

Family Carers Guide – October 2018

Profound and Multiple Learning Disability (PMLD)



When using the term ‘profound and multiple learning disability’ we are thinking of those individuals who have a severe learning disability and other significant difficulties, such as physical disabilities, sensory impairment or other medical conditions.



National Conference

Family carers, health and social care professionals, academics, education and social care providers came together in November 2017 for the first national conference ‘Raising the Bar’ with an exclusive focus on profound and multiple learning disability.



It saw the launch of Core and Essential Service Standards for supporting people with profound and multiple learning disability, setting aspirational benchmarks for best practice care. For more information go to: <https://www.choicesupport.org.uk/news/raising-the-bar-national-pml-d-conference>



Raising the Bar II will be taking place on the 2nd of November 2018. If you are interested in finding out more or booking a place go to: <https://www.eventbrite.co.uk/e/raising-the-bar-ii-national-pml-d-conference-tickets-44284684684>



Raising Our Sights - Mencap

Mencap and the PMLD Network have produced a range of how-to guides and films aimed at families, commissioners and anyone responsible for developing services for people with profound and multiple learning disability.

These focus on the recommendations made by Jim Mansell in his report in 2010 Raising Our Sights. For more information go to

www.mencap.org.uk/advice-and-support/pmld/raising-our-sights-guides



Assistive Technology

Developments in technology are increasingly being used to enhance an individual's skills and maximise their independence.

Examples of this can be seen with the use of wiki's in personalised planning. See:

<http://rixresearchandmedia.org/>

HfT have a dedicated Personalised Technology Team working to introduce such initiatives into people's care and support. See:

<https://www.hft.org.uk/our-services/personalised-technology/>

How assistive technology can support is of course individual to each person. As family carers you know your loved one best and can best gauge their response and engagement with technology. Knowledge of what is available will however be helpful in considering what might be possible. For more information go to: <http://www.inclusive.co.uk/>



PMLD Network

This is an online meeting place for those committed to improving the lives of people with profound and multiple learning disability. Members include parents, friends, relatives, people working in the field, national and local policy makers, service providers and commissioners.

For more information go to:

<https://our.choiceforum.org/c/pmlidnetwork>



Intensive Interaction

A technique where meaningful interactions can be created by making ourselves interesting and engaging by joining the individual with profound and multiple learning disability in their world and adopting a behaviour style they can understand and respond to. For more information go to:

www.intensiveinteraction.org



PMLD Link - journal

The only journal dedicated to people with profound and multiple learning disability and their families. To find out more go to:

www.pmlidlink.org.uk/



PAMIS (Promoting a more Inclusive Society)

PAMIS is the only organisation in Scotland that works solely with people with profound and multiple learning disability and their families for a better life. To find out more about what they do and the resources they have go to:

www.pamis.org.uk



Mental Capacity Act

The Mental Capacity Act is key legislation ensuring an individual's rights, liberty and involvement in decision making are protected. The Act is currently being reviewed and its progress through parliament can be monitored here: <https://services.parliament.uk/bills/2017-19/mentalcapacityamendment.html>