

# Profound and Multiple Learning Disability (PMLD) Practice Guidance

## Using this guidance

This guidance has been written by tri.x from using material from a range of sources. It's aimed to support practitioners to gain an understanding of those with PMLD and think about some of the ways that they can improve or adapt their practice as necessary. This could include how best to maximise the involvement of a person with PMLD in care and support processes.

It should be used as supplementary guidance to available procedures, and all statutory requirements of the Care Act 2014 apply.

## What does the PMLD term mean?

A profound and multiple learning disability (PMLD) as defined by the NHS is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent.

The PMLD LINK charity describes people with PMLD as having profound intellectual and multiple disabilities, very severe communication problems, often extreme physical and/or sensory disabilities, and complex health needs

In ascertaining the degree of a person's Learning Disability, establishing the person's IQ level is a tool that can be used. However, the National Institute for Health and Care Excellence (NICE) cautions against its usage stating that in practice IQ scores are often uncertain in people with more severe learning disabilities. It is also widely recognised that IQ scores are not fixed throughout life, so provide only an approximate guide to intellectual ability. Accordingly, many health and social care professionals object to subdividing learning disabilities because such subdivisions create labels that are then used to describe people, often inaccurately.

People with a profound and multiple learning disability need support to help them with some areas of their life, such as eating, washing or personal care.

Lots of people with a profound and multiple learning disability can still be involved in decisions about themselves, do things they enjoy and be independent.

The Mencap Charity for people with Learning Disabilities adds that children and adults with profound and multiple learning disabilities have more than one disability, the most significant of which is a profound learning disability. All people who have profound and multiple learning disabilities will have great difficulty communicating. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties. The combination of these needs and/or the lack of the right support may also affect behaviors. Some other people, such as those with autism and Down's syndrome may also have profound and multiple learning disabilities.

Other disabilities could include but is not limited to:

- a) Physical e.g. Cerebral palsy or because of an injury;
- b) Complex health needs;

- c) A sensory or dual sensory impairment;
- d) Behaviours that may pose a risk towards themselves or others;
- e) Mental Health e.g. depression, eating disorders and schizophrenia.

People with multiple learning and physical disabilities are often reliant on others to help manage any associated symptoms or risk to their health and wellbeing.

**Note:** To help manage their health needs, every adult with a learning disability should be invited to a free annual health check from their GP.

## Mental Capacity

The Mental Capacity Act 2005 and its Code of Practice provides a comprehensive legal framework for acting and making decisions on behalf of people who lack the mental capacity to make their own decisions.

Under the principles of the Mental Capacity Act, a person must be assumed to have capacity unless it is established that they lack capacity. Additionally, a person is not to be treated as unable to make a decision unless all practical steps to help them to do so have been taken.

## Maximising the involvement of people with Profound and Multiple Learning Disabilities in their Care and Support Processes.

The involvement of a person with PMLD in care and support processes should *always* be maximised, even if they have been assessed as lacking capacity to make any decisions that may be required.

This section of the practice guide explores some of the steps that practitioners can take to maximise this involvement, and is divided into two sections;

- a) Communication;
- b) Other practicable steps to maximise involvement.

## Communication

People with PMLD are likely to find it difficult to understand what is being communicated to them and respond in a way that has meaning to others.

The person's communication style is likely to be unique, so it is helpful to consult and seek the assistance of others who know the person to help.

To help ensure that communication is as effective as possible practitioners should consider taking the steps set out in the following table.

Step	Further information
<b>Use the communication passport</b>	<p>Most people with PMLD will have a communication passport. This is a document developed by a Speech and Language Therapist (SALT) following a full communication assessment. It sets out the person's preferred communication style, explains the best way to provide information to them, the support they may need to understand it and how to maximise their ability to respond in a meaningful way.</p> <p>If there is no communication passport available consider;</p> <ul style="list-style-type: none"> <li>• Making a referral to a Speech and Language Therapist; and</li> <li>• Whether it is possible to delay the care and support process until the passport is in place.</li> </ul>
<b>Consult others and use existing information</b>	<p>Consult with those people who already know the person with PMLD well, as they are a rich source of information.</p> <p>This could include;</p> <ul style="list-style-type: none"> <li>• Carers, family members and friends</li> <li>• Service providers</li> <li>• Other professionals (e.g. teachers, SALT)</li> </ul>

	Make effective use of other existing information regarding communication, for example in a care plan or previous assessment report.
<b>Build rapport</b>	<p>If possible, arrange to spend time with the person before the care and support process begins, to;</p> <ul style="list-style-type: none"> <li>• Build rapport;</li> <li>• Observe how they communicate with others;</li> <li>• Observe how others communicate with them.</li> </ul>
<b>Provide the right support</b>	<p>Directly involve those people who;</p> <ul style="list-style-type: none"> <li>• The person would likely want to be involved;</li> <li>• Are familiar with their communication;</li> <li>• Are best placed to interpret the meaning behind their expressive communication; and</li> <li>• Are likely to help the person feel at ease.</li> </ul> <p>This could include;</p> <ul style="list-style-type: none"> <li>• Carers, family members and friends</li> <li>• Service providers (in particular care workers)</li> <li>• An advocate</li> <li>• Other professionals (e.g. teachers, SALT)</li> </ul> <p>A person with PMLD will always meet the threshold of substantial difficulty defined in the Care Act 2014. As such, ensure that an independent advocate is provided where there is no other appropriate person to act.</p> <p>If independent advocacy is to be provided, wherever possible delay care and support processes so that the advocate can;</p> <ul style="list-style-type: none"> <li>• Build a rapport with the person;</li> <li>• Develop an understanding of their communication;</li> <li>• Prepare them for the care and support process.</li> </ul>

<p><b>Be prepared to take a back seat</b></p>	<p>People with PMLD may not be responsive to someone they do not know, regardless of the steps that person has taken to understand and adapt to their communication needs.</p> <p>Be prepared to take a back seat and allow someone else to be the primary communicator if this is the best way to maximise the person's involvement.</p>
<p><b>Consider observation as communication</b></p>	<p>If it is clear that the person is not going to be receptive to direct interaction and communication, explore whether it would be appropriate to spend some time observing them to allow them to communicate indirectly the things they find enjoyable or challenging.</p>
<p><b>Use the person's preferred communication style</b></p>	<p>Be open to using whatever communication style will work for the person, and don't worry if this seems somewhat unorthodox at times.</p> <p>For example;</p> <ul style="list-style-type: none"> <li>• Sign language or Makaton</li> <li>• Using pictures</li> <li>• Making drawings</li> <li>• Music, song and rhyme</li> <li>• Using objects of reference</li> <li>• Using an iPad or other technology</li> <li>• Unusual terminology</li> <li>• Game playing</li> <li>• Storytelling</li> </ul> <p>As long as the communication is evidence based and relevant to the person it is appropriate to use.</p>

## Other practicable steps to maximise involvement

The following table sets out some of the other steps that it may be practicable for practitioners to take to maximise the involvement of a person with PMLD.

Step	Further information
<b>Make sure the person is well</b>	On the day of any planned meeting make sure that the person is well enough to take part, especially if they have a complex or variable health condition. Reschedule where necessary.
<b>Break the ice</b>	Spend some time talking about the person's specific interests. This can be reassuring and calming, and it can also help build rapport and support the person to move on to engage in communicating their views about other things.
<b>Limit disruption to normal routines</b>	<p>Try to plan any meetings outside of times when key routines normally take place, for example;</p> <ul style="list-style-type: none"> <li>• Taking medication</li> <li>• Using the toilet</li> <li>• Eating or drinking</li> <li>• A regular social event</li> </ul> <p>If this cannot be avoided schedule a planned break to allow a person to carry out the task/activity.</p> <p>The person may be reliant on their routines to provide stability to their day, without which they could become overwhelmed or anxious.</p>
<b>Create the optimum environment</b>	Feeling at ease facilitates involvement. Take steps to ensure that any meeting takes place;

	<ul style="list-style-type: none"> <li>• In a place where the person is most likely to feel at ease; and</li> <li>• In the presence of people in whose company they feel at ease.</li> </ul> <p>Also find out what is likely to be distracting, or cause anxiety or distress and take steps to avoid these things.</p>
<b>Regular breaks</b>	<p>Offer regular opportunities for the person to take a break, particularly if;</p> <ul style="list-style-type: none"> <li>• Any meeting is lasting longer than anticipated;</li> <li>• The person is known to experience fatigue; or</li> <li>• The person appears overwhelmed, anxious, bored, hungry etc.</li> </ul>
<b>Manage duration</b>	<p>Find out how long the person is likely to engage in any meeting situation for, and do not make plans to exceed this. This may mean holding more than one meeting over a longer period of time.</p>
<b>Privacy and dignity</b>	<p>Ensure that the person's right to privacy is respected at all times, especially if meetings are to take place in a setting that is communal (e.g. a day service, hospital or residential home).</p>

## Joint Work and Health Funding

### Joint work

Due to the complexity of their needs a person with PMLD is likely to be receiving support from a number of professionals or agencies, which could include:

- Community nurse (including Community Psychiatric Nurse (CPN) or specialist learning disability nurse);
- Clinical Psychology;
- Consultant Psychiatry;



- d) Physiotherapist;
- e) Speech and Language Therapist (SALT);
- f) Dietician;
- g) Occupational Therapy.

It is important that practitioners;

Establish which professionals and agencies are involved (or need to be involved); and

Consult with them appropriately (and in line with confidentiality); and

Co-operate with any requests to work jointly with others.

This will avoid the need for unnecessary duplication of information for the person (and their carers) and ensure a holistic approach and effective and appropriate response to meeting their needs.

## Health funding

Depending on the overall complexity of their needs people with PMLD are often eligible for;

- a) NHS Continuing Healthcare funding; or
- b) Joint funding between health and social care.

Eligibility should be considered at each care and support process, particularly if the person's needs increase or become more complex to manage.

If a person with PMLD is eligible for joint funding a social care practitioner *and* a health professional **must** work together to arrange and review services.

Many carers of people with PMLD will have been providing substantial support since birth, and the cumulative and continuous effects of caring for a person with such complex needs should not be underestimated.

Every carer of a person with PMLD is likely to need support at some point over the course of their caring role. This may be practical support, emotional support or both.

The risk to the wellbeing of carers is increased when;

- a) The person lives with the carer;
- b) The carer has limited informal networks of support;
- c) The person has complex health needs;
- d) The person's behaviour can be challenging;
- e) The person's needs are unpredictable;
- f) The person requires constant supervision;
- g) The person requires support overnight;
- h) Any formal services in place are not working well.

All carers should be offered a carers assessment in line with the statutory requirements of the Care Act.

Practitioners should also take the time to provide emotional support to a carer, regardless of them having had a carer's assessment and to provide them with advice, information and signposting as required.

Often care and support methods used to manage risk to (or from) a person with PMLD are restrictive. For example:

- a) Regular or PRN (when required) medication;
- b) Restraint;
- c) Physical intervention.

Practitioners should work proactively with service providers and health professionals to ensure that:

- a) Methods of providing support are the least restrictive; and
- b) All deprivations of liberty are authorised.

Examples of steps that can be taken to explore the least restrictive methods of providing care and support could include;

- a) Requesting that Psychology explore the least restrictive ways of managing behaviour;
- b) Requesting a medication review;
- c) Using assistive technology and Telecare to reduce the need for physical monitoring;
- d) Reviewing equipment to see if manual handling ratios can be reduced.

Where concerns about the legality or appropriateness of a deprivation of liberty exist, practitioners should follow local processes to raise a concern and/or instigate a safeguarding enquiry.

### Further Reading

[NHS Overview Learning disabilities](#)

[Mencap What is a learning disability?](#)

[British Institute of Learning Disabilities](#)

[Foundation for People with Learning Disabilities](#)

[Government publications: Inclusive language](#)

[PMLD](#)

[National Institute for Health and Care Excellence](#)

[Physical disability network \(pdnet\)](#)