



Coronavirus and people with learning disabilities study

Key issues for people with learning disabilities – June 2022

This brief report presents the key issues for people with learning disabilities and their families as we move through the coronavirus pandemic. The issues are derived from discussions with our partner organisations and advisory groups across the UK and represent the views of people with learning disabilities, family carers and organisations that support people with learning disabilities. These issues appear to be similar across all four nations, and focus on: changes in support, impact on health, impact of restrictions, cost of living, and digital platforms.

Changes in support:

People with learning disabilities and family carers' concerns about changes in support centred on three related issues: reduction of service provision, the staffing crisis and a shift in the culture of support.

Reduction or removal of support has been and remains a major issue for people with learning disabilities and their families. Provision of day and respite services have not returned to pre-pandemic levels, and transport (e.g. minibuses) to and from day services had also not returned in some areas. Some people reported that their service had not returned at all. Other people reported that their service had returned but at a reduced capacity, e.g. they were attending their day service fewer days per week. This reduction has left many people with learning disabilities socially isolated as day services were often the only opportunities people had to see their friends. Organisations were concerned that the provision of day services by some supported living providers was a retrograde step. Some people with learning disabilities and their families reported still paying for services they were not receiving and the withdrawal of direct payments. As services have not returned for some people with learning disabilities living with their families, some families are now managing care on their own. Whilst this had led to some families becoming closer, this was not viewed as being sustainable. However, families reported having a clearer view on the

type of service needed to support their relative, and want to be involved in the design and planning of services.

Concerns were raised about the impact of significant staff recruitment and retention issues in social care. Staff shortages have affected all services for people with learning disabilities, for example, the replacement of day services with outreach services, and reduced support to enable people with learning disabilities to go out and about in their communities. Family carers and advocacy organisations were concerned about the impact this has had and will continue to have on people's opportunities for independent living. They were worried that people's lives are becoming narrower. Concerns were also raised that the current high turnover of staff in social care is impacting negatively on people with learning disabilities. Families of people with profound and multiple learning disabilities (PMLD) questioned the ability of inexperienced new staff, who had no knowledge of their relative's capabilities pre-COVID, to help them to regain their previous level of skills and independence.

During the pandemic, advocacy organisations and family carers across the UK were concerned that there had been a return to paternalistic practices, with a focus on protection rather than rights. This remains a concern as we move through the pandemic. Experienced staff have left or retired, and new staff employed during the pandemic, working in culture of restriction in the name of protection may have little experience of supporting people to lead fulfilling lives. Advocacy organisations and family carers are worried that what was done in a crisis will become the norm. They stressed that it is important to prioritise the principle of choice and control in all decisions about service provision for people with learning disabilities.

Other concerns raised in relation to changes in support included lack of access to social work, particularly assessments, the redesign of services, the transition process from child to adult services, and the transition out of the family home. Throughout the United Kingdom there is a grave and ongoing concern that the financial and staffing pressures in adult social care has resulted and will continue to result in a loss of services for people with learning disabilities.

Impact on health:

People with learning disabilities and their families continued to report limited contact with health professionals. There were reports of long waiting lists to see health professionals and concerns about the depletion of many specialist learning disability services and professionals and whether these services would be restored. Carers with a relative with PMLD were concerned about the loss of vital allied health professional (AHP) support, for example physiotherapy. This was reported to have negative impacts on their relative's physical health, including postural care, bone health, and ability to weight bear, arising from long term inactivity. This loss of AHP input has also resulted in a regression of the life skills of people with PMLD. Families are concerned that these negative impacts will require prolonged additional support for skills to be regained but fear that this loss may be permanent. In addition, people with learning disabilities who were at the age of transition

when the pandemic began have lost at least two years of essential support for their physical and neurological development. Some families reported having to seek private treatment for their relative due to difficulties accessing services on the NHS.

People with learning disabilities were unhappy with the provision of GP services. Some people with learning disabilities found new telephone or online booking systems for GP appointments difficult to navigate, and were unable to access face to face appointments. The increased use of remote consultations was of particular concern among family carers of people with PMLD. These family carers strongly stated that physical examinations are crucial to monitor the health conditions of their relatives. In addition, staff shortages had made it more difficult for people with learning disabilities and their families to build up a relationship with their GP.

People with learning disabilities and their families had difficulties accessing annual health checks. When annual health checks did occur, the majority were by telephone call and reported to be inadequate. It was also reported that health action plans were not being carried out. Access to high quality annual health checks and the implementation of health action plans remain a priority for people with learning disabilities.

People with learning disabilities reported that they had not had a dental health check during the pandemic. This was a particular concern among families caring for a relative with PMLD, who rely on these regular health assessments to identify dental problems. People with learning disabilities and their families also reported their concerns about accessing future COVID-19 vaccinations. Concerns were also raised that it may be more difficult to identify signs of long COVID in people with learning disabilities due to diagnostic overshadowing.

People with learning disabilities and their families also reported difficulties accessing mental health services and highlighted the need for investment in the provision of these services for people with learning disabilities.

Impact of restrictions:

While restrictions have been fully lifted for society at large, some people with learning disabilities in residential accommodation continue to experience some restrictions. As with service provision, there continues to be a postcode lottery, with some service providers still being very risk averse. In these situations, family carers want individualised risk assessments that take account of the mental health and wellbeing of people with learning disabilities.

Cost of living:

Family carers and people with learning disabilities were extremely anxious about the rise in the cost of living. All were concerned as to how they will be able to afford to pay their bills given rising fuel, food, and energy costs, with this situation likely to be exacerbated for people with learning disabilities and families spending more time at home due to the reduction in day services and lack of access to community activities. The financial pressures for families of those with PMLD is likely to be even greater, with some families also having to run medical machines for 24 hours a day. Family carers and advocacy organisations felt that the small payments offered by the government were insufficient and questioned why

there have been no reasonable adjustments for people with learning disabilities and their families.

Organisations were also concerned about the impact the cost of living crisis has had on the retention and recruitment of care staff. They reported some staff leaving for better paid jobs whilst others were often out of pocket covering costs incurred during their working day, for example driving the person they support to social activities. The impact of staff shortages in other sectors, such as public transport, was also having an impact on the extent to which people could go to the places they wanted.

Digital platforms:

People with learning disabilities and their families continued to report benefits of the increased use of digital platforms, including keeping in touch with family and friends, making new friends, enjoying the shared experiences, and developing skills in using new technology. However, challenges remain around the use of digital communication for people with learning disabilities who require additional support to access these platforms. Many services went online during the pandemic, for example purchasing tickets for public transport. However, some people with learning disabilities and their families reported difficulties in using these services, highlighting that digital platforms are not appropriate for all people with learning disabilities or designed to be accessible to people.

People with learning disabilities who received digital devices during the pandemic spoke positively of the opportunities that this had given them to stay connected and develop new skills. They felt strongly that digital devices should be freely available to all people with learning disabilities but stressed that online activities should be an addition to and not a replacement for in-person social interaction. The sustainability and affordability of these digital devices and wifi access over time were also concerns.

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).