The Impact of COVID-19 on the Mental Health and Loneliness of People with a Learning Disability

Version 1, March 2022

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Introduction

As England builds back following the worldwide coronavirus (COVID-19) pandemic, the country is facing a mental health crisis (Mind, 2020). Prolonged periods of isolation due to national lockdowns have meant loneliness is now a more prominent issue than ever, defined as ‘a discrepancy between what we need and hope for in social relationships, and what we actually have’ (Waldron, 2010, pp.2). Poor mental health and loneliness are intrinsically linked, and may cause or result from each other (2013).

Prior to the pandemic, limited suitable mental health services existed for people with a learning disability in the community, and the services that were available were often inaccessible or provided by professionals without any specialist training (Royal College of Psychiatrists, 2020). Existing issues have only been exacerbated by the pandemic, with many people with a learning disability feeling isolated and disconnected from support (Willner et al, 2020).

Enjoying an active social life and having a circle of support can help people with a learning disability to feel happier, included and valued (Mason et al, 2013; Chadwick, Wesson and Fullwood, 2014; Wilson et al, 2017). However, research suggests that prior to the pandemic 1 in 3 young people with a learning disability spend less than 1 hour outside their home on a typical Saturday (Mencap, 2016). Feelings of loneliness appear to have intensified during the pandemic, with recent research by Flynn et al (2021) showing that 41% of people with a learning disability felt lonely with no one to talk to at least some of the time in a four-week period during the pandemic.

Much of the existing literature exploring the experiences of mental health and loneliness of people with a learning disability is now outdated or does not consider the context of the COVID-19 pandemic. To address this urgent issue, qualitative research is needed to ensure better support can be provided to people with a learning disability. This research aims to gather vital insight into the experiences of loneliness and mental health of people with a learning disability during the pandemic.

This research project was funded by Department for Digital, Culture, Media and Sport (DCMS) as part of their Loneliness Engagement fund initiative. More information about this can be found at https://www.gov.uk/government/publications/loneliness-engagement-fund

This report was written by Ms Phoebe Clifford and Dr Carla Barrett.
Methodology

Six focus groups were carried out across England to better understand the experiences of people with a learning disability during the COVID-19 pandemic, with an emphasis on loneliness and mental health. Participants were recruited through existing Mencap networks with the view of including people with a broad geographic spread. Thirty-two participants took part in the focus groups, including people with a learning disability and/or autistic people and carers. Some participants were supported by support workers or family members during the sessions. The focus groups consisted of three in-person and three virtual sessions, along with one virtual interview. The format of each session was dependent on the needs and availability of the group. In-person sessions were offered to ensure participants without access to the internet were able to take part.

Each focus group was run by at least two facilitators – a primary facilitator responsible for asking questions and guiding the conversation, and a secondary facilitator responsible for recording, taking notes, and supporting the primary facilitator. A focus group guide was created by and for the facilitators, containing questions on a range of topics including relationships with friends and family, life in lockdown and experiences of stigma. Open questions were used to promote discussion between participants on key issues, and allow people to build on what others had said, with a view to generating richer insights.

The focus groups were conducted between January and February 2022. The focus groups were recorded and the audio was transcribed. Following this, transcripts were coded and a thematic analysis carried out on the data. This report explores the themes which were identified during this process.
Overview of themes

During the analysis, several themes were identified that relate to people with a learning disability’s experiences of loneliness and mental health during the pandemic. These themes are: relationship with loved ones, isolation and lockdown, negative effects on mental health, discrimination, bullying and understanding of learning disability.

1. Relationship with loved ones

During the pandemic, participants had mixed experiences of keeping in touch with their loved ones, and for some this had a negative impact on their mental health and led to increased feelings of loneliness. In March 2020, measures legally came into force restricting non-essential contact and travel throughout the UK. In the months following, the country experienced a turbulent change of restrictions as the rules continued to relax and tighten until the eventual exit from lockdown in July 2021 (House of Commons, 2021). When national restrictions were put in place to limit face-to-face contact, many turned to technology such as phone calls and social media websites to communicate with their loved ones:

“My boyfriend kept an eye on me through COVID… my friends have been phoning me up quite a lot, seeing how I am… If it weren't for friends and my boyfriend, I don’t know where I would have been.”

Some people with a learning disability who took part in this study discussed new skills they had learnt during the pandemic to facilitate communication. They noted that support from others was imperative for them to understand and use video conferencing software such as Zoom and Microsoft Teams, which lots of people with a learning disability in this study had not used before the pandemic. Whilst participants were grateful to keep in contact in this way, it was noted that this was not able to fully replicate ‘real-life’ interaction:

“One bright thing was my support worker helped me to learn how to use Zoom… In a way, it was nice to see friends and make friends virtually but… I did miss normal life”

Many participants found a lack of physical contact with their loved ones distressing. This was exacerbated in cases in which an individual was not able to have regular contact via internet access or phone calls. In some cases, this had an extreme effect on individual’s mental health. As one participant with a learning disability explained:

“My children are important to me. They’re far away, they don’t live near me, so I didn’t see them at all in the lockdown… I was on my own and my anxiety and mental health went out the window. I nearly committed suicide.”
It is important to note that not all participants had a close support network even before the pandemic. For some, everyday life provided them with important social contact, which was missing once restrictions were put in place. Without this regular social contact, many people with a learning disability were left feeling lonely due to social isolation:

“I found it a bit lonely because I have no family. My two uncles don’t live very close to me.”

In other cases, lockdown put a strain on existing relationships. One participant with a learning disability spoke about the impact that the pandemic had on their relationship with their son due to their limited opportunities to communicate. This was worsened by a lack of access to technology such as smart phones and laptops. The participant explained that this increased their feelings of loneliness, as well as having a negative effect on their wellbeing:

“I felt angry because I couldn’t see my son! I’ve lost so much contact with my son through the years, and then it even made it ten times worse! So, that made me down... and it makes you feel like you’re drifting from your own child.”

Conversely, some parents and carers of people with profound and multiple learning disabilities who usually lived in services talked about decisions they had made to care for their loved one at home during the pandemic. Safety of loved ones was a key concern driving such decisions. A few parents and carers emphasised the challenges of these increased caring responsibilities:

“I brought [my daughter] home because I was concerned about staff going in and out... It was hard work, but it was worth it to keep her safe. She wouldn’t have coped being in hospital.”

Other participants discussed the long-term impact that the pandemic had on their relationships, for example, keeping a distance from others despite restrictions no longer being in place. Many people with a learning disability and their families continue to be cautious even as restrictions ease, due to fears around health inequalities and the increased vulnerability of people with a learning disability to the effects of COVID-19. It is unclear whether these changes are temporary whilst the country transitions out of lockdown, or whether this represents a more permanent way of interacting with others. As one parent explained:

“I couldn’t see my son... he’s autistic... I come in and see him every other Sunday, he doesn’t even kiss me. His home has taught him that.”

For some participants, the pandemic had sadly led to the death of loved ones. Due to national restrictions, people were unable to visit friends and family in hospital, which meant missed opportunities to spend final moments together. For some, being unable to have a meaningful goodbye added to the trauma of losing a loved one. One family member who took part in this study said:
“My dad died in September, and we weren’t able to go in and see him because you’re only allowed two people in at a time. We’re still not being able to say goodbye to our loved ones the way we’ve been able to in the past.”

Participants often expressed their appreciation for their circle of support during the hardest moments of the pandemic. Many felt that they would not have survived the pandemic without being able to keep in touch with those who were important to them. As one woman with a learning disability explained:

“When I lost my husband to COVID, if it weren’t for my friends being there... I don’t know what would have happened to me.”

2. Isolation and lockdown

Being in lockdown was a particularly difficult time for many participants. Several discussed the physical and emotional impact that the strict measures had on their lives. This is discussed in the following subthemes: staying in and feeling isolated.

a. Staying in

Many participants discussed how their living situation played a significant role in how they experienced the lockdown. Some participants residing in supported living chose to move home during the pandemic due to concerns about safety and fears of loneliness. Lack of face-to-face interaction was particularly hard for those living alone. One participant with a learning disability found not meeting up with their loved ones very distressing and looked for alternative ways to see family and friends:

“When we were in lockdown, I wasn’t allowed to go out and wasn’t allowed visitors. I live on the third floor and have my own window. I could go to the window so my mum and my friends could see me for half an hour or an hour.”

The majority of participants spoke about the array of activities and social groups they attended prior to the pandemic. None of these were able to continue once lockdown began. Some participants were shielding during the pandemic, referring to guidance from the government for people at high risk to protect themselves by not leaving the home and minimising face-to-face contact (DHSC, 2020). Whilst some participants were able to return to their usual activities once lockdown restrictions were lifted, those who were shielding were advised to remain indoors. One person with a learning disability recalled only leaving their home twice during the period of lockdown, in March 2021:

“Before coronavirus I used to go out and meet with my friends and everybody. It was very nice before. But now, I went out on March 12th and March 31st, but I’ve not been out since.”
Many participants said that lockdown meant any sense of routine was cast into disarray, which was difficult for a lot of participants. For people with a learning disability and autistic people, routines are very important; and several participants discussed feeling lost and confused at the sudden change. One family member found the lockdown resulted in their loved one displaying increased challenging behaviour:

“She [my daughter] was finding if anything was out of the usual routine she would get out of all sorts. She would get upset. She’d be throwing things about and hitting me, and you just couldn’t get through to her. It was quite difficult for a while.”

Numerous participants felt that the easing of lockdown did not mean a return to their life before the pandemic. Concerns remain about the increased vulnerability of people with a learning disability to the effects of COVID-19, and many participants are still reluctant to leave the house. Several people with a learning disability described feeling trapped and were unsure when, or if, things would be normal again:

“After you finish the lockdown it’s still like you haven’t finished the lockdown. It’s still like you’re still in prison...”

Despite the hardships faced during the lockdown, a few participants discussed some positives they had found from the period spent indoors. One person with a learning disability had experienced an increase in their confidence being out alone which was previously hindered due to mental health problems:

“I never used to go on my own for a walk, now I'll go on my own to walk to the local chemist and back. Before I wouldn’t because of my anxiety.”

**b. Feeling isolated**

Having to spend extended periods of time indoors meant many participants felt isolated from the outside world. Some talked about the activities they did to pass the time during lockdown, such as watching television or picking up new hobbies such as knitting and baking. However, most people with a learning disability characterised their time spent in doors as repetitive and boring:

“Up in my bedroom [at supported living], I was a little bit alone because I couldn’t do anything. I watched my own TV upstairs, there wasn’t anything I wanted to do really.”

Those living in supported accommodation discussed the impact that the lockdown had on the support they received. Several mentioned that they noticed changes to regular staff as well as a reduced number of hours of support. One person with a learning disability discussed the impact that this had when shielding:

“We have support workers 9-5 there and then they go but during the first lockdown they were doing less hours. I missed out on talking to them because I was on my own, I was shielding as well.”

Despite distractions, several participants found themselves frustrated with their new, limited daily routine. One person with a learning disability found this especially hard as they were geographically isolated from their family:
“I felt so isolated, I was walking the walls because I just had to go out round the block and back because we weren’t allowed to meet. It was really tragic.”

Whilst the majority of participants’ lives had begun to return to normality with the lifting of national restrictions, some people with a learning disability still feel lonely. One participant’s local service was closed permanently during the pandemic. With a lack of places to visit, this means they still spend the majority of their time indoors:

“Some people’s lives were better than mine, they’re going out a couple places, and I’m not! Mine’s all gone... I’m a bit isolated now! Can’t go to places. I go up the road and go back home!”

3. Negative effects on mental health

Many people faced personal, financial or physical difficulties during the pandemic, which can have a negative impact on an individual’s mental health. Several participants explained that their experiences of poor mental health began or intensified during the pandemic. Some participants with a learning disability said they found it hard to talk to their loved ones when they were struggling for fear of burdening them:

“I put [on] a show.. I said I was alright because I didn’t want to worry my kids.”

Physical isolation caused by the national restrictions had a negative impact on many participants with existing mental health problems. One participant with a learning disability who experiences anxiety found their symptoms were heightened during the pandemic due to the lack of social interaction:

“I found it really hard because of my anxiety, not going out and meeting new people... I met up with people over Zoom and Teams because we couldn’t meet up in person.”

Loneliness was cited by many participants as one of the key drivers contributing to poor mental health. With fewer distractions in daily life, and reduced social contact, some people mentioned having more time to overthink and experienced an increase in negative thoughts:

“Not nice thoughts come into your head because you’re just on your own and you think a lot of negative things all the time. You don’t think positively because you’re just on your own thoughts all the time. It doesn’t feel very healthy.”

For some participants, the negative impact on their mental health was severe. As the country fluctuated in and out of lockdown, uncertainty remained as to what would happen next. One participant emphasised their distress at the possibility of another lockdown:
“I think I’d commit suicide if there was another lockdown. I would really, because the first lockdown, it was horrible. It was bad enough the first time.”

With many participants emphasising the negative effects of the pandemic on their mental health, it is encouraging that the majority of participants did feel they had people to turn to if they needed to talk about their mental health. As well as this, several people with a learning disability knew of specific charities and healthcare professionals who would be able to give them support:

“Our support workers are very good; they give us all the numbers… they said these are the numbers who we can contact.”

Some participants had accessed these services in the past and mentioned having a positive experience.

4. Discrimination

Many participants suggested that a widespread misunderstanding of learning disabilities often results in discrimination; and several felt incidences of discrimination had increased during the pandemic. Discrimination is an instance in which someone is treated unfairly due to who they are or because they have certain characteristics such as race, gender or disability (Fibbi, Midtbøen and Simon, 2021). Some participants gave the example of discrimination linked to the government’s mandate to the general public to wear a face mask in public areas. There were several reasons why people – including many people with a learning disability – did not have to wear a face covering when it became mandatory in England. For example, wearing a face mask may not have been possible for some people because of their disability or because it may have caused them severe distress. However, a few participants found that members of the general public misunderstood exemptions to the national restrictions, and said this led to frustrating instances of discrimination:

“I got refused entry [to a shop] because I didn’t have a mask on… my friend told them about it and then later I got an email apologising… ‘we’re really sorry, that was a new member of staff’.”

Some participants commented that having a hidden disability meant they were perceived as ‘breaking the rules’ by not following national restrictions. This meant it was harder for them to access additional support and in some circumstances led to confrontation and hostile behaviour from others:

“I have been judged because people have told me I don’t have a learning disability. I have been bullied and picked on for that during COVID, especially when I have needed support with things.”
Participants also discussed the stigma that they face in their daily lives more generally. Stigma is when an individual is seen in a negative way due to who they are or because they have certain characteristics such as race, gender and disability (Scior and Werner, 2015). Many participants felt that they were often viewed negatively by people because of their learning disability:

“Some people are very rude... because you’ve got a disability you’re stupid. I think they should look at people first and see what their abilities are instead of classing them as a person who is stupid.”

As noted by Werner et al (2012), negative societal attitudes are one of the most disabling factors for people with a learning disability. Several participants discussed the impact that stigmatising comments have had on their self-esteem and confidence. These comments are not necessarily from strangers or members of the general public – they may also be from people they know, including family members:

“I went to a special school, and I asked my mother why I went to a special school, and she said, ‘because you’re slow’ and that stuck with me forever.”

One participant, who described their loved one as having ‘complex needs’, also noted that attitudes formed on the basis of somebody’s appearance can lead to incorrect assumptions about their capabilities:

“Sometimes there are people that think that he cannot understand because he cannot speak. They think that he doesn’t understand speech and sometimes this can be a little annoying for him.”

Another participant, who also described their loved one as having ‘complex needs’, discussed the treatment of their loved one in healthcare settings. Whilst their overall experience was positive, they emphasised that a lack of understanding of challenging behaviour can result in belligerent attitudes:

“I took her [my daughter] to the hospital, and she was very distressed about this situation and there was a nurse in the next ward who said, ‘can’t you take that woman home, she’s upsetting everybody?’.. and the doctor that was in the room said, ‘I think you’d better apologise to her mum’. I never got an apology.”
6. Understanding of learning disability

Many participants felt that the majority of people have a poor understanding of what a learning disability is, which in turns fuels instances of bullying and discrimination. Recent research by Mencap (2021) supports this claim, finding two thirds of people in the UK do not know what a learning disability is. Many participants discussed feeling lonely, isolated and misunderstood by others because of their learning disability:

“People with a learning disability have a difficult time because nobody understands them.”

In particular, parents of people with profound and multiple learning disabilities felt the majority of people rarely understood the reality of being a carer:

“Understanding someone with complex needs is difficult, it’s hard work and people just don’t understand how it affects the family, you donate your life to that situation.”

Several participants felt many people only understood the concept of disability as a physical condition. This made it harder for people to empathise and understand with those who have a learning disability:

“If it isn’t anything obvious like a... [prosthetic] leg or a wheelchair then people assume that you’re fine.”

A widespread misunderstanding of what a learning disability is has had negative consequences for many participants. One participant mentioned that this had been a particular barrier in her search for paid employment:

“I think places need more training about people with learning disabilities and autism. I’ve been having some interviews and stuff because I’m looking for paid work and I put down that I had a learning disability and I didn’t come over as having a learning disability, that’s why I didn’t get the job.”

Whilst the majority of participants felt it was important that people had better education around learning disabilities, some felt doubtful about the real-life impact that this would have. One participant highlighted that not everyone is willing to learn more about the subject, which makes it harder to reduce discrimination in society:

“I get that everyone should have a lot of experience and information about disabilities but if you give a flyer or a poster to people, you can’t make them read it. If you give it to them they may be rude and difficult and just chuck it in the bin.”
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Some participants said they are involved in self-advocacy work to help ensure the experiences and opinions of people with a learning disability are heard. Many expressed that this is crucial to show people the first-hand experience of people with a learning disability. For one participant, this is a very important part of their life which has helped to enhance their confidence:

“I wanted to give other people a voice. I spoke up in conferences about people with learning disabilities to have their voices heard because they’re not being heard. I like to say that people with learning disabilities have a right just as much as anybody else.”
Conclusion

A plethora of research exists exploring people with a learning disability’s experiences of mental health and loneliness. However, little work has been done to understand this in the context of the COVID-19 pandemic. As restrictions in England lift following a period of worldwide turbulence, this research aimed to gather insight into the impact that this has had on people with a learning disability in England with specific reference to mental health and loneliness.

Whilst participants in this research each had a unique experience of the pandemic, several themes were identified which reveal important patterns. Many participants relied on technology to keep in contact with their loved ones during the pandemic, however this was seen as an inadequate substitute for ‘real-life’ interaction and did not always successfully combat feelings of loneliness or isolation. Furthermore, the pandemic often placed strain on existing relationships, particularly for people who were unable to communicate via alternative means such as the internet. For some participants, this made them feel more lonely or disconnected from their loved ones, and had a negative impact on their mental health. Whilst for some people communication was impeded by not having access to the internet or technology, others did not have the skills or knowledge to be able to use these devices; though some participants discussed learning new skills, such as how to make a video call, during the pandemic.

The lockdown had both physical and emotional consequences for people with a learning disability. Many struggled with a lack of routine, including leaving the house regularly and seeing family and friends. Routines are very important to many people with a learning disability and autistic people, and so this was a particular challenge for many people who took part in this research project. Fears around the increased vulnerability of people with a learning disability to the effects of COVID-19 mean that many people are still reluctant to leave the house, or are keeping a distance from others, even as restrictions ease. The future is as seen as uncertain, with many feeling that life has not fully returned to normal. This is contributing to feelings of frustration and loneliness, especially for those who are geographically isolated from their loved ones. Additionally, many participants experienced poor mental health or intensified mental health problems during the pandemic. Physical isolation and feelings of loneliness were seen as the key drivers of this. However, it is encouraging that many participants who took part in this study were aware of services such as charities that they could contact for support.

The restrictions put into place during the pandemic were viewed as catalysts for discrimination, due to widespread misunderstanding of exemptions. Participants felt that knowledge and understanding about learning disability is poor amongst the
general public, and in particular noted a lack of awareness that not all disabilities are physical. Many participants felt that despite spending less time outdoors during the pandemic, instances of bullying had not decreased. This continues to impact the daily lives of people with a learning disability, including how they navigate public spaces.

As England removes all remaining restrictions as part of the government’s ‘Living with Covid’ plan, there is potential for future research to revisit this topic and explore the longer-term impacts on people with a learning disability with regards to loneliness and mental health. Understanding these longer-term impacts is vital to ensure people with a learning disability are appropriately supported.
References


