How-to guide 6
personalisation

For people with profound and multiple learning disabilities

Raising
our Sights

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The voice of
learning disability

Raising our Sights guide to personalisation

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 personalisation 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

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

1. What *Raising our Sights* says about personalisation

There are two recommendations:

Recommendation 1:

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

Recommendation 33:

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

This guide will help local areas implement recommendation 33, and understand and meet the personalisation needs of people with profound and multiple learning disabilities (PMLD). It focuses on what 'good' looks like and what needs to be in place in order to meet the needs of people with PMLD in terms of personalised services and support.

The guide is designed to help families and commissioners (as well as other local campaigners) who believe personalised support is achievable for people with PMLD. The underlying principle of personalisation – the person is at the centre - should inform all thinking relating to the topics covered in the other guides. Some of these areas, such as *Support for families, Training the workforce* and *Housing*, are, in turn, essential to true personalisation. Robust and creative advocacy is particularly important to ensuring people with PMLD receive personalised support.

2. What does ‘good’ look like?

The aim of personalisation is to enable people to be more in control of the services or packages of support they receive. Every person who receives support, whether funded through Social Services or by themselves, should have choice and control over the shape and direction of that support to promote independence, opportunity and inclusion. It is not acceptable to ‘slot’ individuals into existing services that are not designed to meet their specific needs, and expect them just to adapt and live in a way that fits with what the service can offer. Instead, services should be designed and adapted to suit individual needs.

Person-centred planning helps people think about and plan how they wish to live their life. This approach is essential if the person is to be in control of the services or support they receive. It should:

- always place the individual at the heart of planning
- treat family members and other significant people as full partners
- recognise a person’s capacities but also the fact that they will have strengths and preferences
- believe that a person can make a valued contribution to their community.

Many people with profound and multiple learning disabilities (PMLD) are described as receiving a personalised service. However, the actual support they need is not being given and they are not benefiting from true and meaningful personalisation.

For personalised support to transform the lives of people with PMLD there must be:

- evidence of a truly person-centred plan prior to offering services or support and that people with PMLD and their families have been involved in developing these plans
- direct payments and individual budgets, recognising and including the real costs of appropriate support
- budgets available for people to pay supporters who are highly skilled in meeting their communication and complex health needs.

People with PMLD often need help and support from their families to implement and manage their personalised service, as well as plan it. This can be very stressful for family members and requires a great deal of time and energy. They must get the information and support they need to do this.

When a local authority manages a personal budget on the person’s behalf (for example, in a situation where the person with PMLD does not have family, or where the family does not want to or is unable to manage the budget), this should still be seen as a collaboration and leave individuals and families feeling that they still have real choice and control.

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

Most people's packages of support will be funded via an allocation of public money following an **assessment of needs**.

An individual can 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 (e.g. Social Services, local education authority, funding for equipment or employment).

Either of these budgets 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 (e.g. 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.

Because most people with profound and multiple learning disabilities (PMLD) communicate non-verbally, people can worry about how to meaningfully involve them in person-centred planning, so it is vital that:

- families are viewed as experts
- representational and non-instructed advocacy is valued more highly
- a more creative approach is taken to communication.

Personalised packages of support should have the same principles as person-centred planning. The package should be developed with the interests of the individual at the heart, and seek to empower rather than disempower them. These packages should also recognise and be able to respond to an individual's capacity for change. For many people with PMLD, there will also be changes that may come about as a result of very complex health needs. Therefore, a responsive and flexible approach to supporting people is needed.

Research for *Raising our Sights* found that personalised support for people with PMLD works best when a small number of people are supported together (or an individual is supported on their own), as opposed to being supported in large groups. Such situations appeared to lend themselves more naturally to keeping the focus on the individual and developing warm, respectful and genuinely caring relationships between the supporter and the person being supported. There was also evidence of better communication and more creative support approaches. In all these examples of personalisation, families were vital to their success and effectiveness.

The *Raising our Sights* **how-to guide on commissioning services for people with PMLD** has more information about how to achieve these things.

4. How can people access personalised support?

Planning

There are many different ways to help someone plan in a person-centred way. These are often referred to as the 'tools' of person-centred planning.

A good way to plan with people with PMLD is to use **PATH** (Planning Alternative Tomorrows with Hope).

When you use these tools with people with PMLD it can really help if they have a **circle of support**, where a group of people who know them well, meet regularly to help them think about their future and how to achieve them. The circle itself is not a tool of person-centred planning, but is a way to help people get the best out of them.

PATH and circles of support both feature in the detailed case study. There is also information and links to organisations and resources that can tell you more about them at the end of this guide.

Assessment

Anyone who needs support must receive an **assessment of needs** from their local authority. This should be done by a skilled member of social services and:

- is carried out on a face-to-face basis
- anyone else who plays a significant part in the life of the person is present and can contribute to their assessment.

There must be a written record of the assessment and a copy of this must be given to the individual who has been assessed. Make sure:

- all the needs of the person with PMLD have been accurately recorded
- anything relating to meeting these needs has been accurately recorded (e.g. if someone needs two-to-one support to go out, then make sure the assessment states this).

The local authority will then evaluate the person's **risk to independence if each need** were not met (i.e. assuming no support from family or significant others). This will be done with regard to four particular aspects of independence/well-being, which are all equally important:

- autonomy and freedom to make choices
- health and safety, including freedom from harm, abuse and neglect
- the ability to manage personal and other daily routines
- involvement in family and wider community life.

The risk to independence for each need will be rated at one of the following four levels:

- low
- moderate
- critical
- substantial.

The local authority will have already formally decided what level of need it will meet and fund under its **Fair Access to Care criteria** (also known as **eligibility criteria**). You can ask for a copy of this before the assessment.

Any assessed need that meets or exceeds the level set out in the Fair Access to Care criteria is then referred to as an **eligible need**. The local authority has no choice but to meet and fund an individual's eligible needs.

Personal budget

The cost of the support and services needed to meet eligible needs should then be outlined in a **personal budget**. The money allocated should be sufficient to meet these needs.

You can then choose whether to leave the local authority with the responsibility of using the money to commission support and services (**notional budget**), or have the money paid to you as a **direct payment** which you can use to arrange your own support and services.

- This is one reason why it is important to do good person-centred planning before the assessment takes place.
- Local authorities should encourage individuals who leave commissioning responsibilities with them to become more involved in using the money in a way that enables them to have a better life.
- *Raising our Sights* found that highly individualised support works best for people with PMLD.
- Some local authorities commission services that can support families to manage direct payments. These are often local user-led organisations.

Because people with PMLD need help and assistance in most areas of their lives, a large amount of their direct payment will be spent on employing support staff.

This can be done by:

- **Directly employing personal support staff**. There is an example of this in the case study in this guide. Local authorities should ensure the direct payment covers the costs associated with directly employing support staff (e.g. National Insurance, CRB checks, holiday pay and training costs).
- **Using a support provider**. It will take on all the employment duties and responsibilities and include this in the amount it charges. Some providers have done lots of work in recent years to ensure the support they offer people is more personalised and responds better to the individual's needs and wishes. Providers should work alongside families and people with PMLD to ensure this happens and encourage them to be actively involved in recruitment, supervision of staff and identifying training needs.

Accessing personalisation for a family member who has PMLD can be a daunting prospect. Many families find talking to other families in similar circumstances can be an invaluable source of information as well as helping to provide emotional support. There are many carers' support groups, as well as regional local carer networks that feed into the **National Valuing Families Forum**. Additionally, the **Challenging Behaviour Foundation** offers a family linking scheme. Please see *Links to information and resources* at the end of this guide.

Support brokerage. These services provide practical support to people with PMLD and their families. They can help people identify their own support needs, decide what support packages will best meet their needs and preferences, and organise and manage this support. Links to organisations and resources with more detailed information can also be found at the end of this guide.

Law and policy

It is useful to know about any relevant laws and policies that can help someone with PMLD to access personalised support.

Community Care Assessment Directions (2004)

If a person appears to be in need of support, they are entitled to an assessment of needs, regardless of the resources and finances of the local authority. It is a legal requirement that this assessment must:

- consult with the person being assessed
- consult with a carer if appropriate (particularly important for people with PMLD)
- take reasonable steps to reach agreement with the person (and carer) in terms of services provided to meet needs
- provide information about how much the person may be required to pay for any services that may be provided.

Any family member who regularly provides substantial care to someone with PMLD also has the legal right to request an assessment of their own needs. Again, this is regardless of the resources and finances of the local authority.

Direct payments

Direct payments for **social care** have been legal since 2007.

Since 2009, it has been legal to have the direct payment paid 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.

It is already legally possible to offer people a personal health budget where the money is held by the NHS or a third party. Pilot sites authorised by the Department of Health also have the option of offering personal health budgets in the form of a cash direct payment. However, direct payments for healthcare are not yet allowed in areas outside the pilot programme. It is worth checking the Department of Health website for progress and changes with this.

The Mental Capacity Act (2005) supports the values of personalisation by helping people with PMLD to make their own decisions. The act states that people who lack capacity to make a particular decision must participate as much as possible in a decision made on their behalf. Local authorities must ensure they follow this and train staff to understand how to use this law.

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

The Human Rights Act (2008) 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 the right to independent living or the right to services and support in the community.

If the person can't access a truly personalised package of care

Many personal budgets are not truly personalised because of the way some local authorities work, and many people with higher and more complex needs are often not allocated enough resources to enable them to get a truly personalised package of support.

If the person with PMLD you support, or other people with PMLD in your local area, are not able to get a truly personalised package of care, 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). You could 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 (see below)
- 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 cases, such those involving the Human Rights Act or the Equality Act, 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

Christian

Christian is a 26-year-old man with profound and multiple learning disabilities (PMLD) and a very complex form of epilepsy. He requires support in all areas of his life.

Due to the severity and complexity of some of the seizures Christian experiences, he requires a high level of support, currently two-to-one.

Christian does not use spoken words to communicate, but he is a very skilled non-verbal communicator.

When he was younger, large amounts of money were spent trying to accommodate Christian's needs in traditional services such as specialist school and residential respite care. In spite of the large expenditure, this proved to be unsuccessful and Christian's needs were still not met. This led to him becoming increasingly unhappy, something he communicated through self-injurious behaviour. It was also not an ideal situation for other people using these services.

By the time Christian was 19, he already had an established circle of support, made up of family members, family friends and people who had supported him at school. All of the people in Christian's circle had known him for a long time and were very in tune with the way he communicated and expressed his wishes and preferences.

Christian's circle helped him use PATH as a way to think about what he would like to achieve in life and how he could do this. PATH is a creative and visual process that takes the end (dreams/aspirations/goals) as its starting point and then looks at where an individual is in the here and now. It then breaks down the journey from A to B – first steps, six months, a year, etc. It then looks at what needs to be achieved at each stage and who can help to do this. The PATH helped Christian identify that being supported to live independently in his own home was something that was of vital importance to him and consider how he could achieve this.

During his assessment of needs, Christian's mum ensured that as well as family members, an additional representative from the circle was present. During the assessment, they highlighted the failure to slot Christian into traditional services, and produced medical testimonies regarding the complexity of his epilepsy and the needs this presented.

- Christian was allocated a personal budget in the form of a direct payment.
- He uses this direct payment to directly employ his own support staff and uses a small, local human resources company to help with some of the employment duties.
- Christian's house has separate accommodation areas for family members who, alongside Christian's paid team, continue to provide support for him. The consistency this allows was something Christian's circle felt was important to him and he continues to communicate that he is happy with this approach.

Being able to have his own individualised support has really benefited Christian. His team are able to focus solely on him and his needs, and have the time and space to be able to truly listen and respond to his communication as well as build meaningful and trusted relationships with him. Christian no longer has to hurt himself in order to tell people he is unhappy about something. It also means he is able to live his life in a manner and at a pace that is suitable for him.

Those who knew Christian when he was younger have commented on how much happier he appears to be with himself and with life in general. This has positively impacted on his physical health – which, in itself, can be more adequately responded to – and this has resulted in less hospital admissions in recent years. Having been able to secure individualised support has also enabled Christian to fulfil other aspirations identified through his PATH, such as travelling, attending music festivals and undertaking work as a freelance disability adviser/consultant.

6. Film

Watch Christian’s film showing how a personalised package of support has enabled him to live a full life.

www.mencap.org.uk/raisingoursights

7. Frequently asked questions

Q: Can a local authority say that it no longer offers face-to-face assessments, and provide a self-assessment form to be completed instead?

A: No – this is unlawful. The local authority has a duty to carry out face-to-face assessments, regardless of its financial restrictions.

Q: Is an assessment of needs a person-centred planning tool?

A: No – Community Care Assessment Directions state that assessments should aim to be person-centred in their approach but they are not tools themselves.

Q: Can family carers receive direct payments?

A: Yes – in order to meet their own needs. Eligibility for support is assessed using a similar risk analysis to that of the individual being cared for.

Q: Can a direct payment be made to someone with PMLD who is deemed to lack the mental capacity to manage them?

A: Yes – since 2009 it has been lawful for them to have a 'suitable person' to do this for them.

Q: Can allocation of a personal budget be combined as part notional budget and part direct payments?

A: Yes – an individual can opt to receive direct payments to commission some aspects of their support and leave the local authority with the responsibility to commission other aspects.

Q: Are there restrictions on what a direct payment can be used for?

A: Yes – a direct payment cannot be used to finance an illegal activity. It also cannot be used to purchase residential care or services that are provided directly by the local authority.

Q: Can a support broker conduct an assessment of needs?

A: No – they can provide help to families and individuals who are undergoing an assessment (including being present during assessment) but it must be carried out by a social work professional or care manager.

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 **pmldnetwork@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 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/Lambethpmld

8. Links to further information and resources

Challenging Behaviour Foundation

http://www.challengingbehaviour.org.uk

Circles of Support

www.circlesnetwork.org.uk

Disability Law Service

Provides telephone or email advice on community care law. Free to people with a disability and their family carers.
www.dls.org.uk
Tel: 020 77919800
Email: advice@dls.org.uk

Equality Act 2010

www.homeoffice.gov.uk/equalities

Human Rights Act 1998

http://www.legislation.gov.uk/ukpga/1998/42/contents

Mental Capacity Act 2005

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

HFT's guide to the Mental Capacity Act.
http://www.hft.org.uk/supporting-people/family-carers/family-carer-support-service/

Mencap's Mental Capacity Act resource for family carers of people with PMLD.
http://www.mencap.org.uk

Person-centred planning tools

http://www.helensandersonassociates.co.uk

Putting People First

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Socialcarereform/Personalisation/index.htm

Shaping the Future of Care Together

http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Consultations/Liveconsultations/DH_102339

Support brokerage

www.nationalbrokeragenetwork.org.uk

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