

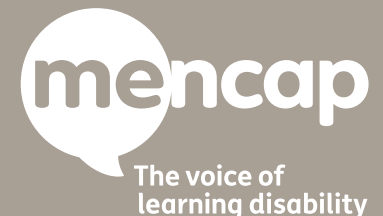


How-to guide 9

what people do in the day

For people with profound and multiple learning disabilities

Raising
our Sights



Raising our Sights guide to what people do in the day

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 what people do in the day is one of 11 guides designed to help local areas implement the *Raising our Sights* recommendations. It is for both families and commissioners.

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 what people do in the day
2. What does 'good' look like?
3. What needs to be in place for people with profound and multiple learning disabilities to access meaningful community, education, employment and leisure activities
4. How can people access different opportunities and activities?
5. Detailed case study
6. Film
7. Frequently asked questions
8. Share good practice!
9. Links to further 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 what people do in the day

There are seven key recommendations:

Accessible buildings and communities

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'.

Educational opportunities

Recommendation 22.

The government should state, as policy, the goal that everyone with PMLD 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 a learning disability, distinguishing people with PMLD 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 PMLD.

Employment and leisure activities

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 they continue to provide somewhere that 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.

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

People with profound and multiple learning disabilities (PMLD) seem to be missing out on the ideas covered in *Valuing People Now* about fulfilling lives, and access to a range of community activities.

The seven *Raising our Sights* recommendations aim to make sure people with PMLD and their families are able to access meaningful and interesting activities in places where their needs can be met.

This guide will help local areas implement these aimed at the local level and understand, plan and commission the types of buildings, resources and activities people with PMLD need. It focuses on what ‘good’ looks like and what needs to be in place for them to access meaningful community, education, employment and leisure activities.

There are several key aspects to ensuring that people with PMLD live fulfilling lives:

- Accessible buildings and communities
- Educational opportunities such as attending college
- Employment and leisure activities

Although the title of this guide is *What people do in the day*, 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 regular activities, opportunities and experiences during the day, and at evenings and weekends, to ensure they lead both full and fulfilling lives.

Although many families of people with PMLD think the ideas about meaningful activities sound good, they want to know how things will actually happen. They are concerned that changes in adult social care will mean the burden for identifying, planning and organising activities will fall on them. They also worry that people will not be able to access regular meaningful activities. As one mother said:
“an arts session every fortnight is welcome, but just a drop in the ocean.”

2. What does 'good' look like?

Planning should build on:

- the person's past experiences and what they like and enjoy
- what is available locally
- links with other people and organisations.

It is useful to think about the following:

- **Accessible buildings** where people with profound and multiple learning disabilities (PMLD) can be involved in meaningful and enjoyable activities. For many people, it is important to have a consistent and accessible building base from which they can go out and do different activities.
- **Educational opportunities** for people to maintain existing skills, experience new things and develop new skills and interests. This could include specialist colleges close to the person's home, and courses at local colleges that are designed and funded to meet the needs of people with PMLD. Colleges should make reasonable adjustments for people with PMLD to attend suitable mainstream leisure courses. For example, courses that involve using the senses, such as cooking or horticulture.

Services must acknowledge that people with PMLD can learn, but will need more time and can require a huge amount of repetition. For people at a very early stage of development, this repetition will be exactly the same each time. Those who are more aware of the world around them should be provided with lots of different ways of experiencing the same thing.

People should have the opportunity to experience both informal and formal learning.

Scenario 1. Victoria's formal learning at college

Victoria attended the local agricultural college for one day a week for three years after leaving school. Among her activities were encounters with small animals, sensory work related to agricultural activities and adapted sports. Victoria had an individual tutor and worked on using both hands together.

Scenario 2. Emma's informal learning from everyday experiences

Emma is at a very early stage of development and is learning to anticipate the routines of her life. Her supporters have worked out routines that are repeated several times a day. These include dressing, eating and drinking, changing, being hoisted out of her chair and having a conversation. When Emma needs to be hoisted from her chair, her supporters indicate to her what is about to happen by humming a tune. They then fetch the hoist and swing the arm a few times for Emma to watch before hooking on the sling. A couple of taps on Emma's legs signal they are beginning the lift. Once she is in the air, her supporters swing her back and forth a few times, something Emma's smiles clearly show she enjoys. After she is lowered and the sling is unhooked, her supporters tickle her on the neck – her cue that it's now time for conversation – and she smiles again.

Emma has slowly learned what the cues mean and sometimes will smile in anticipation of her favourite bits of the manoeuvre. If the routine is repeated many times there is a possibility that Emma will come to anticipate it more and more.

Employment

Although conventional paid or voluntary jobs might not be accessible to, or understood by, many people with PMLD, it is possible to create meaningful employment that enables them to earn money or become involved in the local community. The example below is from **Grapevine** in Coventry.

Scenario 3. Ann's magazine library

Ann has a job which enables her to move round her local community and meet her neighbours. With support, she provides a library service for magazines, which she takes around the houses in a hand-pulled trailer. Ann gets pleasure from the interaction she has with her clients, who show their appreciation of the service she provides and always greet her when they see her out shopping.

Activities within the home

Switches such as a Big Mack can be used to record voices and sounds, and used in storytelling sessions or other activities. There are lots of switch-controlled toys and sensory games available from companies such as **TFH** and **Spacecraft**. Some can be expensive but there are also some really good, cheap ideas on the Sensory Room website.

It is possible to connect any type of switch to a Powerlink box and use it to control a variety of electrical equipment, such as a radio, fan or electric whisk. This is a great way to help people learn about cause and effect and get involved in domestic tasks such as cooking or vacuuming. See *Links to more information and resources* part of this guide for links to websites and suppliers.

Building bases

The number of young people with PMLD is increasing, as is the complexity of their health needs. When these young people leave school, many families would like them to have access to a base in the community – a safe building where specialist services are available. Otherwise they will be concerned about how their complex health needs will be met in the community during the day. From this base, people can go out and use community facilities

when they are well enough but can be assured of the health support they require.

Therapy usually requires a building base, but there is no need for building bases to lead to isolation for the people who use them. The buildings could be drop-in centres for others who would like to use the specialist facilities, and features like a café and meeting rooms for hire can help make it a community hub for everyone.

Leisure

Leisure activities can ensure people with PMLD live meaningful lives and are known and valued in their local communities. Leisure, everyday living and therapy activities should be well researched, planned and supported by trained staff who can help them get the best from what the activity has to offer.

Finding organised leisure activities for people with PMLD can be difficult because opportunities vary around the country. We have included some suggestions here to help you think about what you might find or campaign for in your local area. There are links to more information, organisations and resources at the end of this guide.

Multi-sensory activities

There might be drop-in sessions where people can come with their support workers and try out a range of multi-sensory and musical activities, or the sessions may run as more traditional workshops. There should be a wide selection of stimuli as well as chill-out areas where people can be by themselves.

Music

There are various organisations that offer music sessions and/or can train staff to make music with people with PMLD. One such organisation is the **Joy of Sound**, based in London, which holds regular drop-in workshops in Lambeth.

Art and crafts

Art and crafts with people with PMLD can be much more about the process than the product. It is important to enable the person to be engaged with as little physical prompting as possible. It is often a matter of giving sufficient time for the person to move their hands and arms themselves. **Project Artworks** holds regular sessions in Hastings, where individuals with complex needs collaborate with experienced, professional artists.

Arts therapies

In some areas of the country it is possible to find arts therapists. Arts therapies include music, art, dance movement and drama therapies.

Sport and exercise

There are many activities that allow people with PMLD to move and exercise or experience movement in different ways. Accessible sports can be enjoyed in a wheelchair or played in an adapted way.

In Scotland, **PAMIS** worked with families and leisure staff to develop a range of inclusive indoor and outdoor sports and leisure activities for people with PMLD and their families in their local communities. Some of the more exciting activities featured in the PAMIS Freestyles project include:

- adapted cycling
- water sports (eg motor boating, canoeing and sailing)
- adapted skiing
- wheelchair ice skating
- adventure activities (eg abseiling and zip wire)
- SOMA (Sporting Opportunities for Motor Activities – adapted sports and games).



Scenario 4. A story from a Sheffield activity provider

We have worked with iceSheffield to develop accessible ice mobility and ice curling sessions for people in wheelchairs to access. We worked with them to create a Changing Places toilet and facilitated sessions for people over the past two Learning Disability Week events. This gave people with PMLD, as well as their carers and staff at iceSheffield, the chance to see that this was a fun activity that anybody can enjoy. iceSheffield now hosts weekly ice mobility sessions, and we facilitate accessible ice curling sessions.

Holidays

There are a few specialist providers of holidays for people with PMLD. Some are listed at the end of this guide.

Ordinary activities in the community

Although there is a growing number of adapted activities being developed, the community can also be a source of interesting experiences. For example, buying a magazine, choosing a

DVD at the library or visiting the market, local museum or railway station. ‘Smelly’ shops such as a shop with body products, or a delicatessen or a garden can provide a rich experience if they are visited with the principles of Intensive Interaction (see section below) and multi-sensory approaches in mind.

It is not enough for people with PMLD to merely be present during activities. There are some key principles and approaches that can transform planned activities or everyday events into meaningful experiences.

Communication and interaction

Communication and interaction should be at the centre of everything people with PMLD do. Sometimes the interaction is the reason for the activity, but at other times the interaction enriches the sport, arts or leisure activity the person is involved in, or helps them understand or make sense of it.



Scenario 5. Jeannie and Us in a Bus

US in a Bus is a charity that helps people with PMLD, like Jeannie, to connect with others through interaction.

Jeannie doesn’t use language but does

make sounds and sometimes appears to relax when we sing. What we might do is ‘echo’ her sounds back to her, letting her know that we’ve noticed her and are responding in her language. This can develop into a conversation without words – playing with volume, pitch and pauses. Jeannie can become more confident when this happens and may even let us touch her hand or ruffle her hair. Sometimes she’ll even let us massage her feet with aromatherapy oils.

On another occasion we might sing a song that we’ve noticed has made Jeannie relax before. But we want to make this an interactive experience to help her get the message that she can be in charge of what we do together. So we pause after the first verse and tell her that when she makes a sound, we’ll know she wants us to carry on.

When we first did this we didn’t know whether Jeannie would understand, or whether her sounds would be random or deliberate. Now her responses are clear and consistent; she looks alert and leans forward at the end of each verse and we are sure she knows she is in charge of our singing. This can be an empowering experience and it’s what we are aiming for with all our clients, whatever activity we are sharing.

For details and for information about other providers who focus on communication and interaction, see *Links to more information and resources* at the end of this guide.

Sharing stories

This is usually multi-sensory and involves objects to touch, look at, listen to, smell and even taste. Stories are usually only a few sentences long, with each sentence being repeated several times to help the listeners become familiar with them. They often have a surprise in them which can be anticipated once the story is well known. Personal stories can be very successful, and used to recall or talk about an activity or something that has happened to the person using objects and sensory resources they particularly like.



Scenario 6. Rebecca's story

Rebecca was asked to 'tell her story' to the people at the launch of the campaign for Changing Places toilets. She was able to do this with support from her mum and a series of objects which were kept in a basket. Her mum took the objects out of the basket one by one, to the delight of Rebecca who nearly jumped out of her wheelchair in excitement. Her mother held up car keys, a purse, Rebecca's hat and gloves, a bag and a mug as she told the story of how Rebecca likes to go out but needs a Changing Places toilet to enable her to stay out all day. Rebecca joined in by smiling and laughing and touching the objects as her mum told the story and showed the objects.

Inclusive libraries

Public libraries are gradually becoming good places to visit for people with PMLD. For example Bradford, Leeds and Birmingham have specifically developed services for people with a learning disability in their central libraries. These include story and activity sessions and the use of a touch-screen computer with accessible software. Other libraries are becoming more

aware of the needs of people with a learning disability and are open to discussions about how their needs can be met.

Drama and theatre

Activities like story sharing, Bag Books and sessions in libraries are based on interactive drama in which people are directly engaged with the action and resources. Actual theatre experiences can be accessible to some people with PMLD, depending on how aware they are of their surroundings and how much they enjoy watching.



Scenario 7. Peter and The Snowman

Peter, who enjoys watching television, was supported to see *The Snowman* at Birmingham Repertory Theatre. It was clear he enjoyed the show and although he was not completely silent throughout, his repetitive phrases were fewer than usual. He is able to say 'snowman' and he repeated it to his carers many times following the show. Peter now regularly goes to the pantomime and other family shows.

Communication in the community

It is really important that people with PMLD have opportunities to communicate and interact with their neighbours and friends in the community. Attending religious services can be one way to achieve this.



Scenarios 8 and 9. Julie and Amerdeep

Julie loves going to Coventry cathedral. She moves gently to the music and makes little happy noises throughout. When the organ is playing the closing piece she moves down the centre of the cathedral towards the sound, obviously enjoying the experience. People greet her and chat with her when the music has finished and she wanders round from person to person.

Amerdeep goes with his family to the Sikh temple at 6pm every day. He is welcomed by the community and joins in as much as he can. He enjoys the routine of the process, the prayers, the music and the calm atmosphere.

Multi-sensory approaches

This is a fundamental approach to working with people with PMLD and involves using the senses of touch, taste, sight, hearing and smell. Please see the link to the work of Flo Longhorn at the end of this guide.

Hand-under-hand

If a person cannot use their hands to play an instrument or put paint on paper, rather than taking their hands and guiding them, the supporter does the activity with the person's hands on top of theirs. This means the person with PMLD can choose whether to join in the activity or to take their hands away. They can also feel the pattern of the activity, which they may eventually be able to complete for themselves.

Cues

People with PMLD often have difficulty understanding what is going to happen next, so it can be helpful to provide cues to different activities. These can be on-body cues, such as sliding the hands between the person and their wheelchair back just before moving it, or can involve a personal object, such as a cup, just before a drink. There are also lots of natural cues, like the smell of dinner just before it

arrives or the sound of the bus as it pulls up. Others need to be provided, for example always wearing the same perfume or humming the same tune when approaching a person with PMLD.

Time for responses

People with PMLD may process information slowly and need time to take in what is happening, so it can be good to use a 'burst-pause' way of working. For example, when swimming, splash a little water on the person's face and pause to see their response. Gauge whether it is a deliberate 'like' or 'don't like' response. If it is a 'like' then you can interpret this as 'please do it again'.

Observation and learning from the person

Supporters should be experts at interpreting responses to activities so they can repeat those the person enjoys. Observation is really useful when trying to decide on new activities. For example, if someone really enjoys the sensation from a vibrating cushion, what other resources and activities could that lead to? Other vibrating objects, such as an electric toothbrush, or a different element, such as a foot spa or jacuzzi could be tried, or other kinds of vibrations such as riding in a pony trap, on a

bike or a go-kart, or maybe one of the rides at Alton Towers.

Intensive Interaction

When observing the person, supporters should pick up on what they do and use this to build communication with them. The approach is called **Intensive Interaction**. It involves: responding to the person; celebrating their facial expressions and noises; following what they do; keeping the conversation going by imitating or joining in; and pausing to wait for any response. Please see *Links to more information and resources* at the end of this guide to find out more about Intensive Interaction.



Scenario 10. Juniper Drive

Juniper Drive used to be considered a difficult care home to work in because of the level of challenging behaviour of the people who lived there. The men would often behave aggressively towards each other and sometimes towards our staff, and one man, Tom, would spend most of his time in his room. We believed that he liked his own space and just wasn't particularly social.

After Intensive Interaction training, the staff felt they had been given a new lease of life. Several of the team had been using aspects of the Intensive Interaction approach already, so the training helped to explain and validate what they were doing, and encouraged everyone to do more. Once everyone had completed the training, we incorporated informal Intensive Interaction sessions into the day.

Working with the people at Juniper Drive in this way has transformed the service! One

of the residents, Barry, is calmer and more social, and he has had no incidents of challenging behaviour for over a year. He loves Intensive Interaction and will even initiate physical contact.

The team had found Dave the hardest to engage with socially. The Intensive Interaction sessions have increased in duration and he now laughs frequently. Tom now spends most of his time in the communal area and he initiates touch and laughs during interactions. He will now approach people, take their hand and initiate tapping games. He even joins everyone for the film evenings where we all gather to watch a movie and eat popcorn, something he never used to do.

The reputation of Juniper Drive has now totally changed. We even get invited to parties now! At the last one, we stayed for two-and-a-half hours while everyone socialised, listened to music, ate food and generally had fun. They are obviously so much happier.

3. What needs to be in place for people with profound and multiple learning disabilities to access meaningful community, education, employment and leisure activities

- Families, commissioners and supporters must challenge the situation where too many people with profound and multiple learning disabilities (PMLD) are living restricted lives, confined to their homes or being taken out to the same supermarket or café over and over again.
 - Knowledge about how to enable people with PMLD to live meaningful lives should be embedded in the work of supporters and personal assistants. Once the principles are understood, almost any activity or resource has the potential to lift a mundane experience to a fulfilling one.
 - Families need more support and information to ensure people can access regular and meaningful activities. This could include a growing, local information resource about what is available and where ideas can be shared. All the planning, research and organisation should not be left to families and there should be local brokerage services or coordinators who can facilitate this. Families should also be given information about pooling personal budgets to employ group facilitators, such as musicians, who can plan and organise regular activities. There is more information about pooled budgets on the In Control website. See *Links to more information and resources* section of this guide.
 - Families and supporters should not be afraid to try new things. While it is important to keep risk to the minimum, especially for those with complex medical needs, ‘thinking outside the box’ can reveal new and enriching experiences for both the person with PMLD and their supporter.
 - Truly personalised services and good person-centred planning will help identify activities a person might enjoy and the support they need to do them. Individual budgets and direct payments can enable people with PMLD to access a wider range of activities with more flexible support. Please see the *Raising our Sights* personalisation guide for more information.
 - Families, carers and supporters need up-to-date information about activities in their area and their suitability for people with PMLD.
 - Planners and commissioners need to understand the importance of Changing Places toilets in enabling people with PMLD to get out and about for longer periods of time and access community activities.
 - Community buildings should be fully accessible and have Changing Places toilets where people can be changed in a dignified manner in a toilet area, with sufficient space and specialised equipment such as a hoist.
 - People with PMLD and their families should be involved in consultations or planning decisions about changes to services or the building of new specialist or community facilities.
- The *Raising our Sights* commissioning guide has more information about how to achieve these things.

4. How can people access different opportunities and activities?

The starting point is to think about what the person enjoys and might like to do, and to plan with them in person-centred ways. The *Raising our Sights* personalisation guide tells you more about how to do this and talks about the 'tools' of person-centred planning.

Anyone who needs support must receive an assessment from their local authority. This will identify their needs. The local authority has a duty to meet eligible needs. The person may be allocated either a **personal budget**, where the money comes solely from social services, or an **individual budget**, where money comes from more than one source (eg social services, local education authority, funding for equipment or employment). Either of these budgets can be used creatively and flexibly to pay for activities and support to meet these needs. The budget can be held and managed in one of three ways:

- A **direct payment** where cash is paid to the individual
- An **indirect payment** where the budget is held by a third party who manages it on the individual's behalf (eg user-controlled trust or a voluntary organisation)

- A **notional budget** which is held by the local authority, and where the individual knows how much money is in the budget and discusses with a care manager or other nominated person how to spend it

The budgets do not have to be spent on specialist learning disability services, but can be used for any activity or support that meets the person's assessed needs. Again, the *Raising our Sights* personalisation guide talks about this in more detail.

Some activities could be accessed through **short breaks** (also known as respite). This would give the family a well-earned rest and the person with profound and multiple learning disabilities (PMLD) the chance to try something new. Short breaks can involve overnight stays or just be an hour or two doing something different and enjoyable. The *Raising our Sights* support for families guide has information about using short breaks creatively.

If an activity is important or enjoyable to the person but you cannot show that it meets their assessed needs, they might have to fund it themselves.

Colleges produce a prospectus of courses and will often run 'taster' days or sessions where

people can see if they are comfortable with the environment, tutor and subject. Colleges have a duty to make reasonable adjustments to allow a person with PMLD to access the building or take part in a suitable course. This might include extra support or changes to the way the course is delivered or assessed, as well as adaptations to the buildings or environment.

Most councils have details of specialist services and leisure guides, while libraries and carers' groups can also be a good source of information.

The general message from activity providers is that there are many different indoor and outdoor activities that people with PMLD can be involved in, or that can be adapted to enable them to take part. Some adaptations are easy to achieve but others require more skill and perseverance from supporters and service providers. Opportunities are not available in all parts of the UK but more are being developed all the time. For example, **Wheelyboats** launched in 15 different centres around the country in 2011 alone.

Families should come together to persuade their local area to provide specific facilities for people with PMLD, arguing that facilities such as a sensory garden in the local park, a

hydrotherapy pool or a sensory room would benefit many other people too. They might also ask if there is a coordinator or brokerage service that can help them identify and access new activities.

Law and policy that can help

It is useful to know about any relevant laws and policy that can empower a person with PMLD to access community, education, employment and leisure activities.

Direct payments

Direct payments for social care have been legal since 2007. Since 2009, it has been legal to have the direct payment made to a 'suitable person' (family member, appointed financial or welfare deputy) who can manage it on behalf of a person who lacks the mental capacity to manage the payment themselves.

Direct payments for health are now being rolled out.

The Equality Act (2010)

This protects individuals (and those associated with them) from being treated unfairly and makes sure they have the same rights as other people. This means public organisations,

activity providers, colleges and businesses must make 'reasonable adjustments' to make their services or employment accessible to people with PMLD and their families.

The Human Rights Act (2008)

This states clearly that everyone has the same rights and choices. Article 14 (the right to not be discriminated against in the enjoyment of your other rights) means people with PMLD cannot be discriminated against because of their disability in any part of their life, including their right to independent living or their right to access activities, services and support in the community.

If the person can't access services or activities

Families can find it hard to find activities suitable for people with PMLD and often these are temporary or only available occasionally. Sometimes families need to negotiate adaptations themselves, which can be very difficult and time-consuming.

If the person with PMLD you support, or other people with PMLD in the local area are not able to access meaningful activities 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 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 and 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 publicly 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 and 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 challenge or campaign 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

Saturday Stories in Lambeth

Two years ago, family carers on the Lambeth learning disability partnership board initiated a project to look at the lives of people with profound and multiple learning disabilities (PMLD) and their families in Lambeth. This resulted in a report, *The Lambeth PMLD Project* (see *Share good practice*). One of the key issues identified by the report was that there were not enough meaningful activities for people with PMLD in and around the area. It highlighted that there was very little to do that was accessible and had the right kind of equipment for people with PMLD.

The PMLD sub-group of the Lambeth learning disability partnership board is taking forward recommendations from the report, and their current focus is to address the lack of meaningful activities in the area. Becky Loney, from Lambeth Mencap and family carers of people with PMLD who sits on the sub-group, developed a plan to set up an activity project particularly for people with PMLD. They wrote a bid and

got some money from Lambeth Council and some initial grant funding.

They decided to develop a regular story-sharing session at the weekend for people with PMLD, their family carers and support workers. Stories are made accessible using music and sensory props, lots of repetition, and rhythm and rhyming. It is stimulating on many levels: visual, touch, sound and smell. The sessions are now known as ‘Saturday Stories’.

Making sure people feel comfortable in a warm, accessible setting is crucial. A great deal of attention is given to creating a stimulating environment. In the sessions, time is spent getting to know each person and thinking about what will work for them. Sessions are carefully structured and are run by facilitators with the right skills and experience. Each runs for three hours, which means people can really get a lot out of them.

Getting the right venue has been really important. The project has a good partnership with the council, and the day

centre managers have been happy to offer the day centre to use at the weekend. The group has lots of space to spread out, facilities to heat up food and sit and eat together, and changing rooms with hoists and slings.

Supporting someone in a one-to-one setting can feel isolating and supporters can get stuck for ideas of things to do, especially when the weather is bad. Saturday Stories provides meaningful engagement, friendship and opportunities to share ideas.

Becky Loney says this is just the start for the Lambeth Mencap PMLD activities project. They have some new funding from Guy’s and St Thomas’ Charity, which will allow them to provide a range of activities over the next couple of years. Part of the plan is to work more in partnership with other council departments, such as Parks and Open Spaces, to look at developing things like a sensory walk in the park. They also plan to work with leisure centres to help make sure their facilities are accessible. Becky says that joint-working is

crucial and a lot of this depends on having the right mix of people on the PMLD sub-group. They have health professionals, a PMLD lead from the care management team and managers from day centres and providers, as well as family carers. This has helped drive the project forward and get tangible results for people with PMLD and their families.

6. Film

See the film showing what they are doing in Lambeth to develop meaningful activities for people with PMLD.

www.mencap.org.uk/raisingoursights

7. Frequently asked questions

Q: Our daughter is still getting used to her new support staff and can become very agitated if she spends too much time out of the house. How can they provide stimulating and interesting activities at home while they build their relationship with her?

A: Although it is important for people to get out and about, your daughter's support team can also develop activities around the home. This requires both training and imagination, and depends a lot on the abilities of those who support the person.

They could use Intensive Interaction at any time and in any place. Relaxation can take place in a bath, art and craft or cooking in the kitchen, music and multi-media in the sitting room, massage in the bedroom and sensory gardening outside.

Q: There are lots of different mainstream leisure activities in our area, but how can I find out if they are suitable for my son who has profound and multiple learning disabilities (PMLD)?

A: Talk to other families and to the activity providers who may not be aware that people

with PMLD might want to do their activities. Once they have been approached, many are very willing to provide access such as hoists or adapted equipment, and offer specialist sessions in which the pace is slower, the water warmer or whatever is required. Some providers have even been prepared to build Changing Place toilets.

Q: We are planning a trip to London with my sister who has PMLD. How can we find out about accessible toilets and changing facilities there?

A: There are a number of Changing Places toilets in London. These have enough space for people with PMLD and the right equipment, including a height-adjustable adult-sized changing bench and a hoist. A national register and location map of Changing Places toilets in the UK can be found on the website www.changing-places.org which also provides information about other changing facilities.

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. See the detailed case study.

For more information about the Lambeth PMLD project see:

www.mencap.org.uk/Lambethpmlid

9. Links to more information and resources

Art

Project Artworks, Hastings
<http://www.projectartworks.org>

Charliejoye (London, Bucks and Berks)
<http://www.charliejoye.co.uk>

Cheese Potato and Onion – lots of ideas for resources and activities
<http://www.cheesepotatoandonion.com>

Changing Places

<http://www.changing-places.org>

Communication and interaction

Us in a Bus, Surrey
<http://www.usinabus.org.uk>

SMILE – an Oxfordshire Total Communication project
<http://www.oxtc.co.uk>

Hanging Out Programme (HOP) – Sheridan Forster recommends spending ten minutes interacting with a person, giving them 100% of your attention. The HOP booklet can be downloaded from <http://www.cddh.monash.org/products-resources.html>

A Practical Guide to Intensive Interaction, by Melanie Nind and David Hewett
<http://www.bild.org.uk>
or <http://www.intensiveinteraction.co.uk>

Interactive Story Telling, by Keith Park, published by Speechmark
<http://www.speechmark.net>

Learning to Tell, by Nicola Grove, published by BILD
<http://www.bild.org.uk>

Games, toys and switches – suppliers

TFH – special needs toys: <http://www.specialneedstoys.com/>

Spacekraft – multi-sensory products: <http://www.spacekraft.co.uk/shops/sk/Default.aspx>

Liberator – Big Mack switches: <http://liberator.co.uk>

Grapevine – a charity in Coventry that helps people with disabilities to ‘grow their lives’.
<http://www.grapevinecovandwarks.org>

Holidays

Chrysalis Holidays offers sensory holidays by the sea in its specially resourced house.
<http://www.chrysalisholidays.co.uk>

The Calvert Trust leads outdoor adventure experiences for the whole family, including people with profound and multiple learning disabilities.
<http://www.calvert-trust.org.uk>

Multi-sensory approaches

The work of Flo Longhorn and Richard Hirstwood
<http://www.multi-sensory-room.co.uk>

Bag Books - a charity that produces multi-sensory books. If copies are not available from your library, you can download them from the Bag Books website www.bagbooks.org

Music

Joy of Sound
<http://www.joyofsound.net>

Soundabout
<http://www.soundabout.org.uk>

Living My Song

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

The Music Gym

<http://www.musicgym.org>

Tac Pac

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

Net Buddy – a site for sharing information, tips and ideas about supporting people with a learning disability.

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

Orchard Hill College – provides post-school full- and part-time education, including for older learners with profound and multiple learning disabilities in Surrey.

<http://www.orchardhill.ac.uk>

PAMIS Freestyles - has information in a handbook and on a DVD. You can request a copy by emailing pamis@dundee.ac.uk

Wheelyboats – wheelchair accessible boats in locations across the UK.

<http://www.wheelyboats.org>

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