

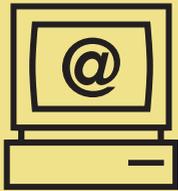
Join the PMLD Network



“If we are going to make a difference we need to work together. That means working with families of people with PMLD, their advocates and other organisations. Together we can make sure people with PMLD are included in society.”



The PMLD Network is a group of people working together to make the lives of children and adults with PMLD better.



We run an email forum where people can talk about the things that are important to people with PMLD and the problems that they face. The forum means that people can get advice and support from each other.



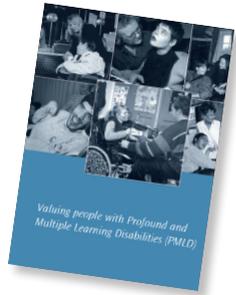
For more information or to find out how you can join the network, go to www.PMLDnetwork.org

The PMLD Network



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





What is the PMLD Network?

The PMLD Network is a group of people working together to make the lives of children and adults with PMLD better.



We want people with PMLD to have the same rights as everyone else – this means making sure they have the same choices and chances to do what they want as everyone else.

What is PMLD?

People with profound and multiple learning disabilities (PMLD) have more than 1 disability. They need a lot of support and find it very difficult to communicate.

Their main disability is a profound learning disability. This means that their learning disability is quite serious.

They may have physical disabilities or problems with hearing and seeing too. They may also have other health problems or mental health problems.



A right to be included



People with PMLD have the right to join in and do things with the people who live around them in their home town, city or country.



Winnie's friends take her to new places they think she might like. She enjoys this but there are things that make it difficult for her like no suitable toilets or transport.



- We must make sure the government thinks about people with PMLD in all its work.



- We must make sure people with PMLD have everything they need to join in.

A right to be heard



Most people do not understand what it is like to be someone with PMLD.



Mencap's *Getting to Know You* project trains people with a learning disability to be peer advocates for people with PMLD. A peer advocate is someone with a learning disability who speaks up for the rights of other people with a learning disability.

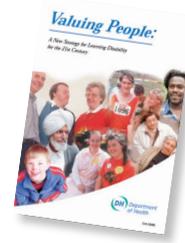


- We must listen to the views and choices of people with PMLD, their families and advocates.



- We must make sure there are more advocates for people with PMLD.

A right to be considered



The government's *Valuing People* report could change the lives of people with PMLD. But the government needs to understand the needs of people with PMLD better.



Life will be very hard for Jessie, (left) as she grows up and becomes an adult unless we plan for her needs as she gets older.



- We must make sure the government works harder to find out the things people with PMLD want and need.



- And we must make sure there is enough money to pay for the things people with PMLD want and need.

A right to be understood



People with PMLD communicate how they feel in different ways – they use speech, change their face or move their body, or they might make a noise or use symbols or signs. But people who support them do not have the right training to support them to communicate better.



Frances has an advocate who spends time with her and then tells other people what she has learned is important to Frances. Frances and her advocate use things like films or photographs to share what is important to her with others.



- We must help people to understand people with PMLD better.
- We must make sure that supporters working with people with PMLD get good training.

A right to the healthcare they need



People with PMLD often have lots of health needs. We want the NHS to provide good healthcare to meet all their needs.



Rebecca has a health action plan to help her tell other people what support she needs – for example hospital staff who care for her.



- We want people with PMLD to be able to see their doctor regularly and get special help when they need it.



- We want all people with PMLD to be given health action plans.