



Key issues for people with learning disabilities during the Coronavirus pandemic – January 2021

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This brief report presents the key issues on the impact of the Coronavirus pandemic identified from discussions with our partner organisations and advisory groups across the UK in January 2021. The issues come from the views of people with learning disabilities, family carers and organisations that support people with learning disabilities, and are similar across all four nations. These key issues include: impact on health, changes in support, concerns around the vaccination process, experience of using digital platforms and accessibility of information and guidance. The issues raised are largely similar to the key issues identified in our first report (November 2020). However, it is evident that the persistent nature of the pandemic is becoming increasingly challenging for people with learning disabilities and their families. Additional concerns were also raised in relation to the vaccination process.

Impact on health

The coronavirus pandemic has continued to negatively impact on both the mental and physical health of people with learning disabilities. Many people with learning disabilities reported finding it increasingly difficult to cope and have found the current lockdown significantly more challenging than the first one. They feel that their lives have become very restricted. Winter weather conditions have further contributed to a reduction in people's quality of life. People with learning disabilities reported feeling down and some had stopped engaging in routine daily activities such as getting dressed. There was a common feeling of despair as to when the pandemic might end. Support providers reported a rise in calls from people with learning disabilities in need of reassurance. Families who care for a person with profound and multiple learning disabilities (PMLD) reported that the closure of community-based day services in particular had led to their relative becoming increasingly withdrawn due to the lack of social contact. This had significantly increased feelings of loneliness and

impacted on people's mental wellbeing, with some becoming depressed. Some family carers reported an increase in seizure activity in their relative with PMLD, which they believed to be an outcome of their low mood. There were concerns that these mental health issues would be less likely to be identified and supported in a timely way given the limited access to health services at present.

Concerns were also raised about the impact of the continuing pandemic on physical health. People with learning disabilities and their families reported that regular medical appointments, health checks and medication reviews had been cancelled or postponed. They were worried that lack of access to routine appointments may result in new health issues not being identified and treated. With many health checks now being delivered remotely, family carers of people with PMLD were concerned that this was not an appropriate way to examine and assess their relatives' health needs. Furthermore, the closure of day centres has resulted in a loss of vital allied health support for people with PMLD, for example physiotherapy. As many families do not have access to suitable equipment at home (walkers, standing frames, accessible showers etc.) this has had substantial implications for their relatives' physical health and wellbeing.

Changes in support

Reduction or removal of support has been and remains a major issue for people with learning disabilities and their families. Concerns were raised about the impact of the withdrawal or reduction of support.

Changes to support were consistently highlighted and included:

- Removal of care packages
- Closure of community based day services
- Reduction in provision of home-based support
- The replacement of face to face support with digital or telephone support (often with reduced contact)

People with learning disabilities and their families continued to report having to pay for services which they no longer receive. They also reported the suspension of direct payments with no indication of when these might be restored. This has resulted in financial difficulties for some families due to the increased costs (e.g. heating bills) of having to stay at home.

People with learning disabilities and their families were concerned about the lack of information and communication as to whether their support packages would return to pre-pandemic levels. They were anxious about what support would be available in the future. Questions were raised about the nature and provision of services coming out of the pandemic. In particular, people were concerned as to whether community based day services would re-open or whether these would be replaced by outreach home-based support on a more permanent basis. Both people with learning disabilities and their families emphasised how important community based day services are as they provided opportunities for increased independence, social interaction, development of new skills and sensory stimulation.

While the impact of support changes is likely to affect individuals differently, it was evident that changes in support have led to a loss of independence for people with learning disabilities, increased anxiety, social isolation and loneliness. The ongoing nature of the pandemic has also impacted negatively on people's confidence, communication and life skills. Family carers and support organisations highlighted the need for vital and timely measures to support people with learning disabilities as they come out of lockdown.

Other issues raised related to the impact of the suspension of formal processes e.g. care inspection processes and legal guardianship and the provision of support with bereavement given the restrictions on attending funerals.

Concerns around the vaccination process

People with learning disabilities were anxious about when they would receive the coronavirus vaccine. They felt that information on the vaccination process had been poorly communicated. People were apprehensive about attending large vaccination centres and had concerns as to whether there would be reasonable adjustments. Nationally, concerns were raised around whether the current legislation regarding capacity would significantly delay the vaccine for people considered not to have the capacity to consent. In Scotland, People First have called for a temporary suspension of the Adults with Incapacity Act and propose to replace this with a framework for supported decision-making. Family carers were concerned as to whether they would receive the vaccine alongside their relative with PMLD.

Experience of using digital platforms

People with learning disabilities reported some benefits of the increased use of digital platforms including keeping in touch with family and friends, making new friends through online groups and activities, enjoying the shared experiences and developing skills in using new technology. Organisations supporting people with learning disabilities reported that online activities were more inclusive for some people and suggested this could be due to the removal of external sensory distractions. Family carers reported that they increasingly engaged with online communities for support, advice and information as a result of other routine supports being withdrawn. However, there are still challenges around the use of digital platforms. While many people have become competent in using a particular online platform (e.g. zoom), difficulties arise when organisations use different digital platforms. There is an increasing gap between people who are connected online and those who are not, with those who cannot access online technology reporting feeling even more excluded than before the pandemic.

Accessibility of information and guidance

The accessibility of information on coronavirus guidelines for people with learning disabilities remains an issue. Family carers also highlighted the lack of guidance for those caring for a person with PMLD in relation to medical procedures and hospital admissions.

Organisations involved in our discussions

Learning Disability England; PMLD Link; Scottish Commission for Learning Disability; Promoting A More Inclusive Society (PAMIS); All Wales People First; Learning Disability Wales; All Wales Forum of Parents and Carers of People with Learning Disabilities; Mencap Northern Ireland; Positive Futures; CAN Northern Ireland; Families Involved in Northern Ireland (FINI).

Additional sources of evidence about the impact of the Coronavirus on the lives of people with learning disabilities

Shakespeare et al. (2021). Disabled People and COVID-19: four urgent messages for the government. [Disabled people and COVID-19: four urgent messages for the government | LSE COVID-19](#)

The Equality and Human Rights Implications of the COVID-19 emergency for people with learning/intellectual disabilities (Source: Scottish Commission for Learning Disability) https://www.sclد.org.uk/wp-content/uploads/2020/06/The-Equality-and-Human-Rights-Implications-of-the-COVID-19-emergency-SCLD-Submission_designed.pdf

The Impact of Coronavirus on People with Learning Disabilities and their Parents, Carers and Supporters: Survey findings (Source: Scottish Commission for Learning Disability)

<https://www.sclد.org.uk/wp-content/uploads/2020/06/SCLD-Coronavirus-Report-FINAL.pdf>

The Impact of Coronavirus on People with Learning Disabilities and their Parents, Carers and Supporters: Survey findings Easy Read (Source: Scottish Commission for Learning Disability)

<https://www.sclد.org.uk/wp-content/uploads/2020/06/SCLD-Coronavirus-Report-Easy-read-Designed-FINAL.pdf>

SBAR - Care pathway for people with a profound learning and multiple complex disabilities requiring acute medical services/hospital admission.

<http://pamis.org.uk/resources/>

How Coronavirus has affected people with learning disabilities and autistic people: easy read (Source: Social Care Sector COVID-19 Support Taskforce: People with Learning Disabilities and Autistic People Advisory Group)