

## Learning Disabilities, Autism and Neurodivergence Bill Consultation Briefing

# Part one - Reach and Definitions

### [Click Here for Reach and Definitions Easy Read](#)

#### **What is the consultation proposing?**

The Scottish Government are proposing three main options regarding who the LDAN Bill should include:

1. People who are neurodiverse and neurodiverse people
2. People who are neurodivergent and neurodivergent people
3. Including people with specific conditions only in the Bill

#### **What you have told us**

Based on what we have heard from people with Profound learning and multiple disabilities and their families over the past thirty years, PAMIS have identified the following key priority points relating to Reach and Definitions:

- People with profound learning (intellectual) disability and additional complex multiple disabilities (PMLD) are a diverse group of individuals with their own personalities, preferences and ways of communicating. The abilities of those described as having PMLD vary considerably and not least because of the varied life experiences they may or may not have had. They are one of the most marginalised group of people in society. Due to the multiplicity of their disabilities, they are often excluded from playing a full role in society, primarily because our communities are not inclusive, or not inclusive enough.
- -Profound means deep, intense, wise, requiring great insight or knowledge and although many people with PMLD have significant areas of disability described below they also have unique areas that never cease to surprise those who care and work with them. The description below is the science, a medical approach, but the experience of being a part of their lives is something very different. The description below also misses the unique contribution people with PMLD make to the lives of others, not least in what they are able to teach about how to care, how to act with compassion and how to make human connections.

- People with PMLD clinically share a number of characteristics that make this term appropriate and leads to challenges for them and those who support them. Their prime disability will be profound learning (intellectual) disability. The causes are many and varied. All have had some form of damage to their brain and central nervous system. This may be caused by injury before, during or after birth, by genetic factors, by infection to them or their mother, or by accidental or non-accidental injury. Whatever the cause, and this sometimes goes undiagnosed, their development as children and adults is severely constrained. Few achieve the cognitive and communicative abilities of a two-year-old, and clinically they are described as having an intelligence quotient less than 20 (IQ<20), hence “profound learning disability”. The physical and sensory disabilities that arise from damaged brain function will also restrict their interaction with the world (the “multiple disabilities” referred to) making them highly dependent on others to ensure that they have the opportunity to experience the value of life that others take for granted. The majority will be life-long wheelchair users. The combination of intellectual, physical and sensory difficulties is often compounded by significant health problems, including epilepsy, respiratory and nutritional difficulties, resulting in many being fed non-orally.
- The majority of people with profound and complex disabilities live at home with their parents. Research has shown that family carers spend on average 8.5 hours per day on basic caring tasks. It is difficult for people with PMLD to access activities in their communities because many facilities are not accessible or inclusive. However, we do know that with the correct help, support and resources that are truly accessible, people with PMLD can and do take an active role as participants in their communities.
- We highlight the definition above because this group of people remain invisible within our communities and therefore facilities and services are not developed to enable them to lead healthy, valued and inclusive lives. If you don't see people within your community or have no experience of caring, why would you consider the development of a changing places toilet? And if you believe that a child will not grow into an adult, why would you invest in facilities and resources? These are the battles families have on an ongoing basis.
- People with PMLD and their families felt invisible, abandoned and forgotten during the COVID 19 pandemic and in many cases, this remains as services have not returned to appropriate levels. The lack of understanding about the complexity of care and the intense caring role is obvious. People with PMLD are already a subgroup of a subgroup within society, and within a wider group of neuro-divergent people there is a real fear that they will be completely disappear.
- People with PMLD can thrive and contribute to all of our lives but it takes all your senses to listen and understand them and it takes time to develop their skills and contributions. This needs to be specifically spelt out and their uniqueness celebrated. Unless specifically named/mentioned as a group we believe this group will continue to be marginalised, ignored and remain invisible.
- There are many unnamed syndromes that lead to a profound learning disability. Many children wait many years for a specific diagnosis.

- People with PMLD will have a range of other conditions that require to be seen in their own right so that the risk of diagnostic overshadowing is minimised. During COVID these underlying health conditions were not registered putting individuals at further risk, not being able to access the shielding opportunities and again facing invisibility.

## **What PAMIS wants to see**

An assurance that the LDAN Bill will not include so many different people who are deemed neuro-divergent that it will not be able to adequately support anyone. People with PMLD are already invisible in policy and communities, PAMIS wants assurance that their very specific needs and assets will be seen and supported.

We want to see:

1. Specifically naming of people with a profound learning and multiple disabilities and their families as a group to be supported by the Bill. Although a part of the learning disability community there are distinct differences in support and opportunities for this group.
2. A recognition that people with PMLD will also have other health conditions that require to be seen in their own right.
3. Specific naming and acknowledgement of the positive lives people with PMLD have, and the contributions that they make to all of our lives and the communities they live in, when they are enabled to do so.
4. People with PMLD being identified and planned for across the age spectrum – an expectation of living.
5. Support for a diagnosis and where there is a delay, an assurance that they will still be covered by the Bill.
6. Clarification that the definition of PMLD occurs before adulthood, as supported by the definition of a learning disability, but which is then confused within the consultation that Acquired Brain Injury happens after birth and will not to be included. This would impact on some children and young people who are currently seen as a person with PMLD.

## **Your Feedback**

Do you agree with what PAMIS wants to see?

Is there anything else you think is important relating to this section?

Please send any feedback or suggestions to [info@pamis.org.uk](mailto:info@pamis.org.uk)