



# How-to guide 7 support for families

For people with profound and multiple learning disabilities

**Raising  
our Sights**



# Support for families: help and advice, short breaks

*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)<sup>1</sup> 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 in 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 really 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 support for families guide 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](http://www.mencap.org.uk/raisingoursights)

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<sup>1</sup> Read the PMLD Network definition of profound and multiple learning disabilities at [www.pmldnetwork.org](http://www.pmldnetwork.org)

# 1. What Raising our Sights says about support for families

There are two recommendations:

## Recommendation 2.

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

## Recommendation 27.

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

This guide will help local areas implement these recommendations about information and short breaks, and understand and meet the needs of families of people with profound and multiple learning disabilities (PMLD).

It focuses on what good support for families looks like and what needs to be in place to meet the needs of families of people with profound and multiple learning disabilities (PMLD).

People with PMLD are among the most vulnerable people in society. Families caring for them provide exceptionally high levels of support, juggling complex needs and engaging with many professionals from health, education, social care housing and social security. Although they have the greatest needs, these families are the least likely to receive good information about what is available to them, or receive adequate breaks from caring.

**Mencap's Breaking Point Survey** in 2003 showed that 8 out of 10 carers of people with severe and profound learning disabilities were at breaking point due to a lack of short breaks. A decade later, Mencap's short breaks report of 2013 has shown that the situation hasn't improved. This is despite the government putting dedicated money into short breaks for children, first through Aiming High for Disabled Children (2008) for children's short breaks, and more recently (2010) the coalition government has put over £1.2 billion in children's and adult's services for short breaks until 2015.

Mencap's 2013 short breaks report has shown that 8 out of 10 families of people with a learning disability have reached, or are close to reaching, breaking point as a result of a lack of short breaks. While this latest survey and report looked at the situation for all people with a learning disability, the majority of those who responded were caring for individuals with needs that required high level of support.

*Raising our Sights* reports how many families find the complex needs of the person they cared for meant they were often "too disabled" to fit into existing services.

***"Some families report that services are extremely risk-averse, to the extent that they injure the person's quality of life rather than manage the risks involved. A common experience appears to be that families are told that they cannot have the services they need because their needs are too great – that the amount of money involved is 'better spent' meeting the needs of a larger number of people with less severe needs."***

*(Raising our Sights, 2010).*

## 2. What does ‘good’ look like?

**Most families** who support a relative who has profound and multiple learning disabilities (PMLD) need these key things:

- **the right amount of support** on a daily basis to function as a family
- **support that is flexible**, skilled, person-centred and provided when needed
- **access to short breaks or respite care** to give them the opportunity to re-charge their batteries and enable them to carry on caring
- **information and advice** from reliable sources who understand the wide range of health and social care issues they have to deal with.

### Good short breaks

The term short breaks is used to describe the time off that carers of a family member with a learning disability are entitled to. These breaks come in different forms. Some families access building-based short breaks services; others are part of schemes involving placements with families. Some receive direct payments to buy their own support.

Breaks are an essential part of the support needed by the whole family, providing much needed time off for the carer to rest and focus on other activities and family members, and a chance for those they care for to spend time with others and take part in different activities. They can also give the individual experience of being independent from their family, which can be useful preparation for moving on from the family home at some point. It also means there will be somewhere familiar for the person to go in an emergency.

The number of people with PMLD is increasing. More young people are surviving well into adulthood due to better technology, medical intervention and quality of care. We need more services to meet these needs, and a more creative and flexible approach to short breaks for people with PMLD and their families.

**Because each person is unique and families also have different needs, a one-size-fits-all approach will not work. However, an effective short break service for people with PMLD should:**

- **be extremely sensitive and responsive** to the needs of the person with PMLD. This will involve paying attention to health and communication needs as well as emotional and cultural needs
- **be planned in a person-centred way**
- **see the family as part of the team**, and involve people who use the service, together with carers, in planning and developing services
- **enable the family carers to take up work, training, education or leisure activities** and have a life of their own, as outlined in the Government’s national strategy for carers (see [links to information and resources](#)).

- **enable carers to get a well-earned rest** and have a positive impact on their health and wellbeing so they can continue in their caring role for as long as they wish
- **provide opportunities for the person with PMLD** to socialise, meet with friends and have new and positive experiences
- **make sure staff have the right skills** so families feel confident in using the service.



## Scenario 1: Helen and Festival Spirit

Helen went to the Glastonbury music festival for five days with Oxfordshire-based charity Festival Spirit, which supports young people with disabilities including PMLD, and life-limiting illness. Her sister chose to go as her supporter because, living in another area, it was a chance to spend quality time with her sister. Other young people were accompanied by supporter 'buddies' as well as nurses and carers.

The young people went 'glamping' in a luxurious tent, complete with height-adjustable beds, hoists and a hard floor. There were specially adapted showers available for them to use.

They were transported to the festival in a "Jumbulance". Helen's oxygen concentrator suitcase and mask were brought along with all her other equipment, including her special buggy, enabling her to enjoy the music and sunshine with other festival-goers.

This innovative approach to short breaks benefited the whole family because it allowed Helen to have an enjoyable

experience while her parents were able to get a much-needed holiday break.

For more information about Festival Spirit, see *Links to information and resources section*

## Good information

**Families need information and advice about issues which affect them and the person they care for. A good local information and advice service should:**

- **provide information** about local services and support
- **run information** days/workshops on different topics at a variety of times convenient to the needs of families of people with PMLD
- **develop and facilitate** carers' support groups
- **signpost** to activities for the person with profound and multiple learning disabilities and family carers. Some information and advice services may run activities of their own.

Local authorities have a duty to provide information and advice services.

However, as **the government's strategy for learning disability, Valuing People**, recognised, families often find that other carers are the best source of support and information.

***“Carers need more and better information provided in ways that are easily accessible. The most effective exchange is often between carers, who share experiences and solutions.”***

*(Valuing People, 2001)*

User- and carer-led groups can be a valuable source of peer support, information and advice. Family carers have a first-hand understanding of the practical and emotional impact that caring for someone with PMLD can have on the whole family. They may also have found ways of overcoming barriers and dealt with similar challenges in finding support.

# 3. What needs to be in place to support the families of people with profound and multiple learning disabilities

## Short breaks services that:

- **listen carefully to the family** and recognise that their experience makes them experts, and that they know much about how to best support a family member who has profound and multiple learning disabilities (PMLD)
- **offer a warm welcome** to people with PMLD and their families. That first impression can make a huge difference. The service should be clean and attractive, and staff should make an effort to personalise the room your relative is using
- **have staff who take time to learn** about how the person communicates, and work with the family and others who know them well to develop a communication passport so that all staff know how to communicate with them. More importantly, they should always communicate with your family member face to face
- **value the people they support** and treat them respectfully at all times
- **build trust with families** by being reliable and consistent
- **keep up-to-the-minute records** of medication or care needs, and view records as living documents that are person-centred and checked constantly
- **ideally, the service would provide a named key worker** who takes time to build a relationship the individual and their family. It is certainly important the individual visits the service before they stay there to familiarise themselves with it, and allow the family to share information and ask questions
- **understand the importance of good postural care** and ensure that staff are trained to carry out daily physiotherapy exercises if the person needs these
- **cope skilfully with emergencies**
- **know how to support a person with their feeding and drinking routines**
- **are skilled in dealing with a wide range of other technical issues** that families cope with daily, such as supporting people who have a catheter, need stoma care, who are tube-fed, or need oxygen.
- **strike the balance** between knowing when they must call the family and when to leave them to their break
- **check with families** if they have concerns about changes they see in the person's behaviour as this could be a signal that something is wrong
- **offer activities that are fun**, creative, meet the needs of the individual and are inclusive and build strong links with the local community
- **if it is a local short breaks service then it should be able to support the individual to do their usual activities.** For example, there should be flexibility to let the individual's personal assistants come into support them, as they would when they are in the family home
- **offer people with PMLD choices and support them to make choices.** People with PMLD should be involved as much as possible in all decisions being made about their lives. It is important that staff have been trained in the Mental Capacity Act and have a good understanding of their responsibilities under this law

- **understand how a multi-sensory approach** can help the individual know where they are, and help them cope with the changes
- **are honest about what they can provide.** If a service won't be able to fully meet someone's needs it is important they say so
- **listen to the family's concerns and act on them** in a prompt and professional way, and explain its complaints procedure clearly
- **has a zero-tolerance approach to abuse** of any kind, and explains to families what they can do if they have any concerns about the safety and wellbeing of the individual.



## Scenario 2:

The Camden Society has set up innovative short breaks schemes in London and Oxfordshire using a hotel model of care. It is able to support people with PMLD. People who use these services are 'guests' and families are able to use the person's own 'My Short break planner' - a tool provided by the Camden Society which enables short breaks to be booked in a flexible way. The hotels provide support workers able to take guests on a range of activities, while their restaurants offer a choice of menus.

For more information about the Camden Society, see links in the information and resources section



## Scenario 3: Getting the right support for Molly through transition into adult services

Molly is 21 and lives with her mother, Lorraine, and little sister, Maisie. Molly has cerebral palsy, a profound learning disability, epilepsy and autism. She doesn't use speech but she is able to understand some clear, short words. Molly's behaviour became challenging after she had surgery to control her epilepsy. She began to self-harm and suffered from poor sleep. Molly's parents divorced as a result of the pressures of coping.

Molly had shared care during her teens, spending two days at home and two in a residential care home. However, the arrangement caused her to become very distressed. The family had been unable to get funding for a residential school that also had adult services.

Molly was given a place in supported living accommodation when she was 18. She became very upset, lost weight and became physically aggressive. Molly's

mum felt that the support staff were not well trained and did not understand her daughter's communication needs nor her need for structure, so she was brought home.

Her mum used a direct payment for two years but did not like being an employer to her two friends who supported Molly.

Molly started to use a short break residential facility run by the local NHS Foundation Trust. The staff were trained in total communication and understood the specific support she needed with her autism and sensory needs. They also took Molly out to do things she enjoyed.

This is working so well that Molly's mum can work once a week and feels that she now has quality time with her other daughter.

## Information

People with PMLD often depend on their families to get them the help and support they need. Families of disabled children and adults talk about the continuous “fight” to obtain information, advice and support for the person they care for. Professionals must have the skills and knowledge to inform, advise and support them.

Families need good information about what services are available, how they get them and their rights in law. This knowledge can empower families and lead to better support for the person with a learning disability.

Local authorities should support the development of user-led groups and self-help groups to provide peer support, and offer independent advice and information on a wide range of issues. They have a key role to play in the development of independent monitoring, quality assurance and information on personal budgets.

There should be a local user-led organisation in each local authority area, whose role is to provide independent advice to service users, from other service users who are experts by experience. They are typically run by disabled people and some may involve carers’ groups.

There are a number of national organisations that can direct people to their local user-led organisations.

### **The role of local user-led organisations will vary from area to area, but usually they provide:**

- **information and advice** about direct payments and personal budgets
- **advocacy** and peer support
- **support** in using a direct payment and/or in using a personal budget
- **assistance** in self-assessment.

They may also help with recruitment and employment of personal assistants.

The main barriers for many people are the anxieties about managing a direct payment or a personal budget. It helps if people understand that they can take a direct payment or a personal budget but do not have to manage it themselves. They can ask the local authority or an agency to manage it on their behalf. They do of course have the right to manage it themselves if they choose, which is known as self-directed support. User-led organisations can be helpful in supporting people to do this.

Your local council for voluntary action should be able to direct people to their local user-led organisations.

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

## 4. How can families get support?

The first step to getting a short break (or any other service) is an **assessment**. During the assessment the needs of the carer must be considered, either in the form of a separate carer's assessment or as part of the core assessment of the person with care needs. A carer can ask for the assessment to be done when the person they care for is not there. It can sometimes be very difficult for families to talk about the level of caring they are undertaking and the impact that this is having on them when the person they care for is present.

Families should state clearly their need for a break and, perhaps more importantly, what could happen if they don't receive one.

Families have a right to an assessment and can arrange it by contacting their local authority, which may have a helpline, access team or customer services department. There will usually be one point of contact for families to be referred to the social care services.

### In an emergency

If a request is urgent, families can ask to be put in contact with the duty social worker in the learning disability team and request an assessment.

In the case of emergencies outside office hours that require urgent support, families can contact the local authority's emergency social work team after 5pm. The local authority can put in place emergency support and complete an assessment later. The number is usually displayed on the council website or can be obtained through directory enquiries.

Some local authorities run an emergency carers' support scheme. Families will need to register with these services which can usually provide a support worker for a few hours or even two to three days, until longer term plans are put in place.

### Children and young people

Families supporting a young person under 18 years of age can ask to be put in touch with the children's disability team. They may then be referred to a transition team social worker for an assessment if the person supported is aged from 14 to 18.

It should be easier in the future for families to see what support is available locally for children and young people with special educational needs (SEN), including those with PMLD. This is because the new **Children and Families Bill** says that all local areas must have a 'local offer' covering health, social care and education, which sets out all the support and services available to children and young people with SEN and their families. This must be developed in consultation with families and children and young people with SEN. The Bill is due to become law by late 2014 or early 2015.

## Carer's assessment

Family carers are entitled to a separate assessment of their own needs. Some local authorities now have an initial on-line self-assessment form. Some people find it difficult to describe their position and the amount of caring involved without having a conversation. It is important for them to know they can still request a face-to-face meeting.

When the assessment is carried out, family carers may find it helpful to meet the care manager at their office or somewhere else convenient if they wish to speak to them without their family member present.

A person providing a “substantial” amount of care on a “regular” basis must be offered a carer’s assessment by their council’s social services department, under the terms of the The Carers (Recognition and Services) Act 1995. This assessment should look at what services they might need to help them care for the person including, but not limited to, short breaks, and should give an accurate account of their willingness to continue caring.

The council should bear in mind that often it is not possible to determine whether a carer’s responsibilities are “substantial” without undertaking a carer’s assessment. Where there is uncertainty, an assessment should take place. While councils have to carry out

assessments of carers who provide regular and substantial care, they can assess carers even if their caring responsibilities are not deemed substantial. However, many carers have never been assessed and some have even had their request for an assessment refused.

During the assessment it is important that family carers explain how the caring role affects them and other family members. They should outline their physical and mental health needs and let it be known if they are feeling under stress.

Carers should make sure the assessor knows how much care they feel they able to give and discuss their needs for a short break. They should also tell them of any needs they have in order to work, train or access education or leisure, as all these can be taken into account.

It can be really helpful to prepare for an assessment. See the resources section for Mencap’s factsheet with tips on how to prepare for a carer’s assessment.

**The new draft Care and Support Bill** offers the potential to give greater support to family carers as it strengthens the assessment rights of carers and, for the first time, gives them a right to support if they meet the eligibility criteria. The guidance published under the new Bill should ensure that the threshold for assessment is as low as possible.

Elements in the draft Bill also seek to ensure children do not see a gap in the support they receive at the point of transition. The proposals give local authorities the power to assess children and their family carers under the adult care and support statute before the child is 18 by completing a ‘child’s needs assessment’. This can help make sure the right services can be planned for when the child enters adult services. If assessment and planning isn’t done by the time the child is 18, then the local authority has to continue providing the services it was providing in children’s services until this is done.

The person being cared for is also entitled to an assessment of their needs. This, in turn, would make it possible to identify the carer’s need for short breaks services. Councils have a duty to identify and assess all disabled children for social care services (Children Act 1989, Section 17 and Schedule 2), and all adults “where it appears to a local authority that they may be in need of any such services”. Therefore the person with PMLD being cared for will most likely be entitled to an assessment for social care support (NHS and Community Care Act 1990, Section 47)

## Following an assessment

Once an assessment has taken place and the person has been shown to have an eligible need, the council **must** produce a care plan (sometimes referred to as a “statement of need”). This states clearly what they are going to provide and how, when and where they will provide it. Family carers should be given a copy of the care plan if their family member lacks the mental capacity to make their own decisions. The plan should also detail their need for a short break or any other carer support. Children and young people have a legal right to a short break. Once a person reaches the age of 18, care managers should not assume a willingness by the carer to continue caring for them at home. Carer’s legislation is very clear that carers have a right to employment, education and leisure, and any assessment must take these needs into account. If there is no provision for short breaks for an adult, a carer could refuse to sign the care plan until this is resolved. Information about how to challenge a care plan is covered in the ‘if families can’t access the support they need’ section,

Section 2 of the Carers and Disabled Children Act 2000 enables social services departments to provide services to carers following a carer’s assessment. The Act does not define what a carer’s service is, apart from saying that it can be anything that could “help the carer care for the person cared for”.

It is very important that a person-centred plan is developed with the person being cared for to help carers think through and describe their detailed support needs. This is particularly helpful for identifying the right kind of support or, if necessary, developing a bespoke support package that meets their needs more effectively. A person-centred plan can also help to match suitable staff with the qualities to best support the person.

## NHS continuing healthcare

NHS continuing healthcare is a package of care and support that is provided to meet all of your individual assessed needs, including physical, mental health and personal care needs. It is arranged and paid for by the National Health Service (NHS).

NHS continuing healthcare is free, unlike social and community care services that are provided by local authorities. Family carers may be asked to pay community care charges for social care depending on the income and savings of the person with a learning disability if they are over 18.

Health needs must be the **primary** need for someone to be eligible for NHS continuing care. The care package covers any setting, including your own home, as well as a nursing home, residential care home or hospital.

Adult health services should be alerted to young people with PMLD aged 16 who have a primary need for health care, who will require continuing health care funding.

An initial assessment can be arranged through a GP or district nurse, or by a consultant if the person is in hospital. The person carrying out the assessment could be a care manager or a nurse or other health professional. They will use the NHS continuing healthcare checklist (see *Frequently asked questions*) which looks at the nature, intensity, complexity and unpredictability of the person’s condition.

Once that assessment has been carried out, the carer will be informed of the decision by the local Clinical Commissioning Group. If it is recommended that continuing healthcare funding is necessary, they will then carry out a more detailed multi-agency assessment.

This means that professionals from a number of health and social care services may be involved in the assessment. At this point, a detailed plan of the support needs for the person with profound and multiple learning disabilities (PMLD) will be carried out, and should include any short breaks required by the carer as part of the plan. The professionals involved use a decision support tool. This is a standard tool that is used across the UK and is designed to prevent a postcode lottery of care.

In some authorities, there may be a limited choice about where short breaks can be offered, as there may be a requirement to support complex health needs with specially-trained staff and equipment.

However, some health authorities are offering personal health budgets to families. These provide the flexibility to create a package of healthcare that is personalised to the needs of the person with a learning disability by enabling support at home to be purchased.

Where a local authority has pooled health and social care budgets, an assessment can be carried out jointly by professionals from health and social care services. The pooling of budgets for learning disability services happens in some but not all authorities. This joint working helps in creating more flexibility in how services are provided. It also prevents disputes about which agency pays for what service.

### **How a package is funded should not make a difference**

An individual with PMLD and their family should be able to get the support they need however the package is funded. For example, short breaks can be funded through social care, NHS continuing health care or a joint health and social care package.

### **Law and policy which can help**

It is useful to know about any relevant laws and policy which can empower a family of a person with PMLD to access the support they need.

### **Rights of people with learning disabilities and their families**

Government policy, such as Valuing People Now, makes it clear that people with a learning disability have the same rights as everyone else. They and their family carers are entitled to the same opportunities in life that anyone else would expect.

### **The NHS & Community Care Act (1990)**

Provides for services for adults. Although many areas have moved or are moving into a system of self-directed support and personal budgets, it is important to note that the law regarding provision of services, however they are delivered, remains the same.

The Challenging Behaviour Foundation information sheet **Ten Top Tips**, by **Luke Clements**, clearly sets out the legal rights to community care services. See *Links to information and resources* at the end of this guide.

### **Carers (Recognition and Services) Act 1995**

introduced the concept for carers to have a separate assessment of their needs – the Carers Assessment

**Carers Act 2000** introduced the right of carers to have support services, and that these services could be offered as direct payments or as vouchers. Direct payments are cash payments from social care services instead of services provided by local authorities. They can be used flexibly to meet assessed support needs identified in a carers assessment, and can be provided directly for a young person aged 16 or over

**Carers (Equal Opportunities) Act 2004** made it a duty for a local authority to inform carers of their rights, and also the right of carers to be able to carry out everyday tasks, to work if they wish or to take up training, education or leisure opportunities.

**Equality Act 2010.** Public bodies have a duty under the Equality Act 2010 to enhance the involvement of disabled people and their families and carers. It widens the anti-discrimination and harassment protection that covers working carers and will also protect carers of disabled people when they ask for services and when they get services.

**Mental Capacity Act 2005** The Mental Capacity Act 2005 says people who lack capacity in relation to a particular decision should be involved as much as possible when a decision is made in their best interests.

The Act also says that when best interest decisions are being made, family and those who know the person well must be involved. For more information, see the resources on the Mental Capacity Act at end of this section, which has tools to help families understand their rights to be involved in decisions about a family member with PMLD.

### **National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care**

The local authority must also notify the relevant Clinical Commissioning Group (CCG) if their assessment indicates that the person has needs which may fall under the National Health Service Act 2006, and invite the CCG to assist in making the assessment (see section 47(3)(a) of the National Health Service and Community Care Act 1990).

This responsibility enables a person whose primary need is health, to be assessed to see if they are eligible for NHS continuing healthcare. This would enable the person to receive funding from the NHS for an holistic package of support.

## **For children and young people**

### **Children and Young Person Act 2008**

Section 25 of the Act - From 1 April 2011, local authorities were required to take on a new duty to provide “breaks from caring to assist parents and others who provide care for disabled children to continue to do so, or to do so more effectively.” It also requires local authorities to provide preventative support to families through the provision of short breaks, as well as providing short break care for those in crisis. These services must be set out in a local authority short breaks statement.

### **Children and Families Bill and Draft Care and Support Bill**

These Bills contain a number of proposals that will help ensure young people and adults with a learning disability and their family carers get the support they need. These proposals have been described already. See the resources section for links to more information.

## **If families can't access the support they need**

All assessments must be needs-led and once needs have been agreed by the local authority, there is a duty on them to provide services. Although the local authority can take into account available resources, this cannot be the only grounds on which a decision to support someone is decided. The level and severity of need has to be taken into account.

If your family, or other families of people with PMLD in your area, are not getting the support they need 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 and your family 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 with PMLD and their family'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.
- If there are other families of 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 and their family 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](http://www.mencap.org.uk/node/14506)

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

## Complaints or legal action

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

### Complaints

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

### Legal action

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

## 5. Detailed case study



### Centre 404

Centre 404 is a centre for people with learning disabilities and their families. It provides a range of services and support. It was started 60 years ago by a group of mums who were finding life tough. They wanted to forge a better life for their sons and daughters, many of whom had profound and multiple learning disabilities (PMLD).

Chairperson Jean Willson has a daughter with PMLD and understands the high level of day-to-day caring that many families do. She knows that it is easy for families in this position to become socially isolated and explains that Centre 404 stops people having to go it alone. It gives families good quality advice and support. Jean understands that knowledge and information is power and can change the quality of life for people with PMLD and those of their families.

Centre 404 supports families from the moment their child first receives a diagnosis, through transition and into adulthood. It provides information and support on all relevant issues, from getting

benefits to recruiting and training support staff. It gives one-to-one practical advice, which may include helping to fill in forms or helping families prepare for a care package review. Some of the staff have been trained by the Department of Work and Pensions, and this official accreditation means that families can get expert help with benefits and applications fast-tracked.

Another important part of Centre 404's work is to run workshops where families can come together and share knowledge and experience. One of them is an inter-generational workshop where older carers pass on their experience and tips the younger generation of family carers. It is also a chance for those who are younger and at the centre of new developments in services and support, to inform older carers about these.

The Centre is a vital lifeline where people can get a warm welcome and find friendship as well as get advice. The friendships people make at the centre last a lifetime. There are frequent social events where families can let their hair down and share laughter, food and their experiences.

Importantly, it is a fully-inclusive venue for people with PMLD, with a Changing Places toilet. (see [www.changing-places.org](http://www.changing-places.org))

Centre 404 is valued by families because it understands, listens and responds to the needs of family carers. It works in partnership with families, and families are represented at every level. It is also a highly valued consultative partner – families and staff regularly take part in focus groups and meetings looking at shaping future health and social care services. It is a huge source of family expertise.

Not every area has a Centre 404 but Jean suggests families find out about their nearest special interest group where families of people with PMLD can come together and get advice, support and comfort. She wants to see somewhere like Centre 404 in every part of the country because it provides continuity families need and want to support them in their lives.

## 6. Film

Watch the film about Centre 404, which provides information and support to people with a learning disability and their families.

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

# 7. Frequently asked questions

There are links to more information and resources at the end of this guide.

**Q: Where can I go to get help, advice and information or to find out about short break services in my area?**

A: There is a lot of information available, particularly online.

Your local library service may be able to help you get information about local groups in your area if you do not have a computer.

Your local authority helpline can put you in contact with local carers centres or services for carers run by the local authority. They can also direct you to local user-led and voluntary groups in your area. If you are from a black or ethnic minority community, they will also be able to direct you to support available from your community, such as a multi-cultural centre or specialist support workers.

They may offer you an opportunity to fill in an online assessment form, but you can also request a face-to-face appointment with a care manager if you need an assessment.

In some local authority areas, GPs are able to provide short break grants to carers whose

health is affected by their caring role.

For information on short breaks for disabled children, see the short breaks statement on the local authority website.

**Q: How are people assessed for continuing health care?**

A: The NHS issued a framework for NHS continuing care to guide health authorities:

The National Framework for NHS Continuing Health Care and NHS Funded Nursing Care. July 2009 (Revised)

This information is held on the Department of Health website below:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/127199/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127199/National-Framework-for-NHS-CHC-NHS-FNC-Nov-2012.pdf.pdf)

The initial screening is done using the NHS continuing care checklist tool and can be arranged by a consultant so that an assessment is carried out in hospital. In the community, it can be done by a GP or nurse, or by a social worker as part of a community care assessment.

This web link tells you about the initial

continuing care checklist, which looks at the range of health needs that the person has to determine eligibility:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/127200/NHS-CHC-Checklist-FINAL.pdf.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127200/NHS-CHC-Checklist-FINAL.pdf.pdf)

A decision on whether you are eligible for continuing health care funding is usually made by the PCT within 28 days. (From April 2013, the decision-making will be done by the local clinical commissioning group).

The decision support tool is the full assessment tool used if the checklist shows that you may be eligible. The assessment carried out is usually multi-disciplinary involving health and social care professionals.

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/127201/Decision-Support-Tool-for-NHS-Continuing-Healthcare.pdf.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127201/Decision-Support-Tool-for-NHS-Continuing-Healthcare.pdf.pdf)

If you are caring for a young person under the age of 18, there are some differences in the factors considered when assessing for continuing health care funding. One of the key differences is that continuing care for children and young people must also take into account their emotional needs and their intellectual developmental needs in carrying out an

assessment, as well as their health and social care needs.

The National Framework for Children and Young People Continuing Care link:

[http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_116469.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_116469.pdf)

For more information about NHS continuing healthcare see *What do I need to know about NHS Continuing Healthcare?* a booklet for the Foundation for People with Learning Disabilities by Alison Giraud-Saunders. See link in information and resources section. <http://www.learningdisabilities.org.uk/publications/continuing-healthcare/>

**Q: How can I ensure I get good information, help and advice when the person with profound and multiple learning disabilities I support is going through transition?**

A: Many local authorities have a transition support team which can link you with the right services and support. Check with your local authority website or helpline. There may be user-led or voluntary sector groups in your area that offer help, information and advice on transition, personalisation and other key topics

Planning is critical. A good example of this is Liz and her daughter Eleanor. They worked with Eleanor's circle of friends to plan for Eleanor

(the link to their story is in the resources section under Transition)

The transition social worker should ideally work with the family, along with the health, education and social care agencies from the 14-plus review onwards, to plan a young person's move from children's to adult care. They should also direct you to relevant information from other professionals.

Your local family information service will also be able to direct you to services and support in transition in your area. There is a directory of local family information services. <http://www.daycaretrust.org.uk/nafis>

The Transition Information Network website has many useful resources and links on transition and on best practice in the UK.

<http://www.transitioninfonetwork.org.uk/home1.aspx>

Parent Partnership Services can offer advice on matters regarding statements and special educational issues.

The national website below will link you to your local service.

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

It may also be worth contacting your local parent participation forum which may be able to direct you to people who can help. The link

below will put you in touch with your local forum.

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



## Case Study

Oxfordshire Family Support Network (OXFSN) is a charity run by carers for carers of people with learning disabilities. It holds an annual family information fair that brings together families, local health and social care services, voluntary groups and providers of services, as well as holding workshops on topics of interest. Families with young people in transition have found this very useful as they can access information directly about the options available locally and nationally.

The charity also produced a guide to transition, again written by carers for carers.

For more information about OXFSN and to read the transition guide, see the links in the information and resources section.

Please see links to information and resources at the end of this guide for national organisations that can help.

**Q: How can we ensure commissioners develop and commission short break services that meet the needs of people with profound and multiple learning disabilities?**

A: Commissioners should work in a person-centred way with people with profound and multiple learning disabilities (PMLD), using the Involve Me tools. They should also work with family carers, local voluntary groups, user-led organisations and providers to develop and commission flexible, person-centred services.

They should also encourage the use of advocacy services to ensure the voice of people with PMLD is heard.

The Children and Families Bill will place a duty on local areas to create a local offer which sets out what local provision is available. This will be developed in partnership with local families. The government has stressed that the process of drawing up the local offer should allow local areas to identify gaps in local provision. This is something that will be supplemented by a duty on local authorities to review the special educational and social care provision available locally and consider whether it is sufficient to meet local need.

*Raising Our Sights* recommendation 5 stressed the importance of basing planning on local need.

***“Local Authority social care services, together with their education and health partners, should keep up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in their area currently and projected in the future to enable effective planning of services.”***

One way this could be fulfilled is through local joint strategic needs assessments and local health and wellbeing strategies. The local area will need to make sure this specific information around people with PMLD is captured as part of these processes.

## 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](mailto: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](http://www.mencap.org.uk/Lambethpmlid)

## 9. Links to further information and resources

### Camden Society

The Camden Society has set up innovative short breaks schemes in London and Oxfordshire using a hotel model of care.

<http://www.thecamdensociety.co.uk/home>

### Carer's assessments

Top tips for preparing for a carer's assessment.

<http://www.mencap.org.uk/all-about-learning-disability/money-benefits-and-assessments/carers-assessments/tips-preparing-assessment>.

### Carers strategy, 2010

The Government's national strategy for carers.

<https://www.gov.uk/government/news/a-national-strategy-for-carers>

### Challenging Behaviour Foundation

Support and information for family carers of people with a learning disability and behaviour that challenges.

[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

### Children and Families Bill

<http://www.education.gov.uk/a00221161/children-families-bill>

### Citizen's Advice Bureau

Advice on welfare benefits and information about local services.

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

### Disability Rights UK site

This site has lots of useful information, including the Disability Rights Handbook which gives information about benefits changes, and has links to other useful information on personalisation and centres for independent living, etc.

<http://www.disabilityrightsuk.org/about.htm>

### Draft Care and Support Bill Factsheets

<http://www.dh.gov.uk/health/2012/07/cs-bill-factsheets/>

### Equality Act 2010

What do I need to know as a carer?

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/127201/Decision-Support-Tool-for-NHS-Continuing-Healthcare.pdf.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/127201/Decision-Support-Tool-for-NHS-Continuing-Healthcare.pdf.pdf)

### Festival Spirit

This charity provides innovative support for young people with a life-limiting illness or disability.

<http://www.festivalspirit.org/index.html>

### Mental Capacity Act 2005

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>

Mencap and BILD's Involve Me resource shows creative ways to involve people with PMLD in decision-making.

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

The Challenging Behaviour Foundation's information sheet for family carers on getting legal authority to make decisions about money, property and welfare.

[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

### **National Association for Voluntary and Community Action (NAVCA)**

This is the national voice of local support and development organisations in England. It gives information on local branches.

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

### **National Brokerage Network**

Brokers can help people negotiate how money agreed for a personal budget is spent. This website describes the role of the broker and links people to brokers in their area.

[www.nationalbrokeragenetwork.org.uk](http://www.nationalbrokeragenetwork.org.uk)

### **National Centre for Independent Living**

This website gives information on local branches.

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

### **National Children's Bureau**

Information about the Transition Information Network.

<http://www.transitioninfonetwork.org.uk/home1.aspx>

### **Other national charities providing information about transition:**

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

Contact a Family <http://www.cafamily.org.uk>

Cerebra <http://www.cerebra.org.uk>

Scope <http://www.scope.org.uk>

### **National Learning Disability Helpline**

<http://www.mencap.org.uk/what-we-do/learning-disability-helpline>

Telephone: **0808 808 1111**

Email: [help@mencap.org.uk](mailto:help@mencap.org.uk)

Typetalk: **18001 0808 808 1111**

Text: **07717 989 029**

Mencap offers a translation service for people whose first language is not English.

### **NHS Continuing Healthcare**

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/193700/NHS\\_CHC\\_Public\\_Information\\_Leaflet\\_Final.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/193700/NHS_CHC_Public_Information_Leaflet_Final.pdf)

<https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

*What do I need to know about NHS Continuing Healthcare?* A booklet for the Foundation for People with Learning Disabilities, by Alison Giraud-Saunders.

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

### **NHS Choices**

This provides information for family carers.

<http://www.nhs.uk/CarersDirect/Pages/CarersDirectHome.aspx>

### **Oxfordshire Family Support Network**

Charity run by carers for carers of people with learning disabilities.

[www.oxfsn.org.uk](http://www.oxfsn.org.uk)

### **Transition guide**

<http://www.oxfsn.org.uk/wp-content/uploads/2011/05/Transition-Matters-Guide.pdf>

### **Person-centred planning**

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

### **10 top tips for families**

A document clearly setting out legal rights to community care services, by Professor Luke Clements, is available on the website of the Challenging Behaviour Foundation.

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

### **PMLD Network**

[www.pmldnetwork.org](http://www.pmldnetwork.org)

### **Princess Royal Trust to Carers**

Details of local carer's centres.

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

### **Shaping Our Lives, the National User Network**

This website provides a range of useful information for service users, including easy read versions.

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

### **Shaping Our Lives Networking Site**

This allows service users to network and contribute to a discussion forum.

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

### **Short Breaks**

Mencap's 2013 short breaks report and Know Your Rights pack can be downloaded from its website, which also provides advice on campaigning.

<http://www.mencap.org.uk/campaigns/take-action/breaking-point>

### **Think Local Act Personal**

This website provides information on personal budgets, which cover all aspects of the support needed for a person's life.

[www.thinklocalactpersonal.org.uk](http://www.thinklocalactpersonal.org.uk)

### **Transition**

Read Liz and Eleanor's story about transition planning.

<http://www.helensandersonassociates.co.uk/media/53637/liz%20and%20eleanor's%20story.pdf>

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