

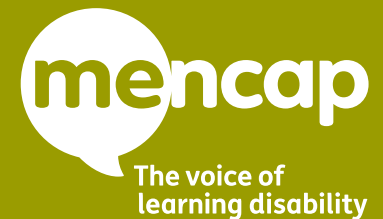


How-to guide 1

advocacy

For people with profound and multiple learning disabilities

Raising
our Sights



Raising our Sights guide to advocacy

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 ensure 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 advocacy 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 advocacy
2. What does 'good' look like?
3. What needs to be in place to meet the advocacy needs of people with profound and multiple learning disabilities
4. How people get independent advocacy
5. Detailed case study
6. Frequently asked questions
7. Share good practice!
8. 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 advocacy

There is one recommendation:

Recommendation 3.

Local health and social care commissioners should commission the development of independent advocacy arrangements suitable to represent the interests of people with PMLD. They should include funding for continued advocacy in the package of self-directed services for adults with PMLD.

This guide to advocacy will help local areas implement the above recommendation, and understand and meet the advocacy needs of people with profound and multiple learning disabilities (PMLD).

It will help families, commissioners and others focus on what ‘good’ looks like, and understand what needs to be in place for people with PMLD.

Good advocacy can also challenge things that might stop other *Raising our Sights* recommendations being followed up locally. It can make sure local commissioners listen to and understand what is important to people

with PMLD, and develop the services, policies and workforce that will enable them to get proper person-centred support.

It sometimes just needs a change to policy or the way you do things to make change happen, rather than more resources.

For many people with PMLD, the starting point will be what is often called ‘representational advocacy’ where an independent advocate speaks on their behalf. However, it is also important to find creative ways to involve and ‘listen to’ people with PMLD. In fact, this should be an everyday part of how services operate. There are good examples of how to do this in **Involve Me**, a Mencap and British Institute of Learning Disabilities (BILD) project to increase the involvement of people with PMLD in decision-making and consultation processes. Families are also important advocates for people with PMLD and their expertise should not be overlooked.

If involving and ‘listening to’ people with PMLD becomes the norm in running and commissioning services, there should be far less need for independent advocacy support.



Scenario 1: Involving Michael in getting the support he needs

Michael’s support worker films him at the swimming pool and at the hydro pool where he has one-to-one support. In the pool he demonstrates a far greater range of leg movements than he shows when not in the pool. Other staff did not know about this until they saw the video evidence.

This is a powerful way for Michael to influence decisions about staffing and resources because it shows how important it is for him to have one-to-one sessions in the pool, and to get the opportunity to move his legs and develop these skills.

2. What does good look like?

Many advocacy services describe advocacy as ‘speaking up for’, or ‘acting on behalf of’, another person.

Advocacy is person-centred and helps people:

- say what they want
- secure their human rights
- represent their best interests
- get the services they need.

When advocates refer to a person’s ‘best interests’ this means making sure decisions are based on their preferences and things that are important to them. It does not mean the advocate makes decisions on the person’s behalf. An advocate’s role is not to make decisions about a person’s life, it is to speak up for a person to help ensure good decisions are made.

In 2002, a working group of 75 advocacy services produced the **Advocacy Charter**, which describes key principles and outlines what good advocacy should look like. From this they developed a **Code of Practice** and a set of **Advocacy Standards**. You can download copies of these from the Action for Advocacy website (see the *Links to more information and resources* section at the end of this guide).

Advocacy gives people a ‘voice’ in decisions about their lives. It makes sure they are not excluded or ignored just because they do not express their views in ways other people find easy to understand. Advocates are independent of services and work in partnership with the person they support to make sure they are included, listened to and treated with respect. Some advocacy schemes employ **professional** or **paid** advocates, but many are volunteers who are supported by the scheme and matched with people who need support. They are usually referred to as **citizen advocates**.

Peer advocacy is when an advocate and the person being supported share the same or similar experiences. For example, when someone who uses the same services or has similar life experiences speaks up for another person who might find it difficult.

Scenario 2. Peer advocacy – acting on what you learn about someone to make things better for them

Kimmy, a young man with a learning disability is a peer advocate for a young woman called Serena who has PMLD. He watches his advocacy partner in a cookery session and sees how difficult it is for her to balance a bowl on her lap. He is also aware that she does not like to get her clothes dirty. He acts on what he observes by talking to her support worker and suggesting she needs a low table and extra clothes to change into when she is cooking.

While many people may be able to ask for advocacy support, or say how they want someone to speak up for them, a person with PMLD won’t be able to do this. They will need someone to make a referral for advocacy on their behalf and they will need the advocate to use their skills to suggest what might be important to them. For this reason, it is often described as **non-instructed advocacy**.

The *Raising our Sights* recommendation talks about ‘continued’ advocacy. However, most people with PMLD have no legal right to an independent advocate who can spend time getting to know them and support them in all decisions about their life. When budgets for all services, including advocacy, are being cut it can be convenient to assume that family members can take on the advocacy role. The type of advocacy available varies greatly from area to area, depending on how it is commissioned and funded locally. Where a person with PMLD has a legal right to advocacy, the support is time limited and only available in very specific situations. There is more information about **Independent Mental Capacity Advocates** (IMCA) and **Independent Mental Health Advocates** (IMHA) later in this guide.

Family advocacy is a valuable service for many carers, particularly if they become too emotionally involved in the situation and find it difficult to see the bigger picture. It becomes even more important as the move towards personalisation means people have a right to choose services, support and greater independence. For many people with PMLD this will assume a greater involvement of parents in interpreting choices, identifying support and taking on the responsibilities of planning and often purchasing services. With an estimated 60% of people with a learning disability living

with families and 40% of carers being over 60 years old, the needs of the family cannot be discounted when looking at greater choice and control for people with PMLD. Family advocacy can support carers to act as advocates with and on behalf of a person with a disability. ‘Family advocacy focuses on the fundamental principle that the rights and interests of the person with disability are paramount’ (Queensland Parents for People with a Disability) but it also helps family carers look at their own needs and express both.

Families often take an important role in speaking up for people with PMLD. However, services can see families as an asset or an irritation, depending on the issues they are raising. Sometimes the family might be told that the person needs independent advocacy support because the family’s views are biased or based on their own needs, while at other times the suggestion might be that the person does not need an advocate as their family is fulfilling this role. The Mental Capacity Act further complicates this as it is often assumed that family members are an alternative to an IMCA (Independent Mental Capacity Advocate).

Given the shortage of advocacy support for people with PMLD, the reality is that many advocates are only introduced at a time of

crisis and have little chance to get to know the person. In these situations, it is really useful if they can work with a circle of support and tap into the information other people have built up over a much longer period of time. A family advocate who can get to know the whole family can be a real asset in these situations. There is a link to more information about circles of support at the end of this guide.

A citizen or peer advocate might be part of a person’s circle of support or work closely with the circle. This means they have a better understanding of what the person might want if an issue arises or a decision needs to be made.

If, for example, there are disagreements about what should happen when a person leaves school, an advocate would collect information from the family, teachers and others to build up a picture of what is important to them. Because they are focusing only on the person’s interests, they often have a clearer view of what the options are and what the person might prefer to do. However, many advocacy services can now only offer time limited or issue-based support and no longer have the capacity to do this.



Scenario 3. Helping George to make sure his rights are met

George has just left school. Funding to go to a residential college in a neighbouring area has been turned down so he goes to a day centre where most other people are much older than him. His family noticed he was becoming more withdrawn and felt he needed someone independent to speak up for him. They recognised that, in this situation, decisions by and for George could have a real impact on the rest of the family (for example care workers coming into the family home could affect other members of the family), so they wanted someone independent to speak up for George's needs. This allowed them to feel able to speak up for their own rights as well, safe in the knowledge that George was also having his needs represented. It meant that their needs as carers and George's needs could be considered separately.

George's advocate talked to his family, staff at his old school and the day centre. She believed the key issue for

George was that he should have the same right as any other 19-year-old to mix with people of his own age, to continue to learn and to develop greater independence. She noticed how animated he became when there was a younger member of staff around and felt his withdrawal indicated that he was bored most of the time.

The advocate also pointed out how important it was for George to have specialist health care support the centre simply could not provide. She used videos from the school to show how his movement had become more limited because he was no longer receiving daily physiotherapy sessions. She suggested the health authority should contribute and part-fund the placement with the local authority.

The local authority has agreed to review George's case.

An advocate working with someone with PMLD must be very clear about their role, the way they are working and what they can and cannot do. For example, they should make it very clear that they are using the principles of the Mental Capacity Act, and are suggesting what the person's preference might be rather than conveying a definite choice. They cannot make a decision on the person's behalf. The advocate will collect evidence of what is important to the person, for example, things they like or dislike, or people and places that are important to them. They will explain how these relate to the decision being discussed, even if the person has been assessed as lacking the capacity to make that decision independently.

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

To truly meet the needs of people with profound and multiple learning disabilities (PMLD), services and commissioners must understand the skills advocates need. They must also understand that advocacy for people with PMLD is likely to take much longer than for people who are able to use formal communication.

Commissioners must regularly review the advocacy needs of people with PMLD in their area to ensure they commission appropriate services. They should include funding for continued advocacy in the package of self-directed services for adults with PMLD.

Service providers must ensure their staff understand the Mental Capacity Act and show how they involve people with PMLD in decision-making and service planning in a meaningful way.

Staff and families need to know what advocacy support is available locally, and when and how to refer people with PMLD for support. They need to understand the role of an independent advocate and be open to involving an independent person who might bring a different perspective to a decision or difficult situation.

The **guide for commissioners** has more information about how to achieve these things.

4. How do people get independent advocacy?

Most local advocacy schemes have an open referral system where you simply contact them and complete a short form. Many will do this for you over the telephone. Information about local advocacy services is available from councils, NHS trusts, libraries, the Citizens Advice Bureau or through an internet search engine like Google.

Action 4 Advocacy has an online database for finding advocacy services in England and Wales (see the *Links to more information and resources* section at the end of this guide).

However, many services rely on word of mouth and low level marketing, which can mean only the most vocal people, or those who know about services, get support.

In reality, there is not sufficient, high quality advocacy for people with high support needs, and most advocacy services have to prioritise their work to deal with the most urgent cases first. This will probably involve a visit to assess

the advocacy issues and decide what type of support the person needs. You should be told roughly how long you might have to wait for an advocate to be allocated.

If the person being supported has a legal right to an Independent Mental Capacity Advocate (IMCA) or an Independent Mental Health Advocate (IMHA), the Health Trust or local authority should provide information about local advocacy services which provide these specialist services.

Law and policy which can help

It is useful to know about any relevant laws and policy that can empower a person with profound and multiple learning disabilities (PMLD) to access advocacy.

In general, people have no legal right to advocacy. However, in some situations, a vulnerable person must be offered the support of an IMCA or IMHA.

Mental Capacity Act 2005

This law says that in some situations a person who lacks capacity is entitled to the support of an IMCA.

An IMCA supports and represents a person who lacks capacity if they are faced with certain significant decisions and if:

- they have been assessed as lacking capacity to make a particular decision, and
- they have no one other than paid staff to speak up for them. It should not be assumed that family members will take on this role unless they are clear that they are happy to do this.

These decisions are usually about serious medical treatment or changes in accommodation, but in certain circumstances IMCA advocates may also represent and support people who are involved in care reviews or adult protection proceedings.

If a person is under a Deprivation of Liberty Safeguards (DOLS) order and their representative is a family member (rather than a paid representative), both the person and their family representative **have the right** to an IMCA.

Mental Health Act 2007

This law says that an Independent Mental Health Advocate (IMHA) is available to people who are:

- detained under the Mental Health Act for assessment and treatment (this does not include people on emergency short-term sections or detained in a place of safety)
- conditionally discharged restricted patients
- on Supervised Community Treatment or Guardianship orders
- informal or voluntary patients who are discussing the possibility of serious treatment.

Both IMCAs and IMHAs have very specific, time-limited roles and are the only types of advocacy that are a legal right. In all other situations, advocacy support depends on how services are funded and commissioned locally.

Valuing People Now says advocacy is really important in order to make sure people get the right support, information and advice.

The **Mental Capacity Act** says people who lack capacity in relation to a particular decision should be involved as much as possible. Local areas must make sure they follow this and train staff to understand and use this law.

The **Equality Act** says public organisations like local authorities and health trusts have to make their services accessible to everyone, including people with PMLD and their families. This could mean making sure people with PMLD have equal access to good advocacy.

The government's **Vision for Adult Social Care, Capable Communities and Active Citizens** says 'councils should focus on improving the range, quality and accessibility of information, advice and advocacy available for all people in their communities – regardless of how their care is paid for – to support their social care choices.'

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 access to appropriate advocacy 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, 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 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 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 sorts of 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



Hammersmith and Fulham Mencap advocacy service

Mencap in Hammersmith and Fulham provides advocacy services for up to 20 people with profound and multiple learning disabilities (PMLD) or complex needs; people whose communication challenges are such that they could not instruct an advocate themselves. The project is funded by the local authority and has recently been extended with funding from a charitable trust.

People are referred to the service by their families, carers or anyone who feels that they may benefit from advocacy support. Sometimes this is for short term, issue-based advocacy where an immediate or particular concern has arisen, other times the support can run up to about two years where there may be a range of issues that need to be worked on.

The skills of non-instructed advocates include very good observational and listening skills, and the ability to

communicate in a variety of ways with the individual. It's also important to be able to communicate well with and support family members, and engage a wide range of professionals. Non-instructed advocates also need a good understanding of human rights and the ability to stand up for people when needed.

The aim of the service is to ensure each person's perspective is considered when decisions are being made, and to achieve a change in the quality of life of the individual. It begins with spending time getting to know the individual well and learning how they communicate. This can take time and it's important to be respectful of the way each person may want to engage. The advocates may visit the person at a variety of places they go to, building up a picture of what works well for them and what doesn't. As the advocate gathers the evidence they are better able to speak up for the person and achieve the changes needed.

Examples of how this has worked:

- Working with a person on how to use their individual budget. The advocate visited the person at home and, by talking to their family and getting to know them, they could see that music was important. They then looked for a music group in the community. The person tried this out while the advocate observed to make sure that it was the right opportunity to continue with.
- Working with a person with housing needs. The advocate became involved because the person was living in a very crowded household which was not good for them or their family. She gathered the evidence to show what impact this had on the person's health and well being and the specific sensory and equipment needs that were not being met, and was able to use this to make a case for re-housing. The whole family was moved to larger and more suitable accommodation.

- Helping a person with transport issues. The advocate was told by the family that the unreliability of transport, the use of unsuitable vehicles and the constant changing of drivers were causing distress to the person, who was having to travel to a day service in another area. The advocate gathered evidence from a variety of sources of the impact that this was having on the person. This resulted in a change of transport provider, the same driver each day and a suitable vehicle. The person now enjoys the journey to the day service.

6. Frequently asked questions

Q: We speak up for our daughter – why does she need an independent advocate?

A: Although independent advocacy is most important where people have no family to speak for them, it can also be valuable for a family to step back and work with someone who brings a fresh perspective to a situation. Any decisions taken by or for your daughter will affect the rest of the family, and sometimes it can be important to feel free to express your views and needs separately from hers. **Family Advocacy** is a valuable service to many carers. It can give them support when they are stuck or have become too emotionally involved in the situation and are unable to see the bigger picture.

Q: As a family carer, can I get an independent advocate for myself?

A: Yes. You could ask for an independent advocate to help you identify and get support for your own needs. You could ask your local family carers centre or the local authority about how you can get independent advocacy support for yourself. It can be very difficult to find a service that just provides advocacy to carers. Often it is just one of many services

they provide and this might compromise their independence as an advocate.

Q: How can an advocate decide what a person with profound and multiple learning disabilities wants after one or two meetings when it takes other people years to get to know them?

A: There are some situations, for example when an emergency placement is needed, when an advocate will have to act quickly and might only be able to meet the person once or twice. Advocates should have a sound knowledge of legal and human rights and the skills to collect information about a person, and be able to suggest what their choices might be. So, even if they are not able to spend much time with the person, they should still be able to suggest what is important to them based on what they have observed, what they have found out from talking to their family and others who know them well, and what they know about legal and human rights.

Q: What's the difference between an IMCA or IMHA and an independent advocate?

A: IMCAs and IMHAs have very specific roles in relation to the Mental Capacity Act and Mental Health Act. In certain situations, people have a statutory right to these types of advocacy, which must be funded locally, but the support is time limited and around specific issues. Longer term independent advocacy is provided by advocacy schemes that are usually funded at the discretion of local authorities or health services. People with profound and multiple learning disabilities can really benefit from longer term support from an advocate who has time to get to know them and ensure they are involved in all decisions about their life. They have no statutory right to this type of advocacy and services are often under-resourced.

Q: The advocacy service is funded by the local authority – how can it be independent?

A: In an ideal world, advocacy services would have independence of mind, place and funding. Independence of mind is the most important of these. How it is achieved will be set out in the advocacy service's policies and protocols. They will be able to tell you about the way they work.

Q: Shouldn't our existing service be able to do all this already?

A: Not unless the local authority is funding it in a way that enables the service to spend enough time with people with profound and multiple learning disabilities and recruit and train staff with all the skills that are needed.

Q: Many people with profound and multiple learning disabilities have families who are really good at speaking up for them – why do we need advocacy as well?

A: Although the advocate will respect and get to understand the relationship with their family, the advocate is only interested in the rights and choices of the person with profound and multiple learning disabilities. This means there are clear boundaries between the needs of the person and the needs of their family. However, the advocate should not dismiss the family's knowledge and skills but should draw on these, even if there are disagreements about what the person's choices might be.

Q: What legal status does an independent advocate have?

A: An advocate will be trained and supported by an advocacy service but has no legal status.

Their relationship with their advocacy partner is based on trust and the ability to focus on their rights and interests, rather than the needs of services or other people with profound and multiple learning disabilities. An advocate has no legal right to access information about the person without permission.

7. 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

Tel 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 take 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

8. Links to more information and resources

The Advocacy Charter, advocacy standards, code of practice and a database of advocacy services in England and Wales

<http://actionforadvocacy.org.uk>

Circles of Support

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

Getting to Know You

Getting to Know You is Mencap's peer advocacy project

www.mencap.org.uk/gettingtoknowyou

Giving us a Voice

Charter for Inclusion – promoting the involvement of people with a learning disability and their families from minority ethnic communities.

www.givingusavoiced.org.uk

Hearing from the Seldom Heard

This project looked at how people with profound and multiple learning disabilities were excluded from formal complaints processes, and recommends six areas of good practice to

create listening cultures within organisations.

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

Human Rights Act 1998

<http://www.justice.gov.uk>

Involve Me

Involve Me aims to increase the involvement of people with profound and multiple learning disabilities in decision making and consultation.

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

Mental Capacity Act 2005

<http://www.legislation.gov.uk/ukpga/2005/9/contents>

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