

## Learning Disabilities, Autism and Neurodivergence Bill Consultation Briefing

# Section 1: Health and Wellbeing

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#### What is the consultation proposing?

The Scottish Government is proposing five areas for action in this section:

1. Introducing statutory strategies relating to health and wellbeing, for example, asking Health Boards, Integration Authorities and Local Authorities to set out in their local strategies how their workforce planning and service planning has taken into account the needs of the neurodivergent and learning disability populations.
2. To legislate for a mandatory training requirement for health and social care services in Scotland. The mandatory training would focus on learning disabilities and neurodivergence.
3. To legislate for neurodivergent people and people with learning disabilities to be able to request access to alternative means of communication where the offered means of communication is not suitable work for them. This could mean being able to request an online or telephone meeting rather than face to face, or other forms of communication. Better access to easy-read versions of public facing communications and documents. A proposal to legislate for an Accessible Information Standard for Scotland which would be applicable to NHS Scotland organisations. Review the existing complaints systems to ensure they meet the needs of neurodivergent people and people with learning disabilities.
4. Place a duty on Health Boards, HSCPs and Local Authorities to ensure that a person's "passport" is able to follow them through whichever care pathways they are accessing. This could be similar to Advance Statements<sup>145</sup> that can be used by people with mental health conditions, or it could be based on PAMIS's Digital Passports.<sup>146</sup>
5. A duty is placed on NHS Health Boards to offer annual health checks to people with a learning disability.

## 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 this section.

- There are some shocking statistics about the health and mortality rates of people with a learning disability in comparison to the general population and this impacts across all ages and affects the health and wellbeing of families.
- Until 2 years ago there were no investigations into the death of a child or young person with PMLD because they were expected to die. This means that essential information about causes and in turn prevention of premature death have been missed. Parents of children, young people and a growing adult population have been frequently told not to expect their child to live and have not had access to the necessary treatment and interventions that would support their loved one's health and wellbeing.
- Families have not been given appropriate information and training to enable them to effectively support their loved one because of this lack of expectancy to live.
- Values have been and continue to be placed on the quality of life of individuals with PMLD and this has influenced treatment and intervention decisions.
- Acute hospital pathways have not enabled a person with PMLD to be supported by the people who know them best. In some cases, people with PMLD have been in unfamiliar, terrifying environments with no one who knows or understands their communication or needs. Being a highly specialist in a medical world is of no use if the person with PMLD cannot take medication or even enter a hospital environment without the right support from their expert carers, both family and paid social care support.
- As people with PMLD transition from a known team of healthcare practitioners into the adult world, families are suddenly thrown into full time appointment keeper roles, many having to give up their jobs to attend the many appointments with a variety of specialists. There is limited specialist experience of a person with PMLD and quality of life judgements are often made without a full understanding, or valuing, of the life of the person they see before them. Many healthcare practitioners have very little experience or knowledge of the preventative interventions that support this group to live into older age and have been trained to expect a person with PMLD to die prematurely or develop scoliosis which will impact on respiration.
- A recent professional doctorate research (Glover, 2023) highlights that healthcare practitioners do not view family carers as part of the multidisciplinary care team and therefore do not recognise their expertise. They override advice and vital information and make decisions which are not fully informed.
- Many practitioners highlight that they do not feel confident in supporting a person with PMLD in acute and primary care.
- Diagnosing and treatment of mental health issues for children, young people and adults with PMLD remains under resourced, deprioritised and therefore ignored.
- Postural care can prevent body distortion and premature death but is not understood or supported by many healthcare practitioners. The assumption that someone will die of cerebral palsy overrides the decision to treat them and prevent the scoliosis.
- People with PMLD are being denied investigations and treatments because they are deemed too difficult.
- There is frequent diagnostic overshadowing.
- During the COVID 19 pandemic many children, young people and adults were left with no health interventions, particularly the loss of their Allied Health Professionals (AHPs). This impacted on health and wellbeing of the person with PMLD and their families. Many people with PMLD lost skills, their health has deteriorated, and their body shape has been impacted. In addition, mental wellbeing has been impacted and skills that were being developed regressed with many losing abilities altogether. The UK COVID Research into the impact of the pandemic on people with a learning disability and those with PMLD, recommended that AHPs should provide an increased service and interventions to redress these declines. Families report this has not yet happened.

## What PAMIS wants to see

1. A change in the narrative about expectations of living - an expectation that a child with PMLD will become a young person who will become an adult and will be properly supported by planning and delivery of appropriate services and interventions to support them to live healthy and valued lives. This needs to underpin all local and national strategies and be explicit in health and social care workforce education both for the current and future workforce. Data that specifically identifies individuals with PMLD is also required for appropriate planning.
2. Annual health checks must be carried out by practitioners who are skilled in supporting people with PMLD.
3. Any outcomes from a health check are followed by prompt referral and treatment.
4. Creation of a PMLD Index providing data on the complexity and multiple long-term conditions to facilitate a proactive understanding of the reasonable adjustments required to access health care and for better targeting of interventions.
5. Investment in the national postural care strategy – *“Your Posture Matters”* namely training of health and social care staff as well as family carers in 24-hour postural care; provision of appropriate equipment and regular reassessments.
6. An increase in AHP interventions as recommended in the UK COVID Research Scottish policy brief.
7. Family carers to be recognised as experts in the care of their relative and recognised formally as part of the multidisciplinary team.
8. Adoption of the PAMIS educational model where family carers are recognised and supported to deliver training to health and social care practitioner.
9. The PAMIS digital passport to be recognised and resourced.
10. Findings from the death reviews of children and young people with PMLD to be acted upon leading to a greater understanding of cause and prevention of early mortality and appropriate interventions to be developed.
11. A training programme for all healthcare practitioners that enables a greater understanding of the lives and the value of life for people with PMLD. This needs to be an experiential approach and must include family carers and people with PMLD themselves. The model PAMIS has for undergraduate practice placements could be expanded and built upon across all professions. This lends itself to an interprofessional educational opportunity, supporting an understanding of the role of family carers within the team.
12. Consideration of training the next generation of social care and health workforce prior to joining a preregistration course. Introduction of a mandatory entry requirement for health and social care courses to require prospective candidates to have completed volunteering courses as part of their S6 secondary education.

Much of the above could be achieved if centres of PMLD excellence in each acute hospital/HSCP were developed where the specialisms relating to PMLD such as nursing, neurology, gastroenterology, dental, orthopaedics, allied health professionals, GP services and many others could coalesce under the leadership of a named professional. The benefits for the PMLD patient would be the person-centred, anticipatory, holistic care that many organisations aim to provide but so rarely do. The benefits for the professionals would include: the synergies and partnerships resulting from working with and learning from other specialists in the PMLD field; opportunities to share best practice; scope to identify the interrelated and interdependent medical, physical, emotional and behavioural issues relating to the individual with PMLD; training health professionals in PMLD will equip them to deal with wider aspects of patient health care thereby benefitting the wider population; more comprehensive and accessible research opportunities; improved career development; reductions in delayed discharge; the creation of centres of excellence.

## **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) .