



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

Roseann Maguire, Amanda Gillooly and the project team

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 May 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: changes in support, impact on health, experience of using digital platforms, impact on the physical and mental health of family carers, and risk assessment and restrictions. Many of the issues raised are similar to the key issues identified in our previous reports (November 2020 & February 2021).

Changes in support:

Although day services are now beginning to re-open, they are often operating on a reduced basis with a lack of flexibility. People with learning disabilities and their families remain concerned about the lack of information and communication as to whether their support packages will return to pre-pandemic levels. Questions were again 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 re-designed and replaced by outreach home-based support on a more permanent basis.

While the impact of support changes is likely to affect individuals differently, it was evident that the continued disruption to support provision has led to a loss of independence, increased social isolation and loneliness for many people with learning disabilities. They consistently reported missing the face to face contact that they normally experience at their day services, community activities and social clubs. The ongoing nature of the pandemic has had a particularly negative impact on the confidence, communication and life skills of people with Profound and Multiple Learning Disabilities (PMLD), and families were concerned that some of these negative impacts would either be permanent or would require prolonged additional support to improve. There remains a need for vital and timely measures to support people with learning disabilities and their families as they come out of lockdown.

People with learning disabilities and their families continue to report having to pay for services which they no longer receive. The way that services are charged has also changed for some people (e.g. newly charging for the travel time of home carers), resulting in less support for the same charge. This situation remains an ongoing challenge for family carers. This has resulted in financial difficulties for some families due to the increased costs of having to stay at home.

Impact on health:

The coronavirus pandemic continues to negatively impact on both the mental and physical health of many people with learning disabilities. There were concerns about the future method of delivery of GP services and whether video consultations are a suitable medium to address the health needs of people with learning disabilities.

Experience of using digital platforms:

Many people with learning disabilities continue to report benefits of the increased use of digital platforms including keeping in touch with family and friends and making new friends through online groups and activities. However, challenges remain around the use of digital communication for people with learning disabilities who require additional support to access these platforms.

Impact on the physical and mental health of family carers:

The coronavirus pandemic continues to affect both the mental and physical wellbeing of family carers. As a result of support services operating on a reduced capacity, many carers continue to provide significantly greater care for their relatives. Family carers report that their continued fight, throughout the pandemic, for the provision of basic support to meet their relatives' needs has had a negative impact on their own physical and mental health.

Risk assessment and restrictions:

Family carers are anxious about the safety of their relative as coronavirus restrictions continue to ease (e.g. returning to day services, increased social interactions in the community). Concerns were raised that the current restrictions for people with learning disabilities living in residential accommodation may continue even as the situation improves. Family carers remain concerned about the lack of clear guidance to make informed risk assessments for their relatives. They continue to report their frustration about their lack of involvement in decision-making processes regarding their relatives' care. Family carers disputed the legitimacy of the blanket approach to risk assessment taken by many local authorities and residential care providers, often resulting in a postcode lottery in terms of people's experiences. As discussed in our earlier report (November 2021) family carers urgently need the development of clear guidance to facilitate individualised risk assessments - guidance which will take account of the mental health and wellbeing of people with learning disabilities, and their family situations.

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

Flynn, S., Bailey T., Hastings, R. P., Hatton, C., Abbott, D., Beyer, S., Bradshaw, J., Caton, S., Gillooly, A., Gore, N., Heslop, P., Jahoda, A., Maguire, R., Marriott, A., Oloidi, E., Mulhall, P., Scior, K., Taggart, L., & Todd, S. (2021). *Coronavirus and people with learning disabilities study Wave 1 Results: March 2021 (Full Report)*. Coventry, UK: University of Warwick. ISBN: 978-1-871501-36-0

[Wave 1 Results \(warwick.ac.uk\)](https://www.warwick.ac.uk/warwick/learning-disabilities/coronavirus/wave-1-results)

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](https://www.lse.ac.uk/COVID-19/research-and-analysis/working-papers/2020/07/Disabled-people-and-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)