

## Learning Disabilities, Autism and Neurodivergence Bill Consultation Briefing

# Section 3: Social Care

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### What is the consultation proposing?

The Scottish Government is proposing three areas for action in relation to social care:

1. The development of national and local learning disability strategies which will say how social care services will meet the needs of neurodivergent people and people with learning disabilities in every area. This will include making sure there are enough staff, that they are well trained and will require an explanation of how they will ensure their services are fully accessible.
2. Introducing a legal requirement for mandatory training of health and social care staff focusing on understanding the support needs of neurodivergent people and people with a learning disability as well as training on inclusive communication.
3. Legislative requirements around inclusive communication and accessibility so that all information for the public includes an easy read version or in a format that best fits the individual's communication needs.

### 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.

- Local authority commissioning services lack knowledge and understanding of how best to support people with PMLD and their families.
- Some care service providers are currently awarded contracts to care for people with PMLD when they do not have an appropriate depth of practical knowledge and understanding of PMLD.
- Lack of support and supervision for care staff delivering services to people with PMLD, as well as a lack of appropriate knowledge, skills and understanding in how to support them.
- Substandard care provision and/or breakdown in provision resulting in admissions to inappropriate care settings such as care homes for the elderly and out of area placements, breaching basic human rights of the person with PMLD.

- Lack of accountability within local authority policies and strategies allowing scope for misinterpretation and subsequently impacting on the quality of services for people with PMLD and their families.
- Significant lack of purposeful and meaningful activities and opportunities for lifelong learning for people with PMLD.
- Lack of appropriate formal training in terms of supporting a person with PMLD for paid care staff. This provides an untenable position and burden on family carers who are frequently left delivering informal training to their loved one's care staff which in turn puts families at risk of litigation should there be any issues with the care provided by the staff.
- A lack of understanding from social workers/social work team and care managers about the complexity of care and interventions required by a person with PMLD. There is also a lack of empathy or understanding about the emotional and physical strain on the family carer of caring 24/7. This frequently leads to ill informed decisions about care packages and SDS budgets awarded. Families have struggled through COVID with a promise that services would resume but are now being judged by the fact that they 'coped', and many current packages are not being adequately resourced. This impacts on the quality of life and the health and wellbeing of both the person with PMLD and their families.
- Lack of appropriate forms of redress when family carers require to lodge formal complaints – current systems far too complex and time consuming for carers to pursue.
- Lack of joined up working across health and social care and family carers certainly not seen as equal partners in care but left to navigate a complex arena of siloed working.
- Lack of recognition about the impact of unpaid caring on poverty.

## **What PAMIS wants to see**

- The involvement of family carers of a person with PMLD and PAMIS in defining the knowledge, skills and values required to work with children, young people, and adults with PMLD. They should then be involved in the co-design and delivery of training as well as playing an essential role in any evaluation.
- The involvement of family carers in ensuring that strategies are enacted and evaluated. We recommend that family carers are involved in the support and supervision of senior health and social care staff. We would recommend the use of the publication "The Ryan Harper Legacy - 'a day in the life of... 'experience influencing allied health professions future practice" as a framework to support this.
- Consideration of training the next generation of social care and health workforce prior to joining a preregistration course, mandatory volunteering courses in sixth form prior to being accepted on a health and social care course.
- Commissioning bodies included in any new workplace training.
- Workplace training to be a mandatory requirement enshrined in law with full accountability.

- Any national and local strategies and policies must be unambiguously worded with no scope for misinterpretation at local level.
- Any workplace training to be co-produced in partnership with people with lived experience and their families as well as organisations who specialise in working with people with PMLD thereby sharing knowledge and expertise.
- Increased investment and value placed on the role of social care staff. PAMIS recommend that a priority should be on reviewing the knowledge, skills and values of the workforce caring for people with PMLD and that their salaries should be enhanced to account for the specialist role. This is urgently required.
- Far greater flexibility and scope for providing communications in a range of formats to make life easier for family carers who often struggle to attend appointments or take spontaneous phone call appointments. Consideration of inclusive and accessible formats for people with PMLD recognising the need for expertise and length of time it takes to ensure they are
- involved and included.
- People with PMLD experience health inequalities which can limit their life expectancy. However, an increase in awareness in the need for quality healthcare combined with appropriate interventions supported by a skilled group of family carers means that there should be an expectation of people transitioning through life. Therefore, social care planning for a person with PMLD requires to consider the full range of services across their life span.
- People with PMLD need to be seen by social care services as individuals with the same rights as the rest of society. People with PMLD are entitled to a full, meaningful life, with access to lifelong learning, stimulating and motivating activities and support from trained specialist, competent staff who can meet their support needs as well as their health needs.

## **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) .