

# The PMLD Network

Working together with children and adults with profound and multiple learning disabilities (PMLD)

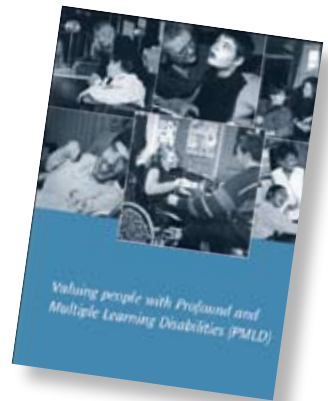


# What is the PMLD Network?

We are a group of people committed to improving the lives of people with PMLD by:

- bringing people with PMLD and their families, carers and advocates together with statutory and voluntary agencies
- sharing good practice and campaigning
- providing information and support.

We formed in 2001 to respond to a government white paper called *Valuing People: A new strategy for learning disability for the 21st Century*. In 2002 we produced the report, *Valuing People with profound and multiple learning disabilities*.



We continue to strive towards inclusion so that **all means all**.

**We want to make sure people with PMLD are fully included in society.**

## **People with profound and multiple learning disabilities:**

- have more than one disability
- have a profound learning disability
- have great difficulty communicating
- need high levels of support with most aspects of daily life
- may have additional sensory or physical disabilities, complex health needs or mental health difficulties
- may have behaviours that challenge us.

# A right to be included

People with PMLD are often excluded by society. But they have the same rights as everyone else.

⌚ **Day centres have closed and so staffing problems, in terms of individual support as an alternative, have a huge impact on whether a client can go out or not. Staff training is often not sufficient to support people with PMLD which closes down their options to go out.** ⌚

*Care manager/social worker*

- We must make sure people with PMLD are valued for who they are.
- We must make sure that people with PMLD are at the centre of every government initiative.
- We must break down barriers to accessing the community.



Winnie's friends from her circle of support take her out to new places they think she might enjoy. Winnie enjoys this but barriers like no Changing Places toilets and not enough support make it very hard.

# A right to be heard

Most people don't understand what it's like to be someone with profound and multiple learning disabilities.

**❗ I don't think the needs, wishes and ambitions of people with multiple disabilities have been considered adequately in the planning of services. Our local partnership board have never discussed the needs of this group of people. ❗**

*Director of a service for adults with a learning disability*

- We must campaign for change so that everyone with PMLD can take their rightful place in society.
- We must listen to family carers and help them get the support they need.
- We must increase advocacy provision for people with PMLD.



Mencap's Getting to know you project encourages self advocates with a learning disability to speak up for their peers who do not use formal language. Leroy and Kunal are peer advocacy partners and enjoy each other's company.

# A right to be considered

Government initiatives like *Valuing People* have the potential to transform the lives of people with PMLD. But there is not enough money in the system to make them work.

**❗ If we don't know about the population of children with PMLD, how can we possibly plan for their future and get it right? We urgently need to address the needs of children and adults with PMLD. ❗**

*Health professional*

- We must make sure there is enough money available to support government initiatives.
- We must research and record the numbers of people with PMLD in the UK.
- We must establish how the needs of people with PMLD are changing.



Jessie (left) faces an uncertain transition to adulthood unless children like her are valued for who they are and their future needs as adults are planned for.

# A right to be understood

People with PMLD sometimes find it difficult to communicate how they feel, partly because the people who support them often don't have the right skills.

🕒 **Communication training is available but not resourced or prioritised to be as effective as it might.** 🕒

*Health professional*

- We must challenge the negative assumptions about people with PMLD in society.
- We must help people to better understand people with PMLD.
- We must make sure that any person working with people with PMLD gets the training they need to support them in every way.



Frances has an advocate who spends time with her and then advocates for what she has learned is important to Frances.

Frances and her advocate use multimedia to share what is important to her with others.

# A right to appropriate healthcare

People with PMLD often have a higher level of associated health care needs and require good and appropriate support from the NHS.

🗣️ **People only get regular health checks and health action plans at the insistence of care home staff.** 🗣️  
*Service manager*



- We must campaign for regular health checks with the person's GP and wider primary healthcare teams as well as health action plans for all.
- We must campaign for better NHS provision in areas such as postural care, dysphagia and so on.
- We must make sure that the needs of people with complex health needs are represented within NHS commissioning.
- We must campaign for better experiences in acute hospital settings for people with complex health needs.

Rebecca has osteoporosis so her health needs can sometimes feel overwhelming. Her health action plan is vital in identifying what kind of support she needs.

The plan was developed by her parents. They have also written a summary version that Rebecca carries with her. She can use this if she has to stay in hospital to help hospital staff care for her properly.

# Join the PMLD Network



*“If we are going to make a difference we need to work together. That means partnerships with families, self advocates, statutory and voluntary organisations. Together we can campaign for change and help to form a truly inclusive society where everyone is valued equally.”*

The PMLD Network is a group of people committed to improving the lives of children and adults with PMLD. We run an email forum where current issues are debated and where individuals can post details of the barriers they are facing and get advice and support.

For more information or to find out how you can join the network, go to **[www.PMLDnetwork.org](http://www.PMLDnetwork.org)**