



# How-to guide 8

## training the workforce

For people with profound and multiple learning disabilities

**Raising**  
our Sights



# Raising our Sights guide to training the workforce

*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) 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 training the workforce is one of 12 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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# 1. What Raising our Sights says about training the workforce

There are two recommendations:

## **Recommendation 6:**

In fulfilling their responsibilities for developing and training the social care workforce, local authorities should ensure that sufficient numbers of personal assistants are available, trained in person-centred approaches to communication and support that meet the needs of adults with PMLD through training that involves families and adults with PMLD in its delivery.

## **Recommendation 28:**

Agencies should offer subsidised or free places to families and personal assistants on any training courses they run which are relevant to adults with PMLD. Individual budgets should include provision for training of personal assistants.

This guide will help local areas implement these recommendations about workforce training and understand and meet the needs of people with profound and multiple learning disabilities (PMLD) and their families.

It focuses on what 'good' looks like and what needs to be in place to ensure we have the right staff to support people with PMLD and their families.

## 2. What does ‘good’ look like?

Valuing People Now identified the need for local, regional and national leadership to ensure we have a workforce that is ready and able to deliver the government’s plans for personalised services and support. This should include a greater involvement of people with a learning disability and family carers in workforce planning, development and training. All training and professional development must promote Valuing People Now principles and a human-rights-based approach.

The skills councils for this sector and other organisations must develop and promote new learning disability qualifications. Local authorities and providers need to develop a local workforce that is well trained to support all people with a learning disability, including those with profound and multiple learning disabilities (PMLD).



### Scenario 1: Working with the family to make sure Tom gets the right support

Tom has a severe learning disability, autistic spectrum disorder, very severe epilepsy and some behaviours that have challenged services. He lives with his family. For many years he has received two days a week of short breaks, with three-to-one, 24-hour support. Tom is unable to speak up for himself and his parents are active advocates on his behalf.

**Positive Support in Tees CIC** was one of ten companies that pitched for the opportunity to provide Tom’s adult social care support. This involved presenting to Tom’s parents who, supported by an independent person, decided to ask Positive Support in Tees to proceed with this service, which is funded by a personal budget arrangement containing both health and social care elements. The specification for the service and forward plan were agreed

after a detailed person-centred plan had been produced.

“We committed to involve and work with Tom and his family closely. In terms of recruitment we have ensured we are clear about the person specification for staff that would work for Tom. We have involved both parents in the decision to hire every member of staff who has joined Tom’s team. We were careful to explain the reasons for a second interview to candidates and all of them accepted that. Although there were occasions when generally promising candidates were felt not to match Tom’s needs and personality, we have always backed the family in their decisions.

“The family has taken an active part in our team induction training, and told the team clearly what Tom needs and how we can best support him (and by definition his family as well). The family input was well received by the team and we have a very effective working relationship.”

**The number of people involved in supporting and meeting the needs of people with PMLD is large, and can include:**

- physiotherapists
- speech and language therapists
- occupational therapists
- dieticians
- community nurses
- school and support staff
- practitioners in postural care
- managers/staff in respite care
- palliative care/end of life care staff
- day centre managers/staff
- local health specialists
- learning disability nurse specialists
- social workers
- dentists
- optometrists
- personal assistants/relief and agency staff.

Each person working with or supporting someone with PMLD will need knowledge and understanding of people with PMLD, underpinned by skills that are specific to their area of work.

**Here are some of the skills and training they need:**

- **high quality** communication skills, including an understanding of Intensive Interaction, communication passports, objects of reference and the use of switches for cause and effect
- **how to** engage with the person day to day in a meaningful way
- **understanding that** photos and keeping information about people's lives and their stories is important
- **training on** complex health needs, for example using suctioning equipment or tube feeding
- **training in** nutrition, eating and drinking
- **postural care training**
- **training around** supporting an individual with behaviour that challenges – which focuses on the principles of positive behaviour support
- **training around** assistive technologies and equipment, for example iPads
- **advocacy training**
- **person-centred** planning
- **understanding of**, and commitment to, the principles of the Mental Capacity Act and 'best interests'. The workforce needs good support from managers and confidence to make day-to-day decisions.

- **understanding of** issues around consent and medication
- **understanding of** the importance of hospital passports and health action plans
- **understanding of** sensory needs and recognition that sensory assessments can be an important part of getting support right
- **moving and handling**
- **managing direct payments**
- **understanding of** the health and social care system.

It is important that all support staff working with an individual with PMLD respond to guidelines from the various involved professionals. For example, speech and language therapists, psychologists and health professionals may put plans and strategies in place for the person but it will often be frontline support staff who actually make them happen.

These frontline staff need to be supported to do this. Part of this support will be ensuring they feel valued and therefore motivated to put the plans into action. It will be important that their managers are skilled and make sure staff adhere to the guidelines.

**People working with or supporting people with PMLD will also need important underpinning values and skills such as:**

- empathy
- understanding
- shared interests
- assertiveness
- respect
- sensitivity
- commitment
- creativity
- facilitation skills
- networking skills
- ability to work as part of a team and in isolation
- understanding of the importance of relationships with family and friends
- understanding of the importance of developing relationships with the wider community
- understanding of the importance of thinking creatively about paid work and developing opportunities for people with PMLD.

The best staff are going to be those who like their work, want to do it and like the person they are working with. Ensuring staff feel valued can help staff to have a positive attitude to their work.

### 3. What needs to be in place for this to happen

- **Clear information** and peer support for families.
- **A person-centred** workforce. Developing a person-centred workforce around someone with complex needs is a challenging role. Sometimes the family will be doing it themselves, other times someone paid to manage the service will be doing this. In both situations, the family is likely to have a key role. It is crucial that there are training and development opportunities for families to access. Partners in Policy Making and other leadership training can be critical in helping families develop their skills and confidence.
- **Peer support** and training and development opportunities for families from early on. It is important families can get these during the early years. If it is left until the person with PMLD reaches adult services, many families can be too overwhelmed by their experiences to be so involved. One way to do this would be to make sure the support is offered when the child is first diagnosed or assessed.
- **Technology.** Use technology as much as possible (for example film clips, photo montages or software activated by a switch or a sound) to empower the person with PMLD to influence and be involved in decisions about their workforce.
- **Workforce training** and development. This should involve people with PMLD and their families wherever possible.
- **A circle of support.** Developing a circle of support for the person with PMLD can be a good way to make sure their needs and preferences are thought about and explored. This can be through trying new things and encouraging support workers to try new experiences with the person, and learning from the person's responses. Anything learned about the person can be used to inform decision-making about their life, including who supports them and how.
- **Funding.** Funds allocated to personal budgets must be high enough to enable the recruitment of skilled staff. Funds also need to cover training and personal development – for both those recruiting and managing staff, and the staff themselves – and the cost of attending or holding meetings.
- **Enough staff** support. As well as having suitably skilled staff, it is important the person with PMLD has enough support staff. People with PMLD with the most complex needs may need more than one support worker to support them throughout the day, or they may need an extra support worker at certain times. If this doesn't happen it could put a lot of pressure on staff, and have a severe impact on the person's health and wellbeing.
- **Training in** person-centred techniques for family members as well as staff.

- **Good recruitment** adverts. Think about how you write the job descriptions and personal specification for PAs. Information about Lily's personal assistants was written in a non-medical way with the help of a support broker (see case study on page 12). It doesn't underplay the personal care aspect of the role but has made sure that the family employs people who are on her 'wavelength'. It should not all be about personal care, but should also stress the importance of things like shared interests.

- **Involvement of** people with PMLD in recruitment. Think carefully about how the recruitment process can be truly co-produced and involve people with PMLD and their families as equal partners. This might include thinking about payment for work done.

- **Clear guidance** around what it means to be a good employer.

- **A wider** understanding of PMLD in society. Think about how you can influence the way the wider workforce responds to people with PMLD and their families – and aim high! Christian Raphael has PMLD and is supported to co-lecture for Birmingham University's social work programme (See the *Raising our Sights* personalisation guide and film to find out more about the work Christian does).

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

## 4. How do you get a suitably trained workforce?

This section is in two parts:

**1. People with profound and multiple learning disabilities (PMLD) who have an Individual Budget and:**

**a. whose family employ personal assistants (PAs) on their behalf**

**b. who have staff via a provider**

**2. People with PMLD who get a service from a local authority that directly commissions a provider.**

**1a. People with PMLD who have an individual budget and whose family employ PAs on their behalf**

If the family chooses to manage the personal budget then they will be given direct payments to provide the support outlined in the person's support plan.

**Step 1. Negotiating the cost of the support package**

When the family works with the local authority to agree a support package, it is important to factor in the costs of employing people with the right skills and experience, and any training.

They may want to talk to other local families who have been through this process or seek support and tips via online forums. See the *Links to more information and resources* section at the end of this guide.

Providing good support and care for someone with PMLD is a highly skilled job, and needs to be acknowledged as such by local authorities. Families may have to pay a higher rate to get someone with the right understanding, skills and experience. If these additional costs are not factored into the budget it could mean that they get staff for less time than needed as they cannot afford to pay them for more hours.

Many families say that in their experience there is an 'upper limit' for budgets, even though that is not lawful and should be challenged:

One parent said:

***“There is an upper limit. We are told categorically, if we want to pay staff higher rates, we can make up the difference in cost from our own money, or choose to have less cover.”***

**Step 2. Recruiting PAs**

The family should think carefully about the individual or team of people the person with

PMLD will need to support them. They will need to think about what skills, experience and values are important, as well as things like matching interests and age.

They may want some support to think this through, draft a job description and person specification, and advertise for and interview candidates. They may have a circle of friends, peer network or other family members who can help them with this. Or they may want to consider getting support from a **support broker** who can offer a range of help for people with personal budgets. Their local authority should be able to give them the details of support brokers in the area. They could also contact their **Skills for Care** regional team.

Their local authority may have their own PA register, which holds the details of PAs and supports employers to match the skills they need with the people available. Some local authorities are signed up to a **Support with Confidence** scheme. This provides a list of businesses and individuals providing care and support services who have been successfully approved which means they have had the appropriate training and met background checks. The scheme is run by a number of local authorities and is a joint initiative between

Trading Standards and Adult Social Care. There is more information about recruiting PAs, in the *Links to more information and resources* section of this guide.

### Step 3. Training PAs

Thinking about the training needs of the person's PA or team of PAs can be a daunting task. A good first step is to establish what skills they already have and what skills are missing. Family members can look at the skills listed in the *What does 'good' look like?* section of this guide and see which skills they feel are most important, and what the support team is missing. The skills audit at **Careskills base** is a simple tool that will help family members assess the skills, knowledge and competences of support staff. Skills for Care have also produced a set of **Common Induction Standards**. These enable staff to demonstrate high quality care and support. The standards apply to staff in regulated care services and can also be applied where a personal budget holder employs staff in their own home. They can help identify the training needs of PAs.

If the personal budget includes funding to pay for training, there are a number of options – from e-learning, to face-to-face training. Local authority personal budgets teams should be able to help with this. **PA Net** has developed a database of training providers who deliver

training specifically for PAs or their employers. Also a number of organisations run courses for those who support people with PMLD.

Although we are unable to recommend courses, some of the providers are listed in the *Links to more information and resources* section of this guide.

Some local authorities provide skills training for PAs – sometimes free of charge. Sheffield, for example, offers a range of free courses through their Communities Workforce Development Unit and those employing staff can claim back some costs to help with expenses.

If no free training is available, there are several other sources of funding you might be able to apply for:

- **The Workforce Development Fund (WDF)** for 2012/13 is a funding stream that focuses on the achievement of qualification units from the Qualifications Credit Framework (QCF) and supports the ongoing professional development of staff across the adult social care sector. Currently there is no formal qualification available specifically for PAs. However, qualifications in the health and social care sector have changed from National Vocational Qualifications (NVQs) to the new Qualifications Credit Framework (QCF) which applies as much to PAs as it does to other types of social care workers.

The new framework is much more flexible and allows learners to study, in bite-sized chunks, the parts of the qualification that are relevant to their work role. The QCF is a new way of recognising skills and qualifications. It does this by awarding credit for units (small steps of learning) and enables learners to gain qualifications at their own pace along flexible routes.

- **To access** funds to support QCF units you have to be registered with the National Minimum Data Set for Social Care (NMDS-SC) which gathers information about the adult social care workforce. It is open to individuals who employ staff to provide care and support services either for themselves or for another person for whom they are a carer.
- **Learn Direct** may be able to provide funding to help employees without a level 2 qualification in health and social care to reach this level. In addition, Learn Direct is likely to fund employees with an identified literacy or numeracy need.
- **Some local** authorities have subscribed to Social Care Information and Learning Services. To find who is entitled to access free training, follow the link in the *Links to more information and resources* section of this guide.
- **Skills for Care** suggests that people looking to get a qualification register for an **individual learning record (ILR)** on the **National Careers**

**Service** website. See the *Links to more information and resources* section of this guide.

**The Skills Funding Agency** helps people get on through learning. It doesn't fund learners directly but is committed to providing more information to inform learner choice. It provides the National Careers Service and also works to strengthen quality assurance by introducing more transparent information to help inform learner choice. It also helps employers by making sure they can improve the skills of their workforces through relevant training programmes. It has dedicated advisers for specialist services such as apprenticeships, and Skills Funding Agency managers and Business Link Advisors work closely with employers to help them find the training they need.

Some local authorities may also be able to help. In Sheffield, for example, some providers offer support networks for PAs by running 'PA cafes'. They are informal places where PAs can meet other PAs, share ideas and develop national links.

As well as training sessions for PAs, which are often one-offs, it will be important that PAs receive support to help embed the training into everyday practice.

#### **Step 4. Supporting PAs**

Some families have said that one of the most important aspects for staff working with people with high support needs is making sure they have an opportunity to debrief - a time when staff know they can discuss the work and its emotional impact on them. To avoid staff 'burn out' some families have said they find it helpful to have a set time when they can meet with the staff (separate to the individual being supported).

One mum said:

***"I think regular opportunities for practice reflection are just as important. Staff are almost never given the opportunity to think and talk through what they do. I've found there is often a 'light bulb' moment when workers understand the individual is not getting 'at them', especially where there are behavioural issues involved."***

#### **Step 5. Support available to employers**

For families, taking on and managing a personal budget and staff team can be daunting, particularly when it is for a family member with PMLD. So it is very important that the family gets support and training too. Peer networks for the family and circles of support around the individual with PMLD can be very helpful in talking through, sharing and solving problems. Local authorities may be able to offer you training. Some are developing mentoring and buddying schemes to assist individuals or family members who are taking on the role of 'employer' for the first time, so it is worth checking what's available locally.

One parent said:

***"In some local areas families are getting good support to manage a staff team. There needs to be more sharing of information between local authorities – so this can happen everywhere. This could happen at the level of learning disability partnership board PMLD sub-groups, where they exist."***



## Scenario 2: Lily's staff team

Lily and her family chose to pay PAs the maximum amount possible under the budget in order to attract, and retain, people with the right level of skills. They wanted help to find the right people to support Lily so used a support broker in their area to help them with recruitment. Lily's mum had previously done some work with the support broker so knew and trusted them. Most importantly, the support broker understood that Lily and her family wanted to be included in everyday life.

Lily's mum says:

***“Trust is the key. It is a buyer's market and providers are going to have to develop very good relationships with people. They will need to be very clear about what they can provide, and what they can't.”***

Lily and her family use a local firm of accountants to do their payroll. It took some of the stress of managing the workforce and accounts away from the family. They felt fortunate that their local authority was flexible enough to allow Lily to use a portion of her personal budget to pay for the support broker and payroll support. When they recruited staff, they

looked for people with different skills to match the different areas and interests in Lily's life. They didn't advertise widely, but instead used informal networks to advertise the roles. They wanted to employ people they felt that they could trust, and who were taking on the role because they really wanted to do it. They were very clear about what the job would be and the amount of hours available.

The family worked with the support broker to put together a job description. They searched the internet for examples of job descriptions they liked, and then changed them to make something that was very specific to Lily's needs. The support broker offered the use of their offices to interview the applicants, and the family put together interview questions based on everyday scenarios. The family found that this was a successful approach. They also asked for up-to-date CRB checks.

Lily and her family regularly bring the staff together for a meeting. They meet for an hour, then have a meal together. They discuss what is working, what isn't

working and share ideas about some of the projects that Lily is involved in. The support broker has offered to provide ongoing supervision for the staff team.

## 1b. People with PMLD who have an individual budget and have staff via a provider

If someone with PMLD is being supported by a provider there are several ways their family can make sure staff have the right skills and understanding to deliver the support.

### **The family should expect to be involved in the recruitment, induction and training of staff**

Providers and commissioners can be unaware of the ways they can involve people with PMLD and their families in workforce development. They may feel that there will be a significant cost attached to involving them in the induction, training and evaluation of staff.

It is important for family members to be clear what their expectations are if they want to be involved in this process, and that the costs should not be prohibitive. Use tools such as Mencap's *Good practice in involving families in workforce development* and *Involve Me* resources, as well as the National Family Carer Network's *Top Tips for families around safeguarding* to give them creative ideas about making this happen.

Family members should be clear that they expect to be treated as an expert partner in care – even if they are not available all the time. It is important providers recognise family members have other commitments, but there

needs to be an open partnership, based on communication, mutual respect, trust and understanding.

### **The family should remember they are the commissioner of the service**

If providers aren't involving the person with PMLD and their family in the way they have asked to be involved in any aspect of workforce development, there are alternatives. With the increasing constraints on social care budgets and tightening of eligibility criteria under Fair Access to Care Services (FACS), it is increasingly likely that only people with the highest support needs will secure funding for services. In this respect, people with PMLD and families have a real opportunity to influence how providers work creatively in partnership with them.

If providers aren't engaging in this way, family members should look elsewhere at how other providers in the area are involving people with PMLD and their families in recruitment, induction, training and evaluation of staff. How are providers working with the whole family around safeguarding? Are their policies family friendly? Are they considered as partners in care? If there are no providers engaging families in this way in the area, the local Learning Disability Partnership Board 'PMLD Champion' should be able to help. The family member could also seek to work with and offer input to the local authority's adult safeguarding board.

### **There is help available from the regional Skills for Care area team**

The Skills for Care area team engage with social care employers and stakeholders in their region to develop workforce solutions and support workforce development. They can signpost to information, resources and tools to support workforce development.

## 2. People with PMLD who get a service from a local authority that directly commissions a provider

Providers directly commissioned by the local authority to deliver a service should be involving families in training, and engaging them proactively with their service. Commissioners need to ensure that their commissioning decisions include checking that providers are meaningfully involving people with PMLD and their families in recruiting, inducting and training staff.

There is a checklist for commissioners about how to ensure a suitably trained workforce in the *Raising our Sights* commissioning guide.

### **Law and policy that can help**

Local authorities have a duty of care to meet assessed needs, either through a personal budget or through services they directly commission.

### **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.

Any family member who regularly provides substantial care to the person also has the legal right to request an assessment of their own needs, 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 or 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 may be necessary to argue for training funds as part of a budget or for the budget to be high enough to pay PAs at a level that reflects their skills and experience. The allocation of funds will be directly related to the rate the council wants to offer and what is currently being paid to other PAs in the area.

The legal question is: what evidence can the council provide to suggest that fewer, cheaper,

untrained staff can adequately meet the needs of a person with complex or profound needs? If there is no evidence, then a budget allocation that is too low to employ the right staff is not rational or lawful.

**The Mental Capacity Act (2005)** supports the values of personalisation by empowering people to make their own decisions. It says people who lack the mental capacity to make a particular decision must participate as much as possible in a decision made on their behalf. Local authorities must make sure this happens 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. As well as protecting people with PMLD from discrimination, it also means family carers have to understand and use this law when recruiting and employing PAs.

Skills for Care ([www.skillsforcare.org.uk](http://www.skillsforcare.org.uk)) and Skills for Health ([www.skillsforhealth.org.uk](http://www.skillsforhealth.org.uk)) have up-to-date information about the latest legal and policy requirements relating to workforce development.

### **If the person can't get a workforce with the right skills, training and support in place**

The local authority has a duty of care to people who are assessed as needing services or support. This includes making sure they are cared for by people with appropriate training, values and skills. If the person with PMLD who you support, or other people with PMLD in the local area, are not getting access to a workforce with the right skills, training and support in place, you may want to challenge or campaign.

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

### **Challenging**

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

Some tips:

- Use the information in this guide, including what ‘good’ looks like, legal rights and policy information, to support your challenge.
- If the person’s needs are not being met, say so in a letter to the lead person at social services or the Clinical Commissioning Group (CCG). Let them know you will campaign publically against their decision if they do not listen to what you have to say.
- Get your local councillor or MP involved. You could ask them to write a letter of support.
- If you are not listened to, you might want to make a complaint or seek legal advice.
- If there are other people with PMLD in the area facing similar issues you may want to get together to campaign publically!

## Campaigning

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

Some tips:

- Organise a campaign for people in your area to send an email or letter to their councillors.
- Launch a petition explaining what you are campaigning for.
- Hold a public meeting to tell people about the campaign and how they can get involved. You could invite a local newspaper or radio station along to cover the story.
- Organise a rally by inviting members of the public to a significant place, such as a town hall, to publicise the issue. Again, your local media might want to cover this.
- Gathering real stories and using photos and film can be very powerful. Social media can be a useful tool to share these.
- Don’t forget to plan your campaign!

## To help you challenge and campaign, see:

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 sorts of 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 email [advice@dls.org.uk](mailto:advice@dls.org.uk)

## 5. Detailed case study



Joe

### How did Joe get his team together?

Joe's family began recruiting his support team when he was a child. Although it was harder to find the right people because there were fewer hours of work available, it gave them a really good understanding of how to recruit and find the right people for Joe. They needed people who would leave any of their own issues at the door, and be prepared to go the extra mile and be flexible when Joe needed them to be. They decided that there would be no hierarchy within the team. Instead, when decisions were taken, input from all members of team was encouraged and valued. This worked brilliantly because people responded positively, and naturally brought their different skills, including leadership, helping Joe connect to the community and keeping him active. Joe's family have been creative in the ways they have supported the team's learning – piggy-backing on training opportunities taking place – but the key thing they have learned from working with Joe's team is that giving people an appetite to learn doesn't always

have to be done in a conventional way. Getting a personal budget was important. In March 2005, Joe was a fairly typical 16-year-old, except that he had a severe learning disability. He had never had a good friend of his own age, but he and his family took on another 16-year-old as one of his four personal assistants. They were one of the first to use a personal budget, being given cash to choose their own service providers, which gave them the freedom to build the right support around Joe.

### Joining with other individuals, their families and support team

In 2009/10 Joe and his team of PAs took part in a project to look at the issues of employing a team of PAs, called Learning our Way. Skills for Care, In Control and Shop4Support were the other partners in the project. The aim was for each member of Joe's team to have their own personal learning budget, based on their training needs and capacity to support him effectively. As Skills for Care was given money to train the social care workforce, Joe and his team felt it should be possible

to personalise this training too, and to be given the cash to develop the individual training needed.

What Joe and his team found was that this was not quite so straightforward. After the recession hit and funding cuts began to impact social care, the team had to think creatively. They developed a group – Our Place – which met weekly with other individuals, PAs and people from their local community.

People with expertise were invited to the group to address training issues. Subjects covered included person-centred approaches, food hygiene, communication, and creating constructive and productive days without spending money.

### Keeping those connections and links together

By 2012, Joe, his family and his team were looking at the next step. Through their experiences and connections they understood that most people who need support, together with their families and the people who support them, need help

with thinking through opportunities. They decided to set up a social enterprise (a business that trades for social purposes) called My Life. The vision of My Life is for people who need support to have a good life. One key aspect of that is making sure they have the right support. My Life will support the workforce to come together and not be isolated. The model covers all aspects of an individual's life, but is based on an understanding of the need for community connections, focus, meaningful opportunities, and the need to develop and adapt training approaches to keep staff motivated, interested and inspired.

## 6. Frequently asked questions

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

### **Q: Why is workforce development important?**

A: It underpins everything. Get the right workforce with the right values, skills and support, and the essential elements of a good service will be achieved.

### **Q: What role can people with PMLD really play?**

A: Most people with profound and multiple learning disabilities (PMLD) do not use formal communication like words and symbols. This makes communication very difficult and can mean they are not involved in important decisions, such as where to live and who supports them. People with PMLD should be involved in all decisions that affect their lives. The Mental Capacity Act says that when people are not able to make their own decisions they should be involved as much as possible. That means finding creative ways to listen to people and involve them in recruitment, induction and training of staff.

### **Q: Why is it important to involve families?**

A: Families are recognised by government as being expert partners in care. They have skills,

experiences and commitment – and they want to be involved.

### **Q: What are the common difficulties providers face when involving families and people with PMLD in workforce development, and how can they be overcome?**

A: Involving people with PMLD and their families involves an investment of time from providers, but also potentially money. Providers need to look at the long-term gains they get from such an investment. For some providers it also entails a culture change, developing a partnership with families based on mutual respect and trust. When the Challenging Behaviour Foundation was asked for its top tips about involving families it gave the following advice:

- Start by having a good relationship or dialogue with families and finding out what the issues are.
- Work on developing a relationship and providing support in a way that is helpful to families.
- Be open to listening to what families tell you.
- Don't rush the process. Take time to process and do the thinking.
- Be sure you are all coming from the same place.

### **Q: What does good practice in involving people with PMLD and their families look like?**

A: When it comes to involving people with PMLD and their families, these things are non-negotiable:

- involving people with PMLD and their families from the beginning
- person-centred and individualised support
- clear expectations and understanding
- a partnership approach
- creative and solution-focused working
- flexibility
- mutual respect.

### **Q: How can families be involved in safeguarding?**

A: National Family Carer Network and HFT have produced safeguarding resources for families including *Top Tips* and an *Essential Guide*. They provide practical suggestions for how families can be actively involved.

## 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](mailto:pmlidnetwork@mencap.org.uk)  
Call **020 7696 5549**



### The Lambeth PMLD project

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

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

Priority areas for change were identified and, two years on, there is an active PMLD sub-group committed to 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)

## 8. Links to more information and resources

### Choice Forum and the PMLD Network

<http://www.learningdisabilities.org.uk/help-information/forums/>

### Resources about decision making and The Mental Capacity Act

Mencap's resource pack.

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

HFT's Mental Capacity Act guide.

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

Involve Me

How to creatively involve people with PMLD in decision making.

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

Safeguarding resources that address the concerns of families.

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

### Recruiting personal assistants

Skills for Care's toolkit for people who want to employ their own PAs.

[http://www.skillsforcare.org.uk/entry\\_to\\_social\\_care/recruitment/employingpersonalassistants.aspx](http://www.skillsforcare.org.uk/entry_to_social_care/recruitment/employingpersonalassistants.aspx)

Some local authorities are signed up to a Support with Confidence scheme. The scheme is run by a number of local authorities and is a joint initiative between Trading Standards and Adult Social Care.

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

West Lancs Peer Support offers an online, password-protected PA register to all local authorities in the UK. The register enables you to find PAs for permanent work or emergency cover.

<http://www.ukpar.org>

### Training

National Careers Service.

<https://nationalcareersservice.direct.gov.uk/Pages/Home.aspx>

Care Skillsbase

A simple tool that will help you assess the skills, knowledge and competences of your staff. Care Skillsbase tools do not require any specialist skills or expertise.

<http://www.scie-careskillsbase.org.uk/>

Skills for Care Common Induction Standards

<http://www.skillsforcare.org.uk/cis/>

BILD provides a range of training for staff working with people with PMLD.

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

Your Pathways (training for personal assistants)

<http://arcuk.org.uk/arcprojects/picking-your-pathway/>

Action for Advocacy and Asist

Non-instructed advocacy training.

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

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

Mencap's Getting To Know You project

This project encourages self-advocates to speak up for people with PMLD.

<http://www.mencap.org.uk/what-we-do/resources-and-training/pml-d-training/getting-know-you>

More than words training course

Helps you find ways to communicate well with people with PMLD.

[http://www.clearforall.co.uk/training\\_words.htm](http://www.clearforall.co.uk/training_words.htm)

CAN Communicate

Training courses and interactive workshops on creative communication. For more information: email [CAN\\_Communicate@yahoo.co.uk](mailto:CAN_Communicate@yahoo.co.uk) call 01709 584842

Person-centred planning tools can be found at

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

Postural Care Community Interest Company  
Postural Care Skills Programme.

<http://www.posturalcareskills.com/training.php>

Training around assistive technologies and equipment.

[www.inclusive.co.uk](http://www.inclusive.co.uk)

[www.ace-north.org.uk](http://www.ace-north.org.uk)

Concept training

Courses for anyone living or working with people with sensory impairments and special needs.

<http://www.concept-training.co.uk/>

### Funding for training

If you register with the National Minimum Data Set for Social Care (NMDS-SC), you get opportunities to access money for training via the Workforce Development Fund.

As part of registering with NMDS-SC, all employers, including individuals and their families employing PAs, need to go through the verification process to confirm they are social care employers. Skills for Care requires evidence that you are a social care employer, but you only have to provide this evidence once.

For more information about this process go to:

<http://www.nmds-sc-online.org.uk/help/Article.aspx?id=1107>

Learndirect

<http://www.learndirect.co.uk/help/>

Some local authorities have subscribed to Social Care Information and Learning Services and may offer free training to those eligible. To find out if you are entitled to access the training for free, go to <http://www.scils.co.uk/index.php?task=freeAccess&PHPSESSID=5i1p2sc4ijubv6mf2c22ncmqc2>

### Support for employers

Being the Boss

A website where disabled people who employ PAs, however they are funded, can share information based on their experiences. It provides a safe forum to discuss and share ideas.

[www.beingtheboss.co.uk](http://www.beingtheboss.co.uk)

Skills for Care

Skills for Care has a number of resources to support individual employers.

[http://www.skillsforcare.org.uk/how\\_can\\_we\\_help\\_you/Individual\\_employers.aspx](http://www.skillsforcare.org.uk/how_can_we_help_you/Individual_employers.aspx)

PA Net

Information about legal responsibilities of being an employer.

<http://panet.org.uk/legal-rights/legal-responsibilities/>

### Getting it Right

A guide for families of people with a learning disability about choosing a support provider and improving the quality of support.

<http://www.learningdisabilities.org.uk/publications/getting-it-right>

Disability Rights UK provides a Directory of Support for Independent Living.

<http://www.disabilityrightsuk.org/how-we-can-help/independent-living>

Skills for Care and Skills for Health have up-to-date information about the latest legal and policy requirements relating to workforce development.

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

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

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