



# How-to guide 11

## commissioning

For people with profound and multiple learning disabilities

**Raising**  
our Sights



# Commissioning services for people with PMLD

In 2009, Valuing People Now updated the government's plans for all people with a learning disability, but those with profound and, multiple learning disabilities (PMLD) seemed to be missing out. Professor Jim Mansell's recommendations in *Raising our Sights*, aim to make sure people with PMLD and their families have the same opportunities as others to have more choice and control over their services, support and lives.<sup>1</sup>

This is one of 11 guides aimed to help local areas implement the *Raising our Sights* recommendations. All the guides focus on what 'good' looks like and what needs to be in place in order to meet the needs of people with PMLD and their families.

Ten of the guides focus on specific topics, such as advocacy and housing (see later for a full list). Each of these guides has a section in them which explains how families or local campaigners can challenge or campaign if people with PMLD are not able to access the support and services they need.

This guide is aimed at commissioners and other people responsible for planning and commissioning health and social care services at a local level. It will also be useful for organisations that provide health or social care services for people with PMLD, to help them deliver services that people want and will benefit from. The guide will also help these organisations demonstrate to commissioners and funders why such support and services are needed. The guide can be used by others, including family carers, user-led organisations and partnership boards to help evaluate local services and make recommendations for change.

## About this guide

This guide focuses on ways to evaluate what services are needed locally and to ensure these services are good quality.

- Section 6 includes a **PMLD screening tool**.
- The **commissioning checklist** in Section 12 contains suggested actions from this guide, based on the recommendations from *Raising our Sights* that relate to local commissioning.
- Section 13 has a **checklist for service providers**.
- There is a **topic checklist for commissioners** from each of the other how-to guides in section 14.

You can read an introduction to the how-to guides, find out more about *Raising our Sights* and download all the guides at:

[www.mencap.org.uk/raisingoursights](http://www.mencap.org.uk/raisingoursights)

<sup>1</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_114346](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346)

## What do we mean by PMLD?

- Children and adults with PMLD have more than one disability, the most significant of which is a profound learning disability.
- All people with PMLD 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 behaviour. See full PMLD Network definition at <http://www.pmldnetwork.org/>

## Sections in this guide

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  - Training the workforce
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  - Wheelchairs

15. References and further reading

# 1. What Raising our Sights says about local commissioning

The following recommendations in *Raising our Sights* were aimed at local areas. The recommendations that were aimed at a national level, including government, are not included here.

**There are 18 recommendations aimed at local areas:**

## **Recommendation 1.**

Commissioners of health and social care services should identify mechanisms for supporting and enabling families to get advice and help in securing and running self-directed services from user-led organisations, or self-help groups of other families.

## **Recommendation 3.**

Local health and social care commissioners should assign the development of independent advocacy arrangements that are suitable to represent the interests of adults with PMLD.

## **Recommendation 5.**

Local authority social care services, together with their education and health partners, should keep up-to-date information about the number, needs and circumstances of people with PMLD in their area. This information should contain current information and future projections to enable effective planning of services.

## **Recommendation 6.**

In fulfilling their responsibilities for developing and training, the social care workforce and local authorities should ensure that sufficient numbers of personal assistants are available. They should be trained in person-centred approaches in communication and support, which meet the needs of adults with PMLD.

## **Recommendation 11.**

NHS bodies should pay particular attention to meeting the needs of adults with PMLD by implementing the government's response to the Michael Report, the report of the local government and the parliamentary and health service ombudsmen.

## **Recommendation 12.**

NHS bodies should ensure they provide health services to adults with PMLD in each area, which focuses on protection of body shape, dysphagia, epilepsy and investigation and resolution of pain and distress.

## **Recommendation 13.**

The board of each NHS trust should consider a report specifically focused on the adequacy of health services for adults with PMLD and approve an action plan to ensure adequate treatment.

### **Recommendation 15.**

Powered wheelchairs should be provided where carers (whether family members, paid staff or others) need them in order to move the disabled person.

### **Recommendation 16.**

People with PMLD who have used powered wheelchairs (e.g. 'smart' wheelchairs) at home or at school during childhood should have the option of continuing to have them provided in adult life, where this sustains or enhances their quality of life.

### **Recommendation 17.**

Other people with PMLD should be provided with powered wheelchairs, suitably adapted with 'smart' technology, where this sustains or enhances their quality of life.

### **Recommendation 25.**

Local authorities should ensure that adults with PMLD are able to take part in a wide range of meaningful activities – including employment, education and leisure.

### **Recommendation 26.**

Local authorities should ensure that they continue to provide somewhere which can be used as a base from which adults with PMLD can attend different activities during the day. This does not have to be restricted to people with PMLD – a place used by a wider range of people might be more interesting and provide more opportunities for social interaction.

### **Recommendation 27.**

Commissioners of health and social care services in every area should have a range of short break services available, which provide staff with sufficient skills, expertise, equipment and facilities to meet the needs of families supporting adults with PMLD. No family supporting an adult with PMLD at home should be denied regular short breaks.

### **Recommendation 28.**

Agencies should offer subsidised or free places to families and personal assistants on any training courses they run which are relevant to adults with PMLD. Individual budgets should include provision for training of personal assistants.

### **Recommendation 30.**

Local policies should be based on the principles that (i) arrangements will be designed so that they sustain and enhance quality of life of the disabled person by enabling clinical procedures to be carried out when and where needed, and (ii) arrangements will be coordinated and consistent between agencies, avoiding unilateral exclusions and consequent service gaps.

### **Recommendation 31.**

Local policies should focus on the procedures that have been identified as a problem by families, including all relevant care settings, such as hospitals, community services and people's own homes. These policies should specify who is responsible for carrying out clinical procedures in different situations and should deal with issues of clinical governance, legal liability and insurance.

### **Recommendation 32.**

For adults with PMLD, both health and social care services should always work in close partnership, both in planning and commissioning services and in providing them. Local authorities should continue to play an active part as the lead agency for learning disability services in all service development and should continue to lead individual assessment and planning, even where continuing health care funding is provided.

### **Recommendation 33.**

Services for adults with PMLD should be developed in line with the government's personalisation agenda, however they are funded. Services should be designed around the individual and the family treated as experts. Focus on the quality of staff relationships should be the key to service quality, and all services should sustain the package of care.

## 2. What is commissioning?

Commissioning determines where public money is spent, on health, adult social care, children's services etc. Commissioning is a step-by-step process that helps to prioritise the resources available for public services. Commissioners act on behalf of the public to provide the services they need, today and in the future. Decisions about where money is spent are based upon assessing what services are needed, and what outcomes a service can deliver. The decisions should be made by involving the public, users of the service and their families, providers or potential providers and other people or organisations who have an interest in the decision (e.g. education services or health services).

***“Commissioning is about understanding the whole system and how it is designed to deliver the outcomes for customers. It is about maximising the inputs and the mechanisms to deliver outcomes. It is about looking at the user pathway from the perspective of the customer rather than managing services in isolation of one-another. It is about making best use of the talents in the system so that we can innovate and re-design delivery approaches to achieve major efficiency improvements and a step-change for outcomes and the public sector.”<sup>1</sup>***

***“Commissioning is not the same as purchasing. Purchasing is a cash driven exchange. The purchaser is only a customer. Commissioning is a needs-led activity. Agencies concerned with commissioning may both customers and suppliers. Once needs are collectively identified, the means of meeting those needs through service provision are agreed and then how to access the resources, financial, staffing and premises necessary to deliver will be finalised. Thus an agency whether statutory, voluntary or private can be included in the commissioning function.”<sup>2</sup>***

1 Audit Commission

2 Hearn, Abraham and Pugh, 2008

# 3. What does ‘good’ look like?

**3.1 This is an important question** to answer in commissioning a service, and also at the beginning of this guide. What does a good service for people with profound and multiple learning disabilities (PMLD) look like?

**There are a number of common pitfalls in commissioning services.** These include:

- not establishing baseline data to be able to measure the effectiveness of a service
- not having a shared vision about the desired outcomes from the service
- choosing outcomes and indicators that are difficult to measure or not relevant
- not including all stakeholders in the evaluation of the service.

These pitfalls also explain some of the issues that can arise within services for people with PMLD.

It is only quite recently that the number of people with PMLD began to be counted by local authorities and the information included within Joint Strategic Needs Assessments (JSNAs<sup>4</sup>). This is still not always the case, and the collection of detailed information about the needs of local people with PMLD is still relatively rare.

There is often a lack of vision and purpose in the commissioning of services for people with PMLD. Although the activities for the service may be specified, the wider goals around what the service is supporting people with PMLD and their families to achieve, can be lacking. This is because the wider goals tend to reflect wider learning disability strategies and therefore focus on issues such as employment, access to universal services and normalisation.

Many people with PMLD need specific specialist support such as postural care, support with non-formal communication, and complex health interventions to enable them to live a fulfilling life where the issues within wider learning disability strategies become relevant. This specific specialist support should be seen as the foundation for fulfilling lives.

People with PMLD are typically not engaged in evaluating and coproducing their services; although there are difficulties in obtaining the views of people with PMLD using traditional methods, this means that a central part of the current commissioning process is omitted.

**3.2 People with PMLD** are marginalised within services in part because the performance indicators that are used to measure success, such as the number of people gaining paid employment, the number of people whose support needs have reduced, or the number of people self managing their health condition, do not reflect their lives. The practice of using outcomes and indicators specifically relevant to delivering a good quality service for people with PMLD is not yet widespread.

**3.3 Another reason** that people with PMLD are marginalised within services is because staff often lack confidence in their ability to understand what the person with PMLD is trying to communicate and what is important to the person. Using a person-centred approach can address this within all services, even those where staff have limited contact with each person. Hospital passports are an example of a person-centred tool that helps staff work with people with communication difficulties in this type of situation. These are discussed more in the *Raising our Sights* how-to guide on health .

4 For more information about JSNAs see [http://www.dh.gov.uk/en/Publicationsandstatistics/PublicationsPublicationsPolicyAndGuidance/DH\\_081097](http://www.dh.gov.uk/en/Publicationsandstatistics/PublicationsPublicationsPolicyAndGuidance/DH_081097)

5 Lyons and Cassebohm, 2012

As well as being a fundamental human right, it is only possible to provide a good service by listening to, understanding and acting upon the opinions of the people using the service. This holds true for people with PMLD and means that a good service must have methods to support people with PMLD in their communication, and processes whereby the things that people with PMLD communicate are used to shape the service at its heart.

Communication is discussed more in the *Raising our Sights* how-to guide on communication. Another Mencap publication, *Communication and people with the most complex needs: What works and why this is essential*, provides research and analysis of the effectiveness of various communication tools<sup>6</sup>.

The views of people with PMLD can be used to shape services through collating information about people's likes, dislikes, important issues and goals from their person-centred plans, using a tool such as *Shaping the Future*. Go to <http://www.learningdisabilities.org.uk/content/assets/pdf/publications/shaping-the-future.pdf>.

People with PMLD must have access to support with their communication, and staff must be trained to recognise, understand and record people's communication, to ensure the information is there to be collated.

**3.4 It is possible**, and necessary, to have performance indicators that measure whether people with PMLD are receiving a good service. People with PMLD are undervalued in society, and this means that they are more likely to receive a poor quality service. Health and social care services place a lot of importance on performance indicators, and they can be used to increase the importance attached to services for people with PMLD. Meaningful and measurable performance indicators can be found for all services, around community participation, preserving body shape, health facilitation, wellbeing and the like.

**3.5 Good services** have clarity of responsibilities, policies and procedures. This is particularly important for people with PMLD, as they usually make up a small proportion of service users, and may have needs that are unusual and unfamiliar to staff in that service or that are the responsibility of a number of services and commissioners. Issues that regularly affect people with PMLD, which can be overcome with the proper use of policies and procedures, include:

- capacity and consent
- improper use of do-not-resuscitate orders
- provision of additional support within hospitals

- use of medical devices in social care services
- access to screening services
- access to attendant-propelled electric wheelchairs
- staff understanding and skills.

Hospitals are responsible for meeting the needs of people who are admitted, including people who need additional support in hospital, such as people with PMLD. Without such a policy and procedure that is known about and used, ward staff, social workers and families spend time trying to ensure the person receives food and drink, is clean, safe and comfortable on the ward, while negotiating how these things will happen and who will pay for any additional support costs.

Policies and procedures about the provision of additional support while people are in hospital enable hospital staff to focus on providing treatment. This can save lives, improve the effectiveness of treatment, enable hospital staff to provide a better quality service, and reduce the stress and anxiety of patients and their family members. Families and support staff can prepare for the possibility of a hospital admission in advance, and know who to speak to on the ward to request additional support.

<sup>6</sup> Goldbart, J and Caton, S 2010, *Communication and people with the most complex needs: what works and why this is essential*, MENCAP, London.

**3.6 Good services** treat the family as expert, asking and listening about the needs and wishes of the person and how to make the service accessible. Services need to be person-centred and also family centred – families need to be supported to remain strong, in order to sustain their involvement and their caring role. In addition to providing respite/short breaks and other carers’ services, giving the family information and support to be fully involved in decisions is key in supporting the wellbeing of the person with PMLD. Many families want to share experiences with other families of disabled people, particularly families of people with PMLD. It is important to facilitate this, as a means of families receiving mutual support and information.

**3.7 Health services** for people with a learning disability are assessed via the Health Self Assessment Outcomes Framework (SAF)<sup>7</sup>. The SAF includes specific outcomes about people with PMLD. All the general outcomes measured in the SAF also apply to people with PMLD. Specialist learning disability services and primary care liaison nurses can be commissioned to focus specifically on health facilitation for people with PMLD, to ensure they receive quality health services that meet the SAF outcomes. Clinical Commissioning Groups (CCGs) need to develop expertise and

understanding around the need of people with PMLD. Commissioning guidance for CCGs suggests that it would be helpful to have a learning disability lead to co-ordinate service improvement<sup>8</sup>. This person will need to have a good understanding of people with PMLD to ensure that they do not get left out of service improvements.

It is important that health services for people with PMLD support people to have a good quality of life and to achieve the outcomes expected for people with a learning disability in government policy, as well as receiving equal access to health treatment. The issues around this are explored within the *Raising our Sights* how-to guides about health and clinical procedures.

**3.8 Government policies** for people with a learning disability since the 1970s have focused on enabling people to have ordinary lives. The outcomes that government policy has tried to encourage include:

- living in your own home, in the neighbourhood you want to be in
- having a choice of who you live with
- having an ordinary domestic life
- accessing paid work or meaningful day activities

- using local mainstream services
- being included in local communities
- receiving support that enables these things to happen.

It was noted in *Valuing People Now*, published in 2009, that people with PMLD were one of the groups of people that had not had equal access to these outcomes.

**3.9 Another way to find out** what a good service for people with PMLD looks like is to think about what makes a good life for someone with PMLD, and how services can support people to achieve this. The notion of a good life is explored more in the book *People with Intellectual Disabilities: Towards a Good Life?*<sup>9</sup>, which identifies a number of themes for a good life, including personal relationships, rights, education in the wider sense of learning through experiences, communities and belonging, duty and commitment to others. For a service to support someone with PMLD to have a good life, the service needs to be able to find out what is important to that person, and ensure the person can have those things in their life. This can be achieved by using a person-centred/personalised approach and focusing on the well being and satisfaction of the individual.

<sup>7</sup> The Health Self-Assessment Framework (SAF) is used by most health communities and has been part of the NHS Operating Framework since 2011.

It brings together many standards for learning disability services that are in other documents. For further information see: [www.ihal.org.uk/self\\_assessment/](http://www.ihal.org.uk/self_assessment/)

<sup>8</sup> Improving Health and Lives. 2012. Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs).

<sup>9</sup> Johnson, K. Walmsley, J & Wolfe, M., 2010, *People with Intellectual Disabilities: Towards a Good Life?*, Bristol, The Policy Press

**3.10 The quality of services** can also be measured using quality of life indicators. The Life Satisfaction Matrix, developed by Lyons, is discussed more in section 10.3. The capabilities approach is another approach to this, developed as a measurement of the minimum entitlements that every person should have. It was originally used within international development, and Martha Nussbaum, an American philosopher, has used a capabilities approach to focus on disabled people in society. Nussbaum identified the following ten capabilities that everyone should be entitled to, regardless of disability:

#### 1. Life

Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.

#### 2. Bodily health

Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.

#### 3. Bodily integrity

Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in relation to having children.

#### 4. Senses, imagination, and thought

Being able to use the senses, to imagine, think, and reason—and to do these things in a “truly human” way, a way informed and cultivated by an adequate education. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain.

#### 5. Emotions

Being able to love and care for others, and to experience love and care in return; to love, to grieve, to experience longing, gratitude, and justified anger. That human emotions are recognised and support given to foster them.

#### 6. Practical reason

Being able to form a conception of what is good, and planning and reflecting on one's life. Nussbaum identified that emotions such as like and dislike are a form of reason about what is good. This entails protection for the liberty of conscience and religious observance.)

#### 7. Affiliation

a. Being able to live with and toward others, to recognise and show concern for other humans, to engage in various forms of social interaction.

b. Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others.

#### 8. Other species

Being able to live with concern for and in relation to animals, plants, and the world of nature.

#### 9. Play

Being able to laugh, to play, to enjoy recreational activities.

#### 10. Control over one's environment

a. Political. Being able to participate in political decisions that are relevant to one's life; having protections of free speech and association.

b. Material. Being able to own and use property on an equal basis with others; having the right to seek employment on an equal basis with others.

Nussbaum, 2000

The capability approach provides an interesting and insightful way to consider the lives of people with PMLD, and a framework to consider the aims and outcomes of services for people with PMLD. How does the service you provide enable people with PMLD to obtain these capabilities?

1 For example see: Nussbaum, M. 2006. *Frontiers of Justice. Disability national species membership.* Cambridge: Harvard University Press.

## 4. The policy context

### 4.1 Valuing people

The white paper *Valuing People* (2001)<sup>11</sup> and the subsequent document *Valuing People Now* (2009)<sup>12</sup> sets the current policy context for commissioning health and social care services for people with learning a disability. *Valuing People Now* is based on four principles:

- rights
- independent living
- control
- inclusion.

*Valuing People Now* identified that some people had been largely excluded from improvements in services, including people with profound and multiple learning disabilities (PMLD). *Raising our Sights* was commissioned as a result, and looks at how to improve services for people with PMLD.

### 4.2 Death by Indifference

Mencap's report, *Death by Indifference*<sup>13</sup>, discussed the deaths of six people with a learning disability, including one person with PMLD who died in NHS care. *Valuing People Now* also included the government's response to *Death by Indifference*, the subsequent parliamentary and Health Service Ombudsman inquiry, called *Six Lives*<sup>14</sup>, and the government inquiry, *Healthcare for All*, which found that "people with learning disabilities receive less effective care than they are entitled to receive"<sup>15</sup>. Recommendations of the government inquiry included the formation of a learning disability Public Health Observatory<sup>16</sup>, and a confidential inquiry into premature deaths of people with a learning disability, which reported in March 2013<sup>17</sup>. All NHS organisations and local authorities were asked to review the effectiveness of their systems to meet the health needs of people with a learning disability, and report to their boards

by March 2010. In February 2012, Mencap published *Death by Indifference: 74 deaths and counting*<sup>18</sup>. The report noted that while there had been progress, there are still major problems with use of the Mental Capacity Act, poor complaints procedures, failure to recognise pain, delays in diagnosis and treatment, poor communication and lack of basic care.

*Death by Indifference*, and the subsequent actions, contributed to the adoption of the Learning Disabilities Self Assessment Framework (SAF) across England. The SAF includes specific questions about how local areas are meeting the needs of people with PMLD. Information from the Learning Disabilities SAF is published on the Learning Disabilities Observatory website: [http://www.improvinghealthandlives.org.uk/projects/self\\_assessment/](http://www.improvinghealthandlives.org.uk/projects/self_assessment/)

11 Department of Health (2001). *Valuing People: A New Strategy for the 21st Century*.

12 Department of Health (2009). *Valuing people Now. A new three year strategy for people with learning disabilities – Making it happen for everyone*.

13 <http://www.mencap.org.uk/campaigns/take-action/death-indifference>

14 <http://www.ombudsman.org.uk/improving-public-service/reports-and-consultations/reports/health/six-lives-the-provision-of-public-services-to-people-with-learning-disabilities>

15 [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_099255](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255)

16 For more information about the Learning Disabilities Public Health Observatory see [www.ihal.org.uk](http://www.ihal.org.uk)

17 For more information about the Confidential Inquiry, see [www.bristol.ac.uk/cipold/](http://www.bristol.ac.uk/cipold/)

18 <http://www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf>

### 4.3 NHS commissioning changes in England

The white paper for health *Equity and Excellence: Liberating the NHS*, was published in 2010 and set out large-scale changes to the way that health services are commissioned. In England, since April 2013, local Clinical Commissioning Groups (CCGs), made up of GPs, hospital doctors and nurses and other specialists, have taken charge of commissioning services for their local population, including people with PMLD. They will be held to account by an independent NHS commissioning board, who will be nationally accountable for the outcomes achieved by the NHS, and provide leadership for the new commissioning system. Patients will be involved in shaping services via a healthwatch organisation in each local authority area, and Healthwatch England, who will support local groups and influence national health policies.

For more information about the new NHS commissioning structure, go to <http://www.commissioningboard.nhs.uk/files/2012/07/fs-ccg-respon.pdf> or <http://www.bbc.co.uk/news/health-12177084>

Under the Health and Social Care Act 2012, CCGs must pay regard to how the services they commission reduce inequalities in access to health care and the outcomes delivered to different groups of people<sup>20</sup>.

### 4.4 NHS commissioning in Scotland, Wales and Northern Ireland

The main changes to NHS commissioning within the Health and Social Care Act 2012 apply only to England. NHS services are organised differently in Scotland, Wales and Northern Ireland. In Scotland, health services are run by 14 health boards. In Wales, there are 22 local health boards. These health boards are responsible for commissioning health services in their area, including the commissioning of GP services. In Northern Ireland, the Health and Social Care Board commissions health services for five local trusts. There are currently no proposals for major changes to the way health services are commissioned in Scotland, Wales or Northern Ireland.

### 4.5 Putting People First 2007

*Putting People First*, published by the Department of Health in December 2007, outlines a shared vision and commitment to the transformation of social care. It has four key dimensions:

1. Universal services – ensuring all public services link up and meet the needs of all citizens and all people have access to information, advice and advocacy.
2. Early intervention and prevention – enabling people to live with maximum independence, for as long as possible.

3. Choice and control for people – shaping services to meet people’s needs rather than fitting people into the services on offer.
4. Building social capital – ensuring that services operate in a way that builds on resources available within families and communities.

*Putting People First* (2007) requires commissioners to engage and involve local people and communities in decisions and to be accountable for the services they commission and provide.

### 4.6 The Care and Support Bill 2012

Once it is passed by parliament, The Care and Support Bill, published in 2012, will replace the numerous pieces of current legislation around the provision of social care services. The bill starts with the principle that the purpose of social care is to promote wellbeing, rather than to just respond to crises. It builds on *Putting People First*, and will introduce personal budgets for all users of social care services.

20 <http://media.dh.gov.uk/network/18/files/2011/10/C2-Tackling-inequalities-in-healthcare.pdf>

The Care and Support Bill is currently making its way through parliament. There are a number of websites containing more information on the bill, and the associated changes to social care, including the Department of Health-run website <http://caringforourfuture.dh.gov.uk/> and Think Local Act Personal <http://www.thinklocalactpersonal.org.uk/>

#### **4.7 Reasonable adjustments and the public sector equality duty**

The Health and Social Care Act 2008 requires all public bodies to make reasonable adjustments to remove any barriers that prevent disabled people accessing a service equitably with non-disabled people. This includes physical barriers, such as steps, lack of parking, narrow doorways and inaccessible toilets, adjustment to policies and procedures such as longer appointment times, providing additional support, producing information in easy read, and proactive screening programmes such as annual health checks.

Putting reasonable adjustments in place is a legal duty, and it is ‘anticipatory’, meaning that health service organisations are required to consider in advance what adjustments people with PMLD will need to access their service. For further information, go to [www.ihal.org.uk/projects/reasonableadjustments](http://www.ihal.org.uk/projects/reasonableadjustments)

The Public Sector equality duty came into force in April 2011. The equality duty replaces the disability, race and gender equality duties. It requires public bodies to have due regard to the need to eliminate discrimination, advance equality of opportunity, and foster good relations between different people when carrying out their activities. All public bodies are required to publish information about how they are responding to the equality duty, and must carry out equalities impact assessments on the changes. For further information, go to [www.homeoffice.gov.uk/equalities/equality-act/equality-duty/](http://www.homeoffice.gov.uk/equalities/equality-act/equality-duty/)

#### **4.8 The Mental Capacity Act**

The Mental Capacity Act 2005 was implemented in England and Wales in 2007. The Act provides the legal framework for supporting people to make decisions, while protecting those who cannot by ensuring they participate as much as possible in any decisions made on their behalf. Professionals have a duty to comply with the Mental Capacity Act Code of Practice (2005)<sup>21</sup>, which sets out the steps that must be followed to decide whether a person has capacity, and how to make a decision for a person who does not have capacity.

Under the Act, a person lacks capacity to make a decision if they cannot:

1. understand information about the decision

2. retain that information in their mind

3. use or weigh that information as part of the decision-making process

4. communicate their decision (by talking, using sign language or any other means).

People with PMLD are unlikely to have capacity to make major decisions about their lives, including medical treatment or where they want to live. They may not have capacity around their day-to-day decisions either, such as what to wear and how they want to spend their time. Using the Mental Capacity Act, the person must have an assessment to determine their capacity to make each specific decision – the decision that someone lacks capacity cannot be carried over from previous assessments.

The responsibility to carry out the mental capacity assessment rests with the responsible person, usually a doctor or other medical professional, social worker or support worker, depending on the decision being made. If the person does not have capacity to make the decision, this responsible person becomes the decision maker. They must take into account the views of family members and other people involved, plus the opinions of the person, when making their decision. This must be recorded appropriately. If a major decision about medical treatment or where to live needs to be made,

21 The Mental Capacity Act Code of Practice <http://www.legislation.gov.uk/ukpga/2005/9/resources>

and the person does not have family who are available and willing to be involved, the person must be referred to an Independent Mental Capacity Advocate (IMCA) to ensure their interests are represented. Some IMCAs also support people without capacity regarding the safeguarding of investigations and social care reviews.

More information about IMCAs can be found in the booklet produced by the Ministry of Justice. Go to <http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/making-decisions-opg606-1207.pdf>

It is important that all staff in all commissioned services used by people with PMLD, understand and follow the Mental Capacity Act, and this should be highlighted within service contracts and performance indicators.

# 5. Commissioning effective services for people with PMLD

**5.1 From April 2013,** Clinical Commissioning Groups (CCGs) will be responsible for commissioning most health services for people with profound and multiple learning disabilities (PMLD), and commissioning ongoing support for people with PMLD who have a primary health need under the Continuing Health Care criteria. GPs, along with dentists, opticians and some other specialist services such as intensive care, will be commissioned nationally by the NHS Commissioning Board. Local authorities will be responsible for commissioning social care services, and will also work with CCGs on addressing health inequalities and providing integrated services. For more information about the commissioning responsibilities of different organisations from April 2013, go to <http://www.commissioningboard.nhs.uk/files/2012/07/fs-ccg-respon.pdf> or <http://www.bbc.co.uk/news/health-12177084>

Health commissioners retain responsibility for the health element in joint-funded services. As the commissioning landscape changes, it is important that commissioning responsibilities in the local area are mapped, and that the responsibilities for people who have more complex or multiple needs are clear.

## 5.2 The commissioning cycle

Commissioning involves:

- consulting and identifying the needs to be met and the desired outcomes
- planning how best to meet needs and achieve better outcomes
- procuring high quality and cost effective services
- monitoring service delivery to ensure outcomes are being achieved.

This is often called the commissioning cycle, and as discussed in section 3, it is important that each of these steps are followed in order to commission 'good' services.

For more information about commissioning you can look at other research including:

Commissioning Integrated Care in the NHS. <http://www.nuffieldtrust.org.uk/publications/commissioning-integrated-care-liberated-nhs>

Commissioning for better public services. [http://www.local.gov.uk/c/document\\_library/get\\_file?uuid=846cdeeb-b1c5-4042-ac2a-887fcf58c2b8&groupId=10171](http://www.local.gov.uk/c/document_library/get_file?uuid=846cdeeb-b1c5-4042-ac2a-887fcf58c2b8&groupId=10171)

## 5.2a Consulting, identifying the needs to be met and the desired outcomes

Understanding local needs – demographic information needs to be collected about the local needs of people with PMLD, and the implications of these needs, to plan and inform future spending decisions. This could be done through the JSNA, or more in-depth information gathered through a specific needs assessment e.g. the Lambeth PMLD Project<sup>22</sup>. Services for people with PMLD tend to be resource intensive, so there is a strong case for the collection of in-depth information to ensure that money is being spent effectively.

Understanding expectations and desired outcomes for people with PMLD – it is important to understand what people with PMLD and their families expect from services, and to have a shared understanding of what outcomes are positive and possible. Desired outcomes can be sourced from:

- consultation and co-production with people with PMLD and their families
- the Learning Disabilities Self Assessment Framework

<sup>22</sup> [http://www.pmldnetwork.org/what\\_do\\_we\\_want/news\\_and\\_events\\_lambeth.html](http://www.pmldnetwork.org/what_do_we_want/news_and_events_lambeth.html)

- collaborative discussions with current providers of specialist services to people with PMLD and the Learning Disabilities Partnership Board
- quality of life measurements, Nussbaum's Capability Framework and other wellbeing measures
- *Raising our Sights*
- these how-to guides.

**5.2b Planning how best** to meet those needs and achieve better outcomes.

At this stage of the commissioning cycle, the services required to meet the desired outcomes are mapped and specified. Decisions around whether to commission to meet these outcomes within mainstream services or within specific specialist services for people with PMLD, need to be made at this stage. This decision will depend on local factors and priorities.

It is important to agree the responsibilities of all stakeholders, including the different commissioners, public health, contracts teams and providers. Workforce development needs should also be identified and planned, including increasing the knowledge and awareness of other commissioners, CCGs and contracts teams.

**5.2c Procuring high quality** and cost effective services.

This stage of the commissioning cycle involves the procurement of services, developing the market to encourage a range of providers to offer services that will assist people with PMLD to meet their desired outcomes in the local area, and the development of policies, procedures and pathways to ensure services achieve the desired outcomes.

**5.2d Monitoring service delivery** to ensure outcomes are being achieved.

Reviews of the services for people with PMLD, to measure how well they are meeting the desired outcomes, should include people with PMLD and their families. There are a range of methods that can be used to do this, which are discussed more in section 11 of this guide. It is also important to review the effectiveness of service policies and procedures in meeting the needs of people with PMLD, and whether these policies and procedures are used consistently with people with PMLD.

**5.3 Cost effectiveness**

There is no research about the cost effectiveness/value for money of services for people with PMLD<sup>23</sup>. Services for people with PMLD need a high level support staff, and so will always be high cost. To establish the cost effectiveness/value for money of services for people with PMLD, the focus needs to be on:

- higher quality of life
- lower costs on families (including non-monetary costs)
- lower needs in other areas (e.g. health)
- lower needs in the future rather than lower costs of the package of care.

The PMLD Network<sup>24</sup> is keen to hear from commissioners who undertake work to look at the cost-effectiveness or value for money of services for people with PMLD.

***“No amount of investment is going to radically change the need for support for [people with PMLD]. Greater efficiency elsewhere in health and social care may free up resources which can be spent on them but they are not going to be the source of savings. Their services are relatively expensive because their needs are high. Greater cost-effectiveness will come from getting the most out of those resources in terms of the quality of life experienced by them and their families, and through the reduction of harm and ill-health to them and their carers.”***

***Raising our Sights, paragraph 122***

<sup>23</sup> Mansell, J. 2010. Raising our sights: services for adults with profound intellectual and multiple disabilities

<sup>24</sup> www.pmldnetwork.org

## Focusing on outcomes

Although it does not talk about services for people with PMLD specifically, the chapter on measuring and improving outcomes in Stirk and Sanderson's 2012 book, *Creating Person Centred Organisations*, provides a discussion on methods of involving customers in evaluating service quality, using person-centred approaches such as Working together for Change<sup>25</sup>.

Commissioning to achieve set outcomes focuses attention on the results – or outcomes – that the services are intended to achieve. There are many approaches and methods used to set expected outcomes, including outcome-based accountability, used widely in children's services. Using this approach, commissioners work alongside people with PMLD, their families and other stakeholders to set desired outcomes, and with potential providers to devise their proposed activities and outputs.

This approach is particularly appropriate for services for people with PMLD, as specialist services are likely to have specific experience and knowledge of what outcomes are possible for people with PMLD. It is also seen as a tool for strategic and cultural change; moving organisations away from a focus on 'efficiency' and 'process' towards making better outcomes the primary purpose of the organisation and its employees<sup>26</sup>.

## 5.4 Including a wide range of outcomes

In addition to service outcomes, it is important to consider questions about wider outcomes such as:

- How does the service meet wider social, economic and environmental outcomes? How does the contract reduce the social barriers faced by people with PMLD?
- How does it improve the economic position of people with PMLD and their families? Perhaps by enabling carers to seek paid employment or by reducing the additional costs borne by people with PMLD as they live their lives.
- How does the service prevent people with PMLD acquiring additional health needs?

It is important to think about how the service supports the outcomes in the local strategic plan. This may be through supporting access to other local services or by providing a specific service to assist people with PMLD and their families in meeting an objective.

**Measuring outcomes and value for money are discussed more in section 7.**

## 5.5 Workforce development

The skills and ability of the people who support them have a fundamental impact on the quality of life of people with PMLD. Appropriately trained staff can facilitate

people with PMLD to be included in community facilities, and participate and build skills in carrying out their everyday tasks. Support staff also have an integral role in maximising the health and wellbeing of the people they support.

**“Support staff report that they do not feel confident in meeting the health needs of people with learning disabilities.”**

(Emerson, E., Baines, S., Allerton, L and Welch, V. (2011). *Health Inequalities & People with Learning Disabilities in the UK. Improving Health and Lives: Learning Disability Observatory*)

It is important to ensure that families are aware of what training is available for support staff working with people with PMLD, locally and as best practice. Families of people with PMLD should also be offered places on these training courses, to support their caring role. Personal assistants (PAs) employed directly to work with people with PMLD must have access to all training opportunities, either through accessing centrally commissioned courses or the purchase of training from the person's personal budget.

25 Stirk, S. & Sanderson, H. 2012. *Creating Person Centred Organisations*, London, Jessica Kingsley Publishers

26 Chamberlain, Golden, and Walker, F. 2010. *Implementing Outcomes-Based Accountability in Children's Services: an Overview of the Process and Impact*

Training that should be provided to people supporting people with PMLD includes:

- health facilitation training
- healthy lifestyles
- communication
- intensive interaction
- mental capacity
- values and attitudes
- person-centred active support
- training specific to the needs of the particular individual – this can be provided via the contract for the Community Learning Disability (Health) Team.

This is discussed more in the *Raising our Sights* how-to guide to training the workforce.

### **5.6 People with PMLD** from black and minority ethnic communities

People with PMLD who belong to black and minority ethnic (BME) communities can face multiple barriers. It is important to ensure that families of people with PMLD from BME communities have equal knowledge of and access to services and support. This can be achieved through acknowledging and seeking a better understanding of the differing understanding and priorities of people from different BME communities, and how this

may relate to people with PMLD. The needs and wishes of people with PMLD from BME communities can be catered for through the wider personalisation agenda. Commissioners may need to develop the market for specific services for people with PMLD from BME communities. Families and service providers may need additional support to arrange these.

Although people with PMLD are not discussed specifically, a recent research project by the Foundation for People with Learning Disabilities explores how the diverse needs of people with a learning disability from BME communities and their families can be planned for and met. The report is accompanied by two guides on culturally competent planning and practice in learning disability services.

The report, and accompanying guides, are available at <http://www.learningdisabilities.org.uk/publications/reaching-out-report/>

### **5.7 Meeting the needs of carers**

People with PMLD need support and supervision/monitoring 24 hours a day. Many people have a number of complex disabilities and health conditions that they require regular assistance for. Most people with PMLD live with their parents or other family members<sup>27</sup>, and the responsibility for providing most of this care is met by these family members.

**“60% of parents of children and adults with PMLD spend more than ten hours per day providing physical care for the person with PMLD.”**

Mencap (2001), No ordinary life.

<sup>27</sup> Mencap. (2001) No ordinary life: the support needs of families caring for children and adults with profound and multiple learning disabilities. London: Mencap.

Research by Mencap<sup>28</sup> found that 60% of parents of children and adults with PMLD spent more than ten hours per day providing essential physical care. A third of these parents said their caring role was continuous and meant they were caring for their son or daughter 24 hours a day. 57% of parents were spending more than eight hours per day on therapeutic and educational activities. Parents were woken up, on average, three times a night by the need to care for their son or daughter.

Nearly half the families interviewed for *Raising our Sights* received no support from outside the family to help with care tasks and less than a quarter received more than two hours' support a week to help them cope at home with care tasks. In another Mencap survey, 70% of families of children and adults with severe and profound learning disabilities said they had reached or nearly reached breaking point because of the lack of short break services<sup>29</sup>. These family members also need to navigate numerous health and social care systems to access services, maintain their family life, paid employment and career.

As reported in *Raising our Sights*, many families of people with PMLD do not have respite services because local services cannot meet the needs of the person they care for.

It is important to understand the needs of carers for people with PMLD, and to ensure that services exist that can meet these needs. It is important that carers receive training to meet the needs of their relative with PMLD, including intensive interaction, health facilitation and other training that is provided to paid support staff. Carers for people with PMLD may want opportunities to meet and to support each other, and may need assistance to facilitate this including the provision of support for the person they care for while they are attending meetings. It is important that self-help groups are supported to stay strong, as many families describe them as a lifeline. Carers for people with PMLD may want to be represented on the Learning Disability Partnership Board, as this can help ensure they have a voice in the development of services. Information about the needs of carers for people with PMLD can be collected as part of your needs assessment work.

**“Most of the work required to tackle the obstacles identified in [Raising our Sights] does not require large amounts of extra resources. It requires reasonable adjustment to policies, procedures, rules and priorities to ensure that adults with PMLD get the support they need. In general, adults with PMLD require such substantial amounts of support from staff that person-centred services are not likely to be significantly more expensive than the old congregate models of care.”**

### ***Raising our Sights, paragraph 123***

Access to suitable housing, for families to live together and for people with PMLD to move away from their families, is a major issue. This is discussed more in the *Raising our Sights* how-to guide to housing.

Providing effective support for carers is discussed more in the *Raising our Sights* how-to guide to support for families.

28 Mencap. (2001) No ordinary life: the support needs of families caring for children and adults with profound and multiple learning disabilities. London: Royal Society for Mentally Handicapped Children and Adults.

29 Mencap. (2006) Breaking point – families still need a break: a report on the continuing problem of caring without a break for children and adults with severe and profound learning disabilities. London: Mencap.

# 6. Meeting the needs of people with PMLD within mainstream services and processes

**6.1 To support people** with profound and multiple learning disabilities (PMLD) effectively within mainstream services (including services for people with a learning disability), it is necessary to understand the needs and desired outcomes of people with PMLD in relation to that service, make provisions to meet those needs, and check whether these needs have been met by the service. People with PMLD are likely to use a number of health services, e.g. continence, dysphagia, wheelchair services. Therefore it is important to provide joined-up, integrated services.

**6.2 The needs of people** with PMLD can be met within mainstream services through the provision of reasonable adjustments - e.g. access to screening services, provision of additional support, staff knowledge. For further information, including examples of reasonable adjustments being made in health services across the country, go to [www.ihal.org.uk/projects/reasonableadjustments](http://www.ihal.org.uk/projects/reasonableadjustments)

**6.3 It is important** that policies and procedures in mainstream services ensure a consistent level of service delivery to people who have differing needs, including people with PMLD. This should be checked within contract monitoring and service review arrangements. People with PMLD often have needs that mainstream services find challenging to meet due to their complexity, and will require flexible services that can be personalised to their needs. Many other individuals who do not have PMLD but who have one or a number of these needs will also want to use the service. By designing policies and procedures to ensure the needs of people with PMLD are met, and monitoring cases where needs are not met or people are dissatisfied with their service, you will be delivering a service that can meet the needs of everyone. By getting it right for people with PMLD you are likely to get it right for everyone.

**6.4 In Newham, London,** the PMLD Task Group developed a PMLD screening tool, to assist mainstream services to identify people with PMLD. The screening tool, based on the PMLD Network definition, is accompanied by

a checklist to assist practitioners to ensure that the person is receiving the services and interventions they require. If additional support is required, the screening tool directs practitioners in mainstream services to the Community Learning Disability Team. It is also used to identify people who should be on the Learning Disability Register. A copy of the Newham tool is included on the following page. You may want to adapt the template to make it relevant for use in your local area.

**6.5 In their 2012 guide for CCGs** on commissioning services for people with a learning disability<sup>31</sup>, Improving Health and Lives identified the following issues for people with PMLD within mainstream services:

- provision of emergency healthcare plans and personal resuscitation plans for adults and children with PMLD
- access to paediatric neuro-disability specialist care for children with PMLD
- access to supplies such as incontinence pads, gloves, sheets and medicines
- access to specialist advocacy from advocacy services

<sup>31</sup> [http://www.improvinghealthandlives.org.uk/publications/1134/Improving\\_the\\_Health\\_and\\_Wellbeing\\_of\\_People\\_with\\_Learning\\_Disabilities:\\_An\\_Evidence-Based\\_Commissioning\\_Guide\\_for\\_Clinical\\_Commissioning\\_Groups](http://www.improvinghealthandlives.org.uk/publications/1134/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-Based_Commissioning_Guide_for_Clinical_Commissioning_Groups)

- access to ongoing advocacy for people with PMLD using self-directed support.

**6.6 The needs of people** with PMLD will change as they get older. It is important that this is planned for, and that the needs of older people with PMLD are considered and met within service planning for older people and for people with learning disabilities. Areas to consider include staff training and the provision of specialist support for older people with PMLD and their carers. It is important that service pathways for older people are flexible, to enable people with PMLD to receive a service that best meets their needs, whether within older people's services or specialist learning disability services.

# The Newham PMLD screening tool

## People with profound and multiple learning disabilities (PMLD):

### 1. Have a profound learning disability

This is the most severe level of learning disability someone can have. Many people with PMLD will be able to express their preferences such as what clothes to wear if they are presented with different options. For most decisions they will 'lack capacity' and a decision will need to be made in their best interests. You will need to think about the person's preferences and involve people who know the person. Throughout their lives a person with PMLD will be learning the same sort of skills as a young child would - e.g. learning if they press something it will make a noise. It is not really helpful to think of IQ as you would not be able to measure IQ for people with PMLD. But sometimes it is said that people with PMLD would have an IQ of less than 20.

### 2. Have more than one disability

People with PMLD will have additional physical or a sensory disability, complex health needs or mental health difficulties. Their most significant disability is their profound learning disability.

### 3. Have great difficulty communicating

Most people with PMLD will not use any formal communication, but will rely on facial expressions, vocal sounds, body language, touch and behaviour to communicate. Some people may use a few spoken words or signs, and some people will need someone to interpret their gestures. Most people's communication will be non-intentional - they will not anticipate an outcome from their communication but will communicate how they feel about something by their responses to it.

### 4. Need high levels of support

People with PMLD need maximum levels of assistance with all aspects of everyday life, and require 24-hour care and supervision/monitoring.

### 5. May have behaviour that challenges

Some people with PMLD may have behaviour that challenges. It should never be assumed that certain behaviours are just part and parcel of having PMLD. A behaviour may be an attempt to communicate a need. Changes in behaviour may be due to undetected health

needs, such as scratching the face because of toothache.

If the **first four boxes are ticked** it is a strong indication that the person has PMLD (not everyone will have behaviours that challenges).

If you identify that a person may have PMLD, the checklist on the following 2 pages will help you ensure that they are receiving the services they need.

If you have any queries, please contact:

Person's name .....

Address .....  
(insert relevant contact)

**This person with PMLD:**

<b>Health needs</b>	<b>Yes</b>	<b>No/Don't know</b>
Has an up-to-date health action plan and hospital passport.		
Has had an annual health check within the last 12 months.		
Is being supported to manage their health conditions effectively.		
Is being supported to stay healthy e.g. hydrotherapy, support to exercise, healthy eating.		
Has an up-to-date communication passport.		
Has had an assessment of their postural care needs within the last two years, and any identified needs are being met (if they have any physical impairments).		
Has had a sensory impairment assessment within the last two years.		
Has had a dysphagia assessment within the last two years.		
Is being supported around sensory stimulation/ sensory integration.		
Has mental capacity assessments undertaken in relation to all health care decisions, and best interest decisions, involving family or circle of support members, are taken when necessary.		
If the answer to any of the above is no/don't know, please contact: (insert relevant contact)		

<b>Social care needs</b>	<b>Yes</b>	<b>No/Don't know</b>
Is receiving a support package to meet their social care needs.		
Has had an assessment or review from the local authority within the last two years, which involved the person's family or circle of support.		
The main family carer has been offered a carers' assessment within the last 12 months, and any needs identified during this assessment are being met.		
Has an up-to-date person-centred plan, which is being used.		
Is meaningfully engaged and involved in their day to day activities (possibly through using person-centred active support).		
Is supported to remain safe and well cared for.		
Is supported to sustain relationships with family and friends.		
Has choice and control over their life and environment.		
Has mental capacity assessments undertaken in relation to all health care decisions, and best interest decisions, involving family or circle of support members, are taken when necessary.		
Has the aids and adaptations they need within their home.		
Is living in appropriate housing.		
If the answer to any of the above is no/ don't know, please contact: (insert relevant contact)		

You can also refer the person to local advocacy services if they, or their carer, are having difficulty obtaining the services needed.

# 7. Specialist services for people with PMLD

**7.1 Specialist services** for people with profound and multiple learning disabilities (PMLD) may be developed within larger mainstream services, or as a distinct service. Specialist services are an important way to develop the expertise and experience required to meet the needs of people with PMLD, but the reason for commissioning a segregated specialist service must be explicit, and must be to address the inequalities experienced by people with PMLD, rather than to suit the needs of mainstream services. The need for specialist services in the local area should be determined through the first two stages of the commissioning strategy, and the local services on offer should reflect these identified needs. Specialist services must not prevent people with PMLD accessing the same level and quality of service provided by mainstream services, including provision of a seven-day-a-week service as well as access to a rehabilitation service. These issues should be addressed within the contracts for specialist services.

Specialist services can facilitate access to mainstream services through:

- coordinating and ensuring the quality of health interventions

- supporting people to become active members of their community.

**7.2 Some specialist services** will be developed because people with PMLD are the main beneficiaries of this type of service. These services may be commissioned as a reasonable adjustment to ensure that people with PMLD have equitable outcomes from their health and social care services, or to meet a specific need for people with PMLD. These types of services may include:

- specialist staff with the training and skills to meet the needs of people with PMLD
- postural care
- person-centred active support training
- intensive interaction
- Changing Places toilets
- accessible leisure opportunities, including warm swimming pools, special needs trampolining, adapted bicycles and sailing opportunities with specialist equipment
- body awareness
- sensory rooms
- sensory story telling.

**7.3 Specialist services** for people with PMLD should be commissioned with the same expectations for outcomes as all other services. They must have clear contract-monitoring arrangements and meaningful outcomes.

# 8. Prevention and enablement services for people with PMLD

**8.1 People with profound** and multiple learning disabilities (PMLD) are often marginalised or excluded from prevention and enablement services. This happens when the focus of the service is to enable an individual to complete a task with no assistance, or to reduce the person's need for paid support. Prevention and enablement services to relieve impairment, prevent complications developing from existing conditions, prevent people with PMLD acquiring new conditions, and to maximise the independence and autonomy of people with PMLD are possible and necessary within health and social care services. Nussbaum's capability framework was discussed in section 3 - enablement services should seek to promote and enhance these capabilities and increase quality of life in the lives of people with PMLD.

**8.2 Commissioners** have a large role around minimising the barriers that prevent people with PMLD accessing mainstream community facilities. This will involve providing a range of things, for example:

- Changing Places toilets in town centres and leisure venues
- hoists, minimum water temperatures and staff with an awareness of the needs of people with PMLD at local swimming pools
- accessible play equipment and wheelchair accessible sensory trails in local parks
- courses beneficial for people with PMLD within further education colleges and adult education.

Through strategic work, activities that enhance and protect the health, wellbeing and independence of people with PMLD can become part of people's everyday leisure and education activities. It is important to undertake work to identify the barriers in your local area for people with PMLD.

**8.3 The other how-to guides** in this series each give further information about services and interventions that have a prevention or enablement focus. Three interventions that warrant a specific mention, due to their potential to impact on peoples' lives, are postural care, support for communication needs and person centred active support. Together these three interventions, which are usually supported by health services, enable people with PMLD to have an active and fulfilling life.

**8.4 The table below** was developed from discussions at the PMLD Task group in Newham, London. It provides a starting point for thinking about enablement and prevention services for people with PMLD, and the commissioning actions needed to support these.

	<b>Questions about the person</b>	<b>Commissioning actions</b>
Activities of daily living	<p>How is the person involved in carrying out their activities of daily living? E.g. Person-centred active support.</p> <p>What choice and control does the person have over their activities of daily living?</p>	<ul style="list-style-type: none"> <li>• Staff training and ongoing support.</li> <li>• Contractual expectations for support providers working with people with PMLD.</li> </ul>
Assistive technology	<p>Has the person had a recent assessment looking at assistive technology?</p>	<ul style="list-style-type: none"> <li>• Provision of assistive technology assessments that include technology beneficial for people with PMLD and their carers.</li> <li>• Provision of a range of equipment beneficial for people with PMLD and their carers.</li> </ul>
Communication	<p>How is the person supported to communicate?</p> <p>How is this system recorded to enable others to communicate with the person? E.g. communication passport.</p> <p>Have staff and family members received the training and support they need to communicate with the person?</p>	<ul style="list-style-type: none"> <li>• Commissioning of speech and language therapy for support around communication.</li> <li>• Commissioning of Alternative Augmentative Communication (AAC) devices.</li> <li>• Performance indicators around communication.</li> <li>• Contracting with social care providers to ensure use of communication tools.</li> <li>• Provision of training around communication for support staff and families.</li> </ul>

<p>Community access and participation</p>	<p>What community facilities does the person use? E.g. swimming pool, public transport, library, restaurants.</p> <p>How is the person involved in their local community?</p> <p>What assistance does the person's support staff or family need to feel more confident when using community facilities?</p>	<ul style="list-style-type: none"> <li>• Identifying local barriers to community participation.</li> <li>• Identifying the activities and facilities that local people with PMLD most want to use.</li> <li>• Working with community facilities to ensure they are accessible for people with PMLD.</li> <li>• Working with community facilities to support them to provide services targeted at people with PMLD, e.g. sensory storytelling at local libraries, special needs trampolining at leisure centres.</li> <li>• Provision of Changing Places toilets</li> <li>• Training and support for families and support staff around using community facilities with someone with PMLD.</li> </ul>
<p>Education and employment</p>	<p>Does the person have opportunities to try and learn new things?</p> <p>Does the person want to explore their opportunities around voluntary work and paid employment?</p>	<ul style="list-style-type: none"> <li>• Strategic work to reduce health inequalities experienced by people with PMLD.</li> <li>• Provision of annual health checks.</li> <li>• Provision of health facilitation training.</li> <li>• Assurance that the health needs of people with PMLD are being met within contract monitoring arrangements.</li> </ul>
<p>Maintaining a healthy lifestyle</p>	<p>Is the person supported to maintain a healthy lifestyle, including eating a healthy diet and taking regular exercise?</p>	<ul style="list-style-type: none"> <li>• Strategic work to reduce health inequalities experienced by people with PMLD.</li> <li>• Staff training and awareness raising.</li> <li>• Access to suitable exercise opportunities for people with PMLD.</li> </ul>

Maintaining relationships	How is the person supported to maintain their relationship with family and friends, and to make new friendships?	<ul style="list-style-type: none"> <li>• Supporting circles of support for people with PMLD.</li> <li>• Staff training and ongoing support.</li> <li>• Contractual expectations for support providers working with people with PMLD.</li> </ul>
Making decisions	How is the person supported to make their own decisions, or to take an active role in decisions about their life? For example, does the person have a circle of support, do they have the support they need to communicate their feelings?	<ul style="list-style-type: none"> <li>• Mental Capacity Act compliance.</li> <li>• Supporting circles of support for people with PMLD.</li> <li>• Commissioning of speech and language therapy for support around communication</li> <li>• Contractual expectations for support providers working with people with PMLD.</li> </ul>
Meaningful occupation	Each week, how many meaningful activities does the person undertake? How can the number/ amount of time spent doing meaningful activities be increased?	<ul style="list-style-type: none"> <li>• Commissioning person-centred active support training.</li> <li>• Contractual expectations for support providers working with people with PMLD to use person-centred active support of similar methods of engaging people.</li> </ul>

<p>Mobility</p>	<p>Does the person have needs around their mobility?</p> <p>Do they have the equipment they need to be mobile inside and outside their home?</p> <p>Is the person supported to engage in exercises or other activities to maintain or improve their current levels of mobility?</p>	<ul style="list-style-type: none"> <li>• Commissioning of wheelchair services, occupational therapy services and physiotherapy services to ensure provision of suitable wheelchair, hoists and other equipment, rehab and reablement services for people with PMLD.</li> <li>• Developing the market and working with leisure centres and other community services to provide a choice of accessible exercise options for people with PMLD.</li> <li>• Social care procedures to ensure that people with PMLD are supported to engage in exercise, as directed by rehabilitation and reablement services and as a leisure activity.</li> </ul>
<p>Personalised services</p>	<p>How is the person supported to receive the type of support they want? For example using multimedia profiles, person-centred plans.</p>	<ul style="list-style-type: none"> <li>• Person-centred planning for people with PMLD.</li> <li>• Ensuring that policies and procedures around personalisation meet the needs of people with PMLD.</li> <li>• Ensuring that people with PMLD and their families have the support they need to arrange personalised services.</li> </ul>
<p>Postural care</p>	<p>Has the person had an assessment of their body shape?</p> <p>Do they have the equipment they need to protect their body shape? Is it being used consistently?</p>	<ul style="list-style-type: none"> <li>• Commissioning of postural care services.</li> <li>• Agreement of a local postural care pathway.</li> <li>• Performance indicators around postural care.</li> <li>• Awareness raising and training around protection of body shape.</li> </ul>

## 9. Personalised services for people with PMLD

Personalisation offers people with profound and multiple learning disabilities (PMLD) and their families the opportunity to receive services that can meet their needs and provide a quality service. As noted in *Raising our Sights*, there is evidence that this is now happening for some people with PMLD.

There are a number of issues that need to be resolved in order to enable people with PMLD to receive a high quality, personalised service:

- ensuring the resource allocation takes account of the needs of everyone with PMLD
- ensuring policies and procedures support families of people with PMLD to arrange and manage their own support
- ensuring support brokers and user led organisations have skills and knowledge around the issues and options for people with PMLD
- agreeing arrangements for people receiving both health and social care funding.

These issues are discussed in more detail in the *Raising our Sights* how-to guide to personalisation.

# 10. Measuring outcomes and value for money

**10.1 The Treasury** defines value for money as “...the optimum combination of whole-of-life costs and quality (or fitness for purpose) of the good or service to meet the user’s requirement. Value for money is not the choice of goods and services based on the lowest cost bid”<sup>32</sup>

A value-for-money judgement must assess the benefits to the quality of life of a person receiving the service or goods, even if the quality of life improvement cannot be given a monetary value.

There is no published research about value for money in services for people with profound and multiple learning disabilities (PMLD)<sup>33</sup>. Services for people with PMLD need a high level support staff, and so will always be high-cost. To establish the value for money of service for people with PMLD, the focus needs to be on:

- higher quality of life
- lower costs on families (including non-monetary costs)
- lower needs in other areas (e.g. health)
- or lower needs in the future, rather than lower costs of the package of care.

The value for money of many services for people with PMLD can be measured in terms of the prevention of issue that would negatively affect quality of life or would require more expensive interventions. Health services in particular can be measured in this way, as can services to support carers and social care services that facilitate participation and wellbeing for the person with PMLD.

The PMLD Network is keen to hear from commissioners who undertake work to look at value for money in services for people with PMLD.

## **Postural care**

Postural care is about using equipment and positioning techniques to protect and correct the body shape of people who have limited mobility. Without postural care, many people with PMLD are at risk of experiencing many serious health complications that cause suffering, pain and even death.

The provision of postural care services has a measureable impact on the quality of life of people with PMLD. Postural care services are also good value for money, and they prevent people with PMLD needing costly health interventions to address the complications caused by body shape changes such as

hip dislocations, scoliosis, recurrent pressure sores, persistent reflux, and chronic pain. The cost-effectiveness of postural care services can be measured through the reduction in the level of health interventions that are required by people with PMLD.

Information about the postural care service commissioned in Wakefield is available via <http://www.mencap.org.uk/posturalcare>

## **10.2 Measuring outcomes**

The outcomes of services for people with PMLD can be measured by a range of meaningful outcome indicators. Suitable indicators may be suggested from the work in the first two stages of the commissioning cycle, when identifying the desired outcomes and designing services that will achieve those outcomes. Most outcomes can be measured within services for people with PMLD. The method of measuring the outcomes may be different to other services and may include collecting feedback from carers and support workers or tracking outcomes via changes in individuals’ lives over time. It is also important to set outcome indicators that ensure the specific needs of people with PMLD are being met.

32 HM Treasury (2006) Value for money guidance, p11. [http://www.hm-treasury.gov.uk/d/vfm\\_assessmentguidance061006opt.pdf](http://www.hm-treasury.gov.uk/d/vfm_assessmentguidance061006opt.pdf)

33 Mansell, J. 2010. Raising our sights: services for adults with profound intellectual and multiple disabilities

People with PMLD, their families, and other stakeholders should be **involved in determining outcome indicators for commissioned services**. The table below provides a starting point for these discussions:

Outcome area	Possible indicators
Identifying needs	<ul style="list-style-type: none"> <li>• Number of people identified/registered as having PMLD – data on how/who identified them.</li> <li>• Number of young people going through transition who are identified/registered as having PMLD.</li> </ul>
Activities of daily living	<ul style="list-style-type: none"> <li>• Proportion of people with PMLD who are meaningfully engaged in carrying out their daily activities e.g. by using person-centred active support.</li> </ul>
Assistive technology	<ul style="list-style-type: none"> <li>• Proportion of people with PMLD who have had assistive technology assessments.</li> <li>• Proportion of people with PMLD who have assistive technology provided to them.</li> </ul>
Communication	<ul style="list-style-type: none"> <li>• Proportion of people with PMLD who have an AAC device.</li> <li>• Proportion of people with PMLD who have a communication passport.</li> <li>• Proportion of people with PMLD whose support plan includes specific support to communicate, e.g. intensive interaction.</li> <li>• Number of carers and support staff trained around communication.</li> </ul>
Community access and participation	<ul style="list-style-type: none"> <li>• Satisfaction survey for families around access to community facilities.</li> <li>• Proportion of people with PMLD whose support plan includes use of community facilities.</li> <li>• Services targeted at people with PMLD available in community facilities.</li> </ul>
Education and employment	<ul style="list-style-type: none"> <li>• Further education and adult education courses aimed at people with PMLD</li> <li>• Number of people with PMLD in paid and voluntary employment.</li> </ul>
Health and wellbeing	<ul style="list-style-type: none"> <li>• Details of strategic work undertaken to reduce health inequalities experienced by people with PMLD.</li> <li>• Proportion of people with PMLD who have had an annual health check in the last 12 months.</li> <li>• Details of reasonable adjustments made for people with PMLD within health services.</li> <li>• Complaints and serious untoward incidents (SUIs) relating to the treatment of people with PMLD within health service.</li> <li>• Tracking of quality life and life expectancy changes for people with PMLD over time.</li> </ul>

Maintaining a healthy lifestyle	<ul style="list-style-type: none"> <li>• Proportion of people with PMLD whose support plan includes regular exercise.</li> <li>• Number of support staff and families who have been attending training or have been supported to learn about healthy lifestyles for people with PMLD.</li> </ul>
Maintaining relationships	<ul style="list-style-type: none"> <li>• Supporting circles of support for people with PMLD.</li> <li>• Staff training and ongoing support.</li> <li>• Contractual expectations for support providers working with people with PMLD.</li> </ul>
Making decisions	<ul style="list-style-type: none"> <li>• Proportion of people with PMLD who have an active circle of support.</li> <li>• Evidence from providers of their awareness and application of the mental capacity act.</li> </ul>
Meaningful occupation	<ul style="list-style-type: none"> <li>• Proportion of people with PMLD who are meaningfully engaged in carrying out their daily activities e.g. by using person-centred active support.</li> </ul>
Mobility	<ul style="list-style-type: none"> <li>• Proportion of people with PMLD who use an electric wheelchair.</li> <li>• Proportion of people with PMLD who use a smart wheelchair.</li> <li>• Proportion of people with PMLD who have had an assessment from wheelchair services in the past 12 months.</li> <li>• Proportion of people with PMLD whose support plan includes regular exercise.</li> </ul>
Personalised services	<ul style="list-style-type: none"> <li>• Number of people with PMLD receiving a personal budget.</li> <li>• Feedback from satisfaction survey of families of people with PMLD around staff training and competencies.</li> <li>• Feedback from satisfaction survey by families of people with PMLD around support to arrange personalised services.</li> <li>• Proportion of people with PMLD who have an up-to-date, active person-centred plan.</li> <li>• Exceptions report around incidents when person with PMLD unable to have service they desired due to current personalisation policies and procedures.</li> </ul>
Postural care	<ul style="list-style-type: none"> <li>• Postural care pathway, that meets the needs of all adults/children with or at risk of body shape distortion, is agreed and in use.</li> <li>• Number of people on postural care pathway that experience a condition associated with body shape distortion – outcome tracked over time.</li> <li>• Tracking of bodyshape changes over time.</li> </ul>

### 10.3a Measuring satisfaction and quality

of life. It is difficult to measure how satisfied someone with PMLD is with a service, or with their life, as they cannot readily communicate their level of satisfaction. Nussbaum's Capability Framework, discussed in section 3.10, can be used to measure quality of life, through evaluating which capabilities apply to an individual with PMLD. The issues around measuring quality of life for someone with PMLD is explored in a recent article about measuring wellbeing of students with PMLD<sup>34</sup>, that is available online. One of the authors of this article, Gordon Lyons says that wellbeing for a person with PMLD is primarily about doing enjoyable things. Lyons developed the Life Satisfaction matrix, an instrument to measure quality of life for a child with PMLD, which contains one central theme, four main categories and 14 subcategories<sup>35</sup>.

#### Central category

Doing enjoyable things. Quality of life for a person with PMLD is primarily about doing enjoyable things. It's about being engaged with people who, and in activities that, are needed, wanted, liked and/or preferred.

#### Main category 1: Just like other children but personal

##### Subcategories:

- Wellbeing discourses. Subjective wellbeing does not make sense for these children, but quality of life and happiness do.
- Disability discourses. Disability is understood in different ways. People who are unfamiliar with PMLD often only see a disability in these children, and not how they are feeling, learning and growing.
- Childhood and adulthood. These children are developing. They have a future, but they live in the here and now.
- Individuality. These children are individuals, and have their own characters and expressions.

#### Main category 2: Happiness and contentment

Life satisfaction is about feeling both happiness and contentment.

##### Subcategories:

- Day-by-day. Happiness and contentment should be experienced daily, and life lived one day at a time.
- Just taking it all in. Contentment can be just taking it all in.
- Balance. Happiness and contentment is about personal balance.

#### Main category 3: Comfort and wellbeing

Life satisfaction is about feeling both comfort and wellbeing.

##### Subcategories:

- Physical health. Relief from acute/chronic pain is a prerequisite.
- Daily wellbeing. Just having a good day is valued.
- Belonging. Relationships are central.

#### Main category 4: Favourite things

Life satisfaction is doing and having favourite things.

##### Subcategories:

- Being with others, caring and sharing.
- Special things. Doing special things with special people.
- Water play. Playing with water expresses freedom, fun and belonging.
- Fun. Having a wicked sense of humour!

34 Lyons and Cassebohm. 2012

35 Lyons 2005

**10.3b The Department for Education** has developed a resource for teachers working with pupils with PMLD about quality of life, based on Lyons' work. This includes tools to help schools measure the quality of life of pupils with PMLD and their families. These resources can be accessed at <http://www.education.gov.uk/complexneeds/modules/Module-1.4-Quality-of-life/All/m04p010a.html>

**10.3c Quality of life** can also be measured and used to evaluate the effectiveness of services. One tool to measure the quality of life of families is the Beach Center Family Quality of Life Scale. This is available at [http://www.beachcenter.org/resource\\_library/beach\\_resource\\_detail\\_page.aspx?intResourceID=2391&Type=Tool&JScript=1](http://www.beachcenter.org/resource_library/beach_resource_detail_page.aspx?intResourceID=2391&Type=Tool&JScript=1)

**10.4 Social return** on investment (SROI) analyses and measures the value of changes brought about across a triple bottom line of social, environmental and economic outcomes.

At this time we are not aware of any social return on investment analysis specifically around services for people with PMLD, although there are a number of areas where this type of analysis is likely to show large benefits. E.g. postural care services or health facilitation. Future contracts and tenders for services for people with PMLD may start to specify a level of social return on investment. It may also be a way for the service provider to demonstrate

the value of their service, particularly to commissioners who do not have specialist knowledge regarding people with PMLD.

More information about social return on investment can be found at [http://www.sroi-uk.org/publications-uk/doc\\_details/241-a-guide-to-social-return-on-investment-2012](http://www.sroi-uk.org/publications-uk/doc_details/241-a-guide-to-social-return-on-investment-2012)

**10.5 It is important** that the people responsible for measuring outcomes, evaluating services and planning new ones have the right skills to do this, including knowledge of the needs and possible outcomes for people with PMLD. It is also crucial they involve people with PMLD and their families in this.

# 11. Involving people with PMLD and their families and friends in the commissioning of services

**11.1 Involving and co-producing** services for people with profound and multiple learning disabilities (PMLD) has particular challenges. Similar to the creative ways that can be used to measure the satisfaction of someone with PMLD, there are a number of ways that a person with PMLD and their families can be actively involved in providing feedback and coproducing services.

Information about the satisfaction of people with PMLD can be used to guide the commissioning of services. Families can be actively involved in co-producing services, representing both their own views and those of the person with PMLD that they support within meetings, and other common methods of customer involvement and co-production. A person with PMLD can be engaged directly to give their views using creative methods of communication to demonstrate the barriers they experience in everyday life, express their likes and dislikes, and express what is important to them. Alternatively information can be collected from individual's support plans and person-centred plans. Information collected

from these various methods can be collated and used for service planning and evaluations. The methods used to support people with PMLD to express their views must be meaningful, in order that the information collected is meaningful. This means that the work to engage people with PMLD will take time and require intensive facilitation.

**11.2 These approaches** were explored in the Involve Me project that looked at a number of creative methods of engaging people with PMLD to be involved in decision making and consultation. More information about the project is available on the website <http://www.mencap.org.uk/InvolveMe>

**Involve Me** looked at four ways of communicating with people with PMLD:

- creative communication
- sharing stories
- multimedia advocacy
- peer advocacy.

More information about these methods is available on the Involve Me website. The *Raising*

*our Sights* how-to guide to communication also contains more suggestions on how to communicate with people with PMLD.

**11.3 Working Together For Change** is a method of using person-centred information from reviews, support plans and person-centred plans to inform the commissioning of services. It sets out to provide:

- an effective approach to ensuring co-production with people using services
- a model for ensuring effective community engagement in the Joint Strategic Needs Assessment
- a way of understanding and measuring the impact of personalisation.

Information from the plans about each individual is translated into useable information about what is working and what is not working, and the top three goals for the person. Information from each individual is then clustered around themes, and analysed. Commissioning actions are then planned from the information that emerges from each cluster.

More information about Working Together for Change is available at <http://www.thinklocalactpersonal.org.uk/Browse/commissioning/coproducing/?parent=8566&child=5802>

**11.4 Some electronic** case recording and person-centred planning programmes will collate the goals and barriers of customers at the touch of a button. Iplanit is an electronic person-centred planning tool that is being used by many organisations supporting people with a learning disability. Go to <http://www.paradigm-uk.org/content/iplanitHome.aspx>

**11.5 Information about** the needs and preferences of people with PMLD can be collected via supported self expression/creative communication sessions, which could be commissioned through self-advocacy services or as a day activity. Increasingly, support providers will have access to this information through their electronic case recording and planning systems, such as Iplanit. Providers can be asked to provide aggregated information from customer support plans and person-centred plans, either voluntarily or from contracting arrangements. In these cases, it is important to take steps to be assured that the information provided are the preferences of the person with PMLD, rather than the support provider. And also to ensure that the needs and preferences of people with PMLD who do not use these support providers are also heard.

# 12. Commissioner checklist and action plan

This checklist can be used to see how locally-commissioned services are meeting the recommendations in *Raising our Sights*, that are directed at local areas (as opposed to national government), and to help identify change and improve local services.

If possible, you should involve a range of people to help you complete this checklist, including families of people with profound and multiple learning disabilities (PMLD), clinicians, service

providers, advocacy organisations, and the preferences of people with PMLD, using some of the methods explored in section 8 above.

Section 14 contains more detailed checklists for commissioners, which are drawn from the ten topic guides: *Advocacy, Communication, Health, Housing, Personalisation, Support for families, Training the workforce, What people do in the day, Wheelchairs and Clinical procedures.*

Raising our Sights recommendation	Things to consider	Good things happening	Where do things need to get better, where are the gaps?	Agreed actions
<p>Recommendation 2. Commissioners of health and social care services should identify mechanisms for supporting and enabling families to get advice and help in securing and running self-directed services from user-led organisations or self-help groups of other families.</p>	<p>How are self-help groups supported locally? Are these groups strong? What assistance does the group want to get stronger?</p> <p>How are user-led organisations and self-help groups supported to be knowledgeable about the needs and opportunities for people with PMLD and their families?</p>			

<p>Recommendation 3. Local health and social care commissioners should commission the development of independent advocacy arrangements suitable to represent the interests of adults with profound intellectual and multiple disabilities. They should include funding for continued advocacy in the package of self-directed services for adults with profound intellectual and multiple disabilities.</p>	<p>What self advocacy/supported self expression groups are available and accessible to people with PMLD?</p> <p>What skills do local professional advocates have for providing non-instructed advocacy for with people with PMLD?</p> <p>How is ongoing advocacy provided for people with PMLD who require it?</p> <p>How is the quality of advocacy for people with PMLD measured?</p>			
<p>Recommendation 5. Local authority social care services, together with their education and health partners, should keep up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in their area currently and projected in future to enable effective planning of services.</p>	<p>What information is in the JSNA?</p> <p>What are the gaps?</p> <p>For example, look at the Lambeth PMLD project report:  <a href="http://www.mencap.org.uk/lambethpmld">www.mencap.org.uk/lambethpmld</a></p>			

<p>Recommendation 6. In fulfilling their responsibilities for developing and training the social care workforce, local authorities should ensure that sufficient numbers of personal assistants (PAs) are available, trained in person-centred approaches to communication and support that meet the needs of adults with profound intellectual and multiple disabilities, through training that involves families and adults with profound intellectual and multiple disabilities in its delivery.</p>	<p>How is this addressed in the workforce development plan?</p> <p>How can this be achieved within the systems used to recruit PAs locally? What barriers are there and how can they be overcome?</p>			
<p>Recommendation 11. NHS bodies should pay particular attention to meeting the needs of adults with profound intellectual and multiple disabilities in implementing the government’s response to the Michael Report and the report of the Local government, parliamentary and health service ombudsmen.</p>	<p>What has happened locally to address the issues raised about health services after <i>Death by Indifference</i>?</p> <p>Do these measures meet the needs of people with PMLD?</p> <p>What more needs to be done?</p>			

<p>Recommendation 12. NHS bodies should ensure they provide health services to adults with profound intellectual and multiple disabilities in each area which focus on protection of body shape, dysphagia, epilepsy and investigation and resolution of pain and distress.</p>	<p>How are each of these areas addressed?</p> <p>Are the outcomes from these services acceptable?</p> <p>Are these services meeting the needs of everyone with PMLD?</p>			
<p>Recommendation 13. The board of each NHS trust should consider a report specifically focused on the adequacy of health services for adults with profound intellectual and multiple disabilities and approve an action plan to ensure adequate treatment.</p>	<p>Has a report on health services been completed?</p> <p>Is there an action plan?</p> <p>Are the targets in the action plan being met?</p> <p>Who is the lead person making sure the action plan is implemented?</p>			
<p>Recommendation 15. Powered wheelchairs should be provided where carers (whether family members, paid staff or others) need them in order to move the disabled person.</p>	<p>Do local policies and procedures allow adults with PMLD to be assessed for powered wheelchairs?</p> <p>How are people assessed for a wheelchair, how is quality of life measured? Are families happy with this measure?</p>			

<p>Recommendation 16. People with profound intellectual and multiple disabilities who have used powered wheelchairs (e.g. ‘smart’ wheelchairs) at home or at school during childhood should have the option of continuing to have them provided in adult life, where this sustains or enhances their quality of life</p>	<p>Do local policies and procedures allow adults with PMLD to be assessed for powered wheelchairs?</p> <p>How are people assessed for a wheelchair, how is quality of life measured? Are families happy with this measure?</p> <p>Are smart wheelchairs also considered? What are the criteria?</p>			
<p>Recommendation 17. Other people with profound intellectual and multiple disabilities should be provided with powered wheelchairs, suitably adapted with ‘smart’ technology, where this sustains or enhances their quality of life.</p>	<p>Do local policies and procedures allow adults with PMLD to be assessed for powered wheelchairs?</p> <p>How are people assessed for a wheelchair, how is quality of life measured? Are families happy with this measure?</p> <p>Are smart wheelchairs also considered? What are the criteria?</p>			

<p>Recommendation 25. Local authorities should ensure that adults with profound intellectual and multiple disabilities are able to take part in a wide range of meaningful activities – including employment, education and leisure activities</p>	<p>Shaping the market to ensure a wide choice of activities are available for people to choose from.</p> <p>Ensuring that all support plans for people with PMLD include a range of meaningful activities.</p>			
<p>Recommendation 26. Local authorities should ensure that they continue to provide somewhere which can be used as a base from which adults with profound intellectual and multiple disabilities can go to different activities during the day. This does not have to be restricted to people with profound intellectual and multiple disabilities – a place used by a wider range of people might be more interesting and provide more opportunities for social interaction.</p>	<p>Is there a base that people with PMLD can use during the day?</p> <p>Does this base meet the needs of all local people with PMLD, in terms of equipment, accessibility, location etc?</p> <p>Can the base be used by people with their own PAs, or is use of the base conditional on buying a service from a specific provider?</p>			

<p>Recommendation 27. Commissioners of health and social care services in every area should commission a range of short break services that provide staff with sufficient skills, expertise, equipment and facilities to meet the needs of families supporting adults with profound intellectual and multiple disabilities. No family supporting an adult with profound intellectual and multiple disabilities at home should be denied regular short breaks.</p>	<p>What short break services are available for people with PMLD?</p> <p>Do these services meet the needs of everyone with PMLD?</p> <p>Do people with PMLD and their families have enough choice about the type of short break services to meet their needs?</p>			
<p>Recommendation 28. Agencies should offer subsidised or free places to families and personal assistants on any training courses they run which are relevant to adults with profound intellectual and multiple disabilities. Individual budgets should include provision for training of personal assistants.</p>	<p>What relevant training is offered - e.g. person-centred active support, intensive interaction, communication, understanding challenging behaviour, using sensory equipment.</p> <p>Are these training courses offered to families of people with PMLD?</p> <p>How are personal assistants trained?</p>			

<p>Recommendation 30. Local policies should be based on the principles that (i) arrangements will be designed so that they sustain and enhance the quality of life of the disabled person by enabling clinical procedures to be carried out when and where needed, and (ii) arrangements will be coordinated and consistent between agencies, avoiding unilateral exclusions and consequent service gaps.</p> <p>Recommendation 31. Local policies should focus on procedures identified by families as currently problematic, including all relevant care settings, such as hospitals, community services and people’s own homes. These policies should specify who is responsible for carrying out clinical procedures in different situations and should deal with issues of clinical governance, legal liability and insurance.</p>	<p>How are the views of families heard? Has information about the procedures they find problematic been collected?</p> <p>Do local organisations have complementary procedures around carrying out clinical procedures in different settings?</p>			
<p>Recommendation 33. However funded, services for adults with profound intellectual and multiple disabilities should be developed in line with the government’s personalisation agenda. They should be designed around the individual and be person-centred, they should treat the family as expert, they should focus on the quality of staff relationships with the disabled person as the key to service quality and they should sustain the package of care.</p>	<p>How are people with PMLD offered personalised services?</p> <p>How is the quality of these services measured?</p> <p>How is service quality ensured? e.g. staff training, support for families, meaningful activities, enablement and prevention.</p>			

# 13. Provider checklist and action plan

This checklist can be used by providers as an internal quality assurance tool, or by commissioners or partnership boards when reviewing the quality of health or social care services for people with profound and multiple learning disabilities (PMLD). People with PMLD, their families and other stakeholders should be involved in the review whenever possible.

Recommendations from this report	Things to consider	Good things happening	Where do things need to get better, where are the gaps?	Agreed actions
Service outcomes for people with PMLD are monitored and collated.	<p>Are the outcomes meaningful?</p> <p>How are you assured that the service is delivering quality outcomes for people with PMLD?</p>			
The mental capacity act is applied and used consistently, and customers with PMLD are supported to make decisions.	<p>How do policies and procedures ensure this?</p> <p>How are staff supported to understand and implement policies and procedures?</p> <p>How is consistency ensured?</p>			

<p>Staff interactions and relationships are high quality.</p>	<p>How do staff know what is expected of them?</p> <ul style="list-style-type: none"> <li>• training</li> <li>• modelling of behaviour</li> <li>• supervision and appraisals</li> <li>• policies and procedures</li> </ul> <p>How is the quality of relationships monitored and assured?</p>			
<p>Staff have the skills and knowledge needed to meet the needs of people with PMLD.</p>	<p>Staff training.</p> <p>Personalised services - matching staff to individuals</p>			
<p>Each person with PMLD receives proactive health facilitation, to ensure all their health needs are being managed.</p>	<p>Staff training.</p> <p>Named health facilitators for each person.</p> <p>Support plans and other documentation.</p> <p>How is this assured?</p>			
<p>Policies and procedures around clinical procedures do not exclude any person with PMLD from activities they want to participate in.</p>	<p>Clinical procedures and policies</p> <ul style="list-style-type: none"> <li>• Does the organisation have these?</li> <li>• Are these consistent with other local organisations?</li> </ul>			

<p>Every person with PMLD has had an assessment to look at assistive technology, and is using the equipment that has been identified as beneficial for them.</p>	<p>How are assessments provided?</p> <p>How is equipment provided?</p> <p>Staff training.</p> <p>How is correct use of equipment assured?</p>			
<p>Every person with PMLD is meaningfully engaged in their daily activities.</p>	<p>E.g. person-centred active support.</p> <p>Staff training.</p> <p>How is this assured?</p>			
<p>Every person with PMLD is supported to be an active member of their community, and to use local facilities.</p>	<p>Staff training.</p> <p>Support planning.</p> <p>How is this assured?</p>			
<p>Every person with PMLD receives appropriate and consistent support for their communication needs.</p>	<p>Staff training.</p> <p>Access to communication assessments.</p> <p>Ensuring people have access to communication methods that are right for them.</p> <p>Recording how people communicate – e.g. communication passports.</p>			

<p>Every person with PMLD receives a personalised service.</p>	<p>How do people with PMLD have choice and control over their services? E.g. Person-centred planning, multimedia advocacy.</p> <p>How are people with PMLD engaged with service development?</p> <p>How do the needs and choices of people with PMLD influence the operation of the organisation?</p>			
<p>Every person with PMLD has the aids and equipment that best supports their mobility inside and outside their home.</p>	<p>Access to assessments.</p> <p>Access to equipment.</p>			
<p>Each person who requires it uses equipment to protect their body shape.</p>	<p>Staff awareness – identifying people who may need postural care.</p> <p>Access to assessments.</p> <p>Access to equipment.</p> <p>Staff training.</p>			

<p>Every person with PMLD is supported to build and maintain relationships with their friends and family.</p>	<p>Person centred planning.</p> <p>Circles of support.</p> <p>Staff training and supervision.</p> <p>How is this assured?</p>			
<p>Every customer with PMLD is supported to maintain a healthy lifestyle, including a good diet and regular exercise.</p>	<p>Support planning.</p> <p>Staff training and awareness.</p> <p>How is this assured?</p>			

# 14. Checklists from the topic guides

These checklists for commissioners are drawn from the individual guides and go into more detail about what local commissioners need to do to meet the *Raising our Sights* recommendations for each of the following topics:

- advocacy
- communication
- health
- clinical procedures
- housing
- personalisation
- support for families
- training the workforce
- what people do in the day
- wheelchairs.

# Advocacy

## Raising our Sights makes one recommendation:

### Recommendation 3:

Local health and social care commissioners should commission the development of independent advocacy arrangements suitable to represent the interests of people with PMLD.

They should include funding for continued advocacy in the package of self-directed services for adults with PMLD.

### What this means for commissioners

Commissioners need to understand and regularly review the advocacy needs of people with profound and multiple learning disabilities (PMLD) and their families and ensure there are appropriate local services to meet these needs.

Key messages:

- Commissioners need to commission independent advocacy to represent the interests of people with PMLD and include funding for advocacy in packages of self-directed support.

- Commissioners need to identify ways to provide independent support for families and carers.
- Commissioners need to meaningfully involve people with PMLD and their families as equal partners in decision-making about their own lives and in planning wider services.

Ways to do this:

Commission a range of advocacy provision that meets the needs of people with PMLD by identifying the numbers, needs, aspirations and circumstances of people and their families.

This will include:

- Independent Mental Capacity Advocates (IMCAs) and Independent Mental Health Advocates (IMHAs) as required by law
- professional advocates skilled in non-instructed advocacy
- citizen and peer advocates trained in communicating with people with PMLD as appropriate
- independent family advocacy.

The numbers and needs of people with PMLD should be reviewed regularly, and local advocacy provision reviewed and commissioned to reflect this.

The rights of families should not be ignored. Commissioners should not assume they are willing and able to provide support (including advocacy) when it is no longer practical for them or their family member.

Understand that advocacy will take longer for people with PMLD. Set realistic targets and budgets for advocacy schemes and do not limit the number of sessions people are entitled to. Expect services to understand and actively demonstrate how they meaningfully involve people in decisions about their lives, and use circles of support to identify and help people achieve their personal goals in life. Circles of support are groups of people who meet together on a regular basis. The members, who may include family, friends and other community members, are not paid to be there. There are recommendations from Mencap and the British Institute of Learning Disability (BILD) project, **Involve Me**, that will help local areas meaningfully involve people with PMLD:

- Involve Me has lots of examples of listening to people with PMLD in creative ways. Make this part of the culture of commissioning. Find out about each individual's preferences and consolidate the learning to inform the development of appropriate services and support (including a range of advocacy support).

- Someone on the Learning Disability Partnership Board should be appointed the PMLD champion to ensure their needs are considered at every stage of planning.
- Invest in training about the Mental Capacity Act and evaluate the effectiveness of the training.
- Ensure services have clear policies and procedures for staff to follow so that a person is able to make as many decisions as possible. If a person is assessed as lacking capacity for a particular decision, they should be as fully involved as possible.
- Develop a culture of engaging with people consistently, not just at times of crisis or change.
- Ensure there are enough speech and language therapists to enable staff working with people with PMLD to be trained and supported to use communication resources appropriately, and maximise people's involvement in decisions about their lives.
- Have an expectation that services will empower staff to find creative and appropriate ways to engage with those they support, using staff meetings, training and supervisions to encourage and develop and share good practice.
- Ensure there are well trained and supported advocates locally who know how to work alongside people with PMLD, and understand non-instructed advocacy approaches.
- Encourage and develop local peer advocacy schemes where people with a learning disability represent and advocate for people with PMLD. A shared experience of services can often mean that peer advocates raise issues that other people overlook

# Communication and the use of communication aids and assistive technology

*Raising our Sights* makes four recommendations:

## **Recommendation 18:**

The government should decide whether funding the provision and repair of communication aids for adults with profound intellectual and multiple disabilities is the responsibility of the NHS or of local authority social care services.

## **Recommendation 19:**

The Department of Health should commission the Social Care Institute of Excellence and/or the National Institute for Health and Clinical Excellence to review and disseminate the available research and practice on the use of communication aids and assistive technology for adults with profound intellectual and multiple disabilities.

## **Recommendation 20:**

The Department of Health should fund research and demonstration projects in each region (perhaps through the Health Technology Assessment programme of the National Institute of Health Research) to identify opportunities for increasing the quality of life of adults with profound intellectual and multiple disabilities through the use of communication aids and assistive technology.

## **Recommendation 21:**

The Department of Health should commission organisations, such as Communication Matters and HFT, which have expertise in this area, to advise families and agencies about new opportunities presented by these communication and control aids; to offer opportunities for people to try out different equipment; and to train staff.

## **What this means for commissioners**

These recommendations are aimed at the national level, but there is still much to be done at the local level to make sure the communication needs of people with PMLD are met. This will include ensuring there is a well-trained workforce and access to the specialist assessment, advice and equipment needed by people with PMLD and those who support them.

Key messages

To truly meet the needs of people with PMLD, commissioners need to understand their particular needs in the area of communication and technology.

This includes:

- meaningfully involving people with PMLD and their families 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
- a coordinated total communication approach

across all services, making sure that this is fully inclusive of the communication approaches required by people with PMLD

- a well-trained workforce, with skills in appropriate communication methods and technologies with people with PMLD
- access to specialist support such as speech and language therapy
- budget resources for equipment purchase and maintenance. Commissioners must establish a clear agreement and policy about funding of communication aids and assistive technology in their local area
- recognition of the cost in terms of the time needed to provide high quality services
- a cultural change to create high expectations and aspirations for people with PMLD.

#### Ways to do this

In order to commission services that support effective communication with people with PMLD commissioners should:

- establish the numbers, needs, circumstances and aspirations of people with PMLD and review these regularly

- find out what is important to people with PMLD on a regular basis, not just at times of crisis or change
- understand that effective communication with people with PMLD needs skill, time and resources. Therefore commissioning decisions must acknowledge and reflect the time and skills required by staff employed to work with people with PMLD
- have a well-trained and supported workforce which knows how to communicate effectively with people with PMLD and when and how to access additional resource and support as needed
- ensure there are enough speech and language therapists employed locally to train and support staff to involve people with PMLD in decisions about their lives
- ensure that the workforce has access to ongoing training and development in the communication approaches that are most effective for people with PMLD, as recommended by Goldbart and Caton (2010). This will include intensive interaction, communication passports, objects of reference and the use of switches for cause and effect
- ensure the communication needs of people with PMLD are well documented and known to

those involved in their support. For example, through the use of communication passports, multi-media profiles and person-centred plans

- ensure ongoing checking and monitoring to make sure services meet the needs of people with PMLD. Involve people with PMLD and their families in this process. Involve Me has examples of creative ways to support people to share stories about what has worked or not worked well for them
- appoint someone as a 'PMLD champion' on any planning or policy groups in the local area
- train staff about the Mental Capacity Act and check that they use what they learn
- have clear policies and procedures for staff to involve people with PMLD and their families as fully as possible in all decisions that are taken on their behalf
- expect services to give staff the support and confidence to find creative and appropriate ways to find out what is important to people with PMLD and share good practice. The key messages from Involve Me provide a useful framework to use to check how well this is being done.

For more information, go to <http://www.mencap.org.uk/involveMe>



# Health

## Raising our Sights makes three recommendations:

### Recommendation 11.

NHS bodies should pay particular attention to meeting the needs of adults with PMLD in implementing the government's response to the Michael Report and the report of the local government, parliamentary and health service ombudsmen.

### Recommendation 12.

NHS bodies should ensure they provide health services to adults with PMLD in each area which focus on protection of body shape, dysphagia, epilepsy and investigation and resolution of pain and distress.

### Recommendation 13.

The board of each NHS trust should consider a report specifically focused on the adequacy of health services for adults with PMLD and approve an action plan to ensure adequate treatment.

There are also three recommendations which relate to policies and procedures for clinical processes. These are covered in the clinical procedures checklist.

### What this means for commissioners

Local commissioners must commit to implementing the recommendations, find out what people with PMLD need, and make sure their policies do not marginalise them.

All actions to address the recommendations from *Healthcare for All* (the Michael Report) must be inclusive of the needs of people with PMLD:

- staff training must address their specific needs
- data about people with learning disabilities should be analysed in a way that enables the specific health needs of people with PMLD to be understood
- annual health checks must be thorough and personalised in terms of the person's complex health needs.

This poses challenges on a number of levels. Firstly, the lack of a nationally-agreed definition of PMLD and, secondly, difficulties sharing health information. A well-established approach is to use the PMLD Network definition during profiling, audit and research activities to strengthen the information collected, and apply the findings to local populations.

### Key messages

- Commissioners need to meaningfully involve people with PMLD in decision-making about their own health, and around planning health services.
- Commissioners need to treat the family as experts.
- Commissioners need to create health services which:
  - are 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
  - are cost effective
  - are forward thinking.
- To fully meet the needs of people with PMLD, commissioners need to understand the intricacies of the skills required to recognise health change and meet the person's complex health needs.
- They also need to understand 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. Many of us take it for granted that we can recognise and

communicate our pain and distress to others. Complex communication and recognition of pain and distress must be a core skill in those working with people with PMLD.

- If commissioners carefully plan and develop health services to meet local needs then it is more likely they will work well for all local people. However, it is also important that the services they develop effectively engage with people with PMLD, and the people who know them well in order to meet their individual health needs.

Ways to do this

In order to commission health services that meet the needs of people with PMLD, commissioners should:

- involve people with PMLD and their families in consultations about health services, and ensure you include those who could be particularly marginalised

**Giving us a Voice** aims to break down barriers to inclusion for people with a learning disability and their families from ethnic minorities.

**Involve Me** has examples of creative ways to support people with PMLD to share stories about what has worked or not worked well for them

- ensure that all services demonstrate consideration and action to ensure fair and equal access in terms of both cognitive and physical access to services
- establish the numbers, health needs, circumstances and health goals of people with PMLD and review these regularly to ensure you are commissioning appropriate health services
- recognise that people with PMLD have complex and unique ways of communicating
- commission training for all NHS staff about the particular health needs of people with PMLD, with a focus on communicating health choices
- ensure there are enough speech and language therapists to train and support staff to involve people with PMLD in decisions about their lives
- understand that it takes time to establish effective therapeutic relationships with people with PMLD. This will require ensuring services have the time and skills to get to know the person, and that their staff are given the support and confidence to find creative and appropriate ways to find out what is important to people and share good practice
- have ongoing checks and monitoring to make sure services are meeting the health needs of people with PMLD, not just at times of crisis or change
- work with people with PMLD and their families to set up circles of support
- appoint someone on the local partnership board as a PMLD champion
- commission health-focused training for all staff supporting people with PMLD
- commission training for health professionals to challenge negative assumptions and beliefs about the quality of life of individuals
- implement the **Getting it right** charter in all health services you commission:
  - Make sure **Hospital Passports** or equivalent, and **Health Action Plans** are developed, used and reviewed in terms of quality and outcomes
  - Make sure all staff understand and apply the principles of the **Mental Capacity Act**
  - Appoint a learning disability liaison nurse in all hospitals
  - Make sure there is adequate local provision to ensure every eligible person with a learning disability can have an annual health check
  - Provide ongoing learning disability awareness training for all staff
  - Listen to, respect and involve families and carers

- Provide practical support and information to families and carers
- Provide information that is accessible for people with a learning disability
- Display the principles for everyone to see.

### **Access to GPs and primary care services**

- Ensure GPs record and provide the reasonable adjustments that people need, and that they are flagged up on the system when the person's family or carer contacts the service. For example, it might be that the person needs a double appointment or the first appointment of the day.
- Monitor the provision of annual health checks with the person's GP and wider primary healthcare teams. (The healthchecks should be thorough and personalised to the person's complex health needs.)
- Encourage GPs and other primary care services to promote pre-treatment visits to help prepare the person for planned or potential emergency interventions such as injections, dental and vision checks. Learning disability community nurses should support this.
- Ensure that GPs and primary care services providers are not only aware of Health Action Plans and Hospital Passports or equivalent,

but are familiar with how to use them during consultations.

### **Access to specialist healthcare services**

- Invest in the growth of local health specialists to meet the needs of the increasing numbers of people with complex health needs, and ensure that there are enough specialists to meet the health needs of people with PMLD when required.
- Encourage specialist healthcare providers to promote pre-treatment visits to help prepare the person for planned or potential emergency interventions. For example, epilepsy monitoring. Learning disability community nurses should support this.
- Ensure that specialist healthcare providers are not only aware of Health Action Plans and Hospital Passports or equivalent, but are familiar with how to use them during consultations.
- Monitor local service provision for specialist health checks.
- Provide local guidance to ensure someone is acting as the co-ordinator of a person's healthcare, so that their needs are met in a holistic way. This may be the person's GP, but if there is a consultant they see regularly for a dominant health issue, then this might be the best person to monitor the person's overall health, as they will be exploring how

other health issues are interacting with the condition they are monitoring (for example, complex epilepsy).

- Ensure that any equipment loaned to people and their families - such as wheelchairs, suction equipment or tube feeding pumps - is kept in full working order and repaired promptly.
- Ensure that people with PMLD are not further disadvantaged by the withdrawal of equipment when they reach adult years. For example, powered/smart wheelchairs provided in childhood should continue to be provided throughout adulthood.

### **Access to hospital admissions or appointments**

- Commission sufficient learning disability liaison nurses and promote this role so people are aware of how and who to contact when needed.
- Ensure that hospital staff know about Health Action Plans and Hospital Passports, or equivalent, and how to use these during consultations.
- Make sure learning disability liaison nurses record any reasonable adjustments in the person's health action plan and hospital passport so the information is there for the next visit.

- Ensure there is a named person coordinating the hospital experience, from pre-admission through to discharge home. The learning disability liaison nurse should support hospital staff to lead on this.
- Promote pre-admission visits to help prepare the person for planned or potential emergency visits. The community learning disability nurse or health facilitator is ideally placed to provide this role, linking with hospital staff and in some cases the learning disability liaison nurse.
- Make sure there is pre-admission and discharge planning for planned stays in hospital. This will help the hospital ensure it has the right equipment and support in place, such as a special mattress or hoist, and will be able to meet dietary requirements and care needs.
- Ensure that the hospital will meet its duty of care when a person with PMLD is admitted. Parents should not have to come in and care for their son or daughter, although they might choose to. To meet this duty of care hospitals may need to commission extra nursing or care staff to support them.
- Ensure hospitals provide suitable overnight accommodation for family carers and personal assistants who choose to remain with the person while they are in hospital.
- Ensure hospitals have clear policies and procedures to support family carers and personal assistants who choose to provide care roles to the person with PMLD while in hospital. There need to be clear lines of accountability.
- Check hospital staff are trained in the provisions of the Mental Capacity Act and that they use what they learn.
- Monitor hospital policies and procedures to ensure staff involve people with PMLD and family carers as fully as possible in all decisions.

#### **What this means for commissioners**

Commissioners should ensure that adults with PMLD are not denied services or access to certain opportunities and activities because staff in those agencies are unwilling or unable to undertake clinical procedures, or use medical devices to sustain or support life.

Clinical procedures are processes or procedures which an individual with complex health needs may require either as part of their routine care, or within an expected emergency situation, in order to maintain their optimal health or sustain their life. These procedures are sometimes referred to as ‘invasive clinical procedures’.

# Clinical Procedures

## Inclusion of disabled adults with complex health needs

### *Raising our Sights* makes three recommendations:

#### **Recommendation 29.**

The Department of Health should lead an initiative to adapt policies and procedures used in children's services for use in services for adults, involving representative bodies of the relevant professions and agencies.

#### **Recommendation 30.**

Local policies should be based on the principles that (i) arrangements will be designed so that they sustain and enhance the quality of life of the disabled person by enabling clinical procedures to be carried out when and where needed, and (ii) arrangements will be coordinated and consistent between agencies, avoiding unilateral exclusions and consequent service gaps.

#### **Recommendation 31.**

Local policies should focus on procedures identified by families as currently problematic, including all relevant care settings, such as hospitals, community services and people's own homes. These policies should specify who is responsible for carrying out clinical procedures in different situations and should deal with issues of clinical governance, legal liability and insurance.

Clinical procedures cover the support required by individuals who depend on a medical device to sustain their life. Within services this support is usually provided by a non-health qualified person who has been trained and assessed as competent to provide it.

#### 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.

#### Ways to do this:

Commissioners and service providers should consider and develop plans, policies and joint working agreements that ensure people with PMLD who need support with clinical procedures can be safely included in all services, whether specialist or universal.

The guide on clinical procedures outlines ten areas which should be put in place:

1. joint working arrangements – local policies and procedures
2. information on the person
3. developing a partnership with the person
4. issues of consent
5. risk management
6. plan outlining health needs
7. training and support of staff
8. written information

## 9. written records

## 10. review and monitoring.

This process is based on the protocols within children's disability services which have now been in place for about ten years. It is an approach which attempts to create a balance between risks and rights. The purpose of the guide on clinical procedures is to help families, providers and commissioners to think through the issues and develop a protocol which is appropriate to their local situation.

The process is equally applicable to adults who manage and arrange their own services and support through individual budgets and direct payments. The arrangements for risk assessments to be carried out and support staff to be trained must be as robust as those for directly-provided services when they are employed by the disabled person.

On the next pages we include a checklist that summarises the key points of the process. This should be used together with the guide and should not be used without reading the whole guide on clinical procedures.

## Checklist

<p><b>Policies and procedures (Area 1)</b></p> <p>Are there clear written policies and procedures detailing how adults with PMLD who require clinical procedures will be included in services? If not, consideration should be given to the setting up of a partnership group to write and agree those policies and procedures across all services in the area.</p>	
<p>Has the drawing up of the policies and procedures involved managers, commissioners, front-line staff (from all agencies) and families?</p>	
<p>Is there agreement by all agencies to follow the same policies and procedures?</p>	
<p>Is there a process for monitoring and reviewing the policies and procedures?</p>	
<p>Does your organisation have its own policy and procedures which are in line with the local area arrangements?</p>	
<p>Does the organisation's policy:</p> <ul style="list-style-type: none"> <li>• cover the roles and responsibilities of staff and other paid carers?</li> <li>• outline what the service expects from families?</li> <li>• outline the training and support staff carrying out clinical procedures can expect?</li> <li>• clarify the insurance or indemnity arrangements?</li> <li>• clarify processes such as risk management, record keeping, etc?</li> <li>• explain the type of arrangements that will be in place in the case of an emergency?</li> <li>• cover activities away from the usual base?</li> </ul>	

<b>Information on the individual (Area 2)</b>	
Does your organisation take a proactive role in promoting an atmosphere of honesty and openness so that families are encouraged to share information about their son or daughter with you?	
Prior to starting a service with an individual who requires a clinical procedure, do you have a method of recording information about their disability, medical condition and support needs?	
Is your organisation clear about who decides how much and what information will be shared with staff?	
Are there clear principles on which this decision is made?	
Is there are process for passing on and receiving information when an individual with PMLD moves from one service to another?	
Do staff know where to seek more information about particular conditions or how those conditions may affect an individual?	

<b>Partnership with the individual (Area 3)</b>	
Does your organisation promote the principles of independence, dignity and ensuring communication is understood?	
If the disabled adult uses non-verbal communication, is the meaning of their non-verbal communication recorded and shared with all staff (for example, through the use of a communication passport)?	

<b>Consent (Area 4)</b>	
Have staff received training on the Mental Capacity Act (2005), and understand how this applies to individuals with PMLD?	
Does your organisation have in place a process for making and recording decisions using the 'best interest' process?	

<b>Risk management (Area 5)</b>	
Have staff received training on risk management?	
Is there clarity on who should conduct the risk assessments relating to clinical procedures?	
Are the risk assessments specific to the individual and specific to a procedure?	
Are the risk assessments written in plain English rather than health and safety jargon?	
Are the risk assessments person-centred, balancing rights with risks and safeguarding the dignity of the individual?	

<p><b>Health care plans (Area 6)</b></p> <p>Does each individual requiring clinical procedures have a plan which details all their health needs, including the clinical procedures they may require?</p> <p>Or does the individual have specific plans covering each clinical procedure that may be required?</p>	
<p>Does the plan cover the following areas:</p> <ul style="list-style-type: none"> <li>• the specific procedures that need to be carried out and who should carry them out</li> <li>• additional risk assessments that may be required and who is responsible for carrying them out</li> <li>• information on how health needs may affect the use the service, for example transport issues</li> <li>• the supply, use, storage and maintenance of equipment</li> <li>• individual preferences for how a procedure will be carried out</li> <li>• anticipated changes</li> <li>• arrangements for reviewing the plan.</li> </ul>	
<p>Is the plan kept in a place which is accessible to staff who need to read it?</p> <p>Is an emergency plan required?</p> <p>If so, is it in a format which is easy to read and accessible in an emergency?</p>	

<b>Training (Area 7)</b>	
Have staff undertaken general training on the most common health conditions, for example epilepsy?	
Is there clarity about who to contact in health when specific training for a procedure is required?	
Is the training on a specific procedure carried out by a registered nurse or medical practitioner who knows the individual?	
Is all specific training signed off once the support staff member has been deemed competent to carry it out?	
Are arrangements for ongoing support by the health trainer in place?	
Are there issues of vicarious liability? If so, has the service manager clarified legal responsibility for the actions of staff not employed by the service?	

<b>Written information (Area 8)</b>	
Does the service hold written information about the individual, such as disability, likes and dislikes, method of communication, emergency contacts, etc?	
Where medication is given, either orally or via an enteral feeding tube, have dosages been verified by a doctor?	
Is there a process for responding to changes of dosages at short notice?	

<b>Written records (Area 9)</b>	
Does the service record the administration of medication and the carrying out of clinical procedures?	
Where the individual takes a number of different medicines, has consideration been given to using a single record agreed by all agencies and the family?	
Does the service have a protocol for recording and reporting errors in the administration of medication and other procedures?	
Does the service record the specific training received by support staff?	

<b>Review and monitoring (Area 10)</b>	
Are the clinical procedures reviewed at each annual review?	
Is the health care plan updated as part of the annual review?	
Are the training needs of staff regularly reviewed and updated?	

# Housing

*Raising our Sights* makes two recommendations:

## Recommendation 7.

The government should revise arrangements for capital subsidy from the Homes and Communities Agency to remove the disincentive to provide adequate housing for adults with profound intellectual and multiple disabilities.

## Recommendation 8.

The governments should resolve the apparent contradiction between social care policy and housing policy created by the Turnbull judgement to facilitate the provision of adequate housing for adults with profound intellectual and multiple disabilities.

### What this means for commissioners

Although the *Raising our Sights* recommendations are directed at national government, there is much that commissioners and housing providers can do on a local level to facilitate the availability and access to suitable housing for people with PMLD.

Key messages

### Housing design

Many people with PMLD use a wheelchair and need a physical environment that differs from most ordinary housing. If people require larger bathrooms and kitchens, space for large pieces of equipment and building structure that can support heavy equipment and overhead hoists, existing housing will be difficult to adapt. The option of new-build properties that meet the needs of people with PMLD should be considered.

### It's not just about the bricks and mortar

Helping people with PMLD to find a good place to live is more than just arranging the bricks and mortar. There needs to be a shift in how the needs of people and families are planned for to give them real control over their lives. Mainstream organisations like housing departments need to understand how they can best serve people and families with PMLD. People need good support to enable them to be control of in their lives and be part of their communities as well as staying safe and well.

### It does not need to be 'all or nothing'

Families often face the stark choice of sending their loved one away from the family home or having total responsibility for their care.

One parent said: *"If only there had been somewhere local where my daughter could have spent a few nights a week, it would not seem such a huge move into independent living. We could have used the same PAs to support her, and worked out what was needed to make the move successful. At the moment it just feels like a leap into the unknown..."*

### Break the cycle of crisis-led and out-of-area placements

Many young people with PMLD are encouraged into the residential-college-and-then-specialist-residential-care route because there are simply not enough, if any, suitable local education, respite and social opportunities available to them. Exhausted families soon learn that they need to fight for the 'prize' specialist college or residential care option, simply because it is the only way they can get some respite. This creates expectations that the needs of people with PMLD cannot be met in their communities and therefore families do not see it as an option.

Many people with PMLD end up living in services outside of their area, or in inappropriate local housing because of the lack of suitable local housing, care, education and social opportunities. But it makes little sense on many levels:

- Family, friends and communities.

If people remain in their communities and close to their families, friends and support networks, they are more connected with a wider group of people who can look out for them and help keep them safe and well supported.

As one family carer said:

***“I often hear from friends and neighbours that they saw my daughter out and about, usually in local cafés or parks. Having an unofficial network keeping an eye on her gives me an additional sense of security - something I wouldn’t have if she was to move away from her neighbourhood.”***

- Knowing who has PMLD in our communities and planning ahead.

Unlike many other groups of people who need support, people with PMLD and their families are known to statutory services from a very young age. This information can be used to proactively plan local housing and care several years in advance of needing it.

People with PMLD are least likely to continue to be cared for in the family home into adulthood because of the complexity of their needs and the stress this places on families, and are likely to need alternative housing and care sooner than other adults with learning disabilities. For these reasons, it is easier to estimate and plan for when local people with PMLD will need alternative housing and care.

- Better managing the cost and quality of care by planning local housing and care.

It is highly likely that most people with PMLD will meet the eligibility criteria for continuing health and/or social care funding and there is a statutory duty on local authorities to fund care for those who meet their eligibility criteria. Monitoring quality care when it is provided outside of the local area is costly when done well and risky when not done well. Monitoring of local services is easier and more affordable.

- Getting the right housing to help people with PMLD lead equal lives.

People with PMLD are highly likely to have an urgent need for housing, or become homeless, at a younger age when their families can no longer continue to provide 24-hour care, and will become a priority for the local housing department.

Most people with PMLD will need housing that is physically adapted and has the right space and equipment to get the care they need. The right housing can be the foundation of social inclusion if it keeps people in their communities and close to valued services and facilities.

Housing departments can plan more cost-effective housing for local people with PMLD if they know who will need housing several years in advance.

Ways to do this

- 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.
- Work with the housing and local planning department to ensure the needs of people with PMLD are understood across all departments.
- Proactively plan for this group of people, based on the understanding that they will require funding and that the funding levels are likely to be high. This will help avoid making placements in crisis where the individual, family and commissioner have less control over the cost and quality of housing and care services.
- Involve families, friends and communities in planning local housing and care as opposed to placing people in traditional services. This allows for more high quality, creative, flexible and potentially cost-effective housing and care options.
- When planning and delivering housing and care, remember that family, friends and communities are important and give richness and meaning to people’s lives.
- Plan early and think creatively. Investigate housing options that do not rely completely

on public sector funding to develop, and that can be better utilised if planning takes place at an early stage. For example, you could explore working with charities and private investments.

- Find out if people with PMLD can access money through family or trust funds that can contribute towards a suitable housing option.
- Use resources more flexibly to enable families to share the care with another family or service, or to build an extension to the family home with carers brought in for part of a week, for example. The transition from the family home could be made easier by building up independence and allowing families to trust their needs will be met, to take the pressure out of the move to adulthood.
- Commission good quality local services, such as shared care/respice, to give families a much-needed rest and allow young people with PMLD to stay with their families longer. By investing in local services, commissioners will save in the medium- to long-term. For smaller local authorities with lower numbers of people with PMLD, they may need to commission specialist respice and education services across neighbouring areas to make those services viable.

Leeds City Council's Shared Lives service specialises in short breaks and day support

provision, working alongside the third sector long-term arrangements Shared Lives service. Individuals receive short breaks in the Shared Lives carer's own home. The service also provides a separate outreach service, using contracted care workers to provide day support in the community to Shared Lives standards and values.

Leeds has developed the short breaks Shared Lives service to offer medium- as well as short-term arrangements for assessment and to support transition to adulthood or independence. It provides emergency support following family bereavement or in reaction to safeguarding concerns. The supportive family environment can offer more intensive emotional support than residential care.

The council has supported one full-time breaks carer to build a fully-accessible extension to their house which allows people with a greater range of disabilities to use the service. It has calculated that supporting the short breaks Shared Lives carer in this way will enable it to make savings of £30k per year (minus the capital investment), based on comparing costs with the costs of equivalent day provision for people with learning disabilities. This would also have great potential to delay the use of residential care through providing more consistent and effective breaks for family carers.

## Building design

As well as standard wheelchair accessible design, commissioners should:

- include assistive technology and smart home technology in design specifications so that individuals have maximum potential to control their environment and be as independent as possible
- consider the extra care model to maximise flexibility of use, funding and sustainability when commissioning new-build properties
- ensure that shared housing models incorporate as much private space as possible
- include additional space requirements for equipment and to enable carers to support individuals comfortably and safely
- think about good street access and availability of parking
- work with local housing associations and housing developers to ensure that local developments include flats built to Lifetime Home Standards, and which can be adapted for people with PMLD.

## Sustainable services

Commissioners must understand how to make services both person-centred and financially sustainable through:

- support such as assistive technology, information and communication technology, support tenants, dogs for the disabled, supported living networks, good neighbour schemes, etc
- a workforce that is fit for purpose and provides a high quality of care
- training and information for housing commissioners and providers covering the needs and rights of people with PMLD
- ensuring housing departments understand the full range of housing options and not just social housing
- developing expertise within social work staff and housing advisors on the alternatives to residential care so that they can provide families with the information and support they need
- recognising that through ‘localism’ it is likely that active families in the area will have the greatest influence on the development of local housing. Commissioners and providers need to provide the means for such families to lead in the process of getting housing and support where families want to and feel able to do this. They also need to support those who don’t want to or aren’t able to do this, to get the right housing and support for their family member with PMLD

- recognising the expertise that families hold about people with PMLD, and ensuring this is used to influence the development of local housing
- developing the knowledge, confidence and skills to commission financially-sustainable services, keeping people with PMLD in their communities.

### **Housing and care commissioners’ pathway to housing**

#### **Pre-16 health and social care commissioners work with education to ensure that there is local education and respite services that enable children with PMLD to avoid being sent to residential colleges.**

- If there are effective and high quality local respite and education services that meet the need of young people with PMLD, this will be key to breaking the cycle of sending people with PMLD away from their families and communities.
- Investment in local services that both give young people a good quality of life and support families who are usually exhausted and often at breaking point, will have cost benefits.

#### **Housing and care commissioners collect local data of people with PMLD and feed into annual planning for local housing and care.**

- Demographic information can be used for general planning purposes. However, this group is already identified through the education system and these figures will be more accurate for planning housing.
- Take a proactive approach to getting people with PMLD on the housing register with the housing department for planning purposes (not necessarily as applications for individual housing) and ensure that there is a mechanism for identifying their additional housing needs.

#### **Housing and care commissioners develop annually-reviewed plans to meet housing and care needs as part of strategic housing and commissioning plans and JSNA.**

##### **Include estimates of;**

- number of family homes needing adaptation
- number of independent units of adapted housing needed
- number of places in extra-care adapted housing needed
- number of places in adapted shared housing needed
- estimated funding for care and support needed.

**Ensure that the housing needs of people with PMLD are included in the Joint Strategic Needs Assessment and Neighbourhood panels and that planning department are made aware of this.**

- Find representation from family carer groups to take part in neighbourhood panels to ensure that people are included in housing planning.
- Ensure that families of people are aware of the Community Right to Buy and the Community Right to Challenge in relation to planning housing for people with PMLD.

**Produce information about housing and care options, funding and rights for people with PMLD aimed at families, social workers, teachers, advisors and advocates that includes:**

- information about supported housing and residential care
- social rented housing (renting from a council or housing association)
- charities providing housing
- home ownership including HOLD, Homebuy and Shared Ownership
- how families can invest in housing and join together with other families to invest in housing

- how families can adapt their own property to provide independent housing
- how personalisation, personal budgets and self-directed support work
- the various types of support available to live in your own home including assistive technology, setting up a micro-enterprise and homesharers
- ways to find housemates if wanting to share with others.

**Make specialist help available through housing and social services to plan and assess housing need with families.**

- Ensure that housing and social services are working together on the ground and with families.
- Have expertise in alternatives to social housing including home ownership options, family investment, bringing families together to set up micro-enterprise and companies to deliver housing and care.
- Have facilitators so that families can come together and plan services.

**Explore and plan capital funding options for housing.**

- Bids through the affordable housing programme.

- Redevelopment of current services or sites.
- Mixed tenure, extra care-type developments.
- Private investment.
- Family investment.
- Partnership with charitable housing organisations.

**Explore partnerships with neighbouring local authorities.**

- If needing to deliver specialist services for small numbers of people, it may be more cost-effective/efficient to deliver in partnership with neighbouring commissioners.
- could specialist housing schemes be shared with neighbouring local authorities to make the scheme more sustainable?

# Personalisation

## Raising our Sights makes two recommendations:

### Recommendation 1:

The government should continue to provide leadership to ensure that personalisation is extended to more people, including more adults with PMLD, in a way which secures the benefits of improved quality of life and cost effectiveness.

### Recommendation 33:

However funded, services for adults with PMLD should be developed in line with the government's personalisation agenda. They should be designed around the individual and person-centred, they should treat the family as the expert, they should focus on the quality of staff relationships with the disabled person as the key to service quality and they should sustain the package of care.

### What this means for commissioners

The government agrees with points made in *Raising Our Sights* and: **“Wants to see a more personalised, preventative service focused on delivering the best outcomes for people**

**who need support, enabling people to live as independently as possible.”** Government response to *Raising our Sights*, 2011.

But it has not adopted any of the recommendations made by *Raising our Sights* as policy.

However, in its **Vision for Adult Social Care, Capable Communities and Active Citizens**, the government makes clear that it is looking to councils, alongside the voluntary sector and local communities, to make this happen.

Personalisation is achievable for people with PMLD and can transform the lives of the person and their family. General strategies and policies do not go far enough to ensure this group is included and this can result in people with PMLD not benefiting from this approach as often as they should. However, good local commissioning and creative service development can ensure that many more people achieve personalised support.

Key messages:

- Commissioners need to recognise 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.

Ways to do this:

- Establish the numbers, needs, circumstances and aspirations of people with PMLD within the local area and review these regularly.
- ‘Trail blaze’ cultural change in the perception of people with PMLD, their capabilities, the contributions they make, aspirations for them and, indeed, expectations of them.
- Regard families of people with PMLD as experts and listen to what they have to say.
- Ensure better and more collaborative working alongside the families (and/or circles of support) of people with PMLD.
- Engage directly with people with PMLD by actively seeking better representation via local partnership boards, advisory groups and user-led advocacy groups, and appointing a PMLD ‘champion’. Mencap’s Involve Me details creative approaches aimed at increasing the involvement of people with PMLD in decision-making and consultation.

- Ignore the short-term benefits of offering only self-directed support where they can make an immediate saving in expenditure. A personalised package for someone with PMLD might appear expensive, but the long-term cost effectiveness cannot be ignored.
- Getting it right in the first place can lower overall care costs by reducing expenditure in other areas, such as health intervention, as well as avoiding expensive emergency placements for people who have challenging behaviour.
- Ensure local authority staff are trained to understand that people with PMLD have the same rights as everyone else.
- Ensure local authority staff recognise and understand the importance of true person-centred planning and circles of support. Work with people who do not have a circle of support to set one up.
- Ensure local authority staff are trained about the Mental Capacity Act and check they put this into practice.
- Train staff in more creative and meaningful approaches to communicating with people with PMLD.
- Expect all services to have clear policies and procedures for staff to involve people with PMLD as fully as possible in decision making.

- Ensure sufficient funding is allocated to recruit and retain highly-skilled supporters, and cover the costs of directly employing support staff.

### Key policy documents for commissioners

The cross-government concordat **Putting People First (2007)** states that personalisation should be the cornerstone of public services and recognises that if people are able to live their own lives as they wish, they must be confident in the fact that they will receive high quality services.

The government green paper **Shaping the Future of Care Together (2009)** reinforces the view that service-led approaches to social care result in people not always receiving the right help at the right time, and being unable to shape the kind of support they need.

**The Mental Capacity Act (2005)** supports the values of personalisation by empowering people to make their own decisions.

**The Equality Act (2010)** protects individuals (and those associated with them) from being treated unfairly and makes sure they have the same rights as other people. The law states that public organisations such as local authorities and health trusts have to make their services accessible to everyone, including people with PMLD and their families. This means people with PMLD cannot be denied access to personalised services.

**The Human Rights Act (2008)**, incorporating the European Convention on Human Rights, states clearly that everyone has the same rights and choices, and should, therefore, be able to have the same opportunities to access personalised services.

# Support for families: help and advice, short breaks

## Raising our Sights makes two recommendations:

### Recommendation 2.

Commissioners of health and social care services should identify mechanisms for supporting and enabling families to get advice and help in securing and running self-directed services from user-led organisations or self-help groups of other families.

### Recommendation 27.

Commissioners of health and social care services in every area should commission a range of short break services that provide staff with sufficient skills, expertise, equipment and facilities to meet the needs of families supporting adults with PMLD. No family supporting an adult with PMLD at home should be denied regular breaks.

## What this means for commissioners

First and foremost, commissioners have a responsibility to know the numbers of people in their area who have PMLD. The lack of a clear standardised definition of PMLD can hamper

identification within local authorities.

*Raising our Sights* says: **“The local authority and NHS in each area should ensure that they have the staff with sufficient skills, expertise, equipment and facilities to meet the needs of adults with profound intellectual and multiple disabilities. Given evidence that short breaks are still not being given sufficient priority, despite extra funding, Learning Disability Partnership Boards should specifically assess and report on the adequacy of short break provision for adults with profound intellectual and multiple disabilities in their annual reports. The Care Quality Commission should address the adequacy of short break provision in its annual review of commissioning of local health and social care services.”** [Page 30, paragraph 105]

Transition arrangements should ensure that adult services have a good understanding of the needs of those moving into adulthood who are likely to require a high level of support. A good transition should ensure that the move from children’s to adult services is as smooth as possible for the person and their family.

Key messages:

- *Raising our Sights* describes good services as “individualised and person-centred”.

Person-centred approaches and planning are essential to ensure that the detail in the person’s life are known to all those who support them.

- The personalisation agenda brings with it a clear need for more person-centred approaches. Person-centred planning should be embedded in all services that work with people with learning disabilities.
- 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 result in services that better meet the needs of the person, but result 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.
- 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.

- Independent brokerage systems need to be in place to enable people to be supported to make best use of personal budgets.
- Commissioning of user-led organisations to promote, monitor and oversee self-directed local support arrangements will also provide an independent source of information and advice on personalised services.
- Where authorities are working together and pooling budgets between health and social care, this can often lead to better joined-up services and support, and improved outcomes for individuals and their families.
- Use pooled health and social care resources to enable flexible outcomes.
- Ensure that the services are resourced sufficiently to meet the needs of people with PMLD and their families.
- Ensure that user-led organisations are given resources to develop monitoring, quality assurance and training to personal assistants, and that brokerage is truly independent.
- Work with local organisations to provide support, advocacy and brokerage services as set out in the Vision for Adult Social Care.

#### Ways to do this:

- Identify the numbers and needs of people with PMLD and ensure that there is a specific focus on PMLD through the Joint Strategic Needs Assessment (JSNA). This will inform the work of the new Health and Wellbeing Boards which are responsible for making the strategic plans for health and social care services in your area.
- Ensure that the new Health and Wellbeing Boards use the JSNA to identify the need for support and advocacy for people with PMLD and their families.
- Commission flexible models of care that are personalised.
- Ensure local authorities and health services are providing accessible information on support and services available to people with PMLD and their families, by supporting advice and information services from user-led, voluntary sector and advocacy groups.

# Training the workforce

## Raising our Sights makes two recommendations:

### Recommendation 6:

In fulfilling their responsibilities for developing and training the social care workforce, local authorities should ensure that sufficient numbers of personal assistants are available, trained in person-centred approaches to communication and support that meet the needs of adults with profound intellectual and multiple disabilities through training that involves families and adults with profound intellectual and multiple disabilities in its delivery.

### Recommendation 28:

Agencies should offer subsidised or free places to families and personal assistants on any training courses they run which are relevant to adults with profound intellectual and multiple disabilities. Individual budgets should include provision for training of personal assistants.

### What this means for commissioners

Commissioners must ensure that people with PMLD and their families can access staff in health and social care at all levels with the right skills, values, knowledge, attitudes and experience to fully support their needs.

Key messages:

**“The staff are key to everything. You could have the most wonderful living room, fantastic kitchen. However, if the staff aren’t able to communicate and engage, it is very distressing.”** Family carer.

To truly meet the needs of people with PMLD, commissioners need to understand:

- the number of people with PMLD is increasing
- the range of individuals who are involved in the care and support of people with PMLD
- that this workforce includes the families and carers of people with PMLD, who are managing personal budgets, and who also require support and training
- the growing number of personal assistants (PAs) required to support individuals with PMLD and their families taking up personal budgets

- the costs, in terms of time, training requirements and expertise needed to provide high-quality services, and what this will mean in terms of the PA workforce
- that 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 (BME) communities
- that people with PMLD and their families have an important role to play in shaping that workforce
- the importance of establishing a culture supported and implemented by the workforce strategy, that recognises and promotes working with people with PMLD as an attractive and valued role.

**“It’s difficult to get the right people to stay long enough. It takes about four to six months to get to know her; her intricate ways, what she enjoys. They needed lots of training from us. But then they move on as we can’t pay them enough.”** Parent of a person with PMLD.

Ways to do this:

In order to commission services and develop a workforce that supports people with PMLD you should:

- establish the current and future number, needs, circumstances and aspirations of people with PMLD, and review these regularly
- assess the capacity and capability of the current workforce, including in-house, private and voluntary sectors
- work across in-house, private and voluntary sectors to develop services to meet these needs
- assess the training provision available, its inclusion of people with PMLD and their families, and its accessibility to their PAs
- develop training opportunities by opening up in-house and provider training to personal budget holders, PAs and their families
- ensure that there is accessible and comprehensive information for people with PMLD and their families about managing personal budgets, and the resources and support available, and that it is proactively given to them
- involve people with people with PMLD and their families and their families in commissioning services
- ensure the involvement of people with PMLD and their families is included in the service specifications for the recruitment, induction and assessment of staff, and that it is made a key requirement
- develop a PA register
- appoint a PMLD champion to any strategic workforce board or steering group
- ensure that the needs of people with PMLD are examined in any employer/commissioner partnership
- ensure that the workforce, including families, has access to ongoing training and development
- make sure that personal budgets reflect the time and skills needed to provide effective support for people with PMLD, and incorporate provision for the training of PAs.

# What people do in the day

*Raising our Sights* makes seven recommendations:

Recommendations from *Raising Our Sights*

## **Recommendation 9.**

The government should amend Part M of the Building Regulations so that all newly built major public buildings provide a Changing Places toilet.

## **Recommendation 10.**

The government should invite the Local Government Association to identify and disseminate good practice in the provision of access for adults with PMLD to public swimming pools, as part of helping its members respond to their responsibilities for 'place-shaping'

## **Recommendation 22.**

The government should state as policy the goal that everyone with profound intellectual and multiple disabilities should have access to further education, in order to help funding bodies develop appropriate objectives and plans.

## **Recommendation 23.**

The government should ask the Young People's Learning Agency\* and the Skills Funding Agency to monitor the volume and quality of provision they fund for people with learning disabilities, distinguishing people with profound intellectual and multiple disabilities within that population.

## **Recommendation 24.**

The Young People's Learning Agency\* and the Skills Funding Agency should create incentives for specialist colleges to partner with local non-specialist further education colleges to increase the quality and amount of local provision for adults with profound intellectual and multiple disabilities.

## **Recommendation 25.**

Local authorities should ensure adults with PMLD are able to take part in a wide range of meaningful activities - including employment, education and leisure activities.

## **Recommendation 26.**

Local authorities should ensure that they continue to provide somewhere which can be used as a base from which adults with PMLD can go to different activities during the day. This does not have to be restricted to people with PMLD - a place used by a wider range of people might be more interesting and provide more opportunities for social interaction.

### **What this means for commissioners**

The scope of these recommendations 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 activities, opportunities and experiences during the day and at evenings and weekends in order to ensure they lead full and fulfilling lives.

Although the first two of these recommendations are directed at government, it is up to local authorities and commissioners to make sure they happen in their areas.

\*Responsibilities have now been transferred to the Education Funding Agency (EFA).

Commissioners have a responsibility to know the numbers of people in their area who have PMLD and work with them and their families to identify their needs. This includes un-met needs for:

- accessible buildings and communities
- educational opportunities such as attending college
- employment and leisure activities.

Key messages:

- People with PMLD have the same right as anyone else to a fulfilling life that includes access to learning, leisure and employment. This must include mainstream activities as well as specialist and therapeutic services.
- The personalisation agenda brings with it a clear need for more person-centred approaches, together with flexible and creative ways to fund activities and support.

Ways to do this:

- Identify the numbers and needs of people with PMLD and ensure that there is a specific focus on PMLD through the Joint Strategic Needs Assessment. This will inform the work of the new Health and Wellbeing Boards that are responsible for making the strategic plans for health and social care services in your area.

- People with PMLD and their families should have information about what is available locally, including the use of direct payments to fund flexible and creative packages of activities and support.
- Independent brokerage systems need to be in place to enable people to be supported to make best use of personal budgets.
- Ensure that local authorities and health services are providing accessible information on support and services available to people with PMLD and their families, by supporting advice and information services from user-led, voluntary sector and advocacy groups.
- Learning disability awareness training should be made available to activity providers.
- Provide training for PAs in how to best support people with PMLD, particularly in communication and interaction.
- Provide a local co-ordinator to negotiate with activity providers for families.
- Ensure the provision through websites and leaflets of information about accessible/ adapted activities in the local area.
- Install Changing Places toilets
- Ensure there are drop-in centres with specific activities that are more specialised, for example physiotherapy, hydrotherapy and multi-sensory environments.
- Ensure that specialist facilities such as hydrotherapy pools and sports centres with adapted or specialist equipment are also open to the general public.
- Set up a forum for families to discuss and influence local decisions on facilities and resources.

# Wheelchairs

*Raising our Sights* makes four recommendations:

## Recommendation 14.

The Department Of Health should reform the wheelchair service to address the problems identified in 2006

## Recommendation 15.

Powered wheelchairs should be provided where carers (whether family members, paid staff or others) need them in order to move the disabled person

## Recommendation 16.

People with PMLD who have powered wheelchairs during childhood should have the option to continue to have them provided in adult life, where it sustains or enhances their quality of life

## Recommendation 17.

Other people with PMLD should be provided with powered wheelchairs, suitably adapted with 'smart' technology, where it sustains or enhances their life

## What this means for commissioners

There have been a number of reports, best practice guidance, related health and social care policies and legislation that affect wheelchair services. *Raising Our Sights* sets out what people with PMLD need commissioners to think about in order to ensure the provision of wheelchair services that meet their needs.

Key messages:

- Wheelchair services need the capacity and volume to enable staff to practise and fine-tune their skills to meet the complex seating needs of people with PMLD.
- This needs to happen, not just be talked about. It is easy to use words like 'multidisciplinary' and 'person-centred approaches' but they must be followed by action.
- Clinicians and others should be sensitive to, and knowledgeable, about the small but highly significant ways in which people with PMLD express themselves and exercise control over their world. People with PMLD will spend many hours each day waiting and being moved by others so anything that gives them a sense of control over when they move, and/or supports movement, will be highly valued.

Independence in this context is not about driving an electric chair unsupervised from place to place, but is person-centred, nuanced and meaningful to the individual.

- Any blanket ban on smart chairs for people with PMLD could breach of Article 8 of the Human Rights Act. People have a right to a private and family life. They have a right to personal development and independent movement as far as possible. Computers and other pieces of equipment provided for use by all sorts of people - who may only use a few functions - should also be available to people with PMLD.
- National Health Service legislation is complemented by other legislation, in particular The Human Rights Act and Mental Capacity Act. Services need to be flexible to deliver full dignity, respect, personal development and involvement in a meaningful and purposeful way. This is particularly relevant to people with PMLD; a small but very vulnerable group of people who rely on others to meet their needs. Health provision should remain dignified and humane.
- The wheelchair should fit the person, rather than the person being fitted to the chair.

Complex seating is very expensive but getting it wrong is even more expensive. It devastates lives, leaving people in poor health and desperately uncomfortable. Sometimes they die.

Ways to do this:

In order to commission wheelchair services that effectively support people with PMLD, it is necessary to:

- establish the numbers, needs, circumstances and aspirations of people with people with PMLD and review these regularly. This data collection and interpretation can be used to track outcomes and predict future service needs
  - find out what is important to people with people with PMLD on a regular basis
  - establish highly trained and experienced multi-disciplinary teams of people to meet the complex seating needs of people with PMLD. (See CSIP, Out and About, p23 Exhibit 4; Department of Health, Local innovations in wheelchair services, case study Queen Mary's, p25, and Case Study A.)
  - ensure wheelchair clinics have a range of highly skilled people to support the complex seating needs of people with PMLD. These should include: occupational therapists and physiotherapists with additional postural training, as well as clinical scientists, rehabilitation engineers, electronic engineers, speech and language therapists, and a rehabilitation consultant
- ensure staff have opportunities for specialist training and to practise and develop their skills to meet the seating needs of people with PMLD. Local clinics trying to equip everyone may not work with many people with complex seating needs. There is no substitute for practical experience and clinicians cannot rely on what representatives of wheelchair companies say different wheelchairs can do
  - ensure premises are fit for purpose. Occasionally, people will need assessment at home because their current seating or health is such they cannot travel
  - offer a full range of moulds and other bespoke services. People often require mixed seating packages sourced from different companies, and bespoke engineered pieces
  - ensure people have regular seating reviews
  - establish clear clinical protocols or guidelines for when someone needs to move from a general wheelchair service to a specialist service.

## References and further reading

**Bennett, S. (2009)**, *Commissioning for Personalisation: A Framework for Local Authority Commissioners*, Department of Health, London

**Chamberlain, T., Golden, S. and Walker, F. (2010)**. *Implementing Outcomes-Based Accountability in Children's Services: an Overview of the Process and Impact* (LG Group Research Report). Slough: NFER [online], available at <[http://www.local.gov.uk/web/guest/research-education/-/journal\\_content/56/10171/3481495/ARTICLE-TEMPLATE](http://www.local.gov.uk/web/guest/research-education/-/journal_content/56/10171/3481495/ARTICLE-TEMPLATE)> [Accessed 02 December 2012]

**Department of Health (2001)**. *Valuing People: A New Strategy for the 21st Century*. [Online], available at <http://www.archive.official-documents.co.uk/document/cm50/5086/5086.htm>

**Department of Health (2009)**. *Valuing People Now*. A new three-year strategy for people with learning disabilities – Making it happen for everyone. [Online] available at [http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH\\_093377](http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_093377)

**Duffy, S. (2008)** *Smart Commissioning – Exploring the impact of personalisation on commissioning*. [Online], available at [www.in-control.org.uk](http://www.in-control.org.uk) [Accessed 04 December 2012]

**Emerson, E., Baines, S., Allerton, L and Welch, V. (2011)**. *Health Inequalities and People with Learning Disabilities in the UK 2011. Improving Health and Lives: Learning Disability Observatory*.

**Goldbart, J and Caton, S (2010)**, *Communication and people with the most complex needs: what works and why this is essential*, Mencap, London.

**Ham, C. Smith, J. and Eastmure, E. (2011)**. *Commissioning Integrated Care in the NHS*, Nuffield Trust. [Online], available at <<http://www.nuffieldtrust.org.uk/publications/commissioning-integrated-care-liberated-nhs>> [accessed 02 December 2012].

**Johnson, K. Walmsley, J and Wolfe, M. (2010)**, *People with Intellectual Disabilities: Towards a Good Life?* The Policy Press, Bristol,

**Local Government Association (2012)**, *Commissioning for better public services*. [Online], available at [http://www.local.gov.uk/c/document\\_library/get\\_file?uuid=846cdbeb-b1c5-4042-ac2a-887fcf58c2b8&groupId=10171](http://www.local.gov.uk/c/document_library/get_file?uuid=846cdbeb-b1c5-4042-ac2a-887fcf58c2b8&groupId=10171)

**Lyons, G. (2005)**, 'The Life Satisfaction Matrix: an instrument and procedure for assessing the subjective quality of life of individuals with profound multiple disabilities', *Journal of Intellectual Disability Research*, vol. 49, no. 10, pp. 4–8.

**Lyons, G. and Cassebohm, M. (2012)**. 'Student wellbeing for those with profound intellectual and multiple disabilities: same, or same but different?' *Journal of Student Wellbeing*. March 2012, Vol. 5(2), 18–33 <http://www.ojs.unisa.edu.au/index.php/JSW/article/viewFile/751/581>

**Improving Health and Lives. (2012).**

*Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs).* [Online] accessed at <[http://www.improvinghealthandlives.org.uk/publications/1134/Improving\\_the\\_Health\\_and\\_Wellbeing\\_of\\_People\\_with\\_Learning\\_Disabilities:\\_An\\_Evidence-Based\\_Commissioning\\_Guide\\_for\\_Clinical\\_Commissioning\\_Groups](http://www.improvinghealthandlives.org.uk/publications/1134/Improving_the_Health_and_Wellbeing_of_People_with_Learning_Disabilities:_An_Evidence-Based_Commissioning_Guide_for_Clinical_Commissioning_Groups)>

[accessed 23 November 2012]

**Mencap (2001)** *No ordinary life: the support needs of families caring for children and adults with profound and multiple learning disabilities.* Mencap, London.

**Nussbaum, M. (2006).** *Frontiers of Justice.* Disability national species membership. Harvard University Press, Cambridge.

**Stirk, S. & Sanderson, H. (2012).** *Creating Person Centred Organisations.* Jessica Kingsley Publishers, London

**Turner, S. 2011.** *Health Inequalities and People with Learning Disabilities in the UK: 2011. Implications and actions for commissioners and providers of social care. Evidence into practice report no. 4. Improving Health and Lives: Learning Disabilities Observatory,* [online] accessed at <[http://www.improvinghealthandlives.org.uk/publications/1012/Health\\_Inequalities\\_and\\_People\\_with\\_Learning\\_Disabilities\\_in\\_the\\_UK:2011.\\_Implications\\_and\\_actions\\_for\\_commissioners\\_and\\_providers\\_of\\_social\\_care.\\_Evidence\\_into\\_practice\\_report\\_no.4](http://www.improvinghealthandlives.org.uk/publications/1012/Health_Inequalities_and_People_with_Learning_Disabilities_in_the_UK:2011._Implications_and_actions_for_commissioners_and_providers_of_social_care._Evidence_into_practice_report_no.4)>

[accessed 23 November 2012]

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