JO COX
LONELINESS
start a conversation

"Someone cares if I'm not there"

Addressing loneliness in disabled people

A report by the disability charity Sense for the Jo Cox Commission on loneliness

The Jo Cox Commission on Loneliness

The Jo Cox Commission on Loneliness is starting a national conversation about the scale and impact of loneliness in the UK. Find out more at jocoxloneliness.org

As founder members of the Commission, the disability charity, Sense, has brought together a coalition of disability charities to collectively highlight the issue of loneliness for disabled people, and to call for action. The following charities contributed to the production of this report:

We have far more in common than that which divides us

Foreword by Rachel Reeves MP and Seema Kennedy MP

Research has shown that we are all more likely to experience loneliness at certain times of our lives, such as retirement, bereavement or after becoming a parent. Disabled people experience the same life transitions as everyone else, but in addition to this, having a disability means that they are more likely to be chronically lonely than non-disabled people.

Each disabled person is unique in terms of the impairments and personal circumstances they face. The causes of loneliness among this group are complex, and can be as unique as the individuals themselves, as the stories and descriptions set out in this report demonstrate. However, despite being a hugely diverse group, loneliness is an experience that many disabled people will have in common.

Many of the barriers to building social connections for disabled people are practical ones – including the need for accessible transport and buildings, financial support and appropriate social care. But sadly, for the whole community of disabled people, poor levels of public understanding and awareness of disability is most often the biggest barrier to making connections and finding common interests with others.

Shockingly, one in two non-disabled people (49 per cent) don't believe they have anything in common with disabled people, and a quarter (26 per cent) admit they have avoided engaging in conversation with a disabled person.

Jo Cox strongly believed that 'we have far more in common than that which divides us' and this sentiment is hugely relevant as we turn our attention to the issue of loneliness among disabled people. We would all benefit from seeking to create connections with others by focusing on our similarities and shared interests rather than our differences.

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We would all benefit from seeking to create connections with others"

What is loneliness?

Loneliness is a subjective, unwelcome feeling of a lack or loss of companionship. This can happen when we have a mismatch between the quantity and quality of social relationships that we have, and those that we want. Loneliness is related to social isolation but the two are distinct – social isolation is a measurable lack of social contact, whilst loneliness is a subjective experience. It is therefore possible to be socially isolated, but to not feel lonely.

Loneliness is an emotionally distressing experience, and for individuals who are chronically lonely, there can also be significant impacts on longer-term mental and physical health.

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Loneliness and disabled people

The Equality Act (2010) describes disabled people as those with a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities. This includes people with one or more of the following:

- Physical and mobility impairments and balance disorders;

- Head or brain injuries;

- Cognitive impairment, with long and shorter term causes;

- Autistic Spectrum Conditions;

- Chronic illnesses;

- Learning disabilities;

- Sensory impairments; and

- Long term mental health conditions.

There are 12.9 million disabled people living in the UK.[iii][2]

Research has shown that we are all more likely to experience loneliness at certain transition points throughout life. In addition to this, specific groups, such as disabled people, are more likely to be chronically lonely.

Disabled people are a diverse group – the nature of impairments and personal circumstances varies considerably between each individual. Despite this, loneliness is an experience that many disabled people will have in common. We know that having one or more impairment increases the risk of loneliness and social isolation:

1 For a summary of the evidence on the health risks associated with loneliness and social isolation see:
http://www.campaigntoendloneliness.org/threat-to-health/

- Almost one quarter of disabled people (23 per cent) say they feel lonely on a typical day.
- Over half of disabled people (53 per cent) report feeling lonely, rising to three-quarters (77 per cent) for young disabled people.

As the stories in this report demonstrate, the causes of loneliness among disabled people are complex and will vary for each individual depending on their personal circumstances.

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Loneliness is an experience that many disabled people will have in common"

In many cases, the barriers to making social connections are practical ones, but public attitudes can also have a profound impact on individuals' ability to make connections and find common interests.

For these reasons, a one-size-fits-all solution is not possible to tackle the problem of loneliness among disabled people. A range of practical and policy measures are necessary, alongside a wider shift in societal awareness and understanding of disability.

The following report is not intended to be exhaustive, but to demonstrate a range of different experiences, and some of the barriers to making social connections for disabled people. It is also important to note it is common for cross-overs to exist between different conditions, with many disabled people having more than one type of impairment.

Contents

Loneliness and sensory impairments

There are more than eleven million people in the UK with some form of hearing loss and over two million people are living with sight loss. The extent of the sensory impairment will vary from person-to-person and may coexist – there are 358,000 people in the UK who have both a sight and hearing impairment. Sensory impairments can be congenital (from birth) or acquired and have many causes including age, infection during pregnancy, accidents, illness, genetic conditions or syndromes.

Depending on the nature, severity and onset of the sensory impairment, people may experience difficulties in accessing information, communication and mobility. People with sensory impairments use a range of communication methods including British Sign Language, and may require information in additional formats such as large print or braille.

Fourteen per cent of adults with a vision impairment say they never or rarely have as much social contact as they would like, and say they feel very or completely cut off from the people and things around them.

Forming and maintaining social connections can be a challenge for people with sensory impairments, of all ages.

Ian

Ian was born partially deaf and has limited vision. Ian has Usher syndrome, a progressive condition which slowly causes his eyesight to deteriorate. Ian is a talented photographer, who has had his work displayed at major exhibitions.

Ian experiences loneliness on a daily basis. He says that poor accessibility is one of the main barriers to forming social relationships. "Simple things like going to the pub can be a stressful experience when you have both sight and hearing impairments. I have to try hard to hear in noisy places and even walking to the bar can be a challenge because of my tunnel vision. There aren't many venues for young people that are accessible to someone like me. Meeting friends is difficult."

The loss of his full-time job in his early 30s increased his feelings of loneliness. "My eyesight started deteriorating further and I had to leave my job, as it became unsafe to travel on my own. The loss of employment had a devastating impact. I lost my daily structure, financial independence, self-worth and that vital platform to socialise with other people."

Ian is currently going through training with a guide dog, and hopes that it will make the outside world more accessible. Ian believes a change in public attitudes towards disability would make a great difference to the isolation disabled people feel.

" Meeting with friends has got increasingly hard"

Ricky

Ricky is a university student with a visual impairment. "As I did my A levels," he says, "I was encouraged to go to university and I knew I wanted to carry on studying. I've always had a passion for politics and I wanted to take it further.

"I really enjoyed the academic side of things and my department did everything they could for me, but I don't think they ever had a blind student before. Socially, support was a total disaster, and I was left in my room for 24 hours at a time. It really took its toll on me. I felt really lonely and I didn't really get the student experience at undergraduate level.

"My current support is so much better. I'm now studying for an MA. It has made such a tremendous difference to me. Previously, I only had just about enough support just to live, to survive. I could only have a daily meal cooked and have a sandwich made up for the following day. It also meant that I could only get washing and shopping done, there wasn't any time for social activities.

"Having the right support is really good for my emotional wellbeing. As well as being able to survive, it allows me to socialise, take opportunities and explore avenues that are available to other people at university."

Erin

"My name is Erin, I am 17 years old and I have a moderate hearing loss and wear two hearing aids. When I began secondary school, I felt left out of group discussions, as people would sit with their backs to me. This meant I could not hear them, when this happened I felt lonely and felt left out, like I was not wanted.

"I have felt uncomfortable going out to restaurants because the noise makes it hard to hear or understand my friends or family or even the waiters. I always felt bad making them repeat themselves. I have chosen not to go to things like swimming with my friends, as I would have to take off my glasses and hearing aids. I therefore couldn't communicate with them, I felt useless as I could not join in.

"However, three years ago, I started to do Tae Kwon-Do. It has really helped my confidence and I no longer feel so isolated and alone. The instructor makes sure I understand everything and makes me feel included. He demonstrates the action and repeats instructions when I raise my hand.

"My word of advice to other disabled young people is to join a group or organisation. My advice to organisations is to make sure their activities are accessible to everyone that attends them."

Specific barriers include:

- A lack of understanding from other people about how to communicate and interact with people who have sensory impairments.
- Inaccessible venues and events for social opportunities. This may include settings with poor lighting and acoustics, or that are difficult to get around.
- A lack of information in accessible formats about social opportunities.
- Interacting in large groups can be challenging for people who find following conversation difficult, including those who lipread.
- Using certain communication methods can be tiring and may cause fatigue. This may mean that some people seek to limit their social interaction.
- People with sensory impairments may lack the confidence or skills to navigate outside the home, and may not be able to go out alone. Poor access to reablement support services[3] can compound this.
- A lack of accessible public transport or inaccessible street environments such as pavements blocked by cars or street clutter can make getting out and about more difficult.
- Poor access to professional communication support (such as interpreters) for social occasions can limit social interaction.
- A lack of access to educational or employment restricts opportunities for social interaction and financial independence.

Where to go for help

Sense provide information and support for people with complex communication needs: Tel: 0300 330 9256, Textphone: 0300 330 9256, Email: info@sense.org.uk

The National Deaf Children's Society provide information and support for deaf children and families: Tel: 0808 800 8880, Email: helpline@ndcs.org.uk

RNIB offers emotional support through one-to-one telephone counselling for people with sight loss – Tel: 0303 123 9999. RNIB Talk and Support runs telebefriending groups to help people with sight loss to socialise and find friendship – Tel: 0845 330 3723 or 0207 391 2218. Email: talkandsupport@rnib.org.uk socialise by phone for friendship and support.

Action on Hearing Loss provide an Information Line offering information on deafness, hearing loss and tinnitus. Tel: 0808 808 0123, Textphone: 0808 808 9000, SMS: 0780 0000 360, Email: informationline@hearingloss.org.uk

Guide Dogs provide mobility and independence for people with sight loss, and campaign on a range of related issues. Tel: 0118 983 5555, Email: guidedogs@guidedogs.org.uk

3 Reablement services help people who have support needs, to re-learn the skills required to keep them safe and independent.

Loneliness and learning disability

There are 1.4 million people with a learning disability in the UK. A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life. People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people. The level of support people will need varies according to whether they have a mild or profound level of learning disability.

Research suggests that people with a learning disability are vulnerable to loneliness. Indeed, up to fifty per cent of people with a learning disability experience chronic loneliness[xi].

In a recent survey by the learning disability charity Mencap, nearly 300 people with a learning disability aged 18-35 were asked about their social lives. One in three said they spend less than one hour outside their homes on a typical Saturday. As well as this[xii]:

- 49 per cent said they would like to spend more time outside their home;

- 45 per cent do not think they spend enough time with friends;

- 18 per cent feel alone and cut off from other people.

Additionally, children with a learning disability tend to have smaller social networks, and their social networks are not typically as strong or close as those of children without a learning disability.[xiii,xiv] Fourteen per cent of children with a learning disability identify themselves as having no friends, compared to one per cent of children without a learning disability.[xv] A third of children with a learning disability say they find it harder than average to make friends.[xvi]

There are a number of factors that may inhibit successful friendships and increase feelings of loneliness for people with a learning disability:[xvii, xviii, xix, xx, xxi]

- Limited opportunities for exposure to a variety of social groups and situations.

- Limited access to support staff in the evenings and at weekends, which can prevent people with a learning disability from socialising outside of the home during these hours. Support staff may also inadvertently become gatekeepers to social activities for people needing a high level of support.

- Low levels of employment and the social contact this brings.

- A lack of support available to help people with a learning disability to develop their social skills and self-confidence, make friends, and maintain these friendships.

- Some people with a learning disability experience difficulties processing social information and language. This can mean that they don't understand everything that is being said or might not be able to express themselves.

- The friendships of people with a learning disability can be devalued or restricted by carers, family members or the general public.

- Low levels of awareness and understanding from members of the public who may not meaningfully involve and value people with a learning disability.

Where to go for help

Mencap Direct provides information and advice to anyone wanting to know about learning disability issues and services: Tel: 0808 808 1111, Email: helpline@mencap.org.uk

Beyond Words provides books, training and services to support people who find pictures easier to understand than words. Email: admin@booksbeyondwords.co.uk.

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Up to fifty per cent of people with a learning disability experience chronic loneliness"

"Joining the Friendship Club has changed my life. I now have a lot of friends"

Daniel*

Daniel is a young man with a learning disability. He says:

"Having a learning disability can make things like making or keeping friends very difficult and I needed support. I only had one friend and used to go out by myself because I was lonely. I did not like going out by myself and sometimes felt very scared, so I used to stay home and watch TV. I also used to experience hate crime from the kids by my flat.

"Every week a community nurse and occupational therapist would visit me, to make sure I was ok. They told me about a club, called the Friendship Club, where I might be able to make friends. I was a bit nervous but thought I'd give it a go. It was great. The first time it was in a pub and everyone was very friendly and welcoming.

"At the club, we do things that people who don't have a learning disability probably find easy, but I find challenging. Things like meeting friends in the café, at the pub, ten pin bowling, discos, walks, quizzes and more. We always meet in places like cafés, pubs – rather than booking a hall – so we get to be with other members of the public, which is also good.

"Joining the Friendship Club has changed my life. I now have a lot of friends. I even go out with some of these friends on my own now. Me and two other people from the Club meet every Monday for a boy's lunch in a local pub. Life is so much better. I don't need my community nurse or occupational therapist any more either.

"As well as making lots of friends, the Friendship Club has given me new skills and a lot of confidence, which I didn't have before. Because I'm more confident and capable, I can help other people who need it. I'm more confident using public transport. Before the club I was scared to use it, now I use it all the time. I like taking the trains and buses, and I have a free bus pass so that also helps."

*Pseudonym and indicative image used

Loneliness and autism

Around 700,000 people in the UK are on the autism spectrum.[xxii] Autism is a lifelong developmental disability that affects how people perceive the world and interact with others.

People with autism can find making sense of the world extremely hard. Everyday life can be confusing, meaningless or even frightening.

Understanding and communicating with other people is particularly difficult and can leave people feeling very lonely. As many as 79 per cent of autistic people and 70 per cent of their families feel socially isolated;[xxiii] 81 per cent say they feel lonely at least some of the time because of anxiety relating to their autism[xxiv]; 81 per cent of young people with autism believe they spend less time socialising than their peers.[xxv]

Key factors include:

- People on the autism spectrum can struggle in social situations as they may not understand the meaning and motivations of other people. Difficulties with communication and interaction can make establishing and maintaining social relationships more difficult.

- As autism is a hidden disability, people on the spectrum are often misunderstood by the people around them.

- People with autism may have underlying depression and anxiety that causes them to feel lonely and socially isolated.[xxvi]

- For children and young people with autism, bullying by peers is a significant issue. Sixty five per cent of parents of children with autism have reported that their child was victimised by their peers within the last year.[xxviii]

- Expulsion from school is more common for children on the autism spectrum, meaning they are cut off from peers.

- Only 16 per cent of autistic adults in the UK are in full-time paid employment and only 32 per cent are in some kind of paid work.[xxix] This means social isolation is more likely.

- Seventy per cent of autistic adults say that they are not getting the help they need from social services, and feel that with more support they would feel less isolated.[xxx]

Where to go for help

The National Autistic Society provide an Autism Helpline to give information, advice and support for autistic people and their families and carers: Tel: 0808 800 4104 or via an online form.

NITA

Nita is young woman with Asperger's Syndrome.[4] She says,

"My name is Nita. I was formally diagnosed with Asperger's syndrome nearly two decades ago at 15. For me personally, autism is first and foremost a social disability, and I say disability because it does indeed have a disabling effect on my ability to communicate with others.

Sometimes I feel that there is a wall separating me from others—a barrier that, although invisible, may as well have been as solid and secure as Fort Knox for all the success I had breaking out of it. The fact is, try as I might to make sense of other people for whatever reason, they and I just cannot seem to tune into each other's wavelengths. Sometimes, and only with hindsight, I know where I went wrong, but more often than not, I don't.

It's pretty stressful, given that not only am I hyper-conscious of my condition and how my every word, inflection, pause, move and gesture is coming under intense scrutiny by whoever I'm trying to interact with, but also that I am simultaneously trying to scrutinise, assess and modify myself. This is worse if I'm in a crowded place, because then my senses are going haywire attempting to process every little detail around me. Consequently, any prolonged interaction with other people leaves me exhausted. Yet instead of resting, I re-run said interaction in my head and attempt to work out if I did anything wrong and how I could have done it better.

Socialisation and having friends shouldn't be this hard, should it? I need friends. Not paid friends, or people who feel sorry for me; people who accept and like me for, and even despite, who I am. I am autistic, but I am no less worthy of friendship than anyone else."

> "
> ## I am autistic, but I am no less worthy of friendship than anyone else"

4 Asperger syndrome is a lifelong developmental disability that affects how people perceive the world and interact with others.

Loneliness and mobility issues

More than one in ten people (around five million adults, in Great Britain report some kind of mobility problem. [xxxi] People can experience mobility issues as a result of a range of medical conditions or following an injury, accident or ageing. People with mobility impairments may struggle to get around for various reasons, and some, but not all, will use wheelchairs or other mobility aids.

Physical impairments can make maintaining existing relationships and making new social connections more difficult. Thirty per cent of people with mobility issues say that they are always or often lonely. [xxxii]

Common causes include:

- Poor physical mobility can impede the ability to get out and about and interact socially.

- People with physical impairments may struggle to access public transport,[xxxiii] or find there is limited availability of public transport options, particularly in rural areas.

- Difficulty accessing a wheelchair often prevents people from leaving their homes – and sometimes hospital – which in turn increases social isolation.[xxxiv]

- A lack of designated car parking spaces for use by Blue Badge holders[5] can make accessing social venues a challenge.

- Living in housing that is not suitable for individuals with physical disabilities[xxxv] can mean it is difficult to leave the home to take part in social activities. It can also make it harder to spend time with family and friends at home.

- Public buildings outside of the home may be inaccessible[xxxvi] and this may limit opportunities to join in with social opportunities. Poor access can include a lack of accessible toilets.

- Poor access to technology, or the need for training in its use, can reduce people's ability to make social connections online.

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Physical impairments can make maintaining existing relationships more difficult"

5 The Blue Badge scheme is for people with severe mobility problems. It allows Blue Badge holders to park close to where they need to go.

Where to go for help

Scope provide information and support on all issues that matter to disabled people and their families: Tel: 0808 800 3333, Email: helpline@scope.org.uk

The British Red Cross provide support at home, transport and mobility aids, as well as specific services to tackle loneliness and isolation. They can be contacted on Tel: 0344 871 11 11, Textphone: 020 7562 2050

Age UK run a free national advice line which provides information, support and advice for over 55s. It's open 8am to 7pm 365 days a year. Tel: 0800 678 1174.

Barbara*

Barbara has a degenerative condition that has left her with very limited mobility.

In her 30s, Barbara suffered a slipped disk and had significant back pain. When Barbara was finally diagnosed with a degenerative condition, she says she, "just had to accept it." She began to walk with one stick, and then needed two to get around. Barbara eventually became reliant on a wheelchair for her mobility, and then had to use a mobility scooter because using her arms caused her too much pain.

Barbara's condition became steadily worse two years ago, when one morning she woke up in immense pain and could not move. Her pain is now managed with medication, but Barbara is confined to her bed, and her mobility is extremely limited.

Barbara was supported to learn how to use a computer by a British Red Cross volunteer. She learned to use a laptop so she could do her own supermarket shopping, Skype her family abroad and keep in touch with the outside world. She says,

"I had always planned to visit my brother who lives in Australia when I retired – I would've loved to have travelled, but that dream is over because of my health and it's emotional for me that my family live so far away. Now that I can use Skype, I can actually see him even though he's on the other side of the world. The computer means I can use email and he can send me photos of his family, I can even use Google Maps and see where his house is – it's incredible."

*Indicative image and name

> **Now that I can use Skype, I can actually see him even though he's on the other side of the world"**

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Sue

Sue lives alone in the South West of England. She became a wheelchair user following a stroke in 2012. Sue lived in accommodation provided by a Housing Association, but the design of the home was not accessible. As a result, Sue struggled to physically leave the house, and was limited in her ability to socialise at home, and to develop friendships with neighbours.

Sue said, "I haven't been upstairs in my own house for two years, and I have to sleep in the lounge. I have a care worker who comes in the morning and helps me get washed at the kitchen sink, but there is no privacy – the neighbours can see in to where I wash, and I just want to have a bathroom where I can do these things myself in private."

The door on her downstairs toilet had to be removed in order to fit her wheelchair inside, so if people came round to visit they had to leave if she needed to use it. Sue applied to live in an accessible home, but initially was not successful because there weren't enough suitable properties available.

In 2016, Sue moved into a new accessible apartment. She is now able to use all the space in her home and has the privacy of a wet room which are big improvements, but she can still feel isolated. Sue says "it is hard to get around by bus and taxis are expensive and hard to book. Transport is a big issue, lots of the support groups are not local and I don't have the money to travel to them. I can still go for days without seeing anyone."

Transport is a big issue... I don't have the money to travel so I can go for days without seeing anyone."

Loneliness and mental health conditions

One in four people will experience a mental health problem in any given year. There are a wide range of mental health problems. Diagnoses range from common conditions such as depression and anxiety, to rarer conditions such as schizophrenia and bipolar disorder.

The relationship between mental health and loneliness can often be two-way: loneliness and social isolation can have a significant impact on your mental health, and mental health problems often lead to feelings of isolation.

Studies have shown that people who are socially isolated experience more stress, have lower self-esteem and are more likely to have sleep problems than people who have strong social support. All of these things can have a negative effect on your general wellbeing and can contribute to or exacerbate mental health problems. Social isolation has also been linked to less common conditions like schizophrenia. In turn, social connections can help to prevent mental health problems.

Similarly, for people with mental health problems, the symptoms they experience can increase the potential for them to feel lonely. Over half of people who have experienced depression or anxiety have reported isolating themselves from friends and family.[xxxix]

Common experiences include:

- Mental health problems can often lead to low self-esteem and a poor self-image. People may not feel confident that others want to have social contact with them, or feel that other people don't understand them or see them as different or strange.

- For people who experience conditions such as phobias, social contact or leaving the house may be especially difficult. This can have the effect of reducing the contact they have with other people.

- Some people find the medication that they take for their condition can affect the way they see themselves. It may change someone's appearance or the way they communicate. Many people report having lost or put on weight, or feeling drowsy as a result of taking medication. Some medication can cause shaking or slurred speech and this can lead people to worry that other people will make incorrect judgements about them.

- People with mental health conditions are less likely to be in work. 1.8m people claiming Employment and Support Allowance are unable to work primarily because of a mental health problem.[xi] This can contribute to isolation by reducing the availability of supportive networks that people have access to.

- Nine out of ten people with mental health problems experience social stigma and discrimination[xli] which can have an impact on their level of social connectedness. Often people with mental health problems find that other people don't know how to react to them or what to say when they are unwell – perhaps fearing that they might make a situation worse.

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Half of people who have experienced depression or anxiety have reported isolating themselves from friends and family"

Where to go for help

Mind provides an information line to provide support to people with a mental health problem. Tel: 0300 123 3393. Email: info@mind.org.uk. Text: 86463

Local Mind Services offer support to people with their mental health and help keep them connected to their communities.

Young Minds provide a helpline for parents who are worried about a child or young person: Tel: 0808 802 5544

Imani

Imani is 36 and has been diagnosed with borderline personality disorder and complex post-traumatic stress disorder (PTSD). She says,

"Life with mental health problems is, by its nature, isolating, and that isolation comes from all angles. Every child gets messages from society, sometimes even from their own families, that it is wrong to display emotion and wrong to show vulnerability or weakness.

People will draw attention to you and tell you to 'cheer up, chill out, count your blessings' and how we need to 'buck up our ideas and think positive.' So when we feel we are not conforming to the ideal of the 'always smiling always coping' person you instinctively shrink away. It makes you feel 'less than' other people.

As a woman with PTSD caused by long-standing childhood abuse, people fail to understand how I can still be affected by traumas that happened such a long time ago. Lots of people can't understand why as an adult woman I find it hard to be in a crowd of people, to hear raised voices, or to being looked at as I walk along the street, feeling like every person's eyes are on me. They can't understand why I startle easily, or get nervous when I can't predict what will happen, or meet a stranger, or travel to an unfamiliar place. These things contribute to isolation.

I don't ask strangers for help, because when I have, I have been invariably been met with blank and unfriendly faces. The only place I ever felt safe socially being my authentic self was my local Mind 'Safe Space' drop-in group for people with mental health problems. At Safe Space I wasn't alone. None of my emotion had to be concealed and I knew I'd be met with compassionate understanding. People there would congratulate me for getting to the group, knowing how difficult it was to leave the house in the first place. That helped me massively. For that hour a week I was not alone. I was in the company of people who also knew how it felt to be alone, and together we helped each other feel less alone."

"

That helped me massively. For that hour a week I was not alone"

Oli

Oli, 26, experienced feelings of loneliness as a teen. He felt increasingly isolated in the years that followed as the highs and lows of his mental health issue, bipolar disorder, were misdiagnosed as bouts of depression. He said,

"When I was younger, in my late teens, my mental health problems started to kick in. I've got bi-polar. I always felt like I was the odd one out, the last one picked for the football team, not invited to parties – that sort of thing.

I felt so isolated, and I felt like I was the only one that felt like that so I didn't want to tell anyone in case everyone thought I was weird. So I kept it quiet, it got progressively worse until I ended up trying to take my own life.

After another episode, it [my mental health] got reviewed and I was given a little bit more help. I stopped trying to deal with it all myself and started getting help."

Oli says the first thing you should do if you realise you're lonely – or suspect a friend, relative or acquaintance is feeling isolated – is to talk:

"If saying it out loud feels like a huge deal or an embarrassing admission, simply imagine a friend saying, 'hey I've been feeling a little lonely lately, do you have half an hour for a chat and a cup of tea?'… hardly a revelation is it? Most people wouldn't think twice before sticking the kettle on.

Sometimes all it takes is a little bit of your time. You could end up talking to somebody, then realise they're going through the same thing. Then all of a sudden, you realise you're not alone."

* Indicative image

Susan

Susan is a single woman, with no siblings, in her late sixties. After her parents died, Susan worked as a supply teacher, until she retired from work following a hip replacement operation. She became very isolated and lonely. She experienced depression, and stopped eating, drinking and getting dressed.

A concerned neighbour contacted social services. She was supported by a local voluntary organisation, Lean on Me, and re-engaged with her local church. A carer supported her to get up and dressed, shop and eat, and resume practicalities like going to the bank.

Susan has now moved into a new home, in extra care housing. Two months in, she feels more connected: She sees people at lunch, has met her neighbours, and has had one of them round for a cup of tea. The care staff are keen to hear about what is going well, and to help her with any problems.

Currently Susan feels safe and cared for. She says, "It feels like I matter. Someone cares if I'm not there."

* Indicative image

Loneliness and dementia

There are 850,000 people with dementia in the UK, with numbers set to rise to over 1 million by 2025. Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. People with dementia will experience a range of symptoms which affect daily life, such as memory loss and difficulties with thinking, problem-solving or language. A person with dementia may also experience changes in their mood or behaviour, and the way the person communicates will gradually be affected.

More than a third of people with dementia admit to feeling lonely,[l] rising to nearly two-thirds (62 per cent) for people with dementia who live alone. Difficulties in maintaining social relationships and other features of dementia contribute to this.

A third (33 per cent) of people with dementia said they lost friends following their diagnosis.

The increase in social isolation and loneliness can be down to several factors:

- Cognitive impairment and communication difficulties make it much more difficult for people to socialise.
- 60 per cent of people living with dementia have stopped doing things that they used to do because of mobility difficulties.
- 70 per cent have stopped doing things they used to do, due to a lack of confidence.
- 53 per cent believe a lack of appropriate activities for people with dementia is a barrier to them participating more fully in their communities.
- Public attitudes are key – research has also shown that 35 per cent of people report that they would not feel comfortable having a conversation with a person who has dementia.[li] And 41% of the public disagree that it's just as easy for people with dementia to play an equal part in society as anyone else.[lii]

" People with dementia will experience a range of symptoms which affect daily life"

Where to go for help

The Alzheimer's Society provides the National Dementia Helpline to give information, support or advice about dementia: Tel: 0300 222 11 22 or use an online form.

Age UK run a free national advice line which provides information, support and advice for over 55s. It's open 8am to 7pm 365 days a year. Tel: 0800 678 1174.

Katie

Katie's mum was diagnosed with dementia in 2013. Since her diagnosis, her mother has gone from being a very sociable person to someone she doesn't even recognise. Speaking about how her mum experiences loneliness as a result of her condition, Katie said:

"Mum noticed she was becoming as forgetful, as the rest of us did. She had watched her own mother's battle with dementia and was terrified of the same fate – living on her own compounded these feelings. There was too much time alone to over-think, too much empty space to remind her that she was on her own. Of course friends would come, but when a beloved matriarch has nobody to take care of, days are very long. Mum became afraid to do anything independently, which in turn led to more time alone at home.

There were times when I would phone Mum up to seven times a day, just so she had regular contact. I would suggest she made some food, or watched Strictly Come Dancing, then I would call her back to chat about it. Loneliness is a cruel bi-product of a Dementia diagnosis, and one that is surely easily more curable than the disease itself."

"
There were times when I would phone Mum up to seven times a day, just so she had regular contact."

Gladys*

Gladys is in her eighties and has dementia. After her husband died, Gladys moved to Gloucestershire to live near her family. She lived independently in a small flat in the town centre and was quickly able to make social contacts in her local church which also hosted community events, coffee mornings and social activities. Every day Gladys would visit the church to meet up with friends and join in with the activities, and she also began volunteering in the café.

After Gladys was diagnosed with dementia and her needs changed, it became harder for her to live independently. For a year or so, Gladys was able to remain at home with the support of family and carers.

Following a short illness and progression of her dementia, Gladys and her family decided that living independently, even with support, was no longer possible. Following a number of visits to local homes, Gladys and her family chose a residential home in a village on the outskirts of the town. This home had specialist expertise in supporting people with dementia and Gladys felt happy there.

Once she moved, Gladys's family noticed that whilst she was well cared for, she was lonely. Her new home was a 15 minute drive away from the church that she used to visit daily and many of her friends at the groups she attended didn't drive. Her social contacts reduced significantly and she withdrew as a result.

Whilst her new home met many of her needs, moving there had broken the social connections she had made and meant she no longer had access to the social networks she had established. Once staff realised what was going on, they supported her to establish new friendships within the home, and she is much happier as a result.

*Pseudonym and indicative image used.

❝
They supported her to establish new friendships and she is much happier as a result"

Loneliness and brain injury

Around 350,000 people are admitted to UK hospitals with an acquired brain injury every year.[xlii] Causes of brain injury include a fall, a road accident, tumour or stroke. Survivors of more severe brain injuries are likely to have complex long-term problems affecting their personality, relationships and their ability to lead an independent life.[xliii]

Brain injuries can have a profound impact on the individual, and their relationships. 74 per cent of people with a brain injury report that their social life has been negatively affected as a direct result of their impairment.[xliv]

Several factors contribute to loneliness in people with brain injuries:

- Brain injury survivors sometimes lose their sense of empathy or self-awareness. They may behave inappropriately without being aware that there is anything wrong with their actions, and this can have a negative effect on relationships.

- Behavioural changes such as increased irritability can cause damage to relationships.

- Cognitive and communication issues may make having conversations more difficult.

- Brain injury is a hidden disability, and the cognitive, emotional and behavioural effects can still be present long after any physical injuries have healed. This can have a significant impact on social interactions and relationships – 81 per cent of people with a brain injury feel that their life would be better if other people had a better level understanding of the effects of their condition.

"

Brain injury is a hidden disability"

Where to go for help

Headway – the brain injury association provides a range of frontline services to help those affected by brain injury, including a network of support groups and branches across the UK and a national nurse-led helpline for anyone with a question about brain injury. Tel: 0808 800 2244, Email: helpline@headway.org.uk

John

John* sustained a brain injury due a tumour diagnosed when he was an infant. He was left with mobility problems and chronic fatigue.

John had difficulty maintaining friendships in his childhood and teenage years due to the pressure that his injury, and the numerous operations he had to endure, placed on his relationships. He said,

"When I was at school I had a number of friends who would stick by me. After school was done and dusted, most of those 'friends' kicked me to the curb and I only had a couple of friends who I saw regularly. I was pretty lonely at times.

The problem got even worse when I left college – because I didn't have anything to do at all. Over time, I became more and more antisocial and my confidence got lower and lower. I became a very quiet person and would not want to answer the door or talk to strangers at all. The boredom at times was very hard to handle too. If I was not living with my parents and older brother I would have been very, very lonely indeed.

I'm a keen artist and used to always draw when I was little. It was during those six years after college where I stopped drawing altogether and my family used to ask me why I was not drawing anything. I would tell them that I had, what I called, 'Artist's Block' and did not know what I wanted to draw."

John said since attending Headway – the brain injury association, his confidence and motivation has returned:

"What I have been through over the years is terrible but in some ways I am glad it happened because if it didn't happen then I would not be at Headway. I would not know the wonderful people I know now. Headway has helped to raise my confidence and motivation and I am drawing again. I realise now that 'Artist's Block' was actually a load of rubbish."

*Pseudonym used

"
Headway has helped to raise my confidence and motivation"

Loneliness and neurological conditions

Neurological conditions result from damage to the brain, spinal column or nerves, caused by illness or injury. They include conditions such as Parkinson's, Multiple Sclerosis (MS) and Motor Neurone Disease (MND). Such conditions can be progressive and fluctuating, and affect all aspects of daily living including talking, walking, swallowing and writing.

Around 127,000 people live with Parkinson's in the UK.[xlv] Most are aged over 60, though some people are diagnosed much younger. More than 100,000 people in the UK have MS,[xlv] and MND affects up to 5,000 adults in the UK at any one time.

Loneliness and social isolation is a common experience for people with neurological conditions. For example, people with Parkinson's typically report very sharp increases in social isolation as their condition progresses, with a very negative impact on quality of life.[xlviii]

People with neurological conditions often have specific symptoms that can contribute to social isolation and loneliness:

- People with mobility issues may find that inaccessible buildings and transport may be a barrier to getting out and about.

- 'Wearing off' – where medication stops working, and people have extremely limited mobility until the next dose takes effect, has a major impact on people's ability to be away from their home or in social situations.

- Mental health symptoms including apathy, depression and anxiety can be specific symptoms of a neurological condition. These symptoms can prevent people from maintaining social networks.

- Pain and fatigue have a significant impact on people's ability to be sociable.

- Cognitive changes and communication issues can make social interaction and conversation difficult.

- Some neurological conditions cause visible symptoms such as drooling, excess sweating, incontinence, tremor, swallowing issues, involuntary movements and changes to gait and facial expressions. Sometimes people are mistakenly accused of being drunk in public. This can lead to a loss of confidence.

- Other people's attitudes and misunderstandings about their condition can have an enormous impact. One study found that nearly two-fifths of people with Parkinson's (37 per cent) felt the need to hide their symptoms or lie about having the condition.[xlix]

Where to go for help

Parkinson's UK provide a confidential helpline for anyone living with or affected by Parkinson's. They also provide and a range of local and national support. Tel: 0808 800 0303, Email: hello@parkinsons.org.uk

The MS Society run a free MS helpline providing support and information to anyone living with in the UK. Tel: 0808 800 8000

The Motor Neurone Disease Association provide MND Direct, providing information and support on all aspects of motor neurone disease (MND) Tel: 0808 802 6262, Email: mndconnect@mndassociation.org

Jean

Jean is 82, has Parkinson's, and lives alone in London. She used to be very active and had a career as an Office Manager, when she was diagnosed with Parkinson's.

For the past three years Jean has only been out of the house to attend medical appointments.

Most of her friends have died or are housebound themselves. She has no children and only one sister who lives in Kent and is unable to travel. Her nieces and nephews telephone her occasionally but very rarely visit as they have busy lives and their own parents to care for. There is a neighbour who pops in occasionally, but Jean does not want to be a burden to anybody.

Jean was recently referred to her Parkinson's Local Adviser by the local Parkinson's Nurse Specialist. The Local Adviser has helped Jean to apply for Attendance Allowance to enable her to pay for a mobile hairdresser to visit and pay for occasional taxis. She has also applied for a taxi card to help her to get out and about. These small changes have helped Jean to feel more connected.

"A neighbour pops in occasionally, but Jean does not want to be a burden to anybody"

Loneliness and cancer

Under the Equality Act 2010, cancer is defined as a disability.[liii]There are now an estimated 2.5 million people living with cancer in the UK, with this figure expected to rise to 4 million by 2030.[liv] It is estimated that 22 per cent of people with cancer are suffering with loneliness.[lv]

People living with cancer can experience a range of issues which could lead to an increased sense of isolation or loneliness. These might be:

- One in four people diagnosed with cancer in the UK say they lack the support of family or friends during their treatment and recovery – more than 80,000 people each year.[lvi]

- Many feel that their family and friends are too busy to help or live too far away.

- Others have lost contact with friends and family as a result of their diagnosis.

- Many people have to give up work during treatment and can struggle to return after treatment. This, combined with increased costs, can have a significant financial impact. Four in five cancer patients who report a lack of support say they can't afford to see their family or friends as much as they did before they were diagnosed.[lvii]

These issues go beyond treatment and recovery – one in six people who were diagnosed with cancer more than 10 years ago have not been visited by a friend or family member for at least six months.[lviii]

Further research by Macmillan Cancer Support shows that, amongst those who are lonely, almost half (47 per cent) feel this way despite having as much social contact as they want, showing that loneliness can affect even those surrounded by family and loved ones.[lix] This can sometimes be due to the range of physical, emotional, and practical issues faced by cancer patients after treatment ends. An estimated one in four of those living with cancer – around 625,000 people in the UK – face poor health or disability after cancer treatment.[lx]

"

One in four people diagnosed with cancer in the UK lack the support of family or friends during their treatment and recovery"

Where to go for help

Macmillan Cancer Support provides a support line and one-to-one support for people affected by Cancer: Tel: <u>0808 808 00 00</u>, Next Generation Text Service: 18001 0808 808 00 00.

Shola

Shola was diagnosed with cancer in July 2013. Not having any family in London meant that she often had to attend appointments alone, which meant that she often felt very isolated. She said,

"After my diagnosis I just felt very alone because I don't have a family here, I don't have a partner or children. So although I had a friend with me, I was coming home alone to digest that information. So I felt very, very scared.

My mum was waiting to find out the results and she's from a generation that doesn't really understand illness. She's African and they come from a culture where they're very secretive about diseases like cancer – it's not something you talk about. So I couldn't really engage with her about it.

I didn't want to be a burden to anyone because my treatment was for seven, eight hours a day every three weeks. So people might pop in for 10, 15 minutes and it just heightens how alone you are when you're going through your treatment. So it was difficult.

My work colleagues would cook me nutritious food, sent me kind text messages and gave me words of comfort and hope which is what helped me get through some dark days.

On reflection there was a memorable moment when nearly all of my work colleagues and some friends came to see me in hospital three days post-surgery I was really touched by that. People that I didn't expect to visit did.

I couldn't work for many months because it wasn't just the physical aspects of the illness. It was the psychological aspects. I became very depressed afterwards. So it was a good seven months before I could contemplate returning to work, and it had to be a phased return because I lost a lot of my confidence because of the illness.

Working helped me feel less isolated because I wasn't thinking about my illness or my prognosis. I needed to have something to keep me busy and keep things normal, and that's what work gave me. Plus everyone around me understood and was very supportive. Being in that kind of environment actually aided my recovery, I think."

"Working helped me feel less isolated because I wasn't thinking about my illness or my prognosis"

Loneliness and HIV

HIV is classified as a disability from the point of diagnosis in the Equality Act 2010, although people living with HIV are often overlooked in debates around disability. An estimated 101,200 people were living with HIV in the UK at the end of 2015, although approximately 13,500 of these do not know that they have the virus.[lxi]

Since the advent of effective medication, most people living with HIV in the UK will have a normal life expectancy and are unable to pass on the virus (known has having an 'undetectable viral load'). However, the prevalence of societal stigma and associated self-stigma mean that many of them experience prejudice, discrimination and constant fear of their HIV status being disclosed. As a result, many people living with HIV report that their well-being is seriously affected by isolation and marginalisation.[lxii]

Moreover, the treatment advances of the 1990s mean that we are now seeing the first generation of people who are ageing with HIV, and the evidence suggests that they are likely to experience chronic loneliness. A third of people living with HIV aged 50 and over are socially isolated, and 82 per cent of over 50s living with HIV experience moderate to high levels of loneliness. People aged over 50 living with HIV are at least three times more likely to experience high levels of loneliness than the general population.[lxiii]

For many people living with HIV the experience and the fear of HIV related stigma will contribute more than the physical impact of the virus to social exclusion, isolation and loneliness. Common experiences include:

- Destabilisation of family relationships and existing friendships and support networks.

- Concerns about disclosing HIV status to new friends and acquaintances leading to difficulty meeting new people and forging new friendships.

- A reluctance to pursue sexual or romantic relationships because of the stigma associated with HIV, even when a person has an undetectable viral load.

- Experiences of social exclusion and marginalisation ranging from verbal and physical harassment to pressure to disclose HIV status, resulting from poor public awareness of HIV.

- Roughly half of people living with HIV who responded to the UK Stigma Survey reported experiencing self-stigma – feelings of shame, guilt, low self-esteem, and self-blame in relation to their HIV status. Self-stigma and social isolation are mutually reinforcing.

- Reliance on local HIV support services to provide a community and support network, sometimes in response to rejection from families, with devastating consequences when services close down.

- People living with HIV who are in receipt of residential or domiciliary care are particularly vulnerable to the experience of stigma because of their reliance on care staff and their reduced social circle.

- Many people living with HIV are also subject to discrimination and social exclusion based on their race, immigration status, sexual orientation or gender identity, which serves to exacerbate their HIV-related marginalisation.

- Health conditions associated with HIV can make getting out and about more difficult.

"

Many people living with HIV report that their well-being is seriously affected by isolation and marginalisation"

Where to go for help

The Terrance Higgins Trust provides a helpline, THT Direct, to provide emotional support to people who are worried about their sexual health or have concerns about living with HIV: Tel: 0808 802 1221, Email: info@tht.org.uk

Andy

Andy was diagnosed HIV positive in 2005 when he was 41. He says,

"When I was diagnosed, I was just splitting up with my boyfriend at the time. I knew nothing about HIV except what I remembered from the 1980's adverts; I thought I was going to die despite what the doctors told me.

I had no friends of my own in Birmingham as they were all connected to my previous partner. I was on my own with this information and mental trauma. I only told one friend who lived in Manchester and my older brother who is a priest. They both helped and did their best to support me but I was alone in Birmingham.

My doctor at the clinic gave me some information about support services and I eventually attended ABplus, a support charity for people living with HIV. I was terrified the first time I went into the building, and after meeting a few people that day, I left after about an hour. I went back and stayed longer each time and began to develop friendships and started helping out as well.

Whilst with great treatment and medical care people living with HIV are living a normal life span if detected early, I know from personal experience that I would not be here without the support of other people living with HIV. I was so frightened and it would have been very easy for me to hide away and become isolated, lonely and with a very low quality of life. By coming together with others I gained strength, confidence and a sense of myself again. This in turn has allowed me to help others on their journey through this life-changing diagnosis.

I now have a wonderful partner who loves and accepts me (as do both our families) and life is going well if a bit bumpy at times."

"

I went back and stayed longer each time and began to develop friendships"

Conclusion

The powerful stories contained within this report demonstrate that chronic loneliness is an experience that many disabled people share, despite huge variations in the nature of their impairments and personal circumstances.

The causes of loneliness for disabled people are complex. There can be practical barriers to establishing social connections, such as physical access to transport and premises, or issues related to the nature of conditions themselves. Worryingly, for the groups represented in this report, stigma and poor public attitudes were also directly related to feelings of isolation.

The charities involved in the production of this report wish to take the opportunity, through the Jo Cox Commission on Loneliness, to state that chronic loneliness is an issue that we all recognise, and to express our concern about the negative impact this has on the health and emotional wellbeing of disabled people.

Central government, local government, the voluntary sector and the wider society must all recognise the existence and impact of loneliness on disabled people, and take steps to address it.

Solutions: addressing loneliness in disabled people

Due to the complex range of causes, and the uniqueness of each individual, there is no one-size-fits-all solution to loneliness among disabled people. However, changes in the following areas would be crucial steps towards reducing loneliness and social isolation:

- **Increasing awareness:**

  ### Improving social attitudes

  Negative social attitudes and poor levels of awareness are the most common barriers disabled people face when seeking to establish social connections. All members of society must be encouraged to look beyond an individual's disability, and towards the things they have in common.

  Voluntary sector organisations and the Office for Disability Issues (ODI) should deliver public awareness campaigns to promote increased understanding and acceptance of disabled people. Previous awareness campaigns on issues such as drink driving and smoking have been effective in influencing social norms, attitudes and behaviour.

Increasing professional awareness and support

Professionals working to support disabled people should be aware of the risk and impact of loneliness, and the importance of social relationships. They should provide specific support to help disabled people develop and maintain social networks, and signpost and support opportunities to form connections within local communities.

Professionals working with young disabled people should provide tailored support to help them develop and maintain social networks and friendships. Young people should also be supported to think about how their access to social connections may be affected by future education, social care and housing choices, as part of planning for the transition to adulthood.

- **Improving access to services:**

Enabling independence through access to social care

Good quality social care support in the home and community can support people to remain independent and fully engaged in their communities. Despite this, Forty per cent of disabled people currently feel isolated or lonely as a direct result of not receiving enough social care support.[lxvi]

Local authorities have a legal duty under the Care Act (2014) to provide social care to promote 'developing and maintaining family or other relationships.' The government must look at how to address current and predicted levels of unmet need in the short, medium and long term, and provide the social care system with long-term and sustainable funding.

Providing access to services that respond to loneliness

In recent years, there have been changes to how public and voluntary services, including befriending, buddying schemes, day centres and other social activities, are funded, commissioned, delivered and evaluated. The importance of this work as a preventative intervention which reduces dependence on statutory services needs to be recognised. Local authority commissioners need to think long-term and continue to fund services that help people manage their day-to-day lives, stay well, stay connected and avoid isolation.

The Department of Health should consider funding a national programme of 'social prescribing' through which GPs can refer patients to services to address their social needs, rather than only medical interventions.

- **Tackling poor accessibility:**

Ensuring physical access to communities

Action to remove physical barriers in street environments, such as extending powers to restrict unsafe pavement parking, would help

disabled people access social opportunities in their local community. Local authorities should ensure that street design is inclusive, particularly when considering schemes which involve the removal of safety features such as controlled crossings or kerbs.

Entertainment venues, services and accommodation need to be designed or adapted to provide better physical access for disabled people. Providers must be aware of their legal duties under the Equality Act (2010). This should include a thorough consideration of physical access, acoustics and lighting.

Providing accessible transport

An absence of good quality, accessible public transport can prevent disabled people from accessing social opportunities. The Department for Transport should ensure that transport is accessible to all, no matter the disability. Local authorities should ensure that there is a sufficiency of accessible transport, especially in small towns and rural areas. All drivers and transport staff should also be adequately trained to assist disabled people accessing public transport.

Disabled people use taxis and Private Hire Vehicles (PHVs) 67 per cent more than non-disabled people,[6] therefore the affordability and accessibility of taxis and PHVs is vital. Disability awareness training should be a condition of licence for taxi and PHV drivers.

Addressing the digital divide

In an increasingly digital age, access to the internet provides individuals with the ability to connect and engage with other people online. However, there is currently a digital divide between disabled people and non-disabled people.

As part of its Digital Strategy, the Department for Culture, Media and Sport should ensure that any funding for digital skills training is targeted at disabled people who have never or very rarely use the internet. Government should work with telecoms providers as well as the regulator Ofcom, to tackle the digital divide between disabled and non-disabled people.[7]

- **Addressing financial barriers:**

Providing fair and adequate financial support

Disabled people are more likely to live in low income households and are more likely to rely on welfare benefits than their peers. The Department for Work and Pensions needs to ensure that rates of financial support provided by the welfare benefits system are set at a rate that allows people to remain independent, retain social connections and participate fully in society.

6 Disabled Persons Transport Advisory Committee (2001) Attitudes of Disabled People to Public Transport – a research study conducted for the Disabled Persons Transport Advisory Committee, http://www. transport-research.info/Upload/Documents/200608/20060811_110503_45123_UG395_Final_Report.pdf

7 25 per cent of disabled adults have never used the internet, compared to 6 per cent of non-disabled adults.

Increasing access to employment and work experience

Better support and access to employment opportunities can be a key way to prevent loneliness for disabled people. For those disabled people wishing to enter employment, they should be able to access personalised and tailored employment support, which is optional and appropriate.

Employers should also be encouraged to take a proactive approach to support disabled employees to enable them to remain in work. This should include offering flexible working arrangements and providing access to assistive technologies and adaptions, including through Access to Work. There must also be increased awareness and efficiency of this vital scheme to support disabled people in employment.

Employers should ensure line managers have the skills and capacity to support disabled employees; whilst the Government should make sure that all employers understand and enact their responsibilities under equalities legislation.
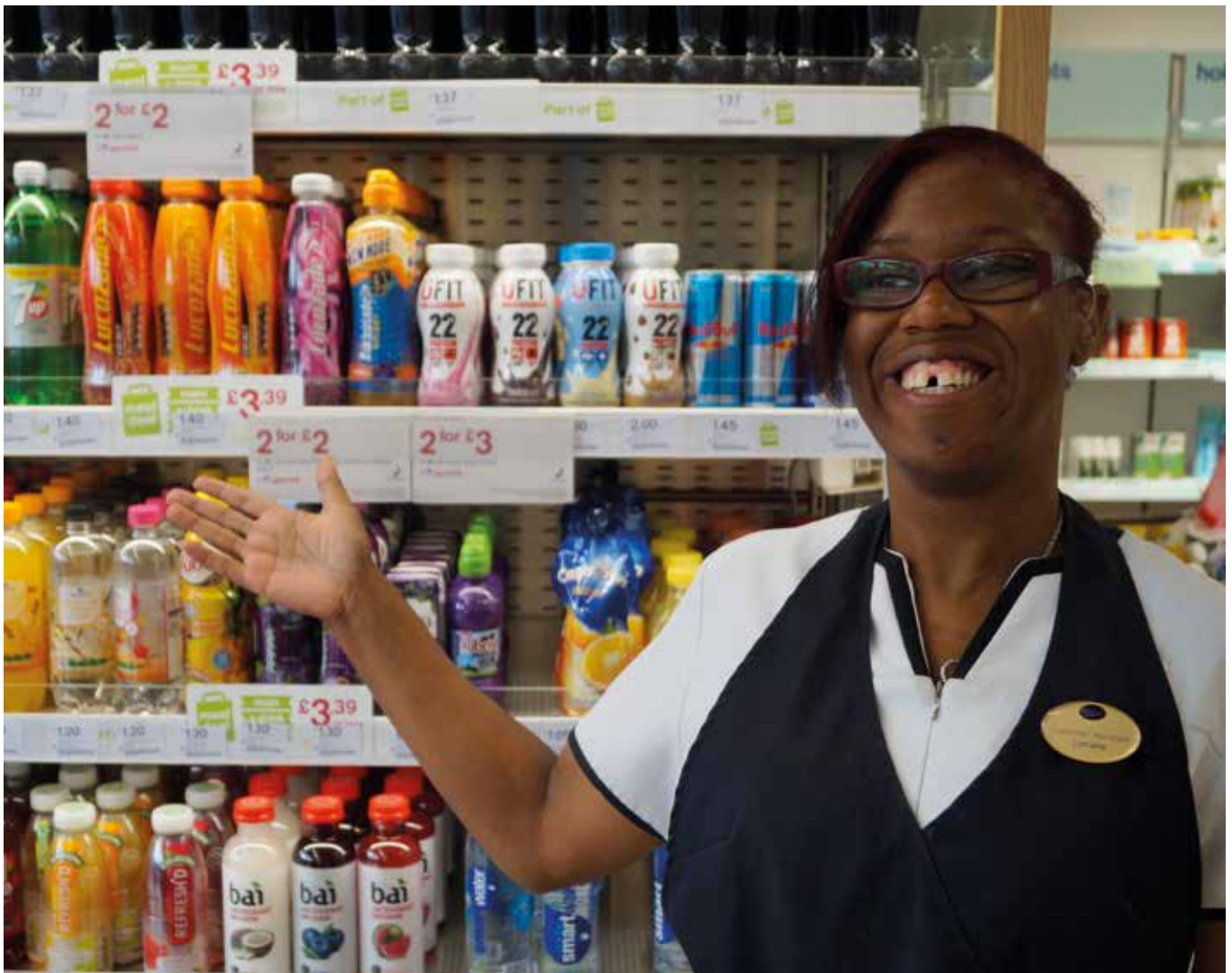
References

[i] Hardeep Aiden and Andrea McCarthy (2014) Current attitudes towards disabled people London: Scope

[ii] Perlman, D., & Peplau, L. A. (1981). Toward a social psychology of loneliness. In S. Duck & R. Gilmour (Eds.), Personal relationships in disorder (pp. 31-56). London: Academic Press

[iii] Family Resources Survey 2014/15

[iv] A right to friendship? Challenging the barriers to friendship for people with disabilities London: Sense

[v] Hearing Matters (2015) Action on Hearing Loss

[vi] http://www.rnib.org.uk/knowledge-and-research-hub/key-information-and-statistics

[vii] Janet Robertson & Eric Emerson (2010) Estimating the Number of People with CoOccurring Vision and Hearing Impairments in the UK CeDR Research Report

[viii] RNIB's My Voice report. Results relate to members of the registered adult VI population.

[ix] Bamini Gopinath, Louise Hickson, Julie Schneider, Catherine M. McMahon, George Burlutsky, Stephen R. Leeder, Paul Mitchell; Hearing-impaired adults are at increased risk of experiencing emotional distress and social engagement restrictions five years later. Age Ageing 2012; 41 (5): 618-623

[x] A right to friendship? Challenging the barriers to friendship for people with disabilities London: Sense

[xi] Gilmore, L. & Cuskelly, M. (2014) 'Vulnerability to loneliness in people with intellectual disability: an explanatory model,' Journal of Policy and Practice in Intellectual Disabilities, 11(3): 192-199.

[xii] Mencap (2015) Almost 1 in 3 young people with a learning disability spend less than an hour a day outside homes. Press release. https://www.mencap.org.uk/press-release/almost-1-3-young-people-learning-disability-spend-less-hour-day-outside-homes-survey

[xiii] Jahoda, A. & Pownall, J. (2014) Sexual understanding, sources of information and social networks: the reports of young people with intellectual disabilities and their non-disabled peers. Journal of Intellectual Disability Research, 58(5): 430-441.

[xiv] Baker, J. K., Fenning, R. M., Crnic, K. A., Baker, B. L. and Blacher, J. (2007) 'Prediction of social skills in 6-year-old children with and without developmental delays: contributions of early regulation and maternal scaffolding,' American Journal on Mental Retardation, 112(5): 375-391.

[xv] Emerson, E., & Hatton, C. (2007). The Mental Health of Children and Adolescents with Learning Disabilities in England.

[xvi] Emerson, E., & Hatton, C. (2008). People with Learning Disabilities in England, (May)

[xvii] Mason, P., Timms, K., Hayburn, T., & Watters, C. (2013). How do people described as having a learning disability make sense of friendship? Journal of Applied Research in Intellectual Disabilities : JARID, 26(2), 108–18

[xviii] Bates, P. and Davis, F. A. (2004) Social capital, social inclusion and services for people with learning disabilities. Disability and Society, 19(3): 195-207

[xix] Mason, P., Timms, K., Hayburn, T. and Watters, C. (2013) How do people described as having a learning disability make sense of friendship? Journal of Applied Research in Intellectual Disabilities, 26(2): 108-118.

[xx] Milner, P. and Kelly, B. 2009 Community participation and inclusion: people with disabilities defining their place. Disability and Society, 24(1): 47-62.

[xxi] Mansell, J. (2010) Raising Our Sights: Services for Adults with Profound Intellectual and Multiple Disabilities. Available online: https://kar.kent.ac.uk/24356/1/DH_2010_Raising_our_sights.pdf

[xxii] The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey.* Leeds: NHS Information Centre for Health and Social Care

[xxiii] NAS (2016) *Too Much Information* London: The National Autistic Society

[xxiv] NAS (2017) TMI year 2 survey. Unpublished

[xxv] Research by Ambitious about Autism together with the Centre for Research in Autism Education – citation needed

[xxvi] Micah O Mazurek Loneliness, friendship, and well-being in adults with autism spectrum disorders *Autism* Vol 18, Issue 3, pp. 223 – 232

[xxvii] Carter S (2009) Bullying of students with Asperger syndrome. Issues in Comprehensive Pediatric Nursing 32(3): 145–154.

[xxviii] Moore, C. (2016). School Report London: The National Autistic Society

[xxix] The National Autistic Society (2016). *The autism employment gap: Too Much Information in the workplace.* p5

[xxx] Bancroft et al (2012). *The Way We Are: Autism in 2012.* London: The National Autistic Society

[xxxi] The hidden housing crisis (2014) London: Leonard Cheshire Disability. ComRes interviewed 2,006 GB adults aged 18+ online between the 4 and 6 June 2014; including 238 who self-identified as having a mobility impairment. Data were weighted to be representative of all GB adults aged 18+. Extrapolation was based on the Census 2011 data (47,754,569 people aged 18+ in Great Britain).

[xxxii] *Trapped in a Bubble* (2016) London: British Red Cross

[xxxiii] Catherine Blanchard and Andrea Brittain (2016) The crises facing our independent living service users London: British Red Cross; *Trapped in a Bubble* (2016) London: British Red Cross

[xxxiv] British Red Cross (2015) Putting the wheels in motion: Assessing the value of British Red Cross short-term wheelchair loan

[xxxv] Mind the Step: An estimation of housing needs among wheelchair users in England (2010) London: Habinteg Housing Association

[xxxvi] Office for Disability Issues (2011) ODI Life Opportunities Survey Wave One results

[xxxvii] McManus, S., Meltzer, H., Brugha, T. S., Bebbington, P. E., & Jenkins, R. (2009). Adult psychiatric morbidity in England, 2007: results of a household

survey. The NHS Information Centre for health and social care.

xxxviii Relationships in the 21st Century: The forgotten foundation of mental health and wellbeing (2016) London: The Mental Health Foundation

xxxix Mental Health Foundation (2010) The Lonely Society? Data from a survey completed by a nationally representative, quota-controlled sample of 2,256 people carried out by Opinium Research LLP.

xl Figures calculated using the Department for Work and Pensions tabulation tool: http://tabulation-tool. dwp.gov.uk/

xli Time to Change (2008). Stigma shout: service user and carer experiences of stigma and discrimination. London: Time to Change.

xlii Acquired Brain Injury: The numbers behind the hidden disability (2015), Headway – the brain injury association

xliii Jones JM, Haslam SA, Jetten J et al. (2011) . That which doesn't kill us can make us stronger (and more satisfied with life): the contribution of personal and social changes to well-being after acquired brain injury. Psychol Health vol. 26, (3) 353-369.

xliv A New Me: Experiences of life after brain injury (2017), Headway – the brain injury association.

xlv https://www.parkinsons.org.uk/content/facts-journalists

xlvi Statistics summarised in MS in the UK Jan 2016 London: MS Society. The figure is based on analysis of 2014 data from the Office of National Statistics.

xlvii https://www.mndassociation.org/news-and-events/news-room/journalists-guide-to-mnd/

xlviii Karlsen KH, Tandberg E, Årsland D, Larsen JP (2000) Health related quality of life in Parkinson's disease: a prospective longitudinal study J Neurol Neurosurg Psychiatry 2000;69:584-589; Forsaa, E. B., Larsen, J. P., Wentzel-Larsen, T., Herlofson, K. and Alves, G. (2008), Predictors and course of health-related quality of life in Parkinson's disease. Mov. Disord., 23: 1420–1427.

xlix ComRes interviewed 1868 people with Parkinson's between 14th January and 11th February 2016 using both online and paper surveys. Full data tables are available at www.comres.co.uk.

l Dementia 2013: The hidden voice of loneliness. This study is Alzheimer's Society's second annual report looking at the quality of life for people with dementia in England, Wales and Northern Ireland.

li Dementia 2013: The Hidden Voice of Loneliness London: Alzheimer's Society

lii Turning Up the Volume: unheard voices of people with dementia, May 2017, Alzheimer's Society

liii The Equality Act 2010 applies to England, Wales and Scotland only. The Disability Discrimination Act 1995 and its extension, the Disability Discrimination Order of 2006, protect workers in Northern Ireland.

liv Maddams J, Utley M, Møller H. Projections of cancer prevalence in the United Kingdom, 2010-2040. Br J Cancer 2012; 107: 1195-1202. (Projections scenario 1). Macmillan Cancer Support analysis based on extrapolation of 2010 and 2020 projections that the number of people living with cancer will hit an estimated 2.5 million in 2015.

lv Macmillan Cancer Support and Ipsos MORI research into isolation and loneliness amongst people affected by cancer

lvi Macmillan Cancer Support/YouGov online survey of 1,794 people living with cancer in the UK. 437 respondents were identified as isolated (i.e. received no support from friends or family during treatment or recovery, or only received support some of the time/occasionally) and completed a follow-up interview. Fieldwork conducted 10–20 July 2012, with additional fieldwork conducted in Northern Ireland 26 November–13 December 2012. Survey results are unweighted. Estimate of 80,000 is based on applying the survey estimate of 23% to the 350,000 people diagnosed with cancer each year in the UK. This estimate assumes everyone diagnosed receives cancer treatment, and that only those who are newly diagnosed are at risk.

lvii Facing the Fight Alone. Macmillan Cancer Support. 2013.

lviii Facing the Fight Alone. Macmillan Cancer Support. 2013.

lix Macmillan Cancer support/Ipsos MORI Online survey of 1,065 UK adults who have ever been diagnosed with cancer. Fieldwork took place between

12 and 30 September 2013. 1,000 interviews were carried out using Ipsos MORI's Online Access Panel, with an additional 65 sourced from Macmillan's contacts in Scotland, Wales and Northern Ireland. Survey data has been weighted by gender, age and nation using 2008 cancer prevalence estimates. Statistic available in Macmillan press release February 2015.

lx Throwing light on the consequences of cancer and its treatment. Macmillan Cancer Support. 2013.

lxi Kirwan PD, Chau C, Brown AE, Gill ON, Delpech VC and contributors. HIV in the UK – 2016 report. December 2016. Public Health England, London

lxii HIV in the UK: Changes and Challenges; Actions and Answers.The People Living With HIV Stigma Survey UK 2015 National findings [http://www.stigmaindexuk.org/reports/2016/NationalReport.pdf]

lxiv Uncharted Territory A report into the first generation growing older with HIV (2017) London: Terrance Higgins Trust

lxiv HIV in the UK: Changes and Challenges; Actions and Answers.The People Living With HIV Stigma Survey UK 2015 National findings [http://www.stigmaindexuk.org/reports/2016/NationalReport.pdf]

lxv HIV: A Guide for Care providers 2015, National AIDS Trust http://www.nat.org.uk/sites/default/files/publications/NAT_Res_Dom_Care_Report_July_2015.pdf

lxvi Polling from ComRes for Leonard Cheshire Disability. ComRes interviewed 1,032 disabled adults aged 18-65 in Great Britain online between 28th April and 10th May 2016. 299 report not receiving enough social care support.

JO COX
LONELINESS
start a conversation

The Jo Cox Commission on Loneliness is starting a national conversation about the scale and impact of loneliness in the UK. Find out more at jocoxloneliness.org

As founder members of the Commission, the disability charity, Sense, has brought together a coalition of disability charities to collectively highlight the issue of loneliness for disabled people, and to call for action.

About Sense

Sense is a national disability that supports and campaigns for children and adults with complex needs. We provide tailored support, advice and information to individuals, their families, carers and the professionals who work with them.

Sense
101 Pentonville Road
London N1 9LG

Tel: 0300 330 9256 (voice)
Text: 0300 330 9256
Email: info@sense.org.uk
Website: www.sense.org.uk/loneliness

#happytochat

Registered charity number 289868