

The Raising Our Sights How-to Guides

The Raising Our Sights How-to guides were developed with funding from the Department of Health, to help local areas implement the Raising our sights recommendations. They are aimed at families and supporters of people with PMLD as well as commissioners and providers of services. There are 10 How-to guides covering different topics and showing how to: recognise good services and support for people with PMLD; challenge and campaign where people with PMLD are not getting the right support; and ensure that necessary changes happen, with clear messages for commissioners and providers of services. There is an additional Guide targeted at commissioners of local services

In addition, there are six Raising Our Sights videos which accompany some of the guides and highlight the impact that the right support can have on the lives of people with PMLD and their families.

The how-to guides and videos can be accessed via the Mencap website. Go to: <https://www.mencap.org.uk/advice-and-support/profound-and-multiple-learning-disabilities-pmld/raising-our-sights-guides>. The guides are also available on the resources area of the PMLD Link website.

The following text briefly describes each of the guides and picks out some of the key messages contained within each.

How-to guide 1: advocacy



This guide aims to help people understand the skills advocates need. Advocacy for people with PMLD is likely to take much longer than for people who are able to use formal communication.

Some of the key messages:

- Commissioners must regularly review the advocacy needs of people with PMLD in their area to ensure they commission appropriate services.
- Service providers must ensure their staff understand the Mental Capacity Act and show how they may involve people with PMLD in decision-making and service planning in a meaningful way.
- Staff and families need to know what advocacy support is available locally, and when and how to refer people with PMLD for support. They need to understand the role of an independent advocate and be open to involving an independent person who might bring a different perspective to a decision or difficult situation.

How-to guide 2: clinical procedures



Many adults with PMLD who also have complex health needs are being denied access to opportunities and services because service providers do not know how to support their health needs while they are attending the service.

Some of the key messages

- People with PMLD should receive support for their complex health needs to ensure they are included in both specialist and universal services in a way that is safe and respects their dignity.
- Commissioners and support brokers must plan and commission services that support and sustain the health of people with PMLD who require clinical procedures, while ensuring they can enjoy activities and services in the same way as other disabled people.
- Service providers should ensure the safe inclusion of adults with PMLD who also have complex health needs by training and supporting their own staff to carry out clinical procedures.

This guide recommends a process for assessing and meeting needs which was developed in children's disability services. The description covers ten areas including: joint working arrangements and local policies and procedures; developing a partnership with the person; issues of consent; health needs plans; training and support of staff; etc.

How-to guide 3: communication



Meeting the communication needs of a person with PMLD is highly individual. Each person is unique and what works for one person may not work for another. This communication guide focuses on what 'good' looks like and what needs to be in place to meet the communication needs of people with PMLD. There are many examples of things to do at both national and local levels to ensure the communication needs of people with PMLD are met.

Some of the key messages

- It is important to develop understanding of the particular needs of people with PMLD in the area of communication and assistive technology.
- People with PMLD need communication partners who value all communication, whether intentional or not, who take the time to really listen and respond and who are willing to nurture relationships.
- People with PMLD and their families should be involved in a meaningful way in decision-making about their own lives, and around planning wider services. This will require the use of creative ways to 'hear the voice' of people with PMLD.
- There should be a coordinated total communication approach across all local services, making sure that there are high expectations and aspirations for people with PMLD.

- Commissioners and service providers must develop a well-trained workforce, with skills in appropriate communication methods and technologies with people with PMLD.
- Commissioning decisions must acknowledge and reflect the time and skills required by staff employed to work with people with PMLD
- Families and supporters must have access to specialist support such as speech and language therapy.
- There should be a realistic budget for equipment purchase and maintenance and a clear agreement and policy about funding of communication aids and assistive technology in the local area.

How-to guide 4: health



Governments have committed to improving health and wellbeing through providing health and social care to all who need it. However, local areas are mostly responsible for making this happen, and people with PMLD are extremely vulnerable to cuts in spending and services. This health guide will help commissioners in local areas understand and meet the health needs of people with PMLD.

Some of the key messages

- People with PMLD need better access to mainstream healthcare and high quality specialist healthcare.
- Health professionals should never make assumptions about the person's health or the quality of their life.
- People with PMLD must be meaningfully involved in decision-making about their own health, and around planning health services, and their family should be treated as experts.

- Health services must be: individualised and person centred; focus on quality of life; focus on quality of staff relationships with the disabled person and their families; sustain the package of care; be cost effective; be forward thinking.
- There must be recognition that health assessment and identifying health changes for a person with PMLD is likely to take much longer than for people who are able to use formal communication.
- Complex communication and recognition of pain and distress must be core skills in those working with people with PMLD.
- Every person with PMLD should have an annual health check with their GP.
- Hospitals should employ learning disability liaison nurses, or equivalent, to support people with a learning disability to access hospital services and people with more complex or multiple health needs should have a named healthcare coordinator.

How-to guide 5: housing



Commissioners, social care services and housing providers should consider the housing and support needs of people with PMLD when they plan and commission different types of housing. This housing guide aims to address aspects of regulation and policy which are currently acting as barriers to people with PMLD accessing suitable housing.

Some of the key messages

- Existing housing may be difficult to adapt so the option of new-build properties that meet the needs of people with PMLD should be considered.
- Commissioners must find out the numbers and housing needs of people with PMLD in the local area and plan ahead for when they will need alternative housing and care.

- The housing and local planning departments need to ensure that staff understand the needs of people with PMLD and there is recognition that the funding levels required are likely to be high.
- It is important to plan and deliver housing and care locally since family, friends and communities are important and give richness and meaning to people's lives.
- Local authorities must break the cycle of crisis-led and out-of-area placements.
- As well as standard wheelchair accessible design, commissioners and architects of new housing and adaptations of existing housing should include assistive technology and smart home technology and plenty of space for other equipment in their designs.

How to Guide 6: Personalisation



The aim of personalisation is to enable people to be more in control of the services or packages of support they receive. Every person who receives support, whether funded through Social Services or by themselves, should have choice and control over the shape and direction of that support to promote independence, opportunity and inclusion.

Some of the key messages

- Everybody should understand the potential of meaningful personalisation to transform and improve the lives of people with PMLD.
- Commissioners need to take a longer-term view regarding the cost-effectiveness of individualised packages of support.
- It is counter-productive to 'slot' people with PMLD into services that are not designed to truly meet their needs.
- People must be trained to use the 'tools' of person-centred planning properly.
- The cost of the support and services needed to meet eligible needs should be outlined in a personal budget which is sufficient.

How to Guide 7: Support for Families



This guide provides reminders about the importance of information and short breaks, understanding and meeting the needs of families of people with PMLD. It focuses on what good support for families looks like.

Some of the key messages

- Families have a key role to play in the lives of people with PMLD. Involving the family, as experts in the development and delivery of support, not only results in services that better meet the needs of the person, but also results in cost-effective services in the longer term.
 - Families have significant support needs to enable them to continue their caring role. They deal with a wide range of services and agencies, and require agencies to work together to reduce the pressure on them as carers.
- No family supporting an adult with PMLD at home should be denied regular breaks.
- Traditional respite services do not work for everyone and there needs to be a greater investment in more flexible and individual person-centred forms of support.

How to Guide 8: training the workforce



This guide focuses on the development of a workforce that is ready and able to deliver personalised services and support for people with PMLD and their families. This should include a greater involvement of people with PMLD and family carers in workforce planning, development and training’.

Some of the key messages

- Commissioners need to know the wide range of individuals who are involved in the care and support of people with PMLD. This workforce includes a growing number of personal assistants (PAs) required to support individuals with PMLD and their families.
- The families and carers of people with PMLD, who are managing personal budgets, will also require support and training.
- There must be planning to meet the (workforce) costs, in terms of time, training requirements and expertise needed to provide high-quality services.
- The workforce needs to be able to provide appropriate support and services to all people with PMLD and their families, including those from black and minority ethnic communities.
- People with PMLD and their families should be involved in shaping the workforce.
- It is essential to establish a culture, supported and implemented by the workforce strategy, that recognises and promotes working with people with PMLD as an attractive and valued role.

How to Guide 9: what people do during the day



The scope of this guide is far wider than just the 9am to 4pm timetable of a day centre. People with PMLD should be able to access a wide range of regular activities, opportunities and experiences during the day, at evenings and weekends, to ensure they lead both full and fulfilling lives.

Some of the key messages

- Families, commissioners and supporters must challenge the situation where too many people with PMLD are living restricted lives, confined to their homes or being taken out to the same places over and over again.
- Knowledge about how to enable people with PMLD to live meaningful lives should be embedded in the work of supporters and PA's so that all activities or resources are understood to have the potential to be a fulfilling one.
- Families need more support and information to ensure people can access regular and meaningful activities in their area.
- Truly personalised services and good person-centred planning will help identify activities a person might enjoy and the support they need to do them. Individual budgets and direct payments can enable people with PMLD to access a wider range of activities with more flexible support.
- Planners and commissioners need to understand the importance of accessible community buildings and Changing Places toilets in enabling people with PMLD to get out and about for longer periods of time and access community activities.
- People with PMLD and their families should be involved in consultations or planning decisions about changes to services or the building of new specialist or community facilities.

How-to Guide 10: wheelchairs



This guide focuses on what a good wheelchair service looks like and what needs to be in place to ensure people with PMLD have suitable wheelchairs. For people with PMLD, the fundamental truth is that a wheelchair that fully meets their needs is based on a good clinical prescription.

Some of the key messages

- A good clinical prescription (for a wheelchair) is necessary
- Access to highly specialised wheelchair services is required. For people who need complex seating solutions these services should include: training in 24-hour postural management for families and support staff; and complete multidisciplinary teams in wheelchair assessment, provision and maintenance who work closely together.
- Services must recognise everyone's skill and potential and respect the small but significant ways in which people with PMLD are able to: make choices; take part in the world; achieve new learning and skills; and be independent – despite the need for someone to accompany them.
- There should be respect for human rights when delivering services. Good seating saves lives, optimises health, promotes dignity and respect, helps people mix with others and gives people access to opportunities for social and personal development.
- Services should be actively person-centred and take a holistic approach. Each service should work around the needs of the individual, rather than expecting the person to 'slot in' to the service.
- Commissioners should make sure wheelchair services for adults are sufficiently funded to meet the needs of people with complex seating needs.

How to Guide 11: Commissioning



The Raising Our Sights Commissioning Guide is aimed at Commissioners and other people responsible for planning and commissioning health and social care services at the local level. It is also useful for organisations that provide health or social care services for people with PMLD, to deliver services that people with PMLD want and benefit from, and to demonstrate this to commissioners and funders. The guide can be used by others, including family carers, user-led organisations and Partnership Boards to help evaluate their local services and make recommendations for change.

Some of the key messages

The guide includes a number of practical tools to help develop high quality services including:

- A PMLD screening tool to help identify people with PMLD in Section 6
- A commissioning checklist in Section 12 containing suggested actions that relate to local commissioning
- A checklist for service providers in Section 13
- Checklists for commissioners which are drawn from the individual guides and go into more detail about what local commissioners need to do.