disabled people in particular areas. They not only connect people to essential services but they also provide a link to the community and enable people to foster social connections.

What is social isolation?

Some research draws a distinction between 'social isolation', defined as an objective measure of the number of social interactions a person has with other people, and 'loneliness' which is seen as a more subjective feeling of dissatisfaction with the number (or quality) of existing social contacts. Other research has not drawn such a clear distinction between the 'objective' and 'subjective' aspects of isolation.

For our purposes we are interested in both dimensions and would argue that many people involved in delivering services related to tackling the issue, whether they label it 'loneliness' or 'social isolation' or indeed some other term, are all essentially seeking to address situations where people have:

'few social contacts and few social roles, as well as an absence of mutually rewarding relationships with other people.'

What factors contribute to social isolation?

Social isolation most commonly occurs to individuals, though for some recent migrant communities, for example, social isolation may be experienced on a wider, community level. Social isolation may first occur in childhood and may be a lifelong issue. For others, it will be linked to a specific life event, such as being made redundant, getting divorced or the death of a partner or spouse. Gender, plays a role also. Women generally tend to live longer than men, so it is often women who are left alone in later life, but with divorce rates rising nationally, social isolation is increasingly an issue for men from middle age onwards. There is also some research to indicate that men and women experience social isolation/loneliness differently – for men, social isolation is commonly linked to the loss of a partner/spouse, whereas for women the absence of wider social networks can be of equal concern.

Individual experiences are nonetheless influenced and shaped by wider factors. Most people are integrated within their families and communities to some degree, but opportunities for interactions can be affected by such trends as changing family structures (more people of all ages are living alone than in previous decades for example and families are more mobile and more likely to live apart) and changing access to social resources (the government's welfare reform programme will undoubtedly have an effect for a significant number of people, as will the on-going cuts to public sector budgets). Likewise, physical location may impede or prompt interaction. People's desire to go out and see other people may be influenced by such factors as the accessibility of local shops, for example, or the condition and accessibility of pavements and benches, or how safe they may feel in their neighbourhood.

At the community level, social isolation will be less likely if mutual assistance is a principle in the community and if reciprocity is the norm, so a sense of community cohesion is important. Personal social skills obviously also influence the experience of isolation. These are more developed for some people than others, and are determined partially by the individual's cultural background, social class and gender.

Social isolation, therefore, is influenced by factors on three levels - the individual level, the community level and at the wider, societal, level (see diagram on next page). It is a multidimensional issue, encompassing both people and the places where they live. It can be more or less severe, and has a life-course dimension; that is, it could be permanent or episodic if related to particular life events.

Why is tackling social isolation important?

Social isolation can have physically and emotionally damaging effects resulting in depression, poor nutrition, decreased immunity, anxiety, fatigue, and social stigma. Reducing social isolation can have tangible health benefits, with research highlighting the influence of social relationships on the risk of death as comparable to well-established risks such as smoking and alcohol consumption. Weak social connections carry a health risk that is more harmful than not exercising, twice as harmful as obesity, and is comparable to smoking 15 cigarettes a day or being an alcoholic.

There are studies that indicate that socially isolated older adults, for example, have longer stays in hospital, a greater number of physician visits and are more dependent on homecare services. There is therefore an economic as well as a health related case to be made for tackling social isolation. Early intervention to tackle the issue is likely to have longer term cost benefits if it helps improve people's health and wellbeing. Some valuable research has already been done in this area within Bristol. Dr Richard Kimberlee from the University of West England (UWE), for example, conducted a social and economic evaluation on a LinkAge hub in Whitehall and St George and calculated that for every £1 invested in the Whitehall and St. George Hub there is a Social Return on Investment of £1.20. The report added that this figure is "probably an underestimation of the potential return in the medium term."

Other examples from around the country include Brendon Care Friendship Clubs for older people for every £1 invested it was estimated that there was a £1.40 is saved to society at large; Craft Café; a pilot programme from Impact Arts in Scotland that seeks to reduce the isolation and loneliness experienced by older people – analysis showed that overall the Craft Café pilots have created a social return on investment of £8.27 for every £1 spent and Stay Well at Home (Age Concern: Kingston Upon Thames) - which is estimated to have had a social return on investment of 12:1 - £12of value for every £1 spent. The savings in public sector expenditure were estimated to be £240,000 – around three times the investment made by NHS Kingston in funding the pilot.

Yet economic evaluations of interventions to tackle social isolation are not routinely undertaken and it is suggested that more work needs to be done on this in future, integrating evaluation measures into any proposed intervention and highlighting the potential longer term economic benefits of the intervention as well as the estimated cost of not intervening.

Social Isolation: A Contextual Overview

Political climate Greater emphasis on individual responsibility, personalisation agenda etc Economic context

Local geography and condition

Is neighbourhood flat or hilly?

pavements, benches, loos etc

Faith

Condition/accessibility of

Ongoing cuts to public sector budgets Job creation and regeneration Rising energy costs

Welfare reform of local environment Introduction of 'universal credit' Restrictions on housing benefit entitlement

National housing,

policies

planning and transport

development, sustainability of communities etc

Access to local shops, facilities and services Distance and accessibility of local shops, facilities and services Access to public or

Genetics/hereditary factors private transport Overall health/mobility Have own transport? Distance/accessibility to Personality public transport, frequency Confidence of service etc Personal resilience Cultural background

Traffic levels Fewer social connections in communities with heavy traffic levels

> How safe is local neighbourhood? Levels of crime, anti-social behaviour etc in neighbourhood

Socio-economic Drivers Age Gender Sexuality Disability Ethnicity Immigration status/ Proficiency in English Educational attainment Employment/ Occupational status Income

Demographic and family change People living longer More people living alone Divorce rates rising nationally Greater mobility - families/relatives more likely to live apart Fewer people in caring roles than previously Immigration and migration

Access to wider community/ neighbourhoods Positive - Availability of social capital, for example, access to sports, recreational, faith, cultural groups and voluntary sector organisations active in local community Negative - A lack of community cohesion and community assets, or lack of awareness about what's available locally

Access to technology Internet and social media Technology can have both positive and negative effects in terms of tackling social isolation

Relationships to family, friends, peers etc Connectivity and social networks. Preferences for type of contact can differ according to age etc, ie. either face to face, or through social media Twitter/Facebook etc

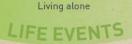
Local economy Availability of local jobs

Pension changes T Impact on standard of living

Media influences Age discrimination. negative stereotypes Social/media attitudes towards drugs and alcohol Fear of crime more prevalent than actual crime

Life Course Transitions Early home/school experiences (ie. bullying at school) Adolescence Moving to a new area Unemployment/redundancy Teenage pregnancy

Single parent Relationship breakdown/divorce **Financial pressures** Depression/mental ill-health Long term limiting health condition/disability Retirement Being a carer for partner/relative Death of partner/spouse Homelessness/living in temporary accommodation



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Social Isolation and Physical and Sensory Impairment

Social isolation is a particular issue for the disabled community, yet research focusing on the impact of social isolation on health outcomes for people with disabilities is still relatively scarce. Most longitudinal research addressing this issue has been conducted in the United States. A longitudinal study commissioned by the National Organization on Disability, for instance, highlighted social isolation as one of the most important, persistent problems that affect people with disabilities along with unemployment, poverty, discrimination in the labour market, lack of adequate school support, lack of transport, unsuitable architecture and infrastructure, and social stigma.

Social isolation has been identified by the U.S.-based Baylor College of Medicine as a common secondary condition associated with any primary disability in women. Moreover, it has been recognised that social isolation can have detrimental effects regarding both mental and physical health in both men and women. The research found that positive school environments, less over protection, more affection at home, and the sharing of experiences tends to lessen the degree of experienced social isolation and potentially contributes to positive health outcomes.

Life Opportunities Survey

In the UK, the Life Opportunities Survey compares how disabled and non-disabled people participate in society in a number of areas.

These areas include:

- work
- education
- social participation
- transport
- use of public services.

The Survey aims to identify the reasons why people do not take part in these areas as much as they would like to. It also explores topics such as living standards, housing, discrimination and crime.

The 2010 survey asked 18,000 people about the "social barriers" they faced in eight key areas of life and found many disabled people in Britain are living socially isolated, cash-strapped lives and struggling to participate in normal activities. Large numbers of disabled people suffered from so much "anxiety and lack of confidence" that they struggled to lead a normal life. Almost a fifth of disabled adults felt so stressed that work was beyond them – compared with just 4% of the general population. One in eight impaired adults felt so insecure they would not venture to take a longdistance train, compared with just one in 50 non-disabled people. A disproportionately high number of disabled adults said they had limited engagement with the modern world and were unable to move freely, work or enjoy leisure pursuits.

Disabled Children and their Families

A UK study entitled 'On Holiday' investigated the experiences of disabled children and their families outside school time and especially during the school holidays. The study was carried out by the Thomas Coram Research Unit, 2004–2006, funded by the Department for Education and Skills. The

findings of the study support the conclusions of previous research and take into account the part played by local government in shaping provisions that supports/fails to support disabled children and their families. In summary, the research highlighted that many young people themselves, despite enjoying aspects of the holidays, said that they often felt bored and missed their friends. They wanted more opportunities for seeing their friends and more activities in mainstream leisure environments.

Disabled children and their families appeared to be best supported through a range of services, including holiday clubs and other leisure activities that took into account their specific requirements. These were often based on the strategic appointment of personnel, in both the public and voluntary sector. Unfortunately, there was usually extensive rationing of any kind of out-of-school leisure and child care for families of disabled children over the school holidays. In addition, children and young people themselves (as well as their parents) told researchers that services were not able to meet their needs appropriately. The lack of out-of-school support for young people over the age of 12 or 13 was striking. There was little youth provision and young people's access to mainstream leisure opportunities was often dependent on their parents.

A Canadian study in 2012 (Experiences of social exclusion and bullying at school among children and youth with cerebral palsy) illustrated how children with cerebral palsy are ostracized and bullied at school. The small qualitative study of 15 youths aged eight to 19 with cerebral palsy published in Disability and Rehabilitation (Volume 34, Number 2, Jan 2012) found that teachers and peers intentionally shut out children with disabilities. Examples included teachers who turned off a communication device for most of the day – rendering a student silent – and a teacher who refuses to allow a child to have a bathroom communication button because it would have disturbed other children. Sometimes accommodations weren't made, researchers found. Other times accommodations themselves – such as having students write tests in a different room – set the children apart physically. "There were more and more accommodations I would need that would make me stick out more different," said one participant.

Many students said they changed schools several times because of the negative attitudes of teachers. They also found teacher attitudes influenced how their peers treated them. Unintentional peer exclusion included leaving children out of activities because they were perceived as 'fragile,' busy with an educational assistant or 'too slow.' Intentional exclusion focused on children's differences and included name-calling and being ignored. "The kids act like I am invisible," one participant said. Four of the participants had been physically bullied over a number of years, which included being kicked and pushed and physically injured. Students reported that they didn't want to tell anyone about the bullying because they were ashamed.

In a follow-up study published in Child: Care, Health and Development, the researchers from the Holland Bloorview Kids Rehabilitation Hospital asked the same group of youths with cerebral palsy how their participation in school life could be improved.

The students identified three key strategies:

• learn how to explain your disability to peers and teachers, rather than trying to hide it;

- improve disability and bullying awareness so students are more comfortable seeking help; and
- develop friendships by engaging in extracurricular activities.

Research shows that having a support network of friends protects children from being isolated and bullied.

According to research conducted by Contact a Family (online survey conducted between July and September 2011) nearly three quarters of families with disabled children have experienced anxiety, depression, isolation or family breakdown. The survey, which received over 1,000 responses, found that almost half had asked their GP for medication or counselling, while 65% said they felt isolated frequently or all of the time. One in five said feelings of isolation had even destroyed their family or marriage. Over half (56%) said their feelings of isolation were due to a lack of support from social services and the education system, while 57% believed it was because they could not work as much as they wanted to and 54% blamed a lack of time and money. Half of the families had experienced discrimination or stigma due to their child's disability.

Disabled Refugee and Asylum Seekers

The presence of disabled people in refugee and asylum-seeking communities in Britain is frequently overlooked and information about their particular experiences is rarely available. Research conducted by Keri Roberts and Jennifer Harris of the University of York in 2002 generated data on the numbers and social characteristics of disabled refugees and asylum seekers living in Britain, reviewed their entitlements to social and welfare services and provided an insight into the experiences of disabled refugees and asylum seekers and service providers. The research showed that:

- There is no official source of data on the prevalence of impairments and chronic illness amongst refugees and asylum seekers in Britain. In a survey for this study, 44 refugee community groups and disabled people's organisations identified 5,312 disabled refugees or asylum seekers known to them.
- Unmet personal care needs, unsuitable housing and a lack of aids and equipment were common among the 38 disabled refugees and asylum seekers interviewed. Other themes were: a lack of knowledge about their entitlements or how to get a community care assessment, communication difficulties and extreme isolation.
- Most workers in 'reception assistant' organisations lacked knowledge about the disabilityrelated entitlements and needs of refugees and asylum seekers.
- Service providers were critical of the government's dispersal policy and its lack of consideration of the needs of disabled people who are seeking asylum.
- The researchers identified an acute need for improved joint working between reception assistant organisations, local authority social services departments and the National Asylum Support Service (NASS). With few exceptions, relations between these key agencies seemed very strained, arising from:

- unclear policies and procedures and lack of named contacts equipped to handle enquiries about disabled asylum seekers, especially in NASS;

- considerable confusion in and across agencies about responsibilities for financing community care packages and suitable housing;

- overstretched social services resources, which sometimes meant the needs of disabled refugees and asylum seekers were seen as less pressing than those of other disabled people in the locality.

Visual Impairment

In a 2003 study, the Thomas Pocklington Trust examined the needs of older people with visual impairment through in depth interviews (Meeting the needs of older people with visual impairment: social care or social exclusion? 2003). The research identified a significant need for greater social contact. Over a quarter of interviewees said that they were not sufficiently in touch with other people and as many as a half wanted to go out more. Six out of ten acknowledged that they did not feel engaged with their local community. As we have discussed elsewhere, poor health, declining mobility and impaired vision limit social contact outside the home (Hanson *et al*, 2002).

Respondents to their interviews often expressed how difficult it was to live with insufficient contact, especially in the evenings and at weekends, when *'I'm longing to hear a human voice'*. For those who do not have family living nearby and whose social interaction centres on contact with neighbours or professionals who provide practical support, the need for informal social contact is often unmet and difficult to bear.

Lack of 'another voice' was upsetting not only because of the isolation experienced but also because individuals felt that their social or basic human skills were diminishing as a result. Mr Chapple told of his trip every Monday to Sainsbury's on the special bus, when he could *'have a little natter with the people'* but that the rest of the week he was on his own at home. Lack of sufficient social contact was a concern to Mr Chapple because: *"I'm finding that my vocabulary is nearly nil. You are not speaking to people."* The mental stimulation of regular social contact was important to interviewees. Several spoke of the lack of 'exercise of the mind'. Interviewees indicated that they could become depressed by lack of sufficient social interaction. This concern repeatedly surfaced throughout an indepth interview with Mrs Burns who, interestingly, also used the word 'human' to describe necessary social interaction: *"I feel I want to scream just for human conversation... I feel that I'm deteriorating so much because I have no stimulant, I suppose. I hardly sleep at all."*

The basic need for contact and the human capacity to compensate when it is in short supply was poignantly illustrated by Mrs Wisden, who had helium balloons tied to her little balcony, originally bought to commemorate the Queen's golden jubilee. These balloons represented the heads of imaginary visitors: *"It's strange you know because I'm here on my own twenty-four hours a day... but as soon as the wind blows it's like somebody else coming in... To me it's company... They [the balloons] come and they poke their heads in... Sometimes I feel very lonely which I think is the worst illness a person can have."* Mrs Wisden went on to speculate that she may be going a little 'crazy' because of social isolation, a perception well understood by Mr Walker who said that his main problem was not his sight loss but rather the ensuing loneliness. Sitting in a silent room with no one to talk to made him feel that he was not far removed from 'the nuthouse'.

All these comments confirm the importance of social contact for those with sight loss. They profoundly feel its absence from their lives. They have a strong need for human contact to help maintain their well-being and to give them a foothold in the world of the socially included.

In addition to earlier detection and more comprehensive assessment of needs, the Pocklington Trust research indicates that there are four significant initiatives that would improve social care and inclusion of older people with visual impairment. These are:

• **Peer support groups** - Peer support groups for visually impaired older people can also provide a much needed monitoring role, with members being contacted if they are absent for more than a week. As well as providing people with information, advice, skills training and monitoring, peer support groups provide people with an opportunity to socialise and to leave behind the isolation of home and have some human contact.

Peer support groups for older people with sight loss clearly have the potential to meet many important social care and inclusion needs. This is because they offer wide-ranging and preventative help. Such groups are also settings where members' individual rights and advocacy skills are potentially strengthened. Peer groups are also cost effective. This is because services which would be expensive to provide on a one-to-one basis can be made available to a group of peers with similar needs at the same time.

• **Resource centres** - Those interviewed in the Pocklington Trust study, as well as respondents in other research, have called for a resource that provides professionally staffed services for people with sight loss under one roof. In many ways such a resource centre, or one-stop-shop, offers the potential for fair access to care services, in that it would be holistic, in terms of the range of needs it would be equipped to meet, and yet capable of delivering a personal service. Interviewees considered that a *'one-stop-shop'*, *'all singing, all dancing'* enterprise such as this could, in time, become a catalyst for development of well publicised and supported initiatives in local areas. Although certain types of resource centre existed in each of the fieldwork areas, there were none that met such a range of needs under one roof and therefore provided maximum accessibility to social care services.

Interviewees were generally supportive of resource centres as places where support would be coordinated, accessible, socially oriented and individually tailored. Interestingly, interviewees also suggest that if such an enterprise is to deliver the preferred range of support, it will need to be backed by local authorities in partnership with other agencies and organizations.

• Befriending services - The research indicates that many older people with visual impairment welcome the opportunity to have a more informal form of social contact which is psychologically beneficial. A number of interviewees had a regular monthly home visiting service provided by the Metropolitan Society for the Blind. This service met some of these befriending needs. However, the time available during these visits was necessarily limited and the resource was clearly rationed, as many who could have benefited were not receiving visits. One possible suggestion was the use of volunteers who may be interested in pursuing careers in the social care or medical professions, and who would use their experience of befriending as a sign of their caring capabilities.

Volunteers are, of course, used by befriending agencies. Perhaps a pool of prospective vocational students would be of interest, although agencies would have to be sure that volunteers were sufficiently mature and appropriately aware in order to provide a sensitive service. Interviewees indicated, however, that any expansion of a befriender service would most likely start from a very low base, as neighbourhoods often lacked resources to appoint, train and coordinate volunteers. Nevertheless, there was a great deal of enthusiasm for such development.

• **Community guides** - The research showed that with a significant number unable to go out as regularly as they would have wished, the need for increased social interaction was very important to many interviewees. However, going out was not necessarily a straightforward proposition. The proportion of the Thomas Pocklington interviewees who had some difficulty with public transport because of their sight was nearly five times as high as those who attributed this to other conditions. The problem for many was identifying bus numbers and making their presence known in time to make buses routinely stop. A number had access to Dial-a-Ride or similar schemes operating in their area. Where they existed they were often spoken of favourably. However, the vast majority of interviewees either did not know of any comparable local provision or found it too inflexible to meet their particular needs.

Interviewees advocated a scheme that would ideally provide 'assistants' who could be booked in advance for the time required to accompany individuals to a venue, help them orientate themselves and guide them onto public transport. The need for an escort is not limited to having someone to help orientate and guide the individual. An escort helps the individual develop much needed confidence to face the challenges and obstacles presented by uneven pavements and other hidden hazards, such as the problem of encroachment of pavements by cars and a general lack of confidence in negotiating busy roads.

A study published in December 2012 in the journal *Investigative Ophthalmology & Visual Science* found that between 40 to 50 percent of older adults with visually impairing eye disease limit their activities due to a fear of falling. Vision scientists warn that this protective strategy puts seniors at risk for social isolation and disability. In the paper, "Activity Limitation Due to a Fear of Falling in Older Adults with Eye Disease," researchers report on their examination of patients with age-related macular degeneration (AMD), glaucoma and Fuchs corneal dystrophy, as compared to a control group of older adults with good vision. Of the three groups with visual limitations, the patients with Fuchs corneal dystrophy were the mostly like to report activity limitation due to fear of falling, followed by those with glaucoma and the AMD group.

Visual impairment is likely to affect mobility and access to social contacts. Social isolation, disengagement, loneliness, and loss of social support may result. However, continued social support may be an effective buffer against the consequences of vision loss and the negative effects of stress caused by visual impairment. For example, visual acuity is directly associated with anxiety and depression, but only for subjects with limited access to family support. In addition, results indicate that high quality social support correlates with fewer depressive symptoms and better adaption to vision loss. It is important for family members and communities to understand eye disease and eliminate any associated stigma that can further worsen social isolation.

Hearing Impairment

In a survey conducted by the National Council on the Aging (NCOA) in America in 1999. The survey of 2,300 hearing impaired adults age 50 and older found that those with untreated hearing loss were more likely to report depression, anxiety, and paranoia and were less likely to participate in organized social activities, compared to those who wear hearing aids. Because social isolation is a serious problem for some older people, the study also examined social behaviour and found that people who don't use hearing aids are less likely to participate in social activities. Among respondents with more severe hearing loss, 42 percent of hearing aid users participate regularly in social activities compared to just 32 percent of non-users.

A similar UK survey conducted by Specsavers in 2009 found that nearly two out of three Britons with hearing loss feel socially isolated because of their condition, yet one in ten of the 700 people surveyed said they would not wear a hearing aid due to the stigma attached to it.

Because hearing loss is an invisible disability, denial is common, especially for those who acquire a hearing loss later in life. They may react with increased sensitivity or irritability when they do not understand words. The increased social pressure to understand may cause anxiety and frustration, and they may avoid activities and interactions that they once enjoyed. Unwillingness to acknowledge hearing loss may result in individuals' refusal to participate in hearing evaluations or reluctance to wear hearing aids.

Individuals with hearing loss may limit social contacts to family members and a few close friends, or they may avoid social contacts altogether because of their inability to understand what is being said. Difficulty in understanding verbal communication can cause withdrawal from social situations in an effort to avoid the embarrassment of giving inappropriate responses to questions or statements. Lack of understanding by others can contribute to social isolation. New acquaintances who are unfamiliar with hearing loss or unaware of individuals' inability to hear may perceive them as aloof or even rude because of their failure to respond to a friendly statement that they did not hear.

Individuals with hearing loss may have more difficulty keeping up with conversations in group settings, especially if others in the group are unaware of or insensitive to their needs. Group settings with poor lighting make lip-reading more difficult, and competing sounds, such as the rattling of dishes in a restaurant, may make communication difficult even for individuals with milder hearing loss.

People who suffer untreated hearing loss often find it harder to take part in everyday social activities, even with their family. Common social problems include:

- Isolation and withdrawal
- Lack of concentration
- Problems at work may have to give up work/retire
- Reduced social activity
- Problems communicating with wife/husband, friends and relatives
- Loss of intimacy
- Inattentiveness

- Bluffing
- Problems communicating with children and grandchildren

Dual Sensory Impairment

Many studies show that the combined loss of vision and hearing has a greater impact than that of either impairment alone, since the person affected cannot use one or other sense to compensate for the loss. People who have adjusted to hearing impairment, for example, may lose the ability to lipread as their sight fails, and individuals with visual impairment may lose the ability to hear clearly. In both cases, there is likely to be increased isolation arising from the loss of not only essential information and interactive routes like conversation, but also more solitary leisure activities such as reading, listening to the radio or watching television. The influence of a combined dual sensory impairment on sight and hearing may also make the person more physically vulnerable. In some cases the domestic environment may present physical obstacles or difficulties and require changes to make it safer or easier. While it is important to obtain appropriate diagnosis and treatment for conditions giving rise to sensory loss, the social aspects are often masked by a focus on the medical aspects of impairment and are separated from associated outcomes, such as falls.

Falls are a recognised source of anxiety in older people and are also a potential trigger for isolation as reduced mobility often follows, all factors which are recognised by health and social care professionals. Dual sensory loss is, however, recognised by deaf blind specialists as a clear underlying cause of falls in older people and a greater awareness among non-specialists would act as a preventive measure. For people with dual sensory impairment the potential for isolation increases as their impairment becomes more severe. Visits outside the home or from family and friends may become increasingly difficult when ease of travel and communication are lost, for example.

For people with dual sensory impairment the potential for isolation increases as their impairment becomes more severe. Visits outside the home or from family and friends may become increasingly difficult when ease of travel and communication are lost, for example. As a result, such visits may diminish in frequency, leading to a loss of social interaction and potentially a loss of information about the world outside the home. Older people, their families and carers may also display unwitting ageism and assume that such isolation is an inescapable consequence of ageing, with the result that its effect on mood and motivation are rarely questioned. However, research indicates while visual impairment clearly increases the risk of depression and, to a lesser extent, so does hearing loss, combined dual sensory loss has an even greater effect.

Depression, when identified, is usually considered a medical problem and therefore capable of treatment. However, the combination of assumptions about the natural course of ageing and dual sensory loss means that the depression which can result is often ignored until it becomes severe. Disability in any form, but particularly the combination of vision and hearing loss, results in an increased risk of developing depressive symptoms and disorders which, in turn, can lead to illness, further physical impairments and other restrictions on activities of daily living.

Recommendations made with respect to dual sensory impairment include:

• Raising general awareness of problems and potential solutions is essential to maximising individual quality of life and minimising social isolation.

- Dual sensory impairment in older people may be seen as 'normal' and not identified as problematic or as a disability.
- Simple interventions, such as ensuring regular sight and hearing checks or holding conversations in well-lit areas, can be very effective in improving the quality of life of people with dual sensory impairment.
- Families, carers and other 'non-specialists' can play a crucial role in early identification, hopefully leading to appropriate and timely interventions.

Impaired Mobility, Transport and the Local Environment

Any disease that leads to impaired mobility, such as Parkinson's, musculoskeletal conditions and heart problems, can prevent people from participating in social activities as frequently as they did previously. It has been suggested that there are three categories of 'inhibiters to movement' for those with a disability or impaired mobility:

- "Personal" (pertaining to the individual's health, functional capabilities and expectations for mobility),
- "Environmental" (weather conditions, physical accessibility of the environment) and
- "Trip-related" (length of the trip, the cost of travel, the reliability and availability of transport services provided).

It might be argued that knowledge and awareness of the transport facilities that are available are also important in determining mobility levels, so that pre-trip information in particular becomes an important facilitator to travel. Research has certainly shown that, for disabled people, it is particularly important to have accurate and reliable information on all aspects of a journey, from start to finish, before they embark on a journey. There is a need for an unbroken "chain of accessibility" for a journey to be feasible. Travellers with a disability or impaired mobility tend to place greater importance than non-disabled people on the need for information to be available on each leg of a journey.

The 2012 report of the English Longitudinal Study of Ageing (ELSA), a comprehensive study that aims to understand the economic, social, psychological and health concerns of an ageing society, noted a concern with social isolation as a key finding. The ELSA report suggested that focussing public health intervention efforts on less wealthy, less healthy older people and on improving access to public and private transport for the over-50's is likely to have the greatest impact in alleviating what they termed as 'social detachment'.

There has been a welcome shift within ageing policy in recent years towards ensuring older people can 'age in place', in the houses and communities where they live. Yet, this desire to ensure older people remain in their own homes brings with it a tension, as those who are less mobile or unable to access public transport can be left feeling trapped or isolated in their houses. Research conducted by the campaign to end loneliness has noted that more than one million people feel trapped in their own home and approximately five million regard the television as their main form of company.

This is partly a result of the withdrawal of amenities such as banks, post offices, shops and pubs from local high streets, as they rationalise their operations or are forced out by competitors in out-of-

town locations. This represents an effective withdrawal of the places in which every day social interactions can take place: a drink in the pub, a coffee in a café, a meeting in a church, a function in a community hall or a chat in the doctor's waiting room.

But it is also partly a transport issue. Previous work on 'social exclusion' has highlighted that poor transport can contribute to social exclusion in two ways. First, it restricts access to activities that enhance people's life chances, such as work, learning, health care, food shopping, and other key activities. Second, more deprived communities suffer disproportionately from pedestrian deaths, pollution and the isolation which can result from living near busy roads.

Royal Voluntary Service (formerly WRVS) research has recommended that public transport providers take an age-friendly approach when designing and delivering services to recognise the needs of older and disabled people, including training drivers to assist and support people with mobility issues when they travel and ensuring that bus stops are close to destinations where mobility impaired people would like to travel. The RVS recommended consulting with older people and disabled people over planned changes and designs as part of producing an impact assessment.

The growing role of community transport should also be recognised. Community transport schemes are of vital importance where the public transport system does not fully serve the needs of older or disabled people in particular areas. They not only connect people to essential services but they also provide a link to the community and enable people to foster social connections.

The Campaign to End Loneliness has highlighted several recommendations to local authorities which touch upon the importance on transport issues, namely:

- Paid volunteer coordinators will ensure community transport and low-level support capacity is maintained - The voluntary and community sectors (VCS) play a significant role in providing services that helping older residents stay independent and connected. Befriending, lunch clubs, dementia cafes and transport schemes all play a critical role in countering social isolation. Funding community coordinator schemes or volunteer coordinators can be relatively low cost but can make a significant contribution to the Voluntary and community sectors ability to continue low-level support.
- Funding the training of minibus drivers is a small investment that could lead to savings or expansion of existing charitable transport services -Community transport providers often need more trained minibus drivers, for example to utilise spare bus capacity for older people. However, the cost of putting someone through the relevant training course is around £1000 which can deter volunteers or charities. A small investment by the local authority could therefore help create extra community transport.

Bristol Statistics

Limiting Illness or Disability

The 2011 Census asked the following question: Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? Include problems related to old age?

When using this data, it can be useful to look at the statistics for the working age population rather than all ages as this will exclude many of the limitations due to old age.

Limiting Long-term Illness or Disability

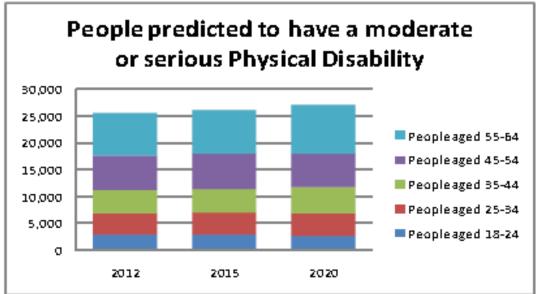
	Day to day activities limited		England and Wales
People aged 16-64	36,407	12.4%	13.0%
All ages	71,724	16.7%	17.9%

Source: 2011 Census Office for National Statistics © Crown Copyright 2012

The proportion of people with a limiting long-term illness or disability in Bristol is lower than the national average – this reflects the younger age profile in Bristol. The proportion of people with a limiting long-term illness or disability has decreased from 17.8% in 2001 to 16.7% in 2011 but due to the large increase in the overall number of people living in Bristol, the actual numbers of people with a limiting long-term illness or disability have increased from 67,739 to 71,724.

Physical Disability

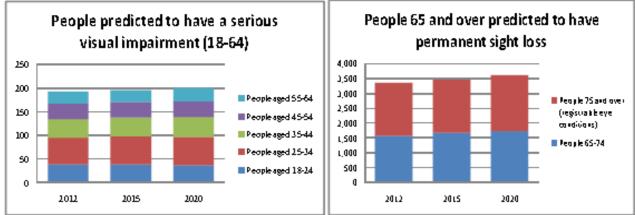
The predictions below are based on national prevalence rates for moderate to severe physical disability and applied to the Bristol population aged 18-64. Projections for 2012 estimated that there are some 25,600 working-age adults (18-64) living with a physical disability in Bristol, predicted to increase to 27,000 by 2020. [This is around 1,000–3,000 less than 2011 estimates, due to reductions in the overall population growth, not to changes in the estimated prevalence rates for physical disability].



Source : Projecting Adult Needs and Service information, u6.0 (June 2012) www.pansi.org.tk

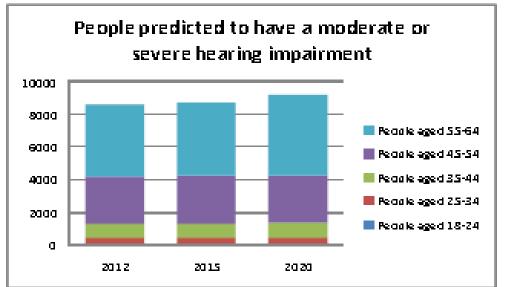
Sensory Impairment

The "Projecting Adult Needs and Service Information" (PANSI) system estimates that 1 in 1500 working-age people has a severe visual impairment, requiring help with daily activities. Applied to local Bristol population estimates, this suggests around 200 people. Many more people will live with sight loss that does not meet the severe threshold. The Royal National Institute of Blind people (RNIB) suggest 1 in 500 as an estimated basis of people who would have register-able eye conditions, and note sight loss prevalence is higher amongst older people, plus people from BME communities and adults with learning difficulties. The RNIB estimate that over 80% of sight loss occurs in people over 60yrs, and PANSI estimates there are 3350 people over 65 in Bristol with non-correctable sight loss (plus around 1,700 over 75's in Bristol with treatable eye conditions).



Source : Projecting Adult Needs and Service Information, u6.0 (June 2012) www.pansi.org.uk.

It is also estimated that Bristol has 8,600 people with a Hearing Impairment:



Source : Projecting Adult Needs and Service Information, u6.D (June 2012) www.pansi.org.uk

RNIB research indicates there is a high prevalence of sight loss within BME communities. People from African and African Caribbean populations are four times more likely to develop Glaucoma; if presenting late with symptoms, sight loss is then irreversible. In some areas socio-economic status can impact on the number of people from BME communities accessing eye health opportunities, missing out on early detection of sight loss. Also, people from the Asian population are at a higher risk of developing cataracts, and the African, African Caribbean and Asian populations are all at a higher risk of developing Diabetic eye disease. There is a need for sight loss prevention services as well services to support people with sight loss (in all communities).

The total number of migrants (who have migrated between 'health systems') in Bristol is about 30,000 people. Primarily these are from Eastern Europe (especially Poland), Somalia, India, and international students at Bristol's universities. Health services for migrants need to include education, familiarisation, interpreting & translation services for health and social care, and screening and diagnostic services.

Disabled Children

In 2009-2010 Bristol City Council and NHS Bristol jointly undertook a pilot to estimate the prevalence of potentially disabling conditions with and without chronic illness in young people (0-18), using GP data sets, and compare this to the prevalence of disability provided using Special Educational Needs and Disability Living Allowance data16. Results were used from 10,756 young people (0-18 yrs) from 5 local GP practices.

Potentially disabling conditions - The prevalence of potentially disabling conditions varied from 3.2% to 7.8% with an **average of 4.9%.** NB Based on the current Bristol estimate of 84,145 children, there may be in the region of **4,100 young people** (0-18) with a significant physical or mental difficulty.

Potentially disabling conditions or chronic illness - The prevalence of potentially disabling conditions or chronic illness varied from 5.2% to 10.5% with an **average of 7.5%**. There may be in the region of **6,300 young people** (0-18) with a significant physical or mental difficulty or severe chronic medical condition that could potentially impact on their daily lives.

Within this, the prevalence by type of condition indicates that, after chronic illness (36%), the majority of all potentially "disabling conditions and chronic illnesses" are mental difficulties, including general and specific developmental delays and mental health difficulties (24% of all, or 36% of potentially disabling conditions only). Some children had both chronic illnesses and potentially disabling conditions. Two-thirds were male, and the prevalence increased with age, especially for "potentially disabling conditions or chronic illness".

Harassment

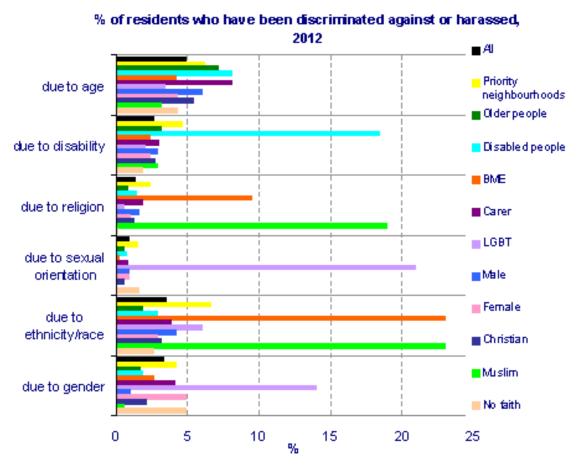
In recent years Bristol has undergone a major demographic change, more so than any other city in Britain, making it one of the most diverse cities outside London. There were 1,584 hate crimes reported to the police and partner agencies in Bristol in 2012/13, an overall reduction on 2011/12 figures. Bristol has the second highest hate crime rate, when compared with Core Cities.

Persistent discrimination and harassment can affect quality of life, perception of safety in the community and can have longer lasting effects, such as increasing feelings of social isolation and depression.

The annual quality of life survey asks a question about whether or not people feel they have been the victim of discrimination and harassment. The question has six sub-indicators residents are asked about discrimination and harassment in relation to age, disability, religion, sexual orientation, ethnicity/race and gender. This indicator was first measured in 2006. Between 2006 and 2012 a very small proportion of the total population said they have suffered different types of discrimination and harassment (5% or less). Of the subindicators, all have remained stable each year, apart from discrimination and harassment due to sexual orientation and this has decreased/improved.

Some residents in certain wards tend to suffer more discrimination and harassment, particularly in Lawrence Hill. Generally men, compared to women experience more discrimination and harassment, except for gender discrimination.

Results shown in the graph below showed people of Muslim faith, black and minority ethnic groups, lesbian, gay, bisexual and transgender people and disabled people experienced discrimination and harassment. Further analysis (not illustrated here) suggests that carers are also exposed to discrimination and harassment disproportionately.



Source: 2012 Quality of Life Survey – Published May 2013

Key Points to Consider

- People with physical and sensory impairments often have high levels of unrecognised health needs and difficulties accessing services. Due to linguistic barriers, those with a hearing impairment in particular can experience extreme isolation, and so suffer from higher levels of ill health. There is therefore a need for a greater degree of awareness-raising, information and advice about solutions that might be avoidable to tackle social isolation, alongside better identification of those at risk, particularly given the cross-cutting nature of social isolation.
- The impact of the economic downturn and welfare reform is likely to affect people with life-limiting conditions in the medium-term due to increased risks of unemployment and low income which may further compound their social isolation.
- Care must be taken that the move towards greater personalisation and the 'eenabling' of care services does not result in those who are less mobile or unable to easily access public transport becoming more isolated in their communities. The RNIB, for example, have noted that in the past five years, between 2008 and 2013, there has been a 35 per cent decline in the numbers of blind and partially sighted people getting council care and support and argue that the criteria local authorities

are using to assess whether someone needs social care are failing to properly recognise the impact of sight loss. They note the focus is increasingly on personal care at the expense of addressing other day-to-day needs such as preparing meals, cleaning and maintaining a safe home environment, communication and getting out and about safely. In short the needs assessment fails to capture the unique challenges of living with little or no sight.



If you require any additional detail on the information contained in this report, please contact Dave Clarke on <u>dave.clarke@bristol.gov.uk</u> or phone 0117 922 4788