Are people with learning disabilities in Scotland feeling lonely and isolated?

A National Survey of the Views of People with Learning Disabilities in Scotland by the Learning Disability Alliance Scotland

March 2018
Introduction

In Scotland we are learning more about the problems of isolation and loneliness in our communities. We are also beginning to learn more about all the mental and physical health problems isolation and loneliness cause for people who experience them.

We know life can be very bad for people who are isolated and lonely. It can cause a lot of mental health problems when people are alone and can’t talk to other people. The effect on the body too can be as bad as being a heavy smoker or living in a damp house.

The Scottish Parliament ran its own survey in 2015 into social isolation and what it is like for elderly people and they found it was a big problem. After that survey they decided to find out more about it. The Scottish Government is now doing a big public consultation to find out how to help people who are isolated and lonely and to build stronger communities. It is called ‘A Connected Scotland.’

Other organisations like Age UK, the Samaritans and the Jo Cox Foundation, have been working on finding out more about social isolation and loneliness and how to help people in need and make more people know about it.

Isolation is being cut off from other people for some reason. For example, if you live far away from others.

Loneliness is a feeling that you cannot connect with people. Sometimes you can feel lonely even when you have people around you.

Both of these things are very difficult for people to cope with and they can lead to serious problems.
At the Learning Disability Alliance Scotland, we wanted to know if people with learning disabilities living in Scotland experience isolation or loneliness.

We also wanted to find out what could be the main reasons for people with learning disabilities feeling lonely or experiencing isolation and how far their learning disabilities contribute to their experiences.

Like our other surveys, this one asked questions and gave people a chance to share their own stories about their own experiences of isolation or loneliness. It also asked people to give their ideas about what things could be done to help.

The survey and all the questions in it were agreed by the LDAS Board and the people who came to our Big Meetings in 2017. We put our easy read survey online and made it available to our membership organisations and ran workshops on it. We started our survey in August 2017 and ended it in 2018.

We would like to say a big thank you very much to everyone who took part in our survey.

Thank you

Ewan Hamilton, Chair
Learning Disability Alliance Scotland
This was the third survey LDAS has run. The first one was on health. The second one was on Self Directed Support. This one was about isolation and loneliness.

We got over 200 responses to the survey from people with learning disabilities from all over Scotland.

More than half said they knew their neighbours enough to say hello.

More than half said they have someone they can call in an emergency who is not their staff.

The biggest number of people live by themselves. This is important because the main time people say they feel most lonely is in the evenings.
We asked people who they see, speak to or have contact with most days and most weeks.

Most people said they have contact with between 1 and 5 people on a normal day.
Mostly these people are staff.

Most people have contact with 10 or more people in a normal week.
Mostly the people they see are colleagues or support service staff.

Most people go out some days but there are some people who stay at home every day of the week normally.

Most people feel they have enough money.
A small number feel lonely at home because they do not have enough money to go out and do things.
Most people said they have a computer, tablet or mobile phone but some can only use it with a bit of help.

Everyone else did not have any of these things.

We asked people if it is hard to travel in their area in case that keeps them isolated and lonely.

For most travel is ok in their area especially with support. For a smaller number it is not.

Most people cannot speak to a stranger if they need help.

Most people find it easy to meet people in their local area.

Most people know of some activities to go to in their local area.

A smaller number live too far away from any day activities.

Some people have no activities to attend.
Most people said they felt lonely sometimes or most of the time.

What people said:

- At night is when I feel lonely the most

- When my care staff go home I feel all alone

- When I was being bullied I felt scared and lonely

More than half of people experience isolation sometimes or all of the time.

What people said:

- I cannot go out a lot because of my disabilities

- I have autism and it is hard for me to socialise

- I cannot get down my stairs to go out myself
We asked for ideas to help people feel less isolated and less lonely.

Most people said they need more people to spend time with and to talk with.

The things that people want to be done to help are:

- Accessible information about activities, travel and local communities to help them join in
- More activities that are on later in the day and evening when people feel most lonely
- Friendship training
- Befriending services or helpline services that are easy to use
- More awareness and identification of the needs of people with learning disabilities in communities
2. The aims of the survey

In this survey it was important to point out that, as noted above, isolation and loneliness can be experienced separately or at the same time. (See fig.1).

It was important to list separate questions for loneliness and isolation. With the help of members our survey used the following meanings:

- **Loneliness**: A feeling that you are cut off from others when you don’t want to be. You don’t have to be alone to feel lonely. You can feel lonely even in a crowd. Loneliness is a bad feeling. No one chooses to be lonely. It’s hard to fix lonely feelings by yourself.

- **Isolation**: When you are cut off from other people that is being isolated. Not everyone who is isolated feels lonely but if you are isolated for a long time it can be very lonely and bad for your mental health. People can be isolated for different reasons such as if they live far away from others or if they don’t have friends.
We also wanted to get lots of information from people about their local areas and their homes because these things can lead to people being more isolated and feeling lonely (see fig.2):

![Figure 2](image)

Many different things can make you feel more lonely or isolated.

### 3. What we found

What did our survey tell us about people with learning disabilities in Scotland and their experiences of loneliness and isolation?

#### 3.1 Isolation:

Among our survey participants the largest single block, 44%, had never felt or experienced isolation. However more than half of participants, 56%, said they had experienced isolation either over a long period of time, 40%, or for small periods of time, 16%. (See fig.3)
3.1 Some things we found out from the question about isolation:

3.1.1 The people who identified themselves as being in the younger age groups, aged 16 to 24 and age 25-34, made up a large proportion of the people who said they were isolated a lot. This same group pointed out special times when they felt isolated the most. These were:

- When school finished and they had no job to go to
- When college finished
- When apprenticeship job finished

3.1.2 The number of people who say they feel they are isolated a lot of the time is 40%. There is not a lot of research available to assess whether or not this figure is well above that of the population as a whole.

3.1.3 Figure 5 gives a breakdown of the kinds of reasons people gave for feeling isolated.

In the additional information section autism, times of bad weather and mental health problems were the most common things people added.
3.2 Loneliness:

Most of the people who answered our survey feel lonely sometimes or a lot of the time, adding up to 80%. Only 20% said they don’t feel lonely ever. The number of people who said they feel lonely sometimes is 11%. That means 69% feel lonely a lot of the time. (See fig.4)

3.2.1 There is some research on loneliness in Scotland from the Mental Health Foundation to compare these results to. The research shows that for the wider community 11% of people often feel lonely and 38% feel lonely sometimes (1).

3.2.2 These figures are in keeping with studies that have shown people with disabilities are more vulnerable to feelings of loneliness. This was noted by Dr Joanna Teuton in her review of social isolation and loneliness in Scotland review of prevalence and trends (2) as follows:

Poor physical health and long-term conditions that limit daily functioning are risk factors for poor social support and less frequent social contact. Adults with poor physical health and/or a disability were more likely to have less social contact with friends, family and neighbours and less social support.

Adults with poor physical health are also at greater risk of loneliness. Survey data from Glasgow and the UK suggest that those with physical health problems, long-term conditions or disability are two times more likely to report severe loneliness than the general population.
Survey data from Scotland and the UK indicate that children between the ages of 11 and 15 years old with a limiting long-term condition or disability were at greater risk of peer relationship problems and being bullied.

Poor mental health emerges as particularly important. The survey data show a link between mental health and wellbeing and the number and quality of friendships. Adults with poorer social support were more likely to have mental health problems and those experiencing anxiety, depression or stress are at increased risk of severe loneliness. The increased risk of loneliness associated with mental health problems is greater than with physical health problems. However, mental and physical health problems can co-exist. In addition, it is likely that the relationship between mental health and both social isolation and loneliness is bi-directional. In other words, mental health problems increase the risk of loneliness, and loneliness contributes to the development and maintenance of mental health problems.

It is also worth noting that children, particularly girls, with fewer friends and more limited close friendships are at greater risk of poor mental health.

3.2.3 The reasons people feel lonely are listed in Figure 5, but in the additional information section the most commonly mentioned reasons were:

- Being alone every evening
- Difficulties communicating
- Being bullied or experiencing hate crime
- Not having a lot of contact with family/relatives
- A friend or family member getting sick or dying
- A family pet dying

‘I am a young person with learning disabilities and autism. I live with my family. One of my parents is sick and won’t get better. I don’t know what to do about this. I have no one I can talk to about it. I am on my own. I am so sad. I want to be a help but I find it very hard.’
3.3 The survey looked at reasons for people being isolated or feeling lonely.

3.3.1 The biggest number of people who feel isolated say it is because of where they live. This would correspond with previous studies that have shown where people live can impact on people feeling lonely or being isolated (3).

3.3.2 Mental health is the next biggest reason for people feeling isolated. Again what there is in terms of previous study has shown this to be the case. NHS Scotland warns that the risk of loneliness is greater with mental health problems than with physical problems (2).

3.3.3 The ‘other’ section was the biggest one for the reasons people gave for feeling lonely. Most of the people gave information about times in their lives or experiences that made them feel lonely. These included things like experiencing the death of a loved one or feeling lonely at certain times of the year, for example, in winter when it gets darks early and is colder and they are home alone for longer.
What people told us:

“I had a dog. After the dog died I felt really sad a lot. I did not have anyone to talk to at home anymore. I felt really lonely and I missed my dog. I know it is an animal and not a person but to me it was my friend and kept me company.”

‘People can’t understand my speech. It makes it really difficult to make friends and do things. I feel so lonely.’

When I don’t have any company I feel bored. I would like to meet a partner but I don’t know how to do that. When my carer goes home I am lonely.

‘I was bullied in the place where I lived. I was bullied for a long time by people in the street and some of my neighbours. I was told to stay at home to keep safe. It was a long time before I got help to move. I was very lonely and very isolated. It was a very bad time.’

‘I feel like my family don’t want to connect with me.’

‘Where I lived there are no buses. It is hard for me to go places. I am isolated.’

‘Where I lived before there was no one who was my age. I had no one to talk to. I was isolated and lonely. I missed out on all the activities for my age because no one else was going. I had no support to help me.’

I have nowhere to go and nothing to do

In the evenings I feel totally isolated and shut off from the world.

I feel incomplete
3.4 Social connections

3.4.1 We asked people about their living arrangements and their local communities (see fig.6).

Most people said they lived by themselves in supported living, 35%, or out in the wider community, 24%. This is significant as one of the main times people said they felt lonely was in the evenings when getting care support or access to activities is more difficult.

Some people, 37%, said they live with family such as parents or siblings or children. A number of workshops took place with participants in the younger age categories and these groups mainly live at home with family.

3.4.2 We asked people if they knew their neighbours and knew them enough to be able to say hello. We wanted to know if people felt comfortable or safe around their neighbours and in their local communities (see fig.7).
We also asked if people had someone they could call on in an emergency who was not their carer (see fig.8).

Most people said they knew their neighbours enough to say hello to, 70%. A lot of people, 39%, said they knew their neighbours well and could speak to them. Some said they knew their neighbours by sight and could say hello, 31%. There was a group of people, 30%, who said they did not know their neighbours and would not be comfortable speaking to them.

Most people, 65%, said they have someone they can call on for help if they need to who is not their carer or from their care staff. A smaller number of people, 35%, said they don’t have anyone who could help them other than their care staff.

This compares unfavourably with research that shows for the wider population in Scotland 14% of all adults have fewer than 3 people they can call on in a personal crisis (4).

Wider community connections

3.4.3 The survey asked people about their wider social connections to find out whether or not people with learning disabilities are isolated from others in their communities and the possible reasons behind this (see fig.9).

The survey asked people to think about the people they have contact with on both a usual day and a usual week, not just family and friends.
but also people out in their local communities. Contact was described as speaking, meeting or being with people.

The most encouraging figure from the survey answers to these questions was that only a very small number of people, 2%, say they have no connections with other people on a usual day.

Most people, 63%, say they have contact with up to 5 people on a usual day. Most people, 52%, have contact with more than 10 people in a usual week.

The survey asked questions about who the people participants connect with are to find out a bit more about the social connections of people with learning disabilities (see fig.10).
Figure 10 above shows that on a daily basis the biggest group of people that people with learning disabilities is connecting with is staff/carers, at 36%.

On a weekly basis the biggest group is ‘others’, also 36%. From the additional information people gave in the survey we know that the biggest number of people in this group is ‘work colleagues’ and ‘other students’ and ‘staff’ from service providers. We can say from this information that having a job, even a voluntary one, or going to college opens up the social connectedness of people with learning disabilities.

We can make some comparisons to other research for the whole population where only 18% of people have limited contact with their neighbourhoods (5).

This information tells us that social connectedness for people with learning disabilities looks different to that of the wider community (see fig.11). Carers and staff occupy the closest sphere for people with learning disabilities normally occupied by family and intimate friends for the wider population.

3.5 Resources
The survey asked people questions about other things that could be causing them to be isolated or feel lonely such as a lack of resources to help them engage with their communities.

We wanted to know if local areas were places people were able to meet, if local travel was working well, if people had access to computers and mobile phones and if they felt they had enough money to do things (see fig.12).

Most people, 49%, said they were able to meet people locally. However, 48% of people said they could not speak to strangers easily.

More than half of people, 56%, gave a thumbs up to their local transport. Many people said they could not travel without support and many said they would be nervous using transport services in the evenings. Both of these factors impact on the ability of people with learning disabilities to engage fully in their local communities.

Nearly half of people, 48%, have access to a computer or mobile phone, although 38% need help to use it. Facebook was listed as a favourite way of communicating with other people by those who have computers/mobiles.

Perhaps the most important resources question was about whether or not people felt they had enough money to do things. Most people, 57%, said they had enough money.
In looking at the resources infrastructure for people with learning disabilities, the survey also asked questions about day activities for people (see fig.13). We used the term ‘day activities’ to cover all types of activities that people with learning disabilities can engage in.

Most people, 53%, said there were some day activities in their local areas that they could go to. The next biggest group, 18%, said they lived too far away to attend day activities. 13% said they had nowhere to go and a further 9% said some of their day activities had now closed.

We asked people how many days a week they usually stay home (see fig.14).
Some people, 26%, say they stay at home 2 days a week usually. 23% say they stay at home 3 days a week usually.

The most worrying figure is that 16% of people said they stay at home every day of the week usually. We were not able to establish it here but if this group also includes people from the group who live by themselves, impact on the mental and physical health of these individuals could be very severe.

3.6 Health

We asked people if they are going to see their GPs more often or only when they are sick. We wanted to find out if people who are lonely or isolated are in need of more health care (see fig.15).

![FREQUENCY OF VISITS TO GP](image)

By far the biggest group, 77%, only go to see their GPs when they feel sick. We must remember though that isolation and loneliness can endanger health, both mental and physical, and can cause major health problems for people but we were not able to establish exact figures for how this is impacting on people with learning disabilities in this survey.

In listing the types of conditions they have, people who took the survey identified specific health conditions that they felt resulted in them feeling lonely or isolated.
For women the menopause was identified as one of those times they experience isolation. Mental health, anxiety related illnesses, were all listed as conditions that people felt were very connected to their feelings of loneliness.

More comments from people who took part in our survey:

‘I hate where I live. I get bullied. I get bullied in the street. I want to be where I can make friends. No one will help me to move. I tell people but nobody listens to me. I want to talk to someone about getting somewhere new to live.’

‘Because of my autism I it is hard for me to socialise and meet new people. I can’t include myself in things.’

‘I get angry and paranoid around others because of my conditions.

‘There’s no one who understands me.’

I get speech problems. It’s hard not to be isolated if people don’t understand you. At the hospital they said I could get a machine to help me. The machine costs money and I don’t have enough to buy it.’

I have speech problems. It’s hard not to be isolated if people don’t understand you. At the hospital they said I could get a machine to help me. The machine costs money and I don’t have enough to buy it.’

‘There’s no one who understands me.’

Nothing ever gets any better in this country. There is no awareness about learning disabilities so nothing gets better. When people don’t understand and don’t know it leaves you feeling cut off.

I use to get care support to go out into the community and do things without my parents. I could go to the café and order my own things or go to the shop. I could see people. I liked it. Now because of the cost of the care I have lost it. Now I don’t get to do that anymore and can only go out when my mum can manage to take me. I have no independence.

I can’t leave the house because of my disabilities.
4. Conclusion

4.1 What would help?

Every LDAS survey aims to find solutions to the problems our members say are experiencing by asking people directly what they need to make things better.

In this survey we asked people to tell us the kind of things they feel could be done to help people with learning disabilities feel less lonely and isolated (see fig. 16).

The biggest answer, 22%, said being with people more. The second biggest answer, 19%, was having more people to speak with. So most of our members want the chance to have access to or be around more people.

More care support – especially flexible support - activities to attend, money to do things and local transport to go places were all chosen as the types of help people say they need to combat isolation and loneliness.

Other suggestions, which made up 3%, included support to make friends, learn how to use computers or phones or other ways to communicate, have access to communication aids to help them to engage with others.

Activities later in the day were also listed as things most people would like to help tackle loneliness at the time of the day when they feel most lonely. Some activities like this already exist but many feel they can’t attend because of fears
of traveling later in the day, being out in the dark, having no care support, and missing out on their evening care support visit.

Diagram 1 below demonstrates how these suggestions can work together to make the positive impact people are asking for:

As the 2 top requests both concerned more engagement with other people these have been combined in the top box as the aim of the changes that have been requested. To get to that stage there has to be 2 services in place, namely more activities and more care support. In order to support these people need money to pay for more care support or contribute to the service, a suitable and flexible transport system and more accessible information about what is happening in order for them to engage.

4.2 Problem areas

The results of our survey indicate there are specific times when people with learning disabilities feel more isolated and lonely because they lack sufficient support. In particular these are either points of transition in their lives or of unexpected events.

4.2.1 Younger age groups respondents were the largest groups of people to say they experience isolation. Despite most of these same age groups living at home with their families they are still experiencing isolation. Periods of transition for these young people, leaving school, leaving
college, struggling to find employment after serving apprenticeships, are difficult for young people with learning disabilities.

4.2.2 Issues around transition periods continue into adult life and for people with learning disabilities the results of our survey show they continue to be a source of loneliness and isolation. For example, a number of female respondents told us that reaching menopause was a difficult time for them. Lack of accessible information, not knowing who to speak to for advice, being unprepared and having no understanding of what was happening to them left them very isolated.

4.2.3 Going into hospital for procedures and having no contact with learning disability nurses to help explain what is happening to them also leaves people with learning disabilities isolated and lonely.

4.2.4 There was a lot of comment from people with learning disabilities who are parents but who feel isolated and vulnerable to losing their children especially in custody battle situations.

4.2.5 Periods of bereavement, loss of family, friends and pets, were all listed as times when people with learning disabilities said they experienced loneliness or isolation. Again lack of awareness, understanding and who to turn to for support were the feelings people had at these times and many said they have never recovered from their losses. E.g. during one survey workshop a man aged 58 broke down as it was the anniversary of his father’s death. His father had died when he was a young man but still he struggles to cope with it especially on significant days such as the anniversary date. He has never had any form of counselling or support to come to terms with his grief.

4.3 Significant factors

4.3.1 Where you live

Our survey responses did not reveal a big difference in the impact of isolation or loneliness on people with learning disabilities in relation to whether they lived in a rural or an urban area of Scotland. Transport and activities were more of an issue for people in rural areas.
4.3.2 Weather

Weather was listed as a factor that impacts on people with learning disabilities feeling more lonely or isolated by many of our respondents especially when it leads to events being postponed or rearranged, which is something many participants find difficult to cope with. Travelling in bad weather can force many to stay away from activities. Incidentally, and rather ironically, the weather did impact on some groups being able to take part in the survey.

4.3.3 Age

As noted in 3.1.1 those from the younger age groups of 16-24 and 25-34 were the largest group identifying as experiencing isolation a lot of the time. Stages of life would appear to be trigger points, such as menopause as stated in 4.2.2.

4.3.4 Disability

Autism, mental health issues, speech and hearing difficulties and mobility problems were the disability issues listed most by participants in our survey as contributing factors to feelings of loneliness and isolation.

4.3.5 Accessibility & Awareness

Proper access to facilities and accessible information were listed by a number of participants in the ideas to help section of the survey. Raising awareness of learning disabilities in the wider community was mentioned as a good way forward to help resolve issues of loneliness and isolation.

4.4 What role can the Scottish government play?

The Scottish government has committed to improving the lives of people living with disabilities in Scotland by the end of this parliamentary term in the Fairer Scotland action plan (6). Some of what they have pledged to achieve coincides with some of the actions respondents of our survey have called for, in particular in relation to transport and access.

The Scottish government is now in the middle of a consultation on how to tackle loneliness and isolation across all of society. A Connected Scotland
is aiming to build ‘stronger communities’ and a society in which, ‘everyone has the opportunity to develop meaningful relationships regardless of age, status, circumstances or identity.’ (7) The consultation runs until 27 April 2018.

Recommendations

In addition to the measures above we would like the Scottish government to act on the following recommendations from our survey respondents as follows:

- Accessible information about activities, travel and local communities such as easy read maps
- Promote awareness of learning disabilities
- Promote negative health implications of isolation and loneliness on vulnerable people
- Incorporate a proper strategy for tackling isolation and loneliness for people with learning disabilities
- Supporting groups and services to provide more flexible care
- Identification of existing services and support for more activities for people with learning disabilities
- More identification of the needs of individuals with learning disabilities to ensure they are not feeling isolated or lonely
- More learning disability nurses
- Bereavement support for vulnerable people
- MSPs and councillors to be more involved with supporting local learning disability groups needs

Conclusion

This third national survey by the Learning Disability Alliance Scotland has shown a range of issues are contributing to people with learning disabilities experiencing isolation and loneliness.

The key findings of the survey are that 80% of people with learning disabilities of all ages and from across Scotland experience loneliness sometimes or a lot. A further 56% experience isolation sometimes or a lot. It is our opinion that these figures are very high and demonstrate that people with learning
disabilities are extremely vulnerable to the damaging effects loneliness and isolation can cause.

People with learning disabilities are aware of their conditions impacting on their ability to connect more with their communities and the limitations they face. Most importantly they know what kind of things could make a difference. It is a major challenge for our society to ensure that people with learning disabilities can get the right support to make this happen for them.

We believe awareness of learning disabilities and the valuable contribution people with learning disabilities can make to our society is needed if we are to create communities that are accessible and inclusive for people with learning disabilities. A first step to making this a reality is a commitment to listen to the recommendations from people with learning disabilities about the support they need and a further commitment to making learning disability needs part of the national conversation if we are to properly tackle the scourge of isolation and loneliness in our communities.

References

3. Glasgow Centre for Population Health Response to call for evidence on age and social isolation from the Equal Opportunities Committee; 2015
4. Scottish Health Survey, 2013/15
5. Scottish Social Attitudes Survey, 2013