



How-to guide 4 health

For people with profound and multiple learning disabilities

**Raising
our Sights**



Raising our Sights guide to health

Raising our Sights, by Professor Jim Mansell, was published in March 2010 with recommendations that aim to make sure people with profound and multiple learning disabilities (PMLD)¹ and their families get the support and services they need, and do not miss out on opportunities for more choice and control over their lives.

Some local areas have started to carry out recommendations from the report. However, many areas have yet to begin and have asked for further guidance on how to do this.

Now that local health and wellbeing boards are starting to lead the commissioning of health and social care services, it is a good time to think about what good support for people with PMLD looks like. It is an opportunity to make sure the right services are commissioned to meet the needs of a group of people who have so often been left out.

These how-to guides were commissioned by the Department of Health, and produced by Mencap and the PMLD Network, to help local areas implement the *Raising our Sights* recommendations, which are aimed at the local level. It does not focus on recommendations aimed at government and national bodies.

About this guide

This guide to health is one of 11 guides designed to help local areas implement the *Raising our Sights* recommendations. It is for both families and commissioners, and will help commissioners in local areas not only implement the recommendations but understand and meet the health needs of people with PMLD.

It will also help families, commissioners and others focus on what 'good' looks like and what needs to be in place to meet the health needs of people with PMLD.

For more information about *Raising our Sights*, and to download all the guides, go to:

www.mencap.org.uk/raisingoursights

Sections in this guide

1. What *Raising our Sights* says about health
2. What does 'good' look like?
3. What needs to be in place to meet the health needs of people with profound and multiple learning disabilities
4. How do people get their health needs met?
5. Detailed case study
6. Film
7. Frequently asked questions
8. Share good practice!
9. Links to more information and resources

¹ Read the PMLD Network definition of profound and multiple learning disabilities at www.pmldnetwork.org

1. What Raising our Sights says about health

There are three key recommendations about health:

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 (Please see Healthcare for all and Six Lives in the *Links to more information and resources* section of this guide)

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 focussed on the adequacy of health services for adults with PMLD and approve an action plan to ensure adequate treatment.

Raising our Sights also made three recommendations about policies and procedures for clinical processes. The **clinical procedures guide** looks at these.

Why we need to focus on health

People with a learning disability are four times more likely to die of preventable causes than people in the general population, and 2.5 times more likely to have health problems.

People with PMLD are likely to experience additional problems with:

- posture and mobility
- dysphagia
- respiration
- epilepsy
- pain/discomfort
- communication
- hearing
- vision
- mental health
- continence support
- dental and oral hygiene and care
- nutrition and hydration
- access to cancer screening
- being dependent on technology for their health.

PAMIS is a voluntary organisation that provides support for people with PMLD, their families and carers, and interested professionals. It has produced a series of leaflets on health topics that are particularly relevant to people with PMLD. They can be downloaded by clicking on the titles below.

- [Managing Bowels and Bladders](#)
- [Understanding and Managing Epilepsy](#)
- [Respiratory Health](#)
- [Understanding and Managing Nutrition](#)
- [Responding to the Mental and Emotional Needs](#)
- [Oral Healthcare](#)

Raising our Sights identified the following specific problems where services for adults are often not sufficiently well developed to recognise and intervene effectively.

Postural care

People often assume that distortion of body shape is inevitable for people with multiple disabilities, but this is not the case. Body shape distortion is preventable with correct positioning and can even be corrected later in life.

Failure to protect body shape can have serious consequences for a person's health and quality of life, and can even cause premature death. It can result in many health complications. For example:

- contractures – where the tightening of muscles prevents the person straightening their limbs
- scoliosis – curvature of the spine
- breathing difficulties
- poor digestion
- constipation
- pressure on internal organs.

Dysphagia – swallowing problems

Over 60% of people with PMLD have been found to have problems with swallowing – either difficulties with dealing with food and drink in the mouth or the process of swallowing. Dysphagia can lead to food or fluid entering the lungs, which is known as aspiration – see PAMIS leaflet on Respiratory Health. Aspiration can cause infections, pneumonia, choking, reduced appetite, weight loss and fear of eating. Lung infections are recognised as a leading cause of death among people with PMLD, so it is very important that an assessment of the person's eating and drinking technique is conducted by a speech and language therapist and/or dietician.

A working group of GPs has developed guidelines for the identification and management of swallowing difficulties in adults with a learning disability. See the *Links to more information and resources* at the end of this guide.

Epilepsy

Epilepsy is one of the most common and persistent health problems in people with PMLD, with over 60% affected. The more severe the developmental delay, the higher the risk of epilepsy. The risk is also increased if there is associated cerebral palsy. Epilepsy is often misdiagnosed because the symptoms resemble a number of other conditions. For example, a variety of repetitive behaviours, muscular movements and apparent unresponsiveness are often interpreted as epileptic seizures when they may not be.

Failure to manage a person's postural care, dysphagia or epilepsy can lead to discomfort, pain and premature death.

Families and professionals also highlight the difficulty of detecting **pain and distress**, providing effective pain relief and treating the underlying cause. Sometimes this may be due to **'diagnostic overshadowing'** where the person's symptoms, or attempts to show that they are in pain, are viewed as part of their learning disability and not investigated or treated. They may also experience discrimination when negative assumptions are made about the meaning and quality of their lives, as is starkly illustrated in the Mencap *Death by indifference* report.



Scenario 1: Tom

Tom had an ulcerated oesophagus that remained undiagnosed until it was too late to save him. This together with a series of nursing and medical failures led to his death (*Six Lives*, Parliamentary and Health Service Ombudsman, 2009). What stands out from the Ombudsman's account of the appalling care and treatment he received (complaints which were upheld), was her conclusion that Tom's death was not avoidable. He was perceived as a young man in 'inevitable decline'. Many families and carers will recognise this fundamental prejudice which characterises the care and treatment received by people with PMLD: the inappropriate judgements about the meaning and quality of the person's life and the discrimination clear in comments such as 'Wouldn't it be better for everyone if we just let him go?'

The people who knew Tom best could understand the many and varied ways he used body language, vocal sounds and his facial expression to communicate with them. That's how his family knew that he was in pain when his health started to deteriorate. The challenge that Tom faced was that for others, and

crucially those who were responsible for his social care and health needs, his lack of formal communication was one of his greatest barriers. Even when Tom was gouging his head and scratching his face to communicate his pain, none of those people had the skills to understand what he was telling them.

In *Valuing People Now*, the government identified better health for people with a learning disability as a key priority. Although the government has changed since, the principle of improving experiences and outcomes of health for people with a learning disability remains a priority. Its overall policy objective is:

“All people with learning disabilities get the healthcare and the support they need to live healthy lives.”

Despite this, people with PMLD still face health inequalities, are not having their health needs identified and not accessing appropriate services to meet these needs.

2. What does ‘good’ look like?

“Good health begins with promoting well-being and preventing ill-health and this is the same for people with learning disabilities; healthy active lifestyles have to be the starting point for all.”

Valuing People Now

Health is often measured by the absence or presence of illness and disease. However, people with people with profound and multiple learning disabilities (PMLD) are very likely to experience a greater and more complex range of health issues than other people. Good healthcare should enable people with PMLD to have their health needs well-managed and address these inequalities.

Raising our Sights describes good services as ‘individualised and person-centred’. This happens when services:

- treat the person with PMLD and their family as experts
- meet the person’s health needs and preferences in a way that makes the best use of all resources to give coordinated, consistent and long-term support.

Good health support for people with PMLD means:

- individualised, holistic and person-centred health services
- good communication and information sharing
- challenging negative assumptions, and valuing and respecting the quality of life of people with PMLD.

Better health and social care means more people with PMLD and fragile health needs are living longer. They need ever-increasing levels of complex technology to ensure they not only survive, but have an acceptable quality of life. Good healthcare should support people with PMLD to have the best possible quality of life.

Some areas already recognise the importance of focusing on the health needs of this group. For example, NHS Midlands and East has produced a booklet, *Top tips for supporting and meeting the needs of people with profound and multiple learning disabilities (PMLD)*. See the *Links to more information and resources* section at the end of this guide.

3. What needs to be in place to meet the health needs of people with profound and multiple learning disabilities

In its response to *Raising our Sights*, the government says it is committed to improving health and wellbeing through providing health and social care to all who need it. However, local areas are mostly responsible for making this happen, and people with profound and multiple learning disabilities (PMLD) are extremely vulnerable to cuts in spending and services.

- **Local commissioners** must commit to finding out what people with PMLD need, and make sure their policies do not marginalise them. They should listen to people with PMLD, their families and those who know them well, and identify the resources required to meet their needs, such as people, equipment and training. Some areas have done this by carrying out a Joint Strategic Needs Assessment (JSNA) for people with PMLD.

- **They should** find creative ways to involve people with PMLD and their families in consultations about services, and make sure they are aware of individual budgets and the choices available to them. This should include families from ethnic minority communities who can face even greater barriers. Involving people with PMLD can be achieved through person-centred approaches, including use of pictures, photographs, objects of reference, music and different sensory experiences, as well as working closely with the people who know the person well.

- **People with** PMLD should be supported by health services and health and social care professionals able to meet their specific needs. This includes understanding the different ways they might communicate their needs.

- **People with** PMLD need better access to mainstream healthcare and high quality specialist healthcare. Good partnership arrangements between health professionals in both types of service can ensure people with PMLD access the best care and treatment in the full range of health services. Health services must make reasonable adjustments to reflect

the specific needs of people with PMLD. For example, by offering double appointment times or using tools like photo stories or objects of reference to prepare people for visits or treatment.

- **Health professionals** should never make assumptions about the person's health or the quality of their life. They should not leave people's conditions undiagnosed because they see their presenting problems as part of their learning disability.

- **Every person** with PMLD should have an **annual health check** with their GP. This should be thorough and take into account the person's complex health needs. Although funding is now available for these checks, it is important to make sure they happen for everyone. Information should be available from GPs about annual health checks for the individual and their family. If not, carers of people with PMLD should ask why. Commissioners should be monitoring the quality of annual health checks; looking at what the outcomes for the person are and whether they have a health action plan.

• **Each mainstream** health service should have training and support from a **health facilitator**. People with PMLD will need additional support to have an annual health check and comprehensive clinical assessment, and to develop these into a **health action plan** and a **hospital passport** or equivalent. These should be reviewed regularly, especially during times of transition.

• **People with** PMLD should have thorough and comprehensive assessments by appropriately qualified and experienced professionals. Assessments should include:

- annual checks of vision and hearing (including functional vision and hearing)
- annual checks and review of epilepsy
- annual medication review
- regular dental/mouth care checks (at least annually)
- continence reviews (at least annually)
- postural assessment and management plan (at least annually)
- pain assessment and monitoring (ongoing)
- quality of life measurement (ongoing).

• **National guidelines** map the pathway for many health issues. It is imperative that

these are followed by those commissioning and delivering services, along with other guidance applying to health services for people with PMLD (including the specialist learning disabilities commissioning guidance, 2007).

• **Local services** should follow national guidelines for many health issues as well as follow guidance around the commissioning of health services for people with PMLD (including the specialist learning disabilities commissioning guidance, 2007).

• **Commissioners should** use real life experiences of services and outcomes for people with PMLD and family carers, collected from health self assessments, along with other sources of information to plan and develop services.

• **The increasing** number of children and adults with PMLD who are dependent on technology to maintain their health – for example, those needing oxygen, tube feeding or suction equipment – must have access to mainstream and high-quality specialist healthcare.

• **Hospitals should** employ **learning disability liaison nurses**, or equivalent, to support people with a learning disability to access hospital services by increasing the awareness and understanding of all staff working in hospitals.

This will include how to make reasonable adjustments and ensure that hospital passports or equivalent are used.

• **People with** more complex or multiple health needs should have a named healthcare coordinator. This is one of the key recommendations that came out of the Confidential Inquiry into premature deaths of people with a learning disability. The inquiry identified lack of coordination as a contributory factor.

The *Raising our Sights* commissioning guide has more information about how to achieve these things.



Scenario 2: Rebecca

Rebecca's story is about the importance of postural care.

Rebecca is 42. She lives in her own bungalow with one-to-one support. She has PMLD and seizures which affect her life. A few years ago her parents noticed her body shape was becoming distorted:

“Rebecca used to lie in a twisted position with her legs over to one side. By using night-positioning equipment (a sleep system), we have been able to counteract this and she can now lie on her back and put her legs straight. We introduced the sleep system very gradually, just for a few minutes during the day, so she got used to it, then introduced it at night.

“It started off as just a sleep system but has now evolved into a whole package of 24-hour postural care with a team effort behind it – Rebecca works with her physiotherapist, takes part in a moving-to-music class, swims and does physiotherapy exercises. Simple things like stroking the dog and just generally keeping her arms moving also help.

“We've seen huge improvements in Rebecca's body shape and health which we never thought we would achieve.”

4. How do people get their health needs met?

You can get information about the services detailed below from your GP, local health centre, community learning disability team or **NHS Direct**, or online from **NHS Choices**. See the *Links to more information and resources* section at the end of this guide.

1. Access to primary health services

In the UK, everyone needs to be registered with a GP practice (rather than with a specific GP). It is a good idea to identify which GP the person with PMLD seems to prefer and then request appointments with them so they can develop an effective communication and therapeutic relationship.

Most GP practices and health centres deal with the most urgent cases first and have routine hours when certain appointments are available. It is important to find out what services are offered by your health centre and when.

You should tell the practice about any specific support or adjustments the person might

need, and ask for these to be noted on their medical record. You could ask about longer appointments or appointments at hours outside the usual clinic times. The surgery should tell you how to get a home visit appointment and how you can complain if the service does not meet your expectations.

Some areas also have community learning disability teams (CLDTs) that specialise in working with people with a learning disability. There will be a number of different health professionals in each CLDT, such as community nurses, speech and language therapists, psychologists and physiotherapists (the exact make-up of professionals will vary from place to place). There are also social care professionals in these teams. The CLDT will work with the person's GP.

The GP and CLDT should identify whether someone has postural care needs, dysphagia or epilepsy and ensure they get appropriate support from them or specialist services, or specialist consultants if appropriate.

Some people with ongoing complex health needs may have their package of care outside hospital fully arranged and funded by the

NHS, rather than by social services or through a joint package. This is called NHS continuing healthcare. The CLDT can tell you more about being assessed for this. For the person with PMLD and their family it shouldn't matter which agency is funding the person – whichever agency it is should meet the person's needs.

2. Access to specialist health services

Your GP will make a referral to other health services if the person needs specialist care that isn't provided by the CLDT. For example, specialist vision, hearing, dentistry, wheelchair services, orthotic footwear, etc. These services are more specialised than those on the high street and are often coordinated through the local hospital.

3. Access to specialist consultants

Many people with PMLD will have a specific health condition that requires regular input from a consultant, for example, scoliosis, epilepsy or cerebral palsy. You access these consultants initially via your GP but then make follow-up appointments directly with the specialist consultant. After each appointment they will send a report to your GP. You may

need to contact your GP to get the results of any tests.

The GP usually acts as the coordinator for the person's healthcare package. However, where the person sees a consultant regularly for their main health issue, such as complex epilepsy, the consultant might be in the best position to monitor the person's overall health because they will be exploring how other health issues may affect that condition. You should talk to the healthcare team about who is best placed to coordinate healthcare and play a lead role in reviewing the person's health action plan and hospital passport.

4. Access to acute hospitals

For planned admissions there will often be time to prepare the person with PMLD for this. But for emergency appointments there will be little or no opportunity to prepare.

In whatever circumstances a person with PMLD visits hospital they should be able to get the support they need. The job of **health facilitators** and/or **learning disability liaison nurses** is to support people with a learning disability to access hospitals. A key part of that is training all hospital staff to meet the needs of people with a learning disability. Through training and providing access to resources,

they need to ensure that hospital staff recognise when and how to make reasonable adjustments. For example, that they are using hospital passports or equivalent, and putting these in place if they are not available, and that they are listening to those who know the person well. It is not realistic for one learning disability nurse to be responsible for every patient with a learning disability, it is about them empowering and equipping all staff to do this, and obviously acting as an advisor when required.

You can find out about health facilitation in your local area by calling your local hospital, learning disability partnership board or the **Carers Direct** helpline. See the *Links to more information and resources* section at the end of this guide.

Accident and emergency departments provide services for serious injuries or illness requiring immediate treatment only. Dial 999 for life-threatening emergencies. Walk-in centres provide fast access to health advice and treatment of minor ailments, infections and injuries such as cuts, sprains and broken bones. Minor injuries units are able to treat a similar range of conditions.

Law and policy that can help

It is useful to know about relevant laws and policies that can help a person with PMLD to access healthcare.

The Equality Act (2010)

The Equality Act (2010) provides for the right to fair and accessible health treatment and services. Public organisations like health trusts must make 'reasonable adjustments' to ensure their services are accessible to everyone, including people with PMLD and their families.

A list of reasonable adjustments has been published by the Public Health Observatory to help health services understand the type of adaptations they may need to make to enable people with a learning disability to access their services. <http://www.improvinghealthandlives.org.uk/adjustments/>

The Mental Capacity Act 2005

When a doctor needs to make a decision in a person's best interests, they must involve them as much as possible and talk to people who know them well. There is more information about involving people in decisions in the *Raising our Sights Advocacy* guide.

The Human Rights Act (1998)

There are a number of rights that are particularly important for people with PMLD:

- Article 2 – the right to life. People have the right to life-saving medical treatment and to treatment that prolongs life.
- Article 3 – an absolute right prohibiting torture and inhuman or degrading treatment or punishment. This includes any form of neglect, such as not being dressed or not getting the right care and treatment. Public services can be prosecuted if they do not protect people from abuse or neglect.
- Article 14 – the right to not be discriminated against in the enjoyment of your other rights. This right helps to make sure people with PMLD are not discriminated against because of their disability, in any part of their life, including healthcare.

The NHS Constitution

People with PMLD have the same rights as any other citizen regarding access to health services, and the opportunity to improve their health.

There are a number of key publications and government policies that should encourage local areas to develop the right types of health services for PMLD:

Valuing People Now

The government accepts all the recommendations from *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*. This means the NHS must implement these, along with the recommendations from the local government ombudsman and parliamentary and health service ombudsman report *Six Lives*.

Confidential Inquiry into premature deaths of people with learning disabilities

This was commissioned by the Department of Health in 2010 and the findings were published in March 2013. As expected, it found evidence that showed people with a learning disability are still not receiving equal healthcare in all NHS settings. The inquiry found that 37% of deaths would have been potentially avoidable if good quality healthcare had been provided. The most common reasons for premature deaths were problems with investigating and assessing the cause of illness, and delays or problems with treatment. It has a number of recommendations.

Personalisation

Personalised budgets can give people more control over their lives by allowing them to plan and pay for their own services and support.

Equal treatment: closing the gap

Health professionals should avoid making assumptions about a person's physical health needs, and ensure that they communicate effectively to recognise and meet their needs.

A Vision for Adult Social Care: Capable communities and active citizens

This document says good partnership working between health and social care is vital in helping people manage their health and live independently.

If the person can't access the services they need

If the person with PMLD you support, or other people with PMLD in the local area are not getting their health needs met you may want to challenge or campaign.

Your local learning disability partnership board (LDPB) can be a good place to get advice or support and link up with other people to campaign. Many now have a PMLD champion or PMLD sub-group. Carers groups, local Mencap groups or advocacy organisations can also be good places to bring people together to support each other and campaign.

Challenging

Sometimes you may just be trying to change things just for the person with PMLD who you support rather than trying to get wider change.

Some tips:

- Use the information in this guide, including what 'good' looks like, legal rights and policy information, to support your challenge.
- If the person's needs are not being met, say so in a letter to the lead person at social services or the Clinical Commissioning Group (CCG). Let them know you will campaign publically against their decision if they do not listen to what you have to say.

- Get your local councillor or MP involved. You could ask them to write a letter of support.
- If you are not listened to, you might want to make a complaint or seek legal advice.
- If there are other people with PMLD in the area facing similar issues you may want to get together to campaign publically!

Campaigning

If a particular issue is affecting more than one person with PMLD in your area, you may want to work with others to raise awareness about this and campaign publically for change. An example of an issue that many local areas have successfully campaigned against is the lack of appropriate changing facilities for people with PMLD. Thanks to campaigning, many local areas now have Changing Places toilets.

Some tips:

- Organise a campaign for people in your area to send an email or letter to their councillors.
- Launch a petition explaining what you are campaigning for.
- Hold a public meeting to tell people about the campaign and how they can get involved. You could invite a local newspaper or radio station along to cover the story.
- Organise a rally by inviting members of the public to a significant place, such as a town

hall, to publicise the issue. Again, your local media might want to cover this.

- Gathering real stories and using photos and film can be very powerful. Social media can be a useful tool to share these.
- Don't forget to plan your campaign!

To help you challenge or campaign, see:

The Challenging Behaviour Foundation information sheet **Ten Top Tips**, by **Luke Clements**, which sets out the legal rights to community care services, has a template letter to follow if you want to challenge a community care decision. See <http://www.thecbf.org.uk>

Mencap's Know your rights local campaigns guide (this is specifically about cuts, but it has some useful general information about campaigning). See www.mencap.org.uk/node/14506

The **KnowHow NonProfit** website, which is part of the National Council for Voluntary Organisations, has lots of useful ideas about campaigning, including how to plan a campaign. See <http://knowhownonprofit.org/campaigns/campaigning/planning-and-carrying-out-campaigns/planning/planning>

Complaints or legal action

Some people may choose to go down the complaints or legal route if their challenging or campaigning is not successful.

Complaints

See our factsheet about making a complaint. It includes some specific information about making complaints in relation to each of the topics in the *Raising our Sights* how-to guides. See <http://www.mencap.org.uk/raisingoursights/complaintsfactsheet>

Legal action

Getting legal advice can be helpful. It is useful to do this sooner rather than later as some cases such as Human Rights Act and Equality Act cases have time limits on them. It doesn't necessarily need to cost you anything because you might be entitled to legal aid or be able to get a law firm to take on your case for free. For further information, or to find a solicitor, contact the Disability Law Service on 020 7791 9800 or at advice@dls.org.uk

5. Detailed case study



Victoria

Victoria is a 42-year-old woman with profound and multiple learning disabilities (PMLD). She likes going out, people-watching and visits from family and friends. She loves flicking her special silver paper at the same time as listening to her eclectic tastes in music, from Mozart to Marley.

Victoria communicates with her eyes and eyebrows, as well as through a range of sounds and body language. She doesn't use words. Victoria needs one-to-one support most of the time she is awake, and support from two people in order to walk, have personal care and go out. The support has to be person-centred using a gentle and consistent approach, otherwise she can get confused and angry and will self-harm.

Victoria has a rare condition called Tuberous Sclerosis, which means that tumours can affect all the organs in the body. In Victoria's case this means she has physical disabilities and profound learning disabilities. She has two life-threatening conditions: partially-controlled epilepsy and the final stage of kidney failure. She

sometimes exhibits behaviour which can challenge services and people.

To maintain her current health, Victoria needs careful, consistent management. She now has a palliative team input as well as weekly monitoring from community nurses. Decisions have to be made regularly about her healthcare.

Victoria can't tell people if she is feeling unwell, so her staff team have to be good detectives in picking up those little signs which indicate that something is wrong. A hospital passport and health action plan are two important tools which help ensure Victoria gets the healthcare she needs and can stay as healthy as possible. These hold all the up-to-date information about her health, including all the knowledge her family has about her health and communication needs.

The hospital passport is vital in an emergency. It details all the medication Victoria takes, any emergencies she has had before, and what the triggers and solutions were. Her family and staff team update it every three months. As well as being crucial for Victoria, it is also cost-

effective for health professionals, as it is all done for them; it is like an immediate care plan when she goes in to a ward. Her passport means doctors can quickly understand her needs and make informed decisions about what treatment to give her. Her family feel much more confident about her going into hospital in an emergency situation because of it.

Victoria's health action plan had input from her family and staff team. It gives an overview of her disabilities and focuses on each aspect of her health. For example, the condition of her eyes, her hearing, her digestive system, her physical ability and whether that's deteriorating. When putting it together, some action points emerged of what needed to be dealt with. Action points are identified and modified all the time to make sure Victoria gets the healthcare she needs. It helps her GP make good decisions, and helps her support workers manage her health on a day-to-day basis.

Tools like this can be invaluable when someone has very complex health needs and doesn't have capacity to make their own health decisions.

6. Film

Watch film clips about how initiatives such as hospital passports and health action plans are improving healthcare for people with PMLD:

Rebecca's story: <http://www.mencap.org.uk/node/26398>

Victoria's story: <http://www.mencap.org.uk/node/26399>

Both of these clips are part of Mencap's Mental Capacity Act resource for family carers of people with PMLD:

<http://www.mencap.org.uk/all-about-learning-disability/health/mental-capacity-act>

Watch film clips about the importance of **postural care** for thousands of people with multiple disabilities, including those with PMLD:
<http://www.mencap.org.uk/posturalcare>

7. Frequently asked questions

Q: How can my daughter or son get an annual health check?

A: Health checks are available on request from your GP. However, some areas require a referral from the local social services team.

Q: Who is eligible for an annual health check?

A: Annual health checks should be offered to all people with a learning disability known to social services.

Q: What about young people in transition?

A: Local services should develop transition arrangements to ensure young people approaching transition are included in annual health checks. This should happen well before the actual transition.

Q: How can my son or daughter have an assessment for posture or mobility, sight or hearing, or continence?

A: These are all available via referral by your GP. However, some areas require a referral from the local social services team.

8. Share good practice!

We know there is already good practice out there and some examples are referred to in these *Raising our Sights* how-to guides. But we would like to hear of more examples and share them so other local areas are inspired to develop good support and services for people with PMLD too.

Please tell us about any good practice in your local area relating to support or services for people with PMLD:

Email pmlidnetwork@mencap.org.uk
Call **020 7696 5549**



The Lambeth PMLD project

This project aimed to show what life was like for people with PMLD in Lambeth, and use the information to better plan to meet their needs. It was initiated by family carers of people with PMLD on the Lambeth Learning Disability Partnership Board and run in partnership with Lambeth Council, NHS Lambeth, 'I Count' Register Services, National Mencap and Lambeth Mencap.

The project identified people with PMLD on the learning disability register using criteria developed from the PMLD Network definition. Information was also collected through surveys and interviews with families and support staff.

Priority areas for change were identified and, two years on, there is an active PMLD sub-group committed to taking these forward. The focus is currently on developing meaningful activities for people with PMLD in Lambeth. There is a case study and film of Lambeth's work on meaningful activities work in the *What people do in the day* guide.

For more information about the Lambeth PMLD project see:
www.mencap.org.uk/Lambethpmlid

9. Links to more information and resources

General resources

NHS Direct

Telephone: 0845 4647

NHS Choices

Information website about health conditions and choosing health services.

<http://www.nhs.uk/>

Carers Direct

Telephone helpline: 0808 802 0202.

Health resources on the PMLD Network website

<http://www.pmldnetwork.org>

Mencap information about health

<http://www.mencap.org.uk>

Top Tips for supporting and meeting the needs of people with Profound and Multiple Learning Disabilities (PMLD)

http://www.csp.org.uk/sites/files/csp/secure/top_tips_for_supporting_people_with_profound_multiple_learning_disabilities.pdf

Equal Treatment: Closing the Gap

This report highlighted failings in access to healthcare and providing appropriate treatment for people with a learning disability.

<http://www.leeds.ac.uk/disability-studies/archiveuk/DRC/Health%20FI%20main.pdf>

A life like no other

This national audit found that adults with a learning disability are particularly vulnerable to breaches of their human rights in healthcare.

http://archive.cqc.org.uk/_db/_documents/LD_audit_report1.pdf

Death by indifference

Mencap's report described the circumstances surrounding the deaths of six people with a learning disability while they were in the care of the NHS

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

Healthcare for all

Independent inquiry into the healthcare of people with a learning disability, responding to *Death by indifference*.

<http://www.mencap.org.uk/node/6954>

Six Lives

Six Lives: the provision of public services to people with learning disabilities. Part one: overview and summary investigation reports. Parts two to seven: individual cases. Parliamentary and Health Service Ombudsman, 2009

<http://www.ombudsman.org.uk/>

Treat me right

<http://www.mencap.org.uk/node/5880>

Putting people first: a shared vision and commitment to the transformation of adult social care

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_081118

A vision for adult social care: Capable communities and active citizens

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_121508

A-Z of other information

Annual health checks

A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability (Hoghton Dr, and the RCGP Learning Disabilities Group, 2010) <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/learning-disabilities.aspx>

Assistive Technology

The Foundation for Assistive Technology website
<http://www.fastuk.org/home.php>

Breathing/Respiration/Ventilation

Respiratory health of people with PIMD. Wallis C (2009), in Pawlyn J and Carnaby S (Eds), *Profound Intellectual and Multiple Disabilities: Nursing Complex Needs*. p186-201. <http://www.wiley.com/WileyCDA/WileyTitle/productCd-1405151706.html>

Changing Places

Information and location of Changing Places accessible toilets in the UK.
<http://www.changing-places.org/>

Communication passports

<http://www.communicationmatters.org.uk>

Continence

<http://www.bladderandbowelfoundation.org/>

Dental

Guidelines and policy documents for oral care of people with disabilities.
<http://www.bsdh.org.uk/guidelines.html>

Dysphagia

Information from NHS Choices site
<http://www.nhs.uk/conditions/dysphagia/Pages/definition.aspx>

Understanding and Managing Nutrition for People with Profound and Multiple Learning Disabilities
www.pamis.org.uk/cms/files/managing_nutrition.pdf

Problems swallowing? Ensuring safer practice for adults with learning disabilities who have dysphagia.
<http://www.nrls.npsa.nhs.uk/EasySiteWeb/getresource.axd?AssetID=60131&..>

Guidelines for the identification and management of swallowing difficulties in adults with a learning disability
http://www.eguidelines.co.uk/downloads/dl/download_now.php?id=90

Epilepsy

Information about epilepsy and learning disability
<http://www.epilepsy.org.uk/info/learning-disabilities> www.pamis.org.uk/cms/files/epilepsy_leaflet.pdf

Equality Act (2010)

<http://www.legislation.gov.uk/ukpga/2010/15/contents>

Getting it right

Mencap campaigns for health trusts and hospitals to sign up to the *Getting it right* charter to show their support for equal healthcare, high standards of treatment and making reasonable adjustments where necessary.
<http://www.mencap.org.uk/campaigns/take-action/getting-it-right>

Hearing

An information site and forum about people with a learning disability and hearing loss.
<http://www.hald.org.uk/>

Health action plan

[http://www.easyhealth.org.uk/listing/health-action-plans-\(leaflets\)](http://www.easyhealth.org.uk/listing/health-action-plans-(leaflets))

Hospital passport

[http://www.easyhealth.org.uk/listing/hospital-passports-\(leaflets\)](http://www.easyhealth.org.uk/listing/hospital-passports-(leaflets))

Hospital care

Working together: easy steps to improving how people with a learning disability are supported when in hospital. HFT (2008)

<http://www.hft.org.uk/Supporting-people/family-carers/Resources/Health-resources/>

Human Rights Act 1998

http://webarchive.nationalarchives.gov.uk/+www.direct.gov.uk/en/governmentcitizensandrights/yourrightsandresponsibilities/dg_4002951

Involve Me

This Mencap project aims to increase the involvement of people with profound and multiple learning disabilities (PMLD) in decision making and consultation.

<http://www.mencap.org.uk/involveMe>

Mental health

Clear Thoughts website about mental health for people with a learning disability.

<http://arcuk.org.uk/arcprojects/category/health-projects/>

Mental Capacity Act (2005)

Using the Mental Capacity Act: A resource for families and friends of people with learning disabilities. HFT (2011)

http://www.hft.org.uk/Family_Carer_Support/MCA_Resource_Guide

Mencap's website contains Mental Capacity Act resources for family carers of people with PMLD – with a particular focus on involvement in health decisions <http://www.mencap.org.uk/all-about-learning-disability/health/mental-capacity-act>

NHS Continuing Healthcare funding

What do I need to know about NHS Continuing Healthcare? Alison Giraud Saunders (2012). Published by the Foundation for People with learning disabilities. Information about NHS Continuing Healthcare for families of people with a learning disability

<http://www.learningdisabilities.org.uk/publications/continuing-healthcare/>

Pain and distress

DisDAT Assessment intended to help identify distress cues in people who because of cognitive impairment or physical illness have severely limited communication.

<http://www.disdat.co.uk/>

Paediatric Pain Profile

A behaviour rating scale for assessing pain in children with severe physical and learning impairments. <http://www.ppprofile.org.uk/>

Postural care

Booklet and film produced by Mencap and the Postural Care Action Group www.mencap.org.uk/posturalcare

Personal health profiles

Oxleas NHS Foundation Trust has developed documents which can be downloaded to create a personal health profile.

<http://www.oxleas.nhs.uk/gps-referrers/learning-disability-services/personal-health-profiles/>

Vision/Sight assessment

SeeAbility's website contains lots of great resources about vision and eye health.

<http://www.seeability.org/>

Acknowledgements

Thank you to Jill Pawlyn, registered nurse (learning disabilities) and lecturer, who was the lead author for this guide. Thanks also go to all those who read and commented on the guide. Their input has been invaluable.