



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

Survey Findings

The Scottish Commission for
People with Learning Disabilities

June 2020



About SCLD

The Scottish Commission for People with Learning Disabilities (SCLD) is an independent charitable organisation and partner to the Scottish Government in the delivery of Scotland's learning disability strategy, *The keys to life* (2013)ⁱ and *The keys to life* Implementation Framework (2019-2021)ⁱⁱ. The implementation framework defines a learning disability as follows:

"A learning disability is significant and lifelong. It starts before adulthood and affects a person's development. This means that a person with a learning disability will be likely to need help to understand information, learn skills and live a fulfilling life. Some people with learning disabilities will also have healthcare needs and require support to communicate."

(The keys to life, 2019-2021, p.9)

SCLD is committed to creating an environment in Scotland in which systems and culture are changed to ensure people with learning disabilities have opportunities and are empowered to live the life they want in line with existing human rights conventions. SCLD believes that the discrimination and barriers faced by people with learning disabilities and other disabled people are not inevitable. These barriers stop people with learning disabilities and other disabled people being included in society and participating on an equal basis.

SCLD is focused on sharing innovation and good practice so that those providing services and interventions can learn from each other. SCLD also aims to be a knowledge hub and to build an evidence base, sharing how policy is being implemented and building on an understanding of what really works.

About the Research

The current Coronavirus (Covid-19) crisis is impacting on the lives of every one of us, changing the way we work, relax, and socialise. However, despite claims that the crisis will be *'the great equaliser'*, we know that Coronavirus itself, as well as measures taken to slow its spread, are having a disproportionate impact on those groups who faced inequalities before the crisis began.

SCLD wanted to explore the impact of the crisis on people with learning/intellectual disabilities and their parents, carers and supporters. Two surveys were created, one for people with learning/intellectual disabilities and one for their parents, carers and supporters. Because of the current restrictions, these were online surveys only, though people were able to telephone and submit their response. Because of this, the survey sample was biased towards those with access to the internet, which we know many people with learning/intellectual disabilities do not have.ⁱⁱⁱ The survey ran from the 14th of April until the 5th of May 2020.

In total, 350 responses were received: 127 from people with learning/intellectual disabilities and 223 from their parents, carers and supporters. Questions were not mandatory, and therefore not all questions were answered by every respondent. SCLD has used the findings from these surveys to inform responses to the Equalities and Human Rights Committee, the Joint Committee on Human Rights, and the Coronavirus Committee, about the impact of the Coronavirus public health emergency on people with learning/intellectual disabilities. SCLD will also use the findings to feed into work by Public Health Scotland to assess the impact of Coronavirus on marginalised groups.

Responses to the two surveys and key themes are outlined below.

Summary

Our survey findings show that people with learning/intellectual disabilities and their parents, carers and supporters are feeling the impact of the Coronavirus emergency. By far the most common concerns raised across the two surveys were the **reduction or removal of support**, **increased social isolation**, compounded by digital exclusion, and the **mental health impact** this is having on people with learning/intellectual disabilities.

Increased **pressure on family carers**, because of reductions in support from care providers or fears of accepting support due to the risks of Coronavirus; and **pressure on paid carers**, due to staff shortages, and changes to how support is given were also key issues.

While a small majority felt information about the Coronavirus emergency was relatively clear, many carers in particular felt there was a **lack of clear guidance** on specific issues, such as whether the person they were supporting should 'shield' and how often they were allowed to leave the house.

The survey also found that people with learning/intellectual disabilities were very worried about the **health implications** of Coronavirus on them and their loved ones. People also expressed feelings of **anxiety** and **uncertainty** about how long measures would last, and whether their usual support and activities would return once measures were lifted.

A number of less common, but no less important, issues were also uncovered, including:

- Insufficient Personal Protective Equipment, and inconsistency of use,
- Concerns over medical decision making and access to routine health appointments,
- Difficulties accessing food supplies,
- Lack of access to school hubs and/or inadequate support available for children with learning/intellectual disabilities.

It is important to stress that our survey findings do not tell the whole story of the Coronavirus emergency for people with learning/intellectual disabilities and their parents, carers and supporters. The small sample size and the fact that the survey was online means that there are many stories that we have yet to hear. As we discuss below, it is imperative to seek out and listen to those voices as we move forward.

The Impact of Coronavirus on People with Learning Disabilities

Survey Findings

"I'm worried if I don't get back to my groups soon what is going to become of me. I'm going to be a nobody and lost and very upset"

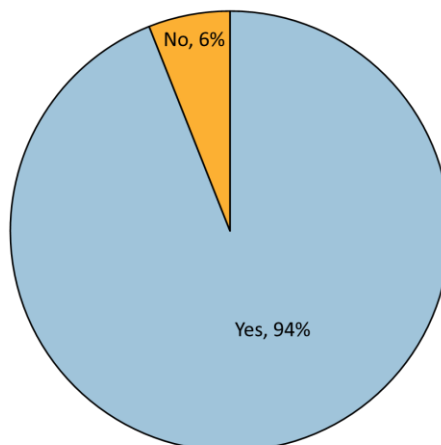
"Have nothing to motivate me so can't see the reason to get out of bed to get showered or dressed"

"I wish I had technology in my flat that I could use to see my family and friends"

"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"

Question 1. Has your life changed because of the Coronavirus emergency? (n=126)

- Yes: 118 (94%)
- No: 8 (6%)



Unsurprisingly, most respondents said that their lives had changed due to the Coronavirus public health emergency. Feeling cut off from loved ones, supporters, groups, and the community was a common theme in this question. Of the 109 people who provided comment, 82 (75%) mentioned that they felt more socially isolated.

“Everything has stopped, and I am stuck at home. Can’t meet my friends or family.”

“I wish I could go see my friend whilst keeping distance just to have someone.”

Many people (31:28%) specifically mentioned reductions in their support as a big change in their life, with some highlighting the impact this was having on their independence.

“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.”

27 (25%) people said that they felt that the measures brought in to deal with the coronavirus public health emergency were having a negative impact on their mental health.

“Have nothing to motivate me so can’t see the reason to get out of bed to get showered or dressed.”

“It’s made me feel very anxious and very worried and sick and tired.”

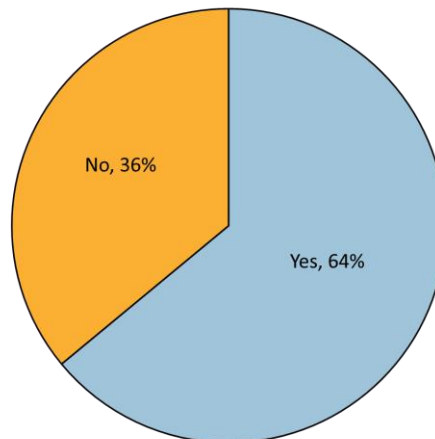
Of the small number of people who said their lives had not changed, this tended to be because their support was continuing in the same way as it had before.

“I’m not missing anything. I never had support – it is just mum.”

“I have 24-hour support.”

Question 2. Has the support you get changed because of the Coronavirus emergency? (n=121)

- Yes: 78 (64%)
- No: 43 (36%)



Almost two-thirds of respondents said that the support they receive had changed because of the Coronavirus public health emergency. Of the 88 individuals who commented on this question, 58 (66%) said that their support had reduced or stopped completely.

“No support at present. Day service and respite cancelled.”

“I don't have any support now I am at home with my family.”

9 individuals (10%) said that their support had been adapted in some way because of the measures taken to slow the spread of Coronavirus.

“My support has not changed a lot, as I have the staff from the Day Centre coming to the house where I live to deliver as best a service as they are able, since they do not have the same facilities here to work with.”

“Different staff coming in to support.”

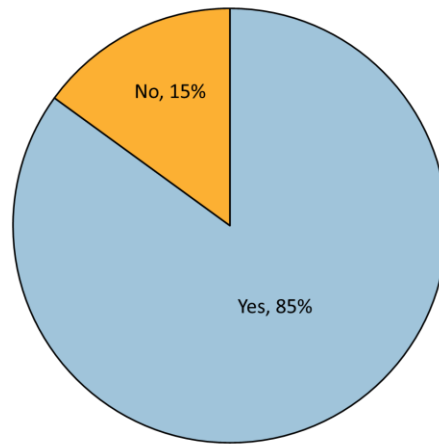
15 individuals (17%) said that they were now receiving support by phone or over the internet, rather than face to face.

“I have to use online and phone support when I usually have face to face support.”

“Can't see my workers, only via call once a week. It's hard for me.”

Question 3. Are you getting all the information you need to understand the Coronavirus emergency? (n=123)

- Yes: 104 (85%)
- No: 19 (15%)



Most people who responded to the survey felt that they were getting enough information to understand the Coronavirus public health emergency. Of the 33 people who commented on this question, 11 (33%) said that they were able to get their information from the news.

“I listen to daily news update.”

However, 7 (21%) of those individuals who commented, said that accessible communications would be helpful to aid understanding.

“Something simple to help me understand.”

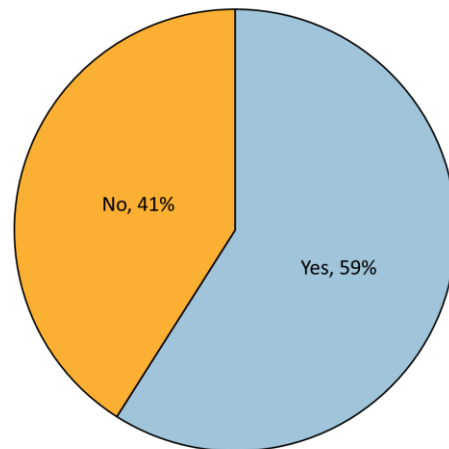
“Easy read.”

A number of respondents (4:12%) highlighted confusing messages about the measures that they should be taking as individuals.

“At the start were worried because we were not sure about if we were to self-isolate or shield. Lives with older parent and self has health issues. Did not receive a letter but has been watching news and is unsure.” (Completed on behalf of a person with a learning/intellectual disability.)

Question 4. Are you able to access support from volunteer groups? (n=115)

- Yes: 68 (59%)
- No: 47 (41%)



The majority of people said that they were able to access support from volunteer groups. It is worth noting that many people who answered 'no' to this question said that they did not need to access this support. Indeed, of the 47 people who said they were not able to access support from volunteer groups, 44 provided further comment. 17 (39%) said that this support was being provided by their family.

"I am lucky, my family helps me."

"My parents have got support for our needs, but I can't use internet so if they weren't around, I wouldn't know how." (Completed on behalf of a person with a learning disability.)

A further 7 (16%) people said that they were not able to access information about what type of volunteer support was available.

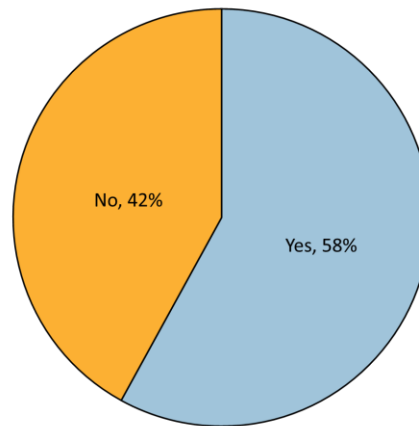
"I don't know them."

"Can't read the information."

People who were able to access volunteer support mentioned local community groups, third sector organisations and people they know from a church providing this support. It is also worth noting that some respondents were checking in with their neighbours to make sure they were alright.

Question 5. Are you feeling more lonely now because of changes to your life during the Coronavirus emergency? (n=121)

- Yes: 70 (58%)
- No: 51 (42%)



Most survey respondents said that they were feeling lonelier now because of measures to respond to the Coronavirus emergency. This is particularly concerning as previous studies, including SCLD's 'How's Life' survey, have found that people with learning/intellectual disabilities are already more likely to feel lonely than the general population.^{iv}

Of the 77 respondents who commented, 21 (27%) said they missed seeing friends.

"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."

A quarter of those who commented (19:25%) said they are not able to see their family.

"Staff keep me company but not seeing other people such as family."

"If I was able to visit and spend time with my family."

A number of respondents (15:19%) said that alternative ways to communicate with their friends, family and supporters would help them feel less lonely, but highlighted the barriers they faced accessing these.

"I get a phone-call from one of my support workers every week. But because I am not good with computers and technology, I can't access WhatsApp or Zoom which would help me chat with others."

"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? (n=107)

Of the 107 individuals who answered this question, the most common worry, expressed by 29 (27%) respondents, was other people close to them getting ill or dying from Coronavirus.

"Losing my older friends."

"Yes, because I'm worried in case close family catch it."

People were also worried about catching the virus themselves (28:26%)

"Surviving if I take the virus."

"My support housing getting an outbreak."

Uncertainty about how long the measures would be in place, and a timeline for returning to normality was causing concern for 22 (21%) individuals.

"Are we ever get out of this lockdown when will it be that's my answer really."

"When will it end, and will I get back to day service soon?"

14 (13%) people expressed concern that life would not look the same as it did before when the 'lockdown' measures are lifted.

"I'm worried that my groups are not going to be there for me after the coronavirus ends."

"Worried about how long we will be in lockdown, what is life going to be like after?"

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

Survey Findings

"In a strange way the limitations and social isolation that we always experience feel normalised as society at large coped with a bit of the same feeling"

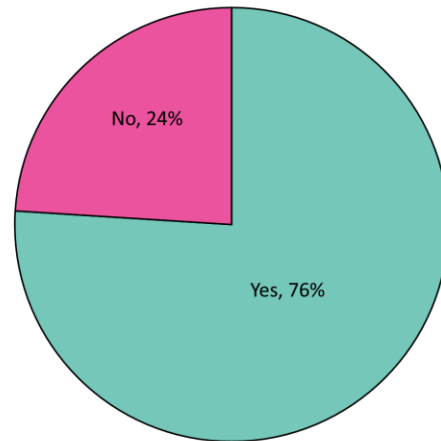
"Unpaid carers seem to be a group who have been left to pick up the work when services to those with learning disability is stopped. Everyone seems to be compensated by the government but not us"

"It is difficult to take my son out due to social distancing. He doesn't understand so we are staying home which is really affecting his mental health"

"Less social interaction which means my son is more isolated and withdrawing into his own world more and more."

Question 1. Are the measures that have been put in place to tackle Covid-19 causing difficulties for you in relation to the support and care you provide for a person with a learning disability? (n=222)

- Yes: 168 (76%)
- No: 54 (24%)



Over three-quarters of survey respondents said that the measures introduced to deal with the Coronavirus emergency were causing difficulties for them in relation to the support and care they provide to a person with a learning/intellectual disability.

Question 2. If the measures are causing difficulty, can you tell us what are the main issues you are experiencing? (n=160)

Survey respondents spoke about a number of issues that were causing them difficulties. Concerns over increased social isolation and the subsequent mental health impacts were key themes in this question alongside increased pressure on carers.

Indeed, 60 (38%) people said that social isolation was a cause for worry.

“My son lives in his own flat and I look after his finances and general well-being daily, but I’m worried he’s not eating properly and is more isolated than usual as he walked to our home every day to visit and see his cat but now he’s sitting in nearly all day.”

“Less social interaction which means my son is more isolated and withdrawing into his own world more and more.”

Many people (45:28%) spoke explicitly about their concerns over the mental health impact of the measures on the person they were caring for.

“It is difficult to take my son out due to social distancing. He doesn’t understand so we are staying home which is really affecting his mental health.”

“My daughter doesn’t understand that she can’t go to college and see her friends - she has been very depressed at times and that has been very worrying.”

Increased pressure; on both family carers and paid carers; was mentioned by many (54:34%) respondents.

“No support now from Support Services so son stuck at home. Having to juggle work and being at home to support him.”

“At times staff shortages due to them self-isolating causes extra pressure on the existing teams.”

Lack of information and uncertainty; including unclear guidance on measures specific to the person they were supporting, as well as difficulties explaining the situation were concerns for 28 (18%) respondents.

“My daughter can't understand why she has no visitors so a lot of behaviour issues.”

“Guidelines about out walking not clear for someone with a disability.”

A small number of respondents (8:5%) expressed concern over a lack of personal protective equipment (PPE) for those providing personal care, and subsequent risk of spreading Coronavirus.

“Had the stress of tracking down where to get our own PPE supplies.....anxiety of still using carers and the risk around that.”

Some people (7:4%) were finding it difficult get hold of appropriate food supplies for the person they were supporting.

“[My son] has a real limited diet and as such getting his food has been tough.”

Some (6:4%) were struggling with the lack of access to education and school hubs during this time.

“No resources available for young children in the hubs... Local schools open to mainstream but not to ASN.”

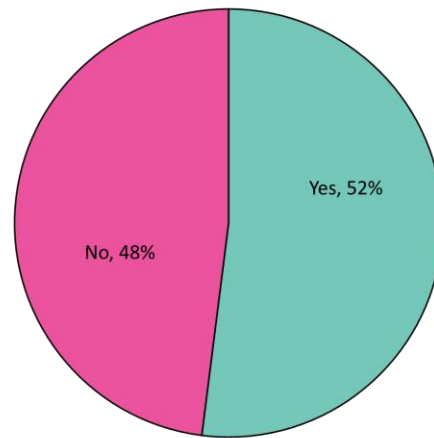
Medical concerns, including medical appointments being cancelled, physical health implications and worries over medical decision making in the event of a person with a learning/intellectual disability being admitted to hospital with Coronavirus were also outlined by a small number (5:3%) of respondents

“We can't attend appointments with professionals. No physio, OT, speech and language intervention.”

“Fear of being helpless to influence the nursing plan if it really came to the point of making decisions, because I have already been through that experience once in my life and was overruled by doctors.”

Question 3. Do you think you are receiving enough information about supporting a person with a learning disability while measures are in place to tackle Covid-19? (n=221)

- Yes: 116 (52%)
- No: 105 (48%)



Almost half of the survey respondents felt that they were not receiving enough information on how to support a person with a learning/intellectual disability.

Question 4. If you are not receiving enough information, can you tell us what you think would be helpful to you? (n=93)

One in four (23:25%) respondents said that they had simply not received any information.

“The key is we’re not receiving it, we’re having to search out the clear factual information. No one we’ve approached; be it social work, health, or carers organisation has actually asked us or our sons whether we have the right information in the right format.”

“Anything, no communication from anyone.”

20 (22%) respondents were concerned that they were receiving unclear guidance about the right procedures in terms of shielding, self-isolating, and using PPE during the Coronavirus emergency.

“It is not been clear enough how we are supposed to use PPE and whether we are supposed to be social distancing (this is not possible where we live). In the original list of vulnerable conditions 'learning disability' was listed and this seemed very vague and we would like more clarification on this.”

“Information as to whether my son should be classed as extremely vulnerable due to other conditions have been unclear and vague.”

A number of people (10:11%) suggested that simply having some support would be helpful to them.

"It would have been helpful to have had some support, anything really."

Some people (10:11%) felt that contact specifically from social work would have been useful.

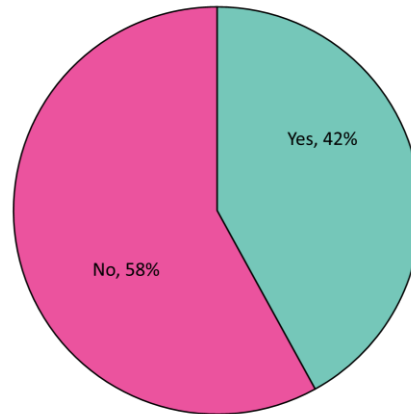
"Social Work contact/advice would be nice."

A small number of respondents (6:6%) also mentioned that practical resources, such as activity packs and physical resources, which they do not have access to at home.

"Perhaps activity packs, ideas and links to helpful resources via email or post would be helpful. Access to physical resources like trampolines, games, therapy toys etc."

Question 5. Based on your experience, are people with learning disabilities getting the support and care they need during the Covid-19 emergency? (n=218)

- Yes: 91 (42%)
- No: 127 (58%)



More than half of respondents 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? (n=115)

The most commonly cited example in this question was the removal of paid support services, with 48 (42%) respondents saying that this was a reason that people with learning/intellectual disabilities were not getting the support and care they need.

"All support was stopped when lockdown came into effect, this has had a negative effect on the caree."

"Abandoned."

"Closure of services, opportunities, care at home etc - almost over-night obvious no contingency because organisations are running so tight to start with."

One in five respondents (23:20%) said that pressure on carers, both paid and unpaid, was leading to extra stress, and the prioritisation of needs in some cases.

"There is huge pressure on carers I feel. I can work from home but I'm also caring for my son so that is putting pressure on us all."

"I just can't do everything by myself, so needs are being prioritised."

"Reduced staffing so those who are not as demanding are losing 1-1 time, increasing stress on staff."

Moving forward

“When things come apart, there is always the opportunity to put them back together differently. We can work together to design the Scotland we want to emerge from this crisis.”

(Scottish Government 2020, Framework for Decision Making)

It is critical to remember that many of the difficulties faced by people with learning/intellectual disabilities and their parents, carers and supporters were not created by the Coronavirus emergency, but exacerbated by it. For example, we already know from previous studies, including our own ‘How’s Life?’ survey, that loneliness and isolation are a big issue for people with learning/intellectual disabilities.

As we move out of ‘lockdown’ there are several actions that should be considered to address some of the issues uncovered in our survey:

1. Ensuring clear, accessible, and timely communication of information to people with learning/intellectual disabilities and their families, carers and supporters, including:
 - a. Ensuring all Scottish Government guidance as we move out of the crisis is available in easy read, alongside clear information on the rights of people with learning/intellectual disabilities and what should be expected regarding medical treatment and reinstatement of support.
 - b. Ensuring that information on changes to services is made available in easy read consistently on Local Authority, Health and Social Care Partnership and support provider websites as well as distributed in hard copy to those individuals who use services.
 - c. Ensuring that changes to individual support plans are co-produced with the individual and others as appropriate and communicated in a clear and accessible way.
2. Support services must be reinstated as soon as is practicable and safe, to counter the physical and psychological harms of social isolation and to enable people to live fulfilling lives even during the Coronavirus emergency. This should be done in such a way as to minimise the risk of those receiving and delivering support getting Coronavirus, including:
 - a. Continuing to ensure that appropriate PPE is available for support services and family carers, and providing clear, accessible, national guidance on its use.
 - b. Increasing the flexibility of support; allowing for appropriate adaptations; in particular where concerns have been expressed about the health risks of reinstatement.

3. Addressing digital exclusion by ensuring access to the Connecting Scotland Fund for people with learning/ intellectual disabilities. Based on interest and uptake of the existing fund, additional funding may be required for individuals with protected characteristics including learning/intellectual disabilities. Consideration must be given to how we best reach those without local authority input by looking at a broader method of referral. There should be guidance for support staff on how to support individuals to access technology during this time.

Looking beyond these immediate actions, a national conversation should take place on how we rebuild and reshape our services and communities going forward. Two things will be imperative as we begin this conversation:

1. Seeking out and listening to the voices of people with learning/intellectual disabilities and their parents, carers and supporters about their lived experience of this crisis, and what matters to them going forward.
2. Ensuring that the equalities impact of any crisis and indeed any future policy provisions on people with learning/intellectual disabilities can be understood more fully, by allowing this information to be disaggregated within routinely collected health and social care data and other national surveys.

If we are to recover both inclusively and fairly, we will need to review what is already not working for this population. This will include learning from the Coronavirus emergency and examining the structures, systems and processes that exist in our services and communities, which create barriers for people with learning/intellectual disabilities living their best lives, and what innovative solutions we can use to overcome them. To do this right will require strong leadership and a commitment to the equality and human rights of people with learning/intellectual disabilities in Scotland.

As we move towards Scotland's recovery and renewal, we must make sure that those groups who already experience inequalities, including people with learning/intellectual disabilities, are front and centre. Now is our opportunity to create the fairer, more inclusive Scotland we all aspire to.

Contact us

Website: www.sclld.org.uk

Twitter: [@SCLDNews](https://twitter.com/SCLDNews)

Facebook: [@ScotCommission](https://www.facebook.com/ScotCommission)

Instagram: [@sclldnews](https://www.instagram.com/sclldnews)

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



ⁱ [The keys to life \(2013\)](#)

ⁱⁱ [The keys to life implementation strategy \(2019-2021\)](#)

ⁱⁱⁱ Office for National Statistics (2019) [Internet Users Dataset](#): 18.2% of disabled people had never accessed the internet compared with 4.1% of non-disabled people.

^{iv} [Gilmore & Cuskelly \(2014\)](#)

SCLD (unpublished) 'How's Life' survey found that people with learning/intellectual disabilities reported feelings of chronic loneliness at almost double the rate of the general population.