

# Self-directed support

## Support for people with profound and multiple learning disabilities

People with profound and multiple learning disabilities (PMLD) have the same right as anyone else to be included, heard, considered and understood. Just because someone does not use words, it does not mean they can't communicate their preferences and share what is important to them.

Self-directed support, such as direct payments and individual budgets, has the potential to transform the lives of people with a learning disability. It is crucial that people with PMLD can benefit from self-directed support too.



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# The basic facts

People with profound and multiple learning disabilities (PMLD) have very complex needs.

People with PMLD:

- have more than one disability
- have a profound learning disability
- have great difficulty communicating
- need high levels of support
- may have additional sensory or physical disabilities, complex health needs or mental health difficulties
- may have behaviours that challenge us.

This is a short definition from the PMLD Network.

Many people with PMLD are often the last to be considered when we talk about people having choice and control. It can be assumed that being unable to speak means you don't have any preferences. However, families, friends and people who know someone with PMLD are often able to identify what makes that person happy and what makes them sad.

The law (the Mental Capacity Act 2005) says that people should be assumed to have capacity to make a decision until proved otherwise. This is an important starting point as it encourages those supporting someone to involve the person as much as possible in making a decision. However, the law says that people will be unable to make a specific decision if they cannot understand information about the decision to be made, retain that information in their mind, use or weigh that information as part of the decision making process. The reality is that people with PMLD will never be able to do these things due to the severity of their learning disability.

People with PMLD will lack capacity to make their own decisions about the type of support they have. But this does not mean that they don't have important preferences to share which can be used to influence decisions made about the support they get.

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People with PMLD should be involved as much as possible in decisions made about their lives. This is not just good practice this is the law. The Mental Capacity Act 2005 says that if someone lacks capacity to make a decision, then a decision needs to be made in their best interests. The person making this best interests decision will differ depending on what type of decision it is (eg it may be a family carer, support worker or health professional). When making a best interests decision the law says that the decision maker should involve the person themselves as much as possible, this means finding out as much as possible what the person's preferences are and using these to inform the decision made.

## More information

### People with PMLD express preferences

Self-directed support is not about doing things on your own. It is, where possible, about bringing in people to help you get support that meets your needs. We all need help and support when planning our lives, and people with PMLD are no different. We may just have to 'listen' a little harder.

The idea behind self-directed support is to try and create a bespoke and individualised support mechanism for an individual. This can be achieved by producing a support plan which examines what would work for a person and what won't. It is about using what we know and the people we know to fill in the gaps of what would lead to a positive outcome for an individual.

So where is the choice and control for the person? When we ask people who know someone well they can explain how that person reacts if they don't like certain foods, whether or not they enjoy swimming, or if they get bored watching certain TV programmes. What we discover is that people definitely do express preferences. It can just be in very subtle ways. Sometimes you have to understand what people are saying by the manner in which they communicate. Then you will notice that different signs and signals often mean something.

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There is a family that for years believed that when their daughter's arm shot up in the air this was because of an involuntary movement. But they started to recognise that this only happened when she was watching motor racing and horse racing. The family realised that fast sports were something she enjoyed. This recognition resulted in having fast sports added to her support plan. This had a huge positive impact on her life.

## Find ways to interpret behaviour

If you watch and listen closely, much of the behaviour of people who present challenging behaviour is communicative or a response to their environment. There are plenty of ways you can start to think about issues around communication and see if you can find ways to interpret a person's behaviour.

For many people who don't make noises and have limited expression and body language we may assume they prefer to be quiet. Therefore snoozelem rooms and softer settings are often used to support them. However, such environments can simply make some people nod off to sleep. But when they are in markedly noisier locations, such as a concert, these same people can become animated and alert.

Discovering who people are is the challenge, not the people themselves.

Learning more about a person will enable you to identify what is important for them. It is helpful to record information about how the person communicates and record information gathered about the person's preferences to help ensure this information can be used in decision making. In order to help people consistently support a person, producing an essential lifestyle plan can be useful (see the factsheet on person centred planning). People's preferences may change though so it is important to keep plans up to date. For some major decisions, it may be appropriate for someone to be appointed as a Deputy (see the fact sheet on the Mental Capacity Act).

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People who have PMLD have a better-quality lifestyle when they have opportunities in their communities and can develop relationships with people beyond paid staff. Being part of your local community does not just mean 'going out and about' to local places. It also means having connections to people and being appreciated for who you are and the qualities you have. These aspects will also need to be considered in terms of people living a good life.

## An example

### Craig's story – control to the end

Craig had been known to services for many years. He was 17 years old when he embarked on self-directed support and his transition into adult services was imminent. In terms of his life expectancy, Craig exceeded everyone's expectations. His needs were so complex that he spent his life in and out of hospital and used the local children's hospice for respite. He had attended special school since the age of two and was in the further education division of the school.

Craig was offered a personal budget which had evolved from the resource allocation system. But the amount offered made no consideration for the fact that Craig was to leave school and would have no support during the day. Nevertheless, we started developing a support plan. Lynne felt it would be asking too much of the family for it to be an employer, so it was decided that choosing a provider would be the best option. However, the cost of this would be more than the indicated amount. Using the support plan we were able to demonstrate clearly why Craig needed more funds to keep him healthy, safe and well. This enabled an open conversation with the council, and a revised amount of money was offered.

The family chose a provider and the arrangement worked well. But gradually the family gained confidence in managing Craig's support themselves. After less than a year they decided to cut out the 'middle man' and be in complete control by becoming employers. Craig's life was as good as transformed over night. He had his own team of personal assistants

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who enabled Craig to take part in activities his peers took for granted – such as swimming, abseiling, canoeing, doing voluntary work, attending college and line dancing. He no longer went ‘to respite’. Instead, by using their caravan at Ribby Hall, near Blackpool, Craig was able to have a break from his family, or his family have a break from him.

Craig’s health improved significantly and his seizures, which used to be daily, almost stopped. Plus he put on weight. It was evident that Craig’s team of personal assistants were providing a continuity of care and support that he had never experienced before. This was the vital ingredient that significantly improved Craig’s quality of life.

His family could live a satisfying and independent life but be together whenever they chose. Mum went back to work. She had not been in employment since Craig was born, and she chose work that used her skills to help other families. Dad kept his job and developed a much more intimate relationship and bond with Craig.

Craig maintained his health, well-being and lived a good life for a further six years. Craig’s family said they were the best years of his life. Sadly Craig died aged 23 years on 13 July 2009 from pneumonia. However, his team were at his side constantly. They provided a personalised service right until the very end of his life.

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## **More information on support for people with profound and multiple learning disabilities**

Mencap and BILD's Involve Me project shows how creative approaches can be used to involve people with PMLD in decision making processes: [www.mencap.org.uk/involveme](http://www.mencap.org.uk/involveme)

The PMLD Network – is an excellent resource made up of many of the key bodies. It is chaired and run by Mencap [www.pmlidnetwork.org](http://www.pmlidnetwork.org)

For all issues relating to the Mental Capacity Act  
[www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)

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### **About the In Control and Me project**

A three-year project to produce accessible information for everyone who wants to direct their own support, funded by the National Lottery through the BIG Lottery Fund. You can find out more at [www.mencap.org.uk/incontrol](http://www.mencap.org.uk/incontrol) or [www.in-control.org.uk/icandme](http://www.in-control.org.uk/icandme)

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