

Why people with profound and multiple learning disabilities (PMLD) and complex health care needs require a different approach when being assessed for support services.

(PAMIS statement re Self-Directed Support (SDS) February 2017)

Profound and Multiple Learning Disability: Definition

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 clinical description also misses the unique contribution they 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 does lead to challenges for them and those who support them. Their prime disability will be profound learning (intellectual) disability. The causes are many and varied. Whatever the cause, and this sometimes goes undiagnosed, their development as children and adults is severely constrained. Many do not have the ability to communicate beyond that of a very young child. However, this can be challenged as they are unable to converse verbally. Family carers are highly attuned to their child's abilities and cite instances where, although perceived as having little cognitive skill, have the ability to bring joy, laughter and love to those who know and care for them. The physical and sensory disabilities that can arise from damaged brain function restricts 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 valuable things 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.

Many 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.

Profound and Multiple Learning Disabilities

All will have a profound learning disability. In addition, they will have one or more of the following:

- Physical disabilities that seriously limit their ability to undertake everyday tasks and usually restrict their mobility, with the majority being lifelong wheelchair users.
- Sensory impairments with vision and/or hearing affected.
- Communication is typically non-verbal, though some will have very limited speech.
- If non-verbal, all have the capacity to communicate in a variety of non-verbal ways.
- Some will also have communicative behaviour which may challenge services.

- The majority will require 1:1 24-hour care and many will require 2:1 care provided.

Healthcare needs are extensive and complex and may be life threatening. Areas of particular challenge relate to:

- Epilepsy - Intractable epilepsy and the administration of emergency/rescue medications
- Respiration
- Cerebral palsy
- Delivery of invasive procedures
- Eating and drinking (dysphagia)
- Invasive procedures including gastrotomy, nasal pharyngeal airway, tracheostomy, baclofen pump.
- Bair hugger systems for temperature control
- Postural care
- Continence
- Sensory impairments including being registered blind and hearing impaired.
- Hoisting for moving and handling transfers
- Special diets

Importantly, and due to the above complex health issues, any consideration of "informal" care must be viewed from a risk management perspective that will still enable people with PMLD safe access to their community. It is also important to recognise that families, caring for a person with PMLD, have real knowledge and understanding of their relative's needs. It is imperative that family carer's knowledge and understanding is fully acknowledged during any SDS assessment and throughout the process of accessing services. It is also important to understand that family carers, as a result of their long- term caring roles, will need well thought through additional support to enable them to continue to care.

What does this mean in regard to the support provided?

People with profound and multiple learning disabilities and complex healthcare needs require high packages of care, which will often require intensive support on a number of levels. Input from education, health, social care and housing is the norm and highlights the complex packages that must be negotiated. This in turn takes extra time and effort which, in itself, can be waring on family carers who are very often already providing high levels of unpaid care. Of course, due to the complexities involved, this also highlights the more intense level of input necessary from statutory and non-statutory support services. Extra effort is necessary to ensure that an appropriate care assessment is completed which will adequately emphasise the real and often complex needs of the person, and his or her family carers.

Importantly, professionals involved in assessing and drawing up the person's Self-Directed Support care plan must have understanding and knowledge of what PMLD actually means on a practical basis. It is also necessary to acknowledge the level of expertise and skill required to be able to provide care that is appropriate and safe. Staff supporting a person with PMLD must often carry out a number of invasive procedures daily. e.g. gastrostomy, tracheostomy, catheter care etc. Therefore, staff involved in caring for people with PMLD must have relevant qualifications, skill and experience to do so safely or have access to appropriate training that will enable them to deliver the care required. Training would also require subsequent sessions for updating of skills when necessary. Remunerations in line with the level of skill required should also be accommodated. Without this level of understanding, of what is realistically essential to deliver a good care package, inappropriate and poorly funded packages of care will continue to be awarded.

Why we need to provide the support necessary?

People with PMLD must be enabled to be truly involved in their community. This will only be realised when access to Self- Directed Support, with regard to the ethos with which SDS was envisioned, is delivered. There must be willingness from all to reflect on the actual level of practical support required that includes risk assessment but with a non-risk averse approach. With good multidisciplinary input, positive partnership working and regard to the value of involving family carer input throughout, this can be realised. We all strive to have meaningful life experiences and relationships with others that feed our emotional and spiritual wellbeing. Having a profound and multiple learning disability does not preclude this most basic need. Providing appropriate, well thought out and well negotiated support, that encourages and promotes family inclusion, will enable family carers to continue to care. Relationships will improve overall, and on many levels, which may result in long-term financial gains in the future.

PAMIS resources

PAMIS is the only organisation in Scotland that provides support for people with PMLD and their family carers. The PAMIS library contains over 1,500 resources on a variety of subjects that are relevant to families, carers and professionals caring for people with profound and multiple learning disabilities, these include books, multi-sensory stories, videos, journals, DVDs, research material and reports. We strive through research to improve the practical experience of people with PMLD and that of their family carers. A number of research projects are now delivered in practice and include work around storytelling and digital communication passports. We campaign tirelessly for fully accessible changing places toilets to enable people with PMLD and others with similar physical disabilities to access toilet facilities within their community. We also deliver training on a number of topics such as digital passports, bereavement and loss and postural care.