

The Coronavirus and people with learning disabilities survey

Coronavirus and people with learning disabilities in Scotland

Policy brief



Introduction

The Coronavirus pandemic has had an extraordinary impact on society, but a devastating impact on many people with a learning disability and their families. The initial lockdown led to a closure of services and a shift to the online delivery of specialist health services and supports.

This survey examined how people with learning disabilities coped with the unfolding events during the COVID pandemic, from December 2020 to summer 2021. Participants were recruited from Scotland, England, Wales and Northern Ireland. In Scotland, researchers at the University of Glasgow worked alongside SCLD (Scottish Commission for Learning Disabilities) and PAMIS (Promoting a More Inclusive Society). The survey questions were informed by people with learning disabilities and family carers, who were part of the research team.

There were three waves of data collection, December 2020 - February 2021; April – May 2021; and July - August 2021. At the start of the study, we spoke to 621 people with learning disabilities who were able to talk about their own experiences, by phone or virtually (159 in Scotland) and 378 family members / paid carers of people with more severe and complex learning disabilities, who could not speak for themselves, completed an online survey about the individuals they cared for (113 in Scotland). The latter group included 166 (74 in Scotland) family members and paid carers of people with profound and multiple learning disabilities (PMLD).

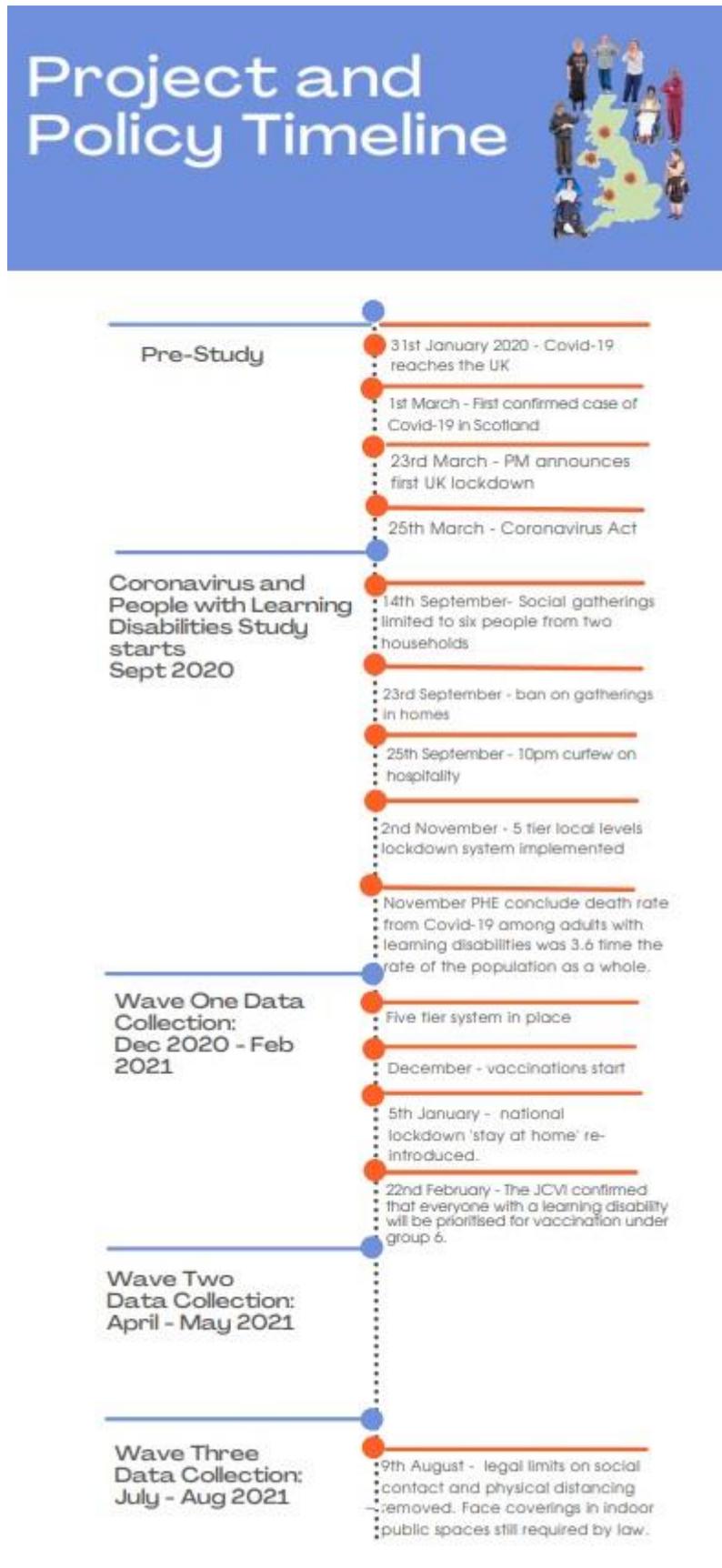
Upon completion of the survey, people with learning disabilities, family members, paid carers, service providers and support organisations attended a series of four online dissemination events in November 2021. Their views have helped to inform the interpretation of the findings and the recommendations made for policy and practice.

During the dissemination events, family carers reported serious deterioration in the physical and mental wellbeing of their relatives and a loss of previously acquired skills. Many were concerned that these would not be regained. The COVID-19 pandemic also brought to the fore longstanding concerns about access to support and services for people with learning disabilities. Families spoke of their worries about the lack of appropriate support and contingency planning for their relative, should they become ill with COVID. This reflects the reducing opportunities, pre-COVID, for families and people with learning disabilities to make plans for their future or about moving from the family home. Families of school leavers were also highly anxious that no plans or arrangements had been put in place for their young adults' transitions. These concerns highlight a lack of funding and a disparity between policy aspirations set out in documents such as the 'Learning / intellectual disability and autism: transformation plan' and the everyday lived experience of people with learning disabilities and their families.

The findings from Scotland are presented but the general pattern of responses was very similar across the whole of the UK. After outlining a number of key findings, this brief provides recommendations for policy and practice, based on the research findings and the views expressed by people with learning disabilities and family carers at the dissemination events.

Policy Timeline

The timeline below illustrates the context in which each of the three waves of data collection took place. Policy decisions that were key for people with learning disabilities and lockdown dates that took place in Scotland are marked on the timeline.



Mental Health and Wellbeing

Throughout the year, people with learning disabilities were worried about the coronavirus. Those who were interviewed were more concerned about their family or friends catching coronavirus. At the last data collection in August 2021, 64% remained worried about their friends or family catching coronavirus and 49% said they were worried about catching it themselves.

People with learning disabilities also reported high levels of emotional distress and loneliness. The majority said they felt anxious (69%), sad (68%), angry (72%) or lonely (62%), when we first spoke to them in December 2020. While there were signs of improvement by August 2021, most people continued to report feelings of anxiety (66%), sadness (64%), and anger (59%). Moreover, 41% of people reported that they still felt lonely with no one to talk to.

The findings were similar for people with more severe learning disabilities. Carers reported that the majority of people with more severe learning disabilities had felt worried (74%), sad (74%) and angry (75%) at the second wave of data collection, with little sign of improvement by August 2021.

Recommendations

- 1) There needs to be additional funding and resource to ensure support is provided to those whose emotional wellbeing has been negatively affected during the pandemic.*
- 2) Official communication contributed to anxiety. Future communication from the Scottish Government should be more easily accessible. Suggestions by people with learning disabilities include increasing font size, use of colour for printed information, and presenting information in alternative formats such as audio and video.*

Access to Health Services

Initial pandemic restrictions meant that it became more challenging to access health services. In August 2021, most people with learning disabilities (64%) and those with more severe learning disabilities (80%) said they had not had any contact with health professionals in the last four weeks. When people did have contact, it was often remotely. For example, 18% of people with learning disabilities consulted their GP by telephone or video call, compared to 17% who had in person consultations. There was a bigger gulf between virtual and in person GP consultations for people with more severe learning disabilities (15% compared to 5%). This is noteworthy because these are individuals who are unable to talk about their symptoms or explain what is causing them discomfort or distress.

Only 16% of people with learning disabilities and 20% of those with more severe learning disabilities had received their annual health check since the start of 2021.

There were also reports of delays for other medical appointments. At the final phase in August 2021, 43% of carers of people with more severe learning disabilities said they had been waiting at least 6 months for a planned medical test, hospital appointment, or operation for the person they support. Moreover, almost a fifth of carers (19%) reported that they were still having difficulties accessing essential equipment.

Recommendations

- 1) Consideration needs to be given to prioritising face to face GP consultations for people with learning disabilities, particularly those with more severe learning disabilities who are unable to provide verbal reports of their symptoms.*
- 2) Annual Health Checks are important for keeping people with learning disabilities healthy and need to be prioritised going forward.*
- 3) Addressing any deterioration in the health and wellbeing of people with Profound and Multiple Learning Disabilities (PMLD) needs to be a priority of Allied Health Professional (AHP) services.*

Access to Support Services

Over a quarter (27%) of people with learning disabilities and 58% of people with more severe learning disabilities used day services before the pandemic started. At the first wave of data collection in December 2020, almost all day and respite services and community activities had stopped. By August 2021, half of all the people in the survey had returned to their day service in person. However, almost a third of people with learning disabilities (32%) and almost half of those with more severe learning disabilities (48%) were still not back at their day service, either in person or online.

By the final timepoint in August 2021, a quarter of people with learning disabilities and over half of carers of people with more severe learning disabilities said they were receiving less support than they had before the pandemic started.

Recommendations

- 1) The full re-opening of day services and community activities for people with learning disabilities need to be prioritised. Provision of online support should be in addition to, and not a replacement for in person support.*
- 2) There should be a national hub where ideas for best practice can be collated and shared across Scotland. This would include possible solutions to restoring or providing social care and health services during periods of restriction or how to reinstate services as restrictions are being lifted. This might include day services, community activities and access to allied health professionals. The hub should work in partnership with people with learning disabilities and their families.*
- 3) Families have struggled to cope with greatly reduced levels of support, resulting in negative impacts on their physical and mental wellbeing. The pressure on families is unsustainable and care packages for people with PMLD need to be reinstated.*
- 4) Broader consideration needs to be given to the ability of families and people with learning disabilities themselves, to plan their transitions, including their move from the family home. There should be clarity about the real choices and options people have. The rhetoric should be in line with reality.*

Social Contact and engagement

We do not know how many people with learning disabilities and those with more severe learning disabilities attended community activities before the pandemic started. However, at the final wave of data

collection in August 2021, 48% of people with learning disabilities and 38% of people with more severe learning disabilities were attending community activities in person. Another 16% of people with learning disabilities and 6% of those with more severe learning disabilities said they were attending online activities. Rather starkly, 34% of those with learning disabilities and 56% of those with more severe learning disabilities were not participating in any community activities.

Recommendations

- 1) Without support and opportunity to engage in social activity people will become more lonely and depressed. This is an essential aspect of support. Proactive measures should be taken to support people's need for social contact and activity.*
- 2) There is a need for both online and face to face services / activities.*

Digital lives

Digital platforms were known to play a major role in people's lives during the pandemic. In August 2021, the majority of people with learning disabilities (94%) were using the internet and just over half of people with more severe learning disabilities (53%) had access to the internet at home.

Many people with learning disabilities were using the internet to speak with their family and friends (60%), for social media (58%), to stream television and films (54%), or to participate in online activities with others (47%). Perhaps unsurprisingly, a smaller proportion of those with more severe learning disabilities were reported to be using the internet for these purposes (friends and family: 29%; social media: 7%; film and television: 35%; online activities: 17%).

At the final timepoint, most people with learning disabilities (61%) were still enjoying taking part in online activities compared to 34% of people with more severe learning disabilities. However, 26% of people with learning disabilities and 44% of those with more severe learning disabilities had never been seen on online activities.

Recommendations

- 1) People with learning disabilities should be supported to use online platforms, building on new opportunities for digital engagement.*
- 2) Specialist online activities and supports are required for people with more severe and profound learning disabilities (but it should be acknowledged that for some people online resources are not appropriate).*
- 3) Online activities should be an addition to rather than a replacement for face-to-face activities.*

Impact of caring and visitor restrictions

Over the three timepoints, carers frequently reported feeling tired, depressed, general feelings of stress and disturbed sleep.

Lack of contact was a source of stress for family members and their loved ones who did not live with them. At the last timepoint, over 40% of those who did not live with their family still had restricted visiting for family and friends. In fact, four percent of people with more severe learning disabilities had still not seen their family and friends in person by August 2021. At this point, around half of carers (51%) felt that visitor restrictions were still having a negative impact on the person they supported.

Recommendations

1) Considerable anxiety was caused by carers' concerns about what would happen to the person with a learning disability if they became ill. Anticipatory care plans need to be put in place, in the event that carers become unwell and are unable to continue their care role. There needs to be a mandatory duty to implement these care plans.

2) In relation to any future visiting restrictions, there is a need for individualised risk assessments that take account of individual factors and put the person with learning disabilities at the centre of the risk assessment process. Health and Social Care Partnerships and service providers need to work in collaboration with families, who are the experts in understanding their relatives' needs.

Next Steps

Family carers highlighted the unique role they play in the care of their relative, providing emotional support and essential support with personal care. Yet, during dissemination events they noted that risk assessments during COVID were rarely carried out in partnership with them. People with learning disabilities also wanted their experiences of the pandemic to be taken seriously and to be involved in future planning. The collective view at the dissemination events, was that a significant event analysis should be carried out on the COVID responses to ensure that lessons are learnt. Family carers and people with learning disabilities should be at the heart of this process, which would inform plans for any future pandemic/crisis situation and a new way forward.

Films about the experiences of people with learning disabilities and family members are shown at:

<https://youtu.be/ZrjMLNSKDLY> (SCLD COV explorers and the COVID-19 pandemic)

https://youtu.be/LS68_ZEBcB4 (PAMIS family carers and the COVID-19 pandemic)

Full findings of this study can be found at [Coronavirus and people with learning disabilities \(warwick.ac.uk\)](https://warwick.ac.uk/coronavirus-and-people-with-learning-disabilities)

For more information on this briefing paper and the research, please contact

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