The Impact of Coronavirus on People with Learning Disabilities and their Parents, Carers and Supporters

Survey Findings Easy Read

The Scottish Commission for People with Learning Disabilities

June 2020
# About the Research

<table>
<thead>
<tr>
<th>Image</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>![Corona Virus]</td>
<td>SCLD wanted to find out how the coronavirus has affected people with learning disabilities.</td>
</tr>
<tr>
<td>![People Filling Survey]</td>
<td>So we asked people to tell us how life has been for them.</td>
</tr>
<tr>
<td><strong>127</strong></td>
<td>127 people with learning disabilities filled in a survey.</td>
</tr>
<tr>
<td><strong>223</strong></td>
<td>223 parents, carers and supporters filled in a survey.</td>
</tr>
<tr>
<td>![Report]</td>
<td>This is a report of what people told us.</td>
</tr>
</tbody>
</table>
Summary

People with learning disabilities and their parents, carers and supporters are feeling the impact of the Coronavirus emergency.

These are the things that a lot of people said in the survey

They said that the support they get has changed and this has been difficult. Some support has stopped completely.

People are feeling more lonely and isolated than usual. People who do not use social media and cannot make video calls can feel even more isolated.

This has made some people very sad and anxious. It is bad for their mental health.

Some family carers are under a lot of pressure where support has been cut.

Some family carers have told support workers not to come into the house. They are worried they might spread coronavirus. This means more work for the family carers. Some feel it is too much.
Some support workers are feeling the pressure because other workers are off sick or self-isolating. These support workers are having to work extra hard. It is making some of them sad and anxious.

Many carers and some people with learning disabilities say there is not enough clear information. For example, not enough information about shielding or how often they are allowed to leave the house.

People with learning disabilities are worried about how the Coronavirus will affect their health and their loved ones health.

People are worried because they do not know how long lockdown will last.

People are worried because they do not know if their usual support and activities will return once lockdown is over.

Here are some more things that people said. Not many people said these things, but they are still important.

People worry that there is not enough PPE (Personal Protective Equipment). They worry that some people can get it but others cannot.
<table>
<thead>
<tr>
<th>Image 1</th>
<th>People are worried that there might not be enough beds or medical equipment for everyone. They are worried that doctors think people with learning disabilities should go to the back of the queue for these things.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Image 2</td>
<td>Some people are finding it difficult to get food when they cannot go to the shops themselves.</td>
</tr>
<tr>
<td>Image 3</td>
<td>It is hard for some people to contact school hubs. They find it hard to get the right support for their children with learning disabilities.</td>
</tr>
<tr>
<td>Image 4</td>
<td>Lots of people with learning disabilities answered the survey but lots of people did not. There are many stories that we have yet to hear.</td>
</tr>
</tbody>
</table>
What people with learning disabilities said

Survey Findings
Question 1. Has your life changed because of the Coronavirus emergency? (126 people answered this question)

Most people said their lives had changed because of the Coronavirus emergency.

What people said:

- Everything has stopped, and I am stuck at home. Can't meet my friends or family
- Living with my parents I don't get any support now. I miss my support worker and missing my flat. I am missing being on my own
- Have nothing to motivate me so can't see the reason to get out of bed to get showered or dressed
Question 2. Has the support you get changed because of the Coronavirus emergency? (121 people answered this question)

Most people said their support had changed because of the Coronavirus emergency.

What people said:

- **No support at present. Day service and respite cancelled**
- **I don't have any support now I am at home with my family**
- **I have to use online and phone support when usually I have face to face support**
Question 3. Are you getting all the information you need to understand the Coronavirus emergency? (123 people answered this question)

Most people said they were getting enough information to understand the Coronavirus emergency.

Some said easy read information would be helpful.

What people said:

I listen to daily news update

Easy read would help

Something simple to help me understand
Question 4. Are you able to get support from volunteer groups? (115 people answered this question)

Most people said they could get help from volunteer groups. A lot did not need it because their family was helping. Some people did not know the support groups.

What people said:

- I am lucky, my family helps me
- Don't know them
- Can't read the information
Question 5. Are you feeling more lonely now because of changes to your life during the Coronavirus emergency? (121 people answered this question)

Most people were feeling more lonely now because of the Coronavirus emergency.

What people said:

I am very sad about not being able to see all my friends from my advocacy group

I haven't seen my friends from the clubs, I could maybe email them or phone them, but I don't know if I have their numbers

I wish I had technology in my flat that I could use to see my family and friends
Question 6. What kind of things are you worried about because of the Coronavirus emergency? (107 people answered this question)

A lot of people were afraid of their family and friends getting ill or dying.

A lot of people were afraid of getting ill themselves.

A lot of people were worried that life would be different after the Coronavirus emergency.

What people said:

- Losing my older friends
- Surviving if I take the virus
- I’m worried that my groups are not going to be there for me after the coronavirus ends
- When will it end, and will I get back to day service soon?
What parents, carers and supporters of people with learning disabilities said

Survey Findings
Question 1. Are the measures that have been put in place to tackle Coronavirus causing difficulties for you in relation to the support and care you provide for a person with a learning disability? (222 people answered this question)

Most people said measures introduced to deal with the Coronavirus emergency were making it harder for them to support a person with a learning disability.

Question 2. If the measures are causing difficulty, can you tell us what are the main issues you are experiencing? (160 people answered this question)

People spoke about lots of different things.

Lots of people were worried about isolation.

People said it was bad for mental health.

Some family carers are under a lot of pressure where support has been cut.
Question 3. Do you think you are getting enough information about supporting a person with a learning disability while measures are in place to tackle Coronavirus? (221 people answered this question)

Almost half said they were not getting enough information on how to support a person with a learning disability.

Question 4. If you are not getting enough information, can you tell us what you think would be helpful to you? (93 people answered this question)

Lots of people said they had not been given any information. Many said that guidance about what people were allowed to do was not clear.
Question 5. Based on your experience, are people with learning disabilities getting the support and care they need during the Coronavirus emergency? (218 people answered this question)

More than half did not think that people with learning disabilities were getting the support and care needed.

Question 6. If you don’t think people with learning disabilities are getting the support and care they need, can you give examples and/or tell us a little bit more? (115 people answered this question)

Most people said removal of paid support services was hard.
Pressure on family and paid carers was making people stressed.
## Moving forward

Many of the difficulties that people with learning disabilities talked about are not new.

The coronavirus just made it worse.

For example, we know that a lot of people with learning disabilities often feel lonely and isolated.

The coronavirus made it worse because people could not go out to meet anyone.

Here are some things that people need to do.

**Make sure that people with learning disabilities, their families and carers get the information they need at the right time and in a way that they can understand.**

Make sure that Scottish Government guidance about moving out of lockdown is available in easy read. This includes information about their rights.

Make sure that information on local authority and Health and Social Care Provider websites is easy to find and easy to understand.

Make sure that people with learning disabilities know what support they will get after lockdown. People should be involved in making their own support plans.
<table>
<thead>
<tr>
<th>People who have lost their support should get it back as soon as possible. It is important to make sure that support is given in a way that is safe for everyone.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make sure that PPE is available for all support services and family carers that need it. Make sure that everyone knows how to use it safely.</td>
</tr>
<tr>
<td>Make sure it is ok to give support in different ways if this is safer.</td>
</tr>
<tr>
<td>Make sure that people have the technology they need to stay connected to friends and family. Make sure there is guidance for staff on supporting people to use technology.</td>
</tr>
<tr>
<td>There should be a national conversation about our services and communities after lockdown. Two things must happen for this conversation to go well.</td>
</tr>
<tr>
<td>1. Seeking out and listening to the voices of people with learning disabilities and their parents, carers and supporters.</td>
</tr>
</tbody>
</table>
2. Make sure that we collect the right information about people with learning disabilities.

<table>
<thead>
<tr>
<th>Image</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Image" /></td>
<td>We want Scotland to become fairer and more equal. So we need to learn from what has happened to people during the coronavirus.</td>
</tr>
<tr>
<td><img src="image2.png" alt="Image" /></td>
<td>We need strong leaders to make change happen.</td>
</tr>
<tr>
<td><img src="image3.png" alt="Image" /></td>
<td>We need to believe in the human rights of people with learning disabilities.</td>
</tr>
<tr>
<td><img src="image4.png" alt="Image" /></td>
<td>People with learning disabilities must lead the change.</td>
</tr>
</tbody>
</table>
Contact us

Website: www.scld.org.uk
Twitter: @SCLDNews
Facebook: @ScotCommission
Instagram: @scldnews

For information on Scotland’s Learning Disability Strategy *The Keys to life*, visit: www.keystolife.info

The Scottish Commission for Learning Disability
Suite 5.2
Stock Exchange Court
77 Nelson Mandela Place
Glasgow
G2 1QY