



## **Key issues for people with learning disabilities during the Coronavirus pandemic – November 2020**

**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. The issues are derived from the views of people with learning disabilities, family carers and organisations that support people with learning disabilities, which appear to be similar across all four nations. These key issues focus on: changes in support, health concerns, lack of access to family members in residential care/hospital, lack of information, experience of using digital platforms, impact on the carer and impact of restrictions.

### **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 and also about changes in assessment processes.

#### *Impact of the withdrawal or reduction of support*

Changes to support were consistently highlighted and included:

- Removal of care packages
- Loss of community learning disability teams (nurses, social workers, psychologists, psychiatrists), speech and language therapists, physiotherapists, occupational therapists and domiciliary care supporting the person with learning disabilities and families
- Closure of day centres and day and residential respite services
- The replacement of face to face support with digital or telephone support (often with reduced contact)

People with learning disabilities and their families also reported having to pay for services which they are no longer receiving during the pandemic, and the suspension of direct payments with no indication of when they might be restored. While the impact of support changes is likely to affect individuals differently, it is evident that changes in support are leading to a loss of independence for people with learning disabilities, increased anxiety, social isolation and loneliness. Also reported is having little or no contact from statutory services, particularly social work services, leaving people feeling abandoned.

People with learning disabilities and their families were anxious about what support will be available for them in the future. Concerns have been expressed that local authorities may try to justify not restoring care packages using the rationale that people with learning disabilities and their families have been 'coping' during the pandemic. As support has been reduced or withdrawn, the caring responsibilities of families have increased. In our discussions, it was highlighted that for some families, the withdrawal of support to care for their relative at home meant that they were unable to sustain their care responsibilities and their relative had to move into residential care. The increase in care responsibilities has had, and continues to have, an impact on the physical and mental health of family carers.

#### *Changes in assessment processes*

Advocacy organisations and family carers across the UK were concerned that emergency measures introduced to speed up decision-making during the pandemic have given rise to the return of paternalistic practices. These included practices of corporate parenting with their concomitant focus on protection, resulting in a lack of individual and family involvement in emergency planning and risk assessments. Family carer organisations point to inconsistencies between government policy and actual health and social care service practices (e.g., the lack of evidence of equality assessments). These stakeholders ask for 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. Involving family carers of people with profound and multiple learning disabilities in the risk assessment process would enable shared ownership of risk. Family carer organisations suggest that health and social care services work collaboratively with family carers and support organisations to implement such guidance.

As family carers of persons with profound and multiple learning disabilities have to interact with multiple agencies (e.g., health, housing, social care) the current pressures on all services have a cumulative impact on the family and the person they care for. Slow communication processes between agencies can also be problematic, resulting in unnecessary delays in the provision of support.

Organisations also point to the difficulties in transitioning from child to adult services and report that young people have been left in a kind of limbo due to the pandemic.

## **Health concerns**

Several issues of concern relating to health were raised: fear and anxiety about catching coronavirus, worries about the impact of the pandemic on the mental and physical health of people with learning disabilities and their families, changes in access to medical care, and concerns regarding medical decision-making around issues such as Do Not Attempt Cardiopulmonary Resuscitation Orders (DNACPRs).

People with learning disabilities reported being anxious or frightened to go out because they were worried about catching coronavirus. Family carers were concerned about the safety of taking their relative out into the community because of other people's behaviour (e.g., others not complying with social distancing). This was also a concern of some people with learning disabilities.

Family carers were worried that the health and wellbeing of their relative has or will deteriorate because they cannot get out to participate in their usual activities. For example, some carers reported that their relative had gained weight, some that they had become withdrawn, and others reported a deterioration in their relative's mental health. People with learning disabilities, perhaps particularly those who are more isolated, were worried about their mental health.

People with learning disabilities and family carers are worried about being able to access medical care, including GP appointments, routine hospital appointments, and the availability of medication. Family carers reported that delays in medical procedures had added to their anxiety about the health of their relative. The changes to the mode of delivery of medical care, such as the increasing use of remote consultations, was a particular concern of family carers of people with profound and multiple learning disabilities. These family carers strongly state that physical examinations are crucial to monitor the health conditions of their relatives. Concerns were also raised about the lack of medical input for people with profound and multiple learning disabilities in residential care.

Family carers are anxious about the restrictions on accompanying their relative to medical and hospital appointments, and not being able to stay with them if they are admitted to hospital. Family carers are particularly concerned about not being able to be present in medical decision-making processes, such as decisions on DNACPRs.

## **Lack of access to family members in residential care/hospital:**

A prominent issue among family carers is their lack of access to their relatives in residential care due to restrictions on visitors. Some family carers with a relative with profound and multiple learning disabilities had not had any face to face contact with their relative since before the pandemic.

Family carers are frustrated that paid carers are in regular contact with their relative but family cannot visit despite also performing caring duties. Family carers describe how they

have devoted their lives to caring for their relative and now feel more invisible than before. Limitations on access to family members is also an issue among some people with learning disabilities living in shared accommodation, where restrictions prohibit visits to and from their family. The lack of proper and fair access is affecting the mental health and wellbeing of both people with learning disabilities and their families.

#### **Lack of information:**

Another issue was a lack of clear guidance and accessible information on coronavirus and associated restrictions. Specifically, a need for clearer guidance on shielding, PPE and testing was identified. Clear guidance for those who are clinically vulnerable and shielding (whether on an official shielding list or not) is urgently needed. Information on walk-in testing centres is also required, as these are more likely to be used by people with learning disabilities. Family carers identify the need for clearer guidance on testing for people with profound learning disabilities and those with complex behaviours.

#### **Experience of using digital platforms:**

Digital exclusion is a key issue among people with learning disabilities. People with learning disabilities may not have access to digital platforms, either due to lacking appropriate equipment (e.g. smartphone/tablet, the internet), and/or because they lack the skills or confidence to navigate new digital platforms. This affects individuals' access to current support and social activities. Some older family carers who do not have access to this technology have also struggled to communicate with their relatives in care homes where restrictions prohibit visiting. However, there have been some reported benefits of the increased use of digital platforms including greater contact with extended family and more regular contact with other people with learning disabilities (e.g., through keep in touch groups). Digital platforms are also potentially more inclusive for some family carers as this is less disruptive to their daily caring responsibilities. Organisations report that some people who did not previously participate in face to face meetings, had become more involved since services have moved online.

#### **Impact on the carer:**

The coronavirus pandemic has affected both the mental and physical wellbeing of family carers. Carers are taking on significantly greater caregiving duties, with usual services such as day centres, community teams and respite currently closed and other supports withdrawn. Understandably, this has resulted in emotional burnout for families who are emotionally and physically exhausted with increased concerns for the health of their relative and loss of caregiving support. Physical tasks such as moving and handling, personal hygiene, dressing, feeding and managing behaviours that challenge of their relative has become increasingly difficult. Some people with learning disabilities will have gained weight due to lack of physical activity during the pandemic, and due to disruption in routines and lack of access to day centres, day and residential respite, community activities and access to professional support/services mental health and behaviours that challenge may worsen. Spending increased amounts of time together has resulted in increased tensions in relationships within some families.

### **Impact of restrictions:**

There is no doubt that the specific coronavirus restrictions have clearly affected the lives of people with learning disabilities and their families across the UK. Social distancing restrictions are a barrier to the usual communication method of many people with profound and multiple learning disabilities as they prohibit physical touch. Shielding has significantly increased social isolation for both people with learning disabilities and their families, many of whom have been shielding since the outbreak of the pandemic. People with learning disabilities and their families feel society has forgotten about them. The increased anxiety around all the changes, including changes in support and access to medical care, has left people with learning disabilities and family carers experiencing a loss of control in their lives.

### **Organisations involved in our discussions**

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

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

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.sclld.org.uk/wp-content/uploads/2020/06/The-Equality-and-Human-Rights-Implications-of-the-COVID-19-emergency-SCLD-Submission\\_designed.pdf](https://www.sclld.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.sclld.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.sclld.org.uk/wp-content/uploads/2020/06/SCLD-Coronavirus-Report-Easy-read-Designed-FINAL.pdf>

Publications: Coronavirus and People with Learning Disabilities Study (Source: PAMIS)

<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)

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/925820/covid-and-people-with-learning-disabilities-or-autism-easy-read\\_v2b.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/925820/covid-and-people-with-learning-disabilities-or-autism-easy-read_v2b.pdf)

The Effect of the Coronavirus Pandemic on People with Learning Disabilities Across Wales: Phase One (Source: All Wales People First).

<https://allwalespeople1st.co.uk/wp-content/uploads/2020/05/The-Effect-of-the-Coronavirus-Pandemic-on-People-with-Learning-Disabilities-Across-WalesPhaseOneFinalDraft.pdf>

The Effect of the Coronavirus Pandemic on People with Learning Disabilities Across Wales. Phase Two – Amber (Source: All Wales People First)

<https://allwalespeople1st.co.uk/wp-content/uploads/2020/08/AMBER-The-Effect-of-the-Coronavirus-Pandemic-on-People-with-Learning-Disabilities-Across-Wales.pdf>

Living with the COVID-19 pandemic: Learning Disability Family Carers in Wales – ‘what matters’ to us? (Source: All Wales Forum of Parents & Carers of People with Learning Disabilities (AWF))

<http://www.allwalesforum.org.uk/wp-content/uploads/Life-in-Lockdown-for-LD-Families-in-Wales-An-All-Wales-Forum-of-Parents-and-Carers-Report-.pdf>