



Involve me

Practical guide

How to involve people with profound and multiple learning disabilities (PMLD) in decision-making and consultation



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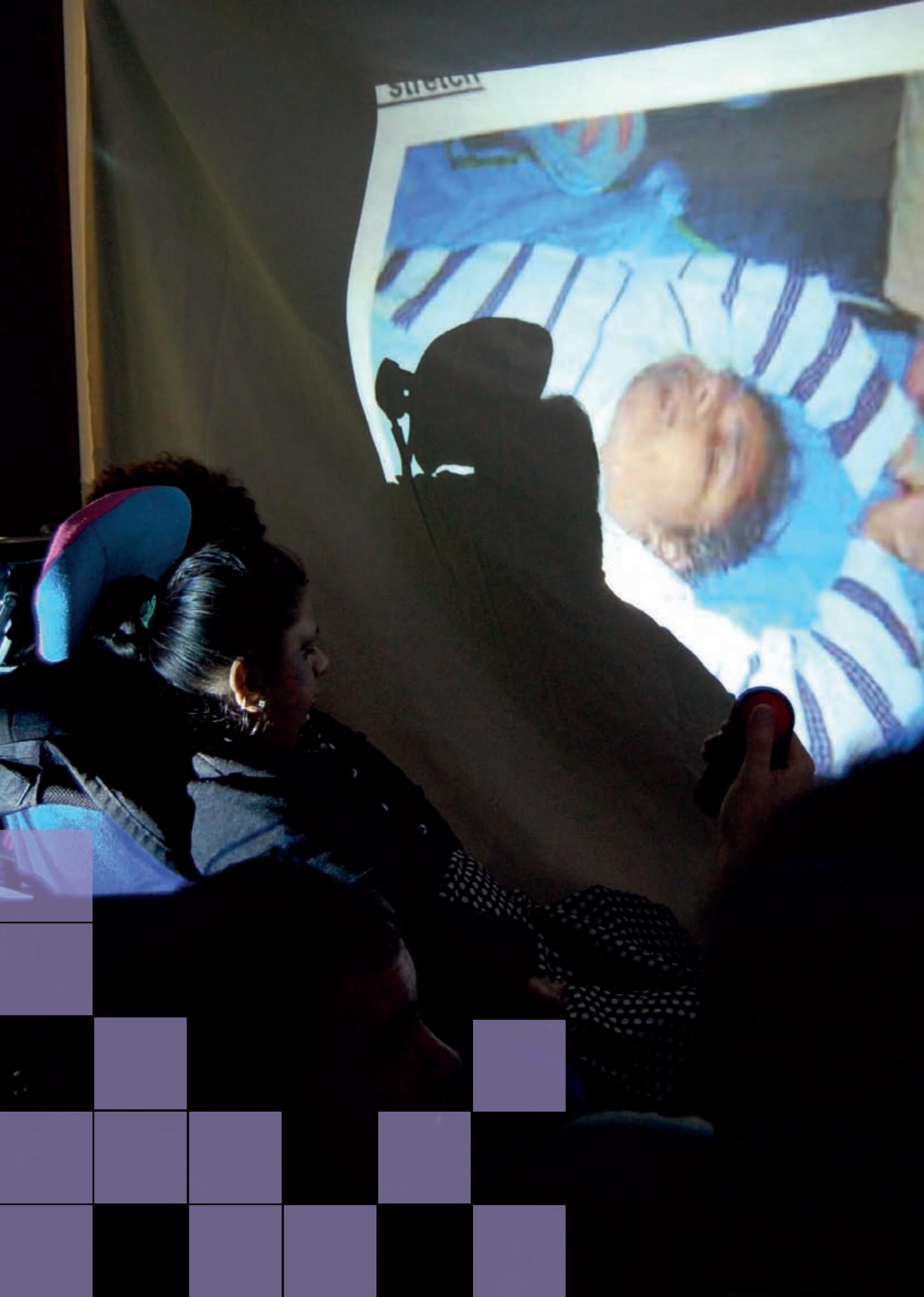
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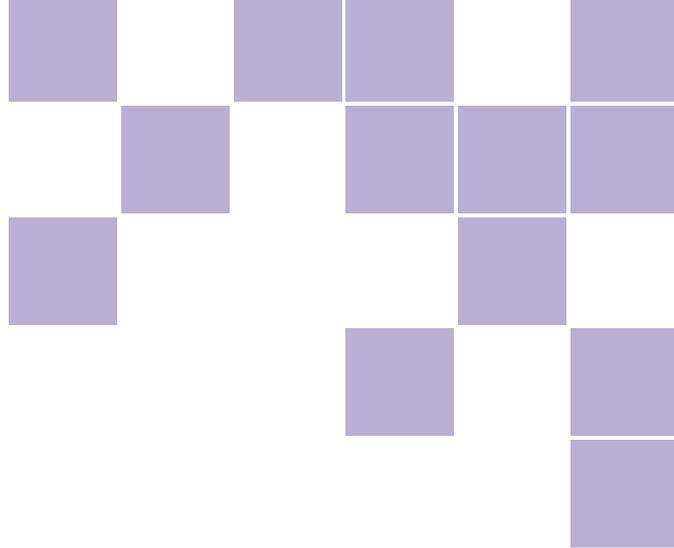
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About Involve Me

1. Introduction to Involve Me

Involve Me is about how to involve people with profound and multiple learning disabilities (PMLD) in decision-making and consultation.

Involve Me aims to:

- increase the involvement of people with PMLD in decision-making and consultation
- keep a very practical focus
- support long-term change for people with PMLD and the way services are designed, planned and delivered.

People with PMLD are some of the most excluded in society. Most don't use formal communication such as words and symbols so people often assume they have nothing to say. The Involve Me film and this guide show how everyone can start involving people with PMLD in decision-making and consultation.

With examples from four sites, using different creative approaches to involvement, the important word in this project is *involvement* – we are not talking about independent choice or decision-making, but ways to increase the level of involvement of people with PMLD.

The project is a partnership between the Renton Foundation, Mencap and BILD (the British Institute of Learning Disabilities).

The Foundation for People with Learning Disabilities carried out an independent evaluation of Involve Me. Its report, together with other information and resources, has been used to write this guide.

What do we mean by PMLD?

People with PMLD have more than one disability. All will have a profound learning disability and will find it difficult to communicate. Most will not use words. Many people will also have sensory or physical disabilities, complex health needs or mental health difficulties.

Given the frequent lack of support to communicate or express preferences, it is hardly surprising that PMLD can also affect a person's behaviour so that others find it challenging or difficult to understand.

We have included the PMLD Network definition in the **Policy and people with PMLD** section of this guide and there is a fact sheet on PMLD in the **Downloadable resources** section of the DVD.

2. Who is Involve Me for?

Involve Me is for everyone – we can all ensure people with PMLD are more involved in decisions that affect them, particularly:

- families
- frontline staff
- service managers
- people who plan and commission services
- advocates – including peer advocates
- decision-makers at national, regional and local level.

The **What you can do** section draws on the independent evaluation of Involve Me to suggest what different people might think about and do.

Policy and people with PMLD reminds us we all have a responsibility to involve and include people with PMLD.

Act on what you learn shows how personal preferences can be interpreted or explored in terms of bigger decisions. It has ideas for taking work forward. The downloadable resources on the DVD include a session plan to get partnership boards or other meetings thinking about involving people with PMLD.

If you are still not sure, take a look at some of the video clips of people talking about Involve Me on the DVD. Some of these people weren't fully convinced to begin with either, but they were won over by the powerful experience of seeing what happens when people with PMLD find their voices.

We understand the demands on your time, so the **Quick start guide** on the DVD has suggestions on how to use the Involve Me practical guide – no matter how little time you have.



3. More about Involve Me

This section provides some background information on the project and covers:

- Involve Me and the practical guide
- why the project is needed
- the evaluation of Involve Me
- recommendations from the evaluation.

Involve Me and the practical guide

Involve Me aims to:

- increase the involvement of people with PMLD in decision-making and consultation
- keep a very practical focus
- support long-term change for people with PMLD and the way services are designed, planned and delivered.

The Involve Me practical guide refers to real-life examples as well as video clips, downloadable resources and the Involve Me film, which are all on the DVD. They show how staff at four sites used different creative approaches to involvement. The guide also demonstrates how everyone, including staff, families and policy-makers, can start involving people with PMLD in decision-making and consultation.

We would like to hear and share stories about how you involve people with PMLD in decision-making and consultation. Please email involveme@mencap.org.uk



Why the project is needed

The **Policy and people with PMLD** section explains that people with PMLD have been missed out of many new initiatives for people with a learning disability because **their ability to understand and be involved in decisions is underestimated.**

People with PMLD should be involved in all decisions that affect their lives, including consultations. They have important preferences and experiences to share. We just need to work in ways that support them to do this.

The Mental Capacity Act 2005 says that people who lack capacity in relation to a particular decision should be involved as much as possible. By interpreting and understanding a person's likes, dislikes or preferences we can enable them to have a substantial input, even if the final decision is made by someone else. Involve Me suggests ways of working in line with this law and ensuring we respect a person's legal and human rights.

How can multimedia advocacy give Michael a voice in decisions about his therapy?



In **video clip 1**, Michael is at the Rix Centre with a video of him at the swimming pool. As well as enjoying the activity, Michael clearly enjoys showing people the video and sharing what he does when he goes swimming. The footage moves to a different activity where Michael has one-to-one support at the hydro pool and is demonstrating a far bigger range of leg movements than he did at the swimming pool. Other staff didn't know about this until they saw the video 'evidence'.

How might this give Michael a voice in:

- decisions about which therapies he needs
- allocating staff so he gets real benefits from hydrotherapy
- decisions that suggest that swimming and hydrotherapy are interchangeable activities for him?

The evaluation of Involve Me

Involve Me has been independently evaluated by the Foundation for People with Learning Disabilities. The evaluation

looked at how people with PMLD in the four sites are involved in decisions and consultation about:

- everyday life
- support and services
- community involvement
- national involvement.

It looked at:

- the kinds of decision the person has been involved in
- the way the person has communicated their wishes and how this may have changed, with particular reference to the approach used at the site
- the way the person has participated in decisions
- the ways in which the person's participation in decision-making has changed and developed
- any changes in the person's life/the outcomes there have been
- what worked well, both in the process and in getting an outcome
- what worked less well in the process and in getting an outcome
- what the participant would like to happen differently in the future – this might be a change to the way they communicate with others or something that needs to change in the external

environment (for example, a partnership board having a different way of working).

The team of evaluators at the Foundation for People with Learning Disabilities was led by Hazel Morgan with assistance from Molly Mattingly, Dr Paul Swift and ‘critical friends’ Jean and Victoria Willson, Pat Charlesworth and Jane Jones. The evaluation report is in the **Downloadable resources** section of the DVD.

Recommendations from the evaluation report (taken from pages 8–10) of the evaluation report)

The evaluation report contains recommendations for:

- government departments
- the Equality and Human Rights Commission (EHRC)
- the Care Quality Commission (CQC)
- commissioners and providers of services (in social care, health, education, housing, leisure, transport, etc) and local councillors
- managers of services (social care, health, housing, education, leisure, transport, etc)
- advocacy services
- support workers.

Government departments

- Use the learning from Involve Me to enable the voices of people with PMLD to be heard. This is of the greatest importance at times of budget cuts.

Those with strong voices will make themselves heard. People with PMLD must be given the opportunity to express what is important to them.

- Ensure that, in consultations and in the development of initiatives, the wishes of people with PMLD are taken into account. For example, members of Equality 2025 at the Office for Disability Issues (ODI) should consider how to include people with PMLD. The Department of Health should ensure that its ongoing guidance on the personalisation agenda emphasises the importance of involving people with PMLD in decisions about their lives.

The Equality and Human Rights Commission (EHRC)

- Give attention to the barriers to freedom of expression and the level of discrimination experienced by people with PMLD. As well as learning from staff, family, friends and advocates, the EHRC should consider how people with PMLD can be involved in demonstrating the barriers they experience in everyday life.

The Care Quality Commission (CQC)

- Ensure that, in its focus on involvement, the CQC uses the learning from Involve Me about supporting people with PMLD to have a voice. It should ensure that services do the same.

Commissioners and providers of services (in social care, health, education, housing, leisure, transport, etc) and local councillors

- Local authority departments, with their partners in education and health, should establish the numbers, needs, circumstances and aspirations of people with PMLD and review these regularly. Learning disability partnership boards, health and wellbeing boards and other agencies engaged in this process should listen to the voices of people with PMLD in creative ways. Identifying a PMLD champion, or champions, locally would be one way to ensure this happens.
- Commissioners and providers should ensure that services have policies and practices in place that enable people with PMLD to be involved in decisions that affect their lives. They should develop a culture of engaging with people consistently.
- Health commissioners should ensure that the provision of speech and language therapy is sufficient to enable the training and support of staff who work with people with PMLD, so they can use communication resources appropriately and maximise people's involvement in decisions about their lives.

Managers of services (social care, health, housing, education, leisure, transport, etc)

- Use the learning from Involve Me to prioritise listening to the voices of people in creative ways, both to find out about each individual's preferences and to aggregate the learning to inform the

development of their service. It should be part of the overall culture.

- Continue to invest in training about the Mental Capacity Act 2005 and evaluate the effectiveness of the training. Ensure that policies set out clear procedures for staff to follow so that a person can make as many decisions as possible, and that if a person is assessed as lacking capacity for a particular decision they are as fully involved as possible, using the learning from Involve Me.
- Note the satisfaction shown by staff in Involve Me in enabling those they support to express their preferences. Empower staff to find creative and appropriate ways to engage with those they support, using staff meetings, training and supervisions to encourage and develop these practices.
- Ensure that focusing on communication is an integral part of the role of support staff, and that communication with the person is incorporated into all aspects of their support and embedded in the culture of the organisation. Prioritise investment in communication training, and in communication that includes using creative approaches.
- Ensure services seek advice from speech and language therapists and other specialists about the resources that can aid communication, such as the Big Mack and the Talking Photo Album. Take advice about what is appropriate for each individual, recognising that communication aids are part of an overall approach to communication.

- Consider and review the ways in which a multimedia approach would assist in developing portfolios and enabling people to be involved in decisions about their lives. Seek out the necessary training and guidance – this should also be offered to families and others who know and care about the person.
- Ensure services work in partnership with families and others who know and care about the person so they can learn from them about the person’s individual ways of communicating, and their likes and dislikes. These should then be recorded and used. Seek consistency across different areas of people’s lives; people need to have a lively and active circle of support to ensure they are supported in the ways they want.

Support staff

- Communicate consistently with those they support in the course of personal care and other activities, enabling them to express their wishes in a two-way communication, as well as spending time to find out in creative ways their wishes for different aspects of their lives.

Advocacy services

- Plan to establish peer advocacy to contribute to providing a service that caters for all people with a learning disability. Ensure there are clear procedures and policies for: the recruitment, selection, ongoing training and support of peer advocates; the matching of peer advocates and advocacy partners; and the agreements between the peer advocate and the service, and the peer advocate and their advocacy partner.



4. Funders and partners

The Renton Foundation

The Renton Foundation funds clubs affiliated to Mencap which offer leisure opportunities to people with a learning disability. Funding supports a range of activities including musical, art and sporting events and equipment, outings and holidays. The Renton Foundation now also funds projects for people with PMLD and Involve Me is one of these.

Website: www.mencap.org.uk/therentonfoundation
Telephone: 01923 776 757
Email: rentonfoundation@mencap.org.uk

Mencap

Mencap is the UK's leading learning disability charity. It provides services and advice, challenges prejudice and campaigns for the changes that people with a learning disability, and their families and carers, want.

Website: www.mencap.org.uk
Telephone: 0808 808 1111
Email: info@mencap.org.uk



British Institute of Learning Disabilities (BILD)

The British Institute of Learning Disabilities (BILD) influences policy-makers, decision-makers and practitioners to help people with a learning disability take charge of their own lives.

Website: www.bild.org.uk
Telephone: 01562 723 010
Email: enquiries@bild.org.uk

Foundation for People with Learning Disabilities

The Foundation for People with Learning Disabilities promotes the rights, quality of life and opportunities for people with learning disabilities and their families.

Website: www.learningdisabilities.org.uk
Telephone: 020 7803 1100
Email: mmattingly@fpld.org.uk



5. What's on the DVD and how to use it

The Involve Me interactive DVD contains information and materials to support and reinforce the eight key Involve Me messages. It includes the following sections:

- Who is Involve Me for?
- More about Involve Me
- How to use the DVD
- The four Involve Me sites
- Different creative approaches to involvement
- Policy and people with PMLD
- Choice, decision-making, capacity and consent
- Downloadable resources
- Video clips and the Involve Me film.

The eight key messages are discussed and illustrated with examples from the sites. The key messages are:

- Know the person really well.
- Take lots of time.
- Don't make assumptions.
- Be responsive to the person.
- Be creative and try out new ideas.
- Learn from what the person 'tells' you.
- Act on what you learn.
- Help the person recall and share things about their life.

There are also links to:

- Information about the Involve Me funders and partners
- Where to find out more
- The Quick start guide.



How to use the DVD

When you insert the DVD in your computer drive, a screen should open in your usual browser window. This is the Involve Me home page.

If the screen doesn't automatically appear when you insert the disk, simply click on the 'index.htm' icon in the containing folder of the DVD (go to My Computer > Devices with Removable Storage > Involve Me (D)).

Playing the video clips

Video clips illustrating the Involve Me approaches are referenced throughout the practical guide and can be viewed by clicking the links in the document.

A text description of the video will appear when you move the cursor over the link. Clicking the link will display a pop-up video player and the clip will play automatically.

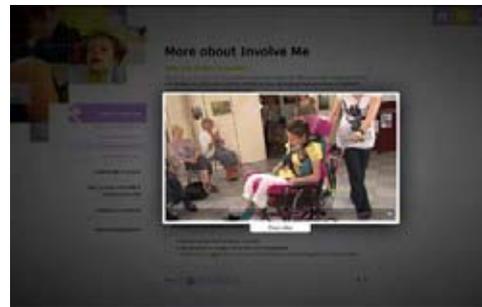


You can pause the video at any time by clicking the pause button (to the left of the progress bar at the bottom of the screen). Click the pause button again to resume playing.

You can skip to any part of the video by moving the arrow in the progress bar.

There is also a button to play the video in full screen mode – this is to the right of the progress bar at the bottom of the screen. Click it again (or press the Esc key on your keyboard) to return to normal view.

When you're finished, click the **Close video** button underneath the video to close the pop-up video player and return to the practical guide.



The video clips, and the Involve Me film, are also available in the **Involve Me media** section of the DVD. From this page you can watch any video clip by selecting the picture in the gallery and clicking the **Play** button. Or, you can click on **Show full list...** to find the clip you want quickly.



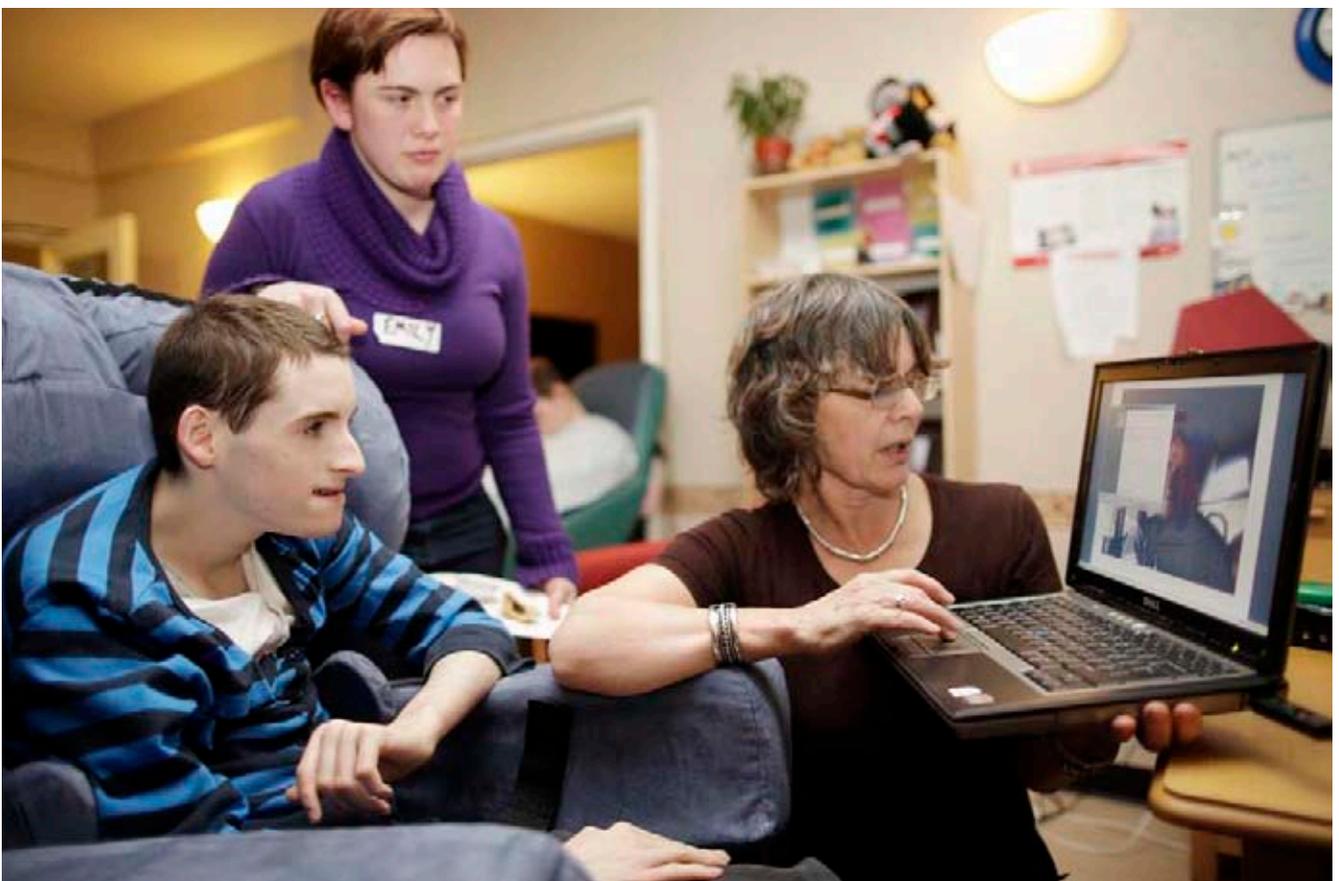
Downloadable resources

The tools, information sheets and evaluation report have been saved as PDF files so you can print off as many copies as you need or include them as attachments to an email. Simply click on the document you want to download.

Quick start guide

Don't know where to start?

- If you only have 15 minutes, watch the Involve Me film and read the Involve Me booklet or look at the **More about Involve Me** section of the DVD.
- If you have half an hour, watch the Involve Me film and look at the **What you can do** section of the DVD. Then write yourself two or three action points about people you could talk to or things you could do to start to change things for people with PMLD.
- If you have two hours, you could use the session plan from the **Downloadable resources** section of the DVD to get your staff team, advocacy group or partnership board thinking about how to involve people with PMLD.
- If you have the time, why not make yourself a drink, sit down comfortably, start at the beginning and just follow the links wherever they take you.

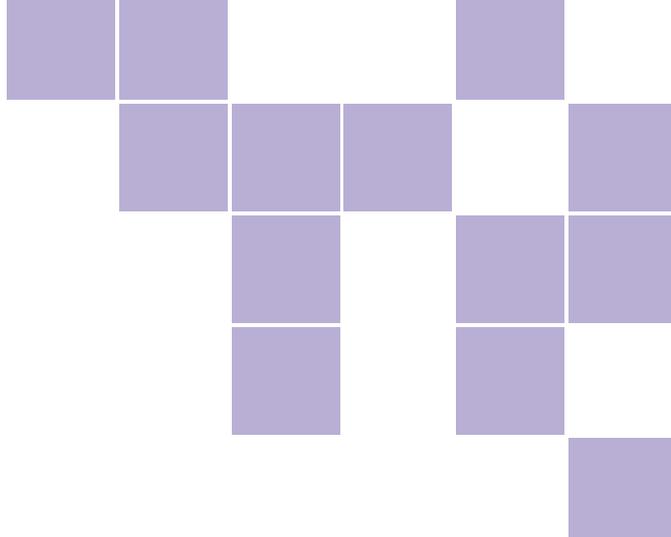


Descriptions of the video clips

No	Description	Length
1	Michael and Ike – using multimedia advocacy to support choice and decision-making	01.14
2	The different creative approaches to involving people	01.33
3	The day centre – T-shirt day at the Coronation Centre	00.45
4	The Rix Centre – Michael’s support worker feeding back using multimedia advocacy	00.55
5	Hammersmith and Fulham Mencap – Kimmy talking about how he works with his advocacy partner	01.10
6	The overlap between approaches – Nick has a peer advocacy role in the sharing stories group	02.36
7	Creative communication – Chelsea’s film	05.52
8	Creative communication – Richard’s film	05.41
9	Creative communication – Robbie’s film	05.51
10	Creative communication – Tanya’s film	04.57
11	Creative communication – Terry’s film	05.42
12	Sharing stories – Ian’s story about buying new aftershave	02.23
13	Peer advocacy – Kimmy talking about how he uses his experience of the day centre to speak up for his advocacy partner	01.48
14	What the approaches have in common – supporting people with PMLD to take the lead	01.24
15	How Tim and Dave are being involved in designing their garden	02.25
16	Using multimedia advocacy to support Michael and Nazia to make everyday choices	01.25
17	Nicola talking about the process of supporting people to influence services and support	00.57
18	Director of adult social care talking about people with PMLD influencing local services	00.33
19	John, a family carer, speaking about Involve Me	00.30

20	Marie, senior supervisor at the day centre, talking about Involve Me	00.47
21	Debbie, a partnership board rep, talking about Involve Me	00.43
22	Build on what you know the person likes – Richard’s creative communication session	02.10
23	Support the person to share this information – using multimedia advocacy to show how Nazia likes to be hoisted	01.02
24	Kate talking about the importance of spending time and ‘just being’ with people	01.32
25	Using every opportunity to support communication and involvement – the crab fishing story	01.17
26	Don’t make assumptions – Tanya’s session and a chance for Richard and Terry to try something different	02.53
27	Kimmy talks about observing and suggesting what might make things better for his partner	01.41
28	The audience responding and getting involved in Terry and Tanya’s creative communication at the presentation day	02.43
29	Richard using the Big Mack to lead his creative communication session	01.36
30	Getting to know people in a multimedia advocacy session and thinking about how to build on this	01.49
31	How Tim used a Talking Photo Album to get a job	01.09
32	Using the sharing stories approach to learn from people with PMLD	01.27
33	Using photographs to find out what Dave wants to keep in his garden and what he wants to throw away	00.54
34	Reflections on the presentation day – learning about what’s important to people with PMLD	00.45
35	The ‘journey’ to produce T-shirts about dreams – how staff at the day centre worked out what people might like to do	02.26
36	Nick talking about what happens for organisations when they start to listen to people with PMLD	01.03
37	Involving people, consultation and advocacy – Nick and Kate	01.13
38	How multimedia advocacy helps people understand what’s important to Nazia	00.33





Involve Me in action

6. The four Involve Me sites

People with PMLD and staff in four sites took part in the project:

- local authority day centre
- service provider
- multimedia centre and a day opportunity provider
- an advocacy scheme.

With support from an experienced communication facilitator, each site focused on one of the following creative approaches to involving people:

- creative communication
- sharing stories
- multimedia advocacy
- peer advocacy.

Each of the four communication facilitators provided information about their approach. This is in the **Downloadable resources** section of the DVD and you can hear the facilitators and a peer advocate talking about the approaches in **video clip 2**.

Each site was given a communication toolkit to encourage staff to try different ways of communicating with people with PMLD. Information about this is also in the **Downloadable resources** section of the DVD.

The sites

A local authority day centre – creative communication

The Coronation Centre is a local authority day centre in Ellesmere Port. Staff were already using photography, drama and other media as a way for people to express their feelings and wishes. Involve Me gave them the opportunity to be supported by Kate, an experienced communication facilitator, to look at the potential for using creative communication in the day centre. The staff have continued the work and gained confidence to adapt and use this approach to involve people in decisions about activities and support. For example, they used what they learned about each person's preferences to design a T-shirt that expressed their hopes or dreams.

Video clip 3 explains how looking at what is important to people with PMLD led to a fashion show where they modelled T-shirts to family and friends.

The service provider – sharing stories

Nicola, the communication facilitator, has developed Storysharing™ as an approach to using conversational stories with people with PMLD. But, as this site demonstrated, anyone can get involved in sharing stories. Nicola worked with different groups of people supported by Turning Point:

- in a residential home for eight people: Josh and Katie were the original participants in the project – along with two other ‘story catchers’ who use words – but all the residents soon became involved
- with Tim and Dave in supported living
- in an arts group attended by up to 12 people with a learning disability and their supporters.

For all the sites, Involve Me probably seemed a bit of a ‘mixed blessing’ at times as staff tried to balance the value of what they were learning against the time needed to record and document their work as part of the project.

The multimedia centre and a day opportunity provider – multimedia advocacy

This site was a late addition to the project when another site withdrew. Eastway Care provides day opportunities in four sites in London. Wayne and Michael attended a 12-week course on multimedia advocacy at the Rix Centre with their support workers from Eastway Care. They were supported to complete the portfolios they started at the Rix Centre during their day activities and

to continue using multimedia approaches. **Video clip 4** shows how the role of workers was crucial in completing portfolios and collecting information between sessions at the Rix Centre.

The advocacy scheme – peer advocacy project

Hammersmith and Fulham Mencap has a well-established advocacy scheme and Involve Me gave the organisation the opportunity to develop peer advocacy. This site supported peer advocates to communicate with their advocacy partners in different ways. It was also different because the facilitator, Alexa, was appointed to set up a peer advocacy scheme and recruit and train volunteers. This took time. Over recent months she has supported five peer advocates in advocacy partnerships with several people who attended the local day service and one who is supported by the day service outreach team. The nature of advocacy means that there is less video footage from this site. However, stories about the role of peer advocates in giving people with PMLD a voice should be no less powerful because of this. In **video clip 5**, Kimmy talks about how he works with his advocacy partner.

The Involve Me communication toolkit

Information about the toolkit is in the **Downloadable resources** section of the DVD. As well as an introduction to communicating with people with PMLD, the toolkit includes:

Big Mack

This is a simple voice output communication aid. Someone can be supported to press it and activate a pre-recorded sound. This can be speech, environmental sounds or vocalisations.



Etran frame

This is a clear Perspex frame in which objects, pictures or words can be placed. It is designed for people who rely on eye-pointing. Because you are looking directly at the person, you can track their gaze.

Talking Photo Album

This is a 'flip-style' album. Voice messages and sounds can be recorded and activated next to each photo and played by pressing the button on each page. These messages can be re-recorded as many times as you wish to keep the album up to date and relevant.

Guide to using objects of reference

Objects of reference are used to signal what is about to happen or to stand for something that has happened.

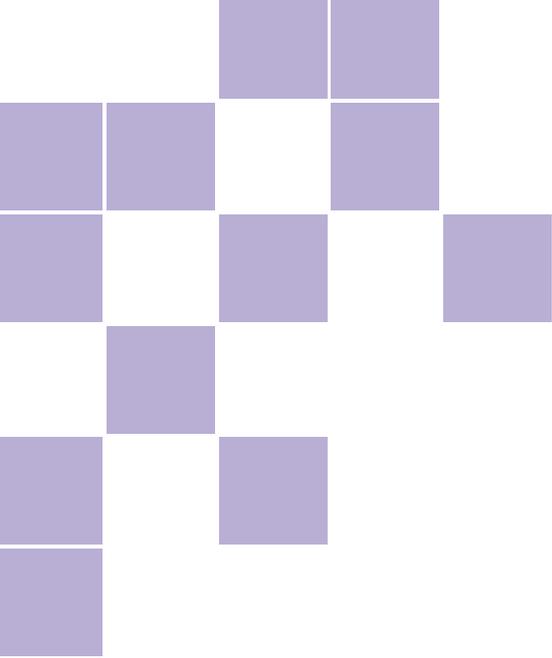


Guide to using symbols, signs and gestures

Although most people with PMLD won't use formal communication, some may use a few signs or symbols. Some people may also use or understand some gestures.

There is a list of suppliers of communication aids in the **Where to find out more** section, and other information about supporting communication in our downloadable resources.





7. Different creative approaches to involvement

With support from an experienced communication facilitator, each of the four Involve Me sites focused on one of the following creative approaches to involving people:

- creative communication
- sharing stories
- multimedia advocacy
- peer advocacy.

Although the sites used these four particular approaches, we know there are many other ways to support the involvement of people with PMLD by:

- putting the person at the centre
- supporting the person to express what is important to them
- supporting the person to share this with others.

The aim is not to compare the merits of different approaches but to learn from what the approaches have in common and how they can be incorporated into many

day-to-day activities. There is a sheet summarising this in the **Downloadable resources** section of the DVD. Involve Me presents ideas and encourages you to think about how you could use or adapt them to involve people you know with PMLD.

While there are key principles underpinning each of these approaches, it is important not to see them in isolation from each other. For example, you could describe Nick's role in **video clip 6** as that of a peer advocate as he articulates what is wrong with Mark's wheelchair and what the provider should do about it.

A number of other clips involve, or appear to be led by, people who do not have PMLD. These are sometimes included because they demonstrate or explain an approach that could be adapted and used with anyone (for example, using a photo album to explain what a person can do or what is important to them: see **video clip 31**).

More frequently the clips emphasise the importance of involving and including people with PMLD in mainstream activities where you can observe their responses and reactions to what other people are saying or doing and they have the opportunity to build their involvement at their own pace and in their own way. An example of this was Katie, who tended to move around the outside of sharing stories sessions or withdraw into another room but always seemed aware of what was going on. Gradually she became more and more interested in what was going on and, since the project has ended, will sometimes sit in the middle of the circle. She shows she is listening by her eye contact, laughter and

smiling. Katie joined in a simple story about what she had bought at the shop. She laughed and took notice when her object was shown to the rest of the group.

Creative communication

Kate Burns (née Duncalfe) has developed an approach using creative communication sessions to:

- use the way an individual already communicates, in a creative way
- enable them to share their likes and dislikes with other people
- help people learn that their action will get a reaction – it is worth communicating

- build on known preferences to explore choices and decision-making and support consultation – but be prepared to have past assumptions challenged.

The work done by staff at the Coronation Centre shows how others can use and adapt these ideas. The key points to remember with creative communication are:

- Keep an open mind: even the most simple everyday items can be used creatively to aid communication.
- Don't be afraid of 'getting it wrong' – the key is shared enjoyment and interaction.

Something we all have in common is our senses, and sensory experiences should extend beyond the sensory room. This



approach creates meaningful objects (for example, a box of sensory objects) that show what is important to the person and can be shared with others. To find out more visit the CAN Communicate website:

www.can-communicate.co.uk

Involve Me looks at how staff can use creative communication to enhance and develop communication and consultation. Each person's session was filmed and can be viewed as **video clips 7–11**. As happened at all the sites, Kate found that the best way to introduce the approach was to involve staff and people with PMLD in practical sessions together. She facilitated five creative communication sessions – each focusing on one of the people with PMLD. Tanya, Chelsea, Richard and Terry shared each other's sessions while Robbie had a session with his staff as he has shown he doesn't like being in groups. There was a follow-up session for each person.

Each session was built around the person's known likes and gave them the opportunity to express their preferences in creative ways. Terry's was based on football and was noisy and energetic while Tanya's was much more quiet and relaxed and based on a poem about a butterfly. This was a chance to find other things that interested the person and see if other participants shared these interests. The contrasts in the pace and style of activities gave staff the opportunity to observe people doing things they might not normally expect them to enjoy and raised some challenges to their assumptions.

Each person had a Talking Photo Album, a short film and an item that related to

their session. These capture the work that was done and enable people to tell their own story in a way that is creative and unique to them. Other people can see and understand what is important to the person, not just by looking at these but also by observing the person's reactions to the film, photo album or items.

Sharing stories

Dr Nicola Grove, the Involve Me facilitator at the Turning Point site, has pioneered Storysharing™ for people with PMLD. Although the name is trademarked, the approach has its roots in the basic human need to share stories and anyone can support groups to:

- recall or create a memorable experience
- tell a story about this to others.

The key points to remember if you are sharing stories are:

- Make sure people are involved in the events that happen around them.
- Find the little stories (as well as the big events) funny, unexpected, tricky or surprising.
- Help the person remember what happened, perhaps with a prop or a photograph.
- Tell the story together and make space for the person to join in however they can – Big Macks are great for this.
- Don't ask lots of questions or it becomes an interview, not a story.

Sharing stories is an important part of our communication as human beings. It is how we learn about one another and make sense of our experiences. Sharing stories enables people to remember together, entertain, make links with other people, create a shared history and develop an identity. Stories provide something we can think back to, they help us make sense of the world and we can use them to make future decisions. You can find out more on the Openstorytellers website: www.openstorytellers.org.uk

These Involve Me sessions were an opportunity to share stories about the experiences of people with PMLD and what

is important to them. Being involved in sharing stories, particularly those about choices, can support people to be more involved in future decisions. **Video clip 12** shows everyone sharing Ian's story about buying new aftershave. Ian and a number of other participants do not have PMLD and are able to communicate verbally. However, the presence and input of people who use words can be an important part of this approach. Stories about events such as choosing the aftershave are shared in a group in a sensory way with objects and sounds, and people with PMLD are supported to join in.



Multimedia advocacy

Many advocacy services describe advocacy as ‘speaking up for, or acting on behalf of, yourself or another person’. The Rix Centre has developed multimedia advocacy using ‘digital portfolios’ to give people with a learning disability, including people with PMLD, a greater voice in their lives.



This approach enables people with PMLD, and people who support them, to use cameras, videos, microphones and computers to:

- explore and understand their personal options
- tell their own stories
- plan ahead
- communicate day to day.

You can find out more about multimedia advocacy on the Rix Centre website: www.rixcentre.org There is a Mencap fact sheet on multimedia profiling in the **Downloadable resources** section of the DVD.

Information about what is important to the person is gathered into a ‘portfolio’ on a computer. This can include film, photos and sound recordings of people and things the person knows well. It supports the person to start to show preferences through their responses or body language as they look at this information.

Photography, video, microphones, computers and assistive devices such as switches or alternative keyboards are all used to capture the person’s communication, choices, likes and dislikes. This supports people to explore options and ‘speak up’ about their personal preferences.

The information can be shown to other people who can see and understand what is important to the person, not just by looking at their multimedia portfolio but also by observing the person’s reactions – just as they can with creative communication. In **video clip 1**, Michael’s reaction to people looking at and talking about the footage of his swimming session demonstrates this very clearly.

Peer advocacy

Advocacy is taking action to help people:

- say what they want
- secure their rights
- represent their interests
- obtain services they need.

Advocates are independent of services and work in partnership with the people they support, taking their side to promote social inclusion, equality and social justice. You can download a copy of BILD's advocacy fact sheet from the **Downloadable resources** section of the DVD.

Peer advocacy is based on shared experience. Someone who uses the same services or has similar life experiences speaks up for or acts on behalf of their advocacy partner.

This initiative for Involve Me grew from the work of Mencap's Getting To Know You peer advocacy project (www.mencap.org.uk/gettingtoknowyou). Hammersmith and Fulham Mencap recruited five people with a learning disability as peer advocates. They were trained and each partnered as a peer advocate with a person with PMLD who uses a local day service or is supported by the day service outreach team.

Although the peer advocates may not have PMLD they do have experience of having a learning disability and receiving similar services and support. This approach focused on self-advocates with a learning disability getting to know, and speaking up for the rights of, people with PMLD. In

video clip 13, Kimmy talks about how his experience of the day centre helps him do this.

What the approaches have in common

The aim of Involve Me was to learn about ways to involve people with PMLD in decision-making and consultation. Although the sites each used one of four particular approaches, we know there are many other ways to support the involvement of people with PMLD. In looking at what we learned from the sites, it is useful to focus on the features that are shared by the different approaches. There is a summary sheet in the **Downloadable resources** section of the DVD.

Core elements of all four approaches were:

- working together to build the story, activity or understanding of each other
- fun, interest and engagement
- creativity and imagination
- staff support
- consistency – everyone working in the same way and understanding why they are doing things
- 'ownership' by the individual – not imposing something but involving the person in every way you can.

In all approaches it was important to think about:

- sensory input – using different senses to communicate with the person
- how to build on the person’s existing communication
- meaning and what’s important to the person
- ethical and cultural implications
- relationships – whether through shared enjoyment in sharing a story or creative communication activity, the relationship between a peer advocate and their partner, or by recording important people in the person’s life through multimedia advocacy.

All approaches supported involvement in choice, decision-making or consultation

All the approaches supported choice, whether directly or indirectly, and helped people to recall past experiences or things that are important to them. This resulted in changes in their lives, mostly in terms of the activities they do or the way they are supported to do them. These changes could result simply from someone spending more time observing the person. However, the important point is that these observations were made with the specific aim of finding out what the person likes or what their preferences might be.

It’s not what you do, it’s the way that you do it!



Take a look at **video clip 14**, which shows Terry, the multimedia advocacy group and Ian in different sessions.



- Think about the way people are working.
- Can you spot the things they have in common, even though people are doing very different things?
- How could you adapt these or integrate them into the work you are already doing?

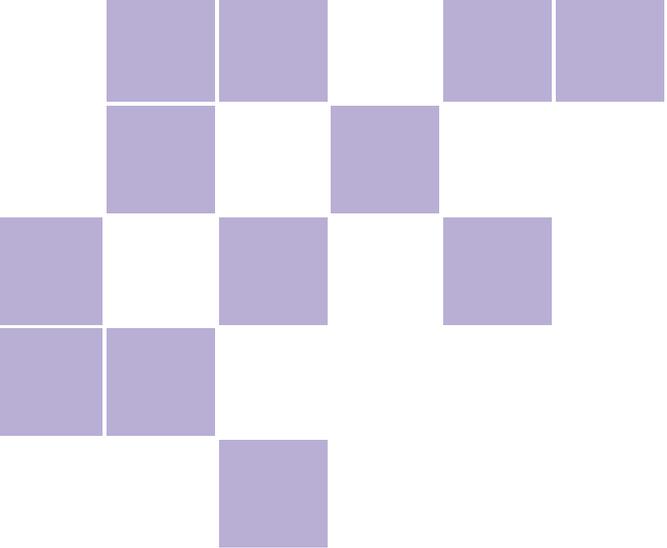
Just to get you started – think of the different examples in terms of ‘ownership’:

Terry is involved in building his football pitch; he doesn’t arrive to find it there.

The multimedia advocacy group spends a lot of time deciding whose voice is coming through each microphone before they start the session and Ian ‘owns’ the communication with the audience when they press the Big Mack and hear him say the word ‘sexy’.

In **video clip 5**, Kimmy explains how he observes things that could make the session easier for Serena – peer advocacy is led by the person, not the advocate.





Why people with PMLD need Involve Me

8. Policy and people with PMLD

- What do we mean by PMLD?
- How many people are we talking about?
- *Valuing People* and *Valuing People Now*
- The Mental Capacity Act 2005
- The Equality Act 2010
- Commissioning and planning services for people with PMLD
- Complaints
- Influencing policy

What do we mean by PMLD?

People with PMLD have more than one disability. All will have a profound learning disability and will find it difficult to communicate. Most will not use words.

Many people will also have sensory or physical disabilities, complex health needs or mental ill health. Given the frequent lack of support to communicate or express preferences, it is hardly surprising that PMLD can also affect a person's behaviour so that others find it challenging or difficult to understand. There is a fact sheet on PMLD in the **Downloadable resources** section of the DVD.

The PMLD Network definition describes a person with PMLD as someone who:

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

Why do we use a definition?

People with PMLD are unique individuals but sometimes it is useful to talk about groups of people:

- who have common concerns
- who have distinct needs
- who face barriers to being included
- who need help to fight for their equal rights.

Although many of these rights are set out in policy or enshrined in law, the Joint Committee on Human Rights reported that people who have complex needs often do not have a say in decision-making 'because people do not know how to communicate with them'.

How many people are we talking about?

Work by the Lancaster Centre for Disability Research in 2009 estimated that there were about 16,000 adults with PMLD in England. It said that in an 'average' area in England with a population of 250,000 there were approximately 78 adults with PMLD.

Valuing People and Valuing People Now

In 2001, the white paper *Valuing People* promoted rights, independence, choice

and inclusion for people with a learning disability. The aim was to improve the lives of all people with a learning disability, but consultations showed that people with PMLD were one of the groups that were clearly not benefiting.

In 2009, *Valuing People Now* acknowledged that people with PMLD were missing out and aimed to include 'those groups who are least often heard and most often excluded' by:

- starting by thinking about those with the most complex needs when planning and delivering services
- thinking about what additional services and support people with the most complex needs require to be included, rather than developing separate services.



In its response to *Valuing People Now*, the PMLD Network welcomed the fact that the government had recognised people with PMLD are missing out. The response suggests ways to make these ideas a reality:

‘Staff should be trained in communication skills, complex health needs, supporting people with behaviour that challenges, understanding what PMLD means, how to make best interests decisions, and how to help people with PMLD show their preferences and choices.’

Involve Me addresses the need for staff confidence and development and provides a powerful argument for the importance of empowering staff in order to empower people with PMLD.

One of the greatest barriers for people with PMLD is the negative attitudes of others. People make assumptions about their communication, levels of involvement and quality of life and this in turn can limit the opportunities available to them. If we learn ways to interpret a person’s preferences and use these to involve them in decisions about health, housing, services and support, there is a greater chance that they will access the opportunities that *Valuing People Now* outlines for people with a learning disability.

Personalisation

Personalisation – using a personal budget to plan and pay for your support – is a key part of government policy. Jim Mansell’s report, *Raising our sights*, suggests some families are benefiting from this agenda and getting the support they and

their disabled family member need. He describes these families as ‘pioneers’ and suggests the barriers to implementing policy for people with PMLD are ‘prejudice, discrimination and low expectations’.

There has been criticism that the government’s response to *Raising our sights* leaves too much to chance and to decisions at a local level, particularly given the vulnerability of people with PMLD to cuts in spending and services.

In their briefing on the government response to *Raising our sights*, Mencap and the PMLD Network express disappointment in the fact that, despite stating its support for the review, the government does not suggest any ways in which it will make sure the recommendations are implemented. The government’s response mostly refers to general policies that had already been shown to marginalise people with PMLD.

Raising our sights calls for a more specific focus on the needs of people with PMLD that many people fear will not be addressed by simply leaving things to be decided at a local level with no clear leadership or direction from government.

The Mental Capacity Act 2005

The Mental Capacity Act 2005 is a key piece of legislation for adults with PMLD. It moves away from previous blanket definitions of capacity to a process that ensures the person is involved as much as possible in decisions that affect them. Involve Me supports the principles of the act by suggesting ways people can be involved and influence what happens in

their lives. These principles should underpin any work with people with PMLD and on page 9 of the evaluation report one of the recommendations is that services should:

‘...continue to invest in training on the Mental Capacity Act 2005 and evaluate the effectiveness of that training. They should ensure that policies set out clear procedures for staff to follow so that a person is able to make as many decisions as possible. They should also ensure that if someone is assessed as lacking capacity for a particular decision, they are as fully involved as possible’.

The act includes the following key principles:

- Capacity is specific to a particular decision.
- All adults should be assumed to be able to make a decision unless it can be shown they are unable to make it.
- The right to make decisions that other people might think are ‘eccentric’.
- A person should not be considered unable to make a decision before all possible steps have been taken to enable them to make that decision. The information should be provided in the way that the person prefers – for example in pictures, photos or using sign language. The person should be in surroundings where they feel comfortable.
- An action or decisions made on behalf of someone who lacks capacity must always be in their best interests after considering what is known about their preferences.

Equality Act 2010

The Equality Act 2010 brings together all the different strands of equality law and makes it easier to understand. It aims to protect individuals from unfair treatment and promote a fair and more equal society. Being involved means having the same rights as other citizens, including the right to access your local community, shopping centre or leisure activities.

The Equality Act 2010 can be an effective tool to make sure companies and public bodies provide accessible services for people with PMLD. A good example is the Changing Places campaign, which challenges public buildings to provide facilities for people who cannot use standard accessible toilets. Without adequate facilities, people have to limit outings or not go out at all, so Changing Places toilets have enough space and the right equipment, including a height-adjustable changing bench and a hoist. The campaign has been successful in getting a recommendation into the British Standard that governs designing buildings to meet the needs of disabled people. It says Changing Places toilets should be installed in larger buildings and complexes.

Commissioning and planning services for people with PMLD

Local learning disability partnership boards drive the work of *Valuing People Now* but most struggle to involve people with PMLD in any meaningful way. In 2009 Mencap and the PMLD Network produced a top tips guide for partnership boards about how to include people with PMLD. They suggest

that finding other ways to hear the ‘voices’ of people with PMLD will help to make sure their needs are included in local planning.

Creative communication helps partnership boards ‘listen’ to people with PMLD



People from the Coronation Centre showed their films to the local learning disability partnership board.

The partnership board set up a PMLD subgroup, which Chelsea’s mother belongs to. It is using the learning from Involve Me to draft the terms of reference for the group.

The PMLD subgroup will use Talking Photo Albums to capture stories of people with PMLD and their families. The carers’ rep will ask people to collect information.

Tanya showed her creative communication film (**video clip 10**) to a partnership board outside her local area. People saw she had a ‘voice’.

Complaints

Government and regulators place a huge emphasis on having effective complaints policies and being responsive to people who use services. But people with a learning disability face many barriers to complaining about the services they receive.

Making Experiences Count was a joint health and social care complaints protocol that came into effect in April 2009 and aimed to improve access to complaints procedures. It was clear that people with PMLD or other complex communication needs would still be excluded, however ‘accessible’ the complaints form or process became.

The Hearing from the Seldom Heard project was funded by the Department of Health to look at how to overcome barriers and create ‘listening cultures’ within organisations, to find ways to hear those who are seldom heard. Six areas of good practice were identified:

- getting to know people really well
- better communication
- raising awareness of the human rights of people who are seldom heard
- improved access to advocacy
- ensuring everyone has their own complaints buddy
- effective complaints procedures.

The resource pack from the project can be downloaded directly from the BILD website: www.bild.org.uk

Influencing policy

Organisations like Mencap and the PMLD Network lobby government and work with politicians of all parties to try to improve the lives of people with PMLD. Locally and nationally, they and other groups raise issues that affect people with PMLD and their families. All of this is very necessary

and important but does distance people with PMLD themselves from the process. Involve Me showed that people with PMLD could be supported to ‘speak’ more directly to policy-makers:

- Two parliamentary candidates became more aware of issues for people with PMLD after a visit to a residential home that was using the approach of sharing stories.
- The creative communication presentation day was a powerful way for people to interact directly with people with PMLD, and **video clips 18 and 21** show the impact this had on local policy-makers and practitioners.

As part of the work to deliver *Valuing People Now*, the Department of Health and Mencap commissioned a guide aimed at including people with PMLD (*Communication and people with the most complex needs: What works and why this is essential*). One of the key messages is that:

‘Communication with people with the most complex needs is most successful with familiar, responsive partners who care about the person they communicate with.’

In reality, most consultations do not support this type of communication. They are often structured in a way that excludes people with PMLD or means their involvement is merely tokenistic or in order to ‘tick a box’. Involve Me could help change the way we think about consultation. The focus would move from formal meetings and one-off opportunities to evidencing the preferences of people with PMLD through filming or photographing work they have

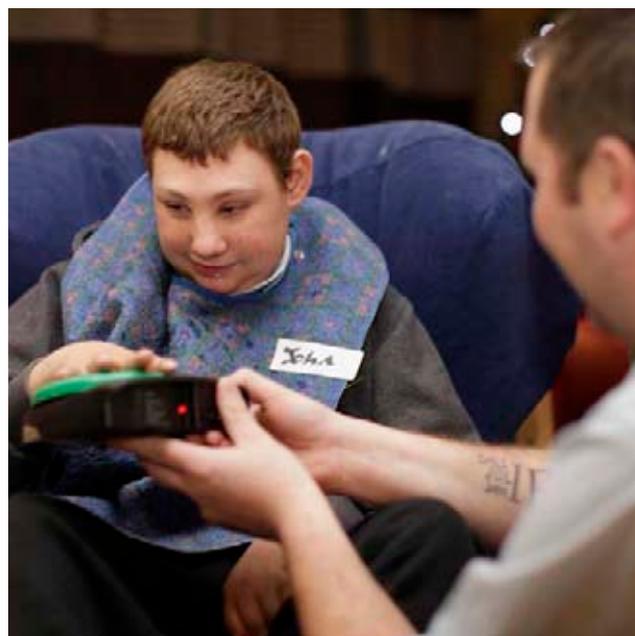
done with familiar people over a longer period of time.

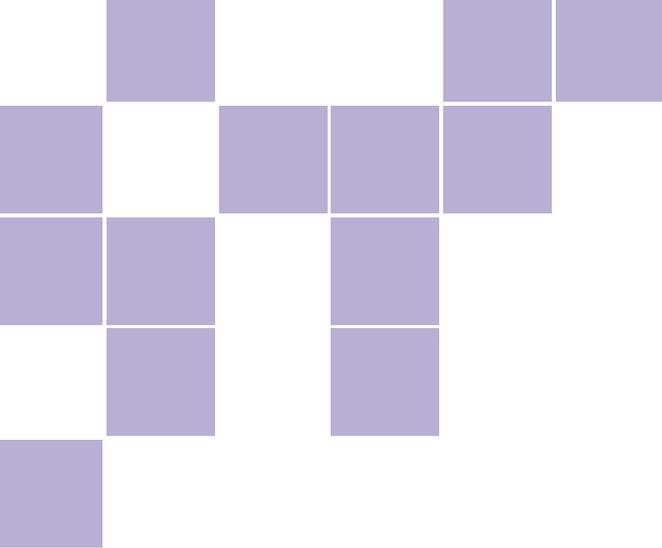
Sharing stories helps Turning Point involve Tim and Dave in a consultation about their garden

In **video clip 15**, you’ll hear how Nicola – together with Tim and Dave’s support worker, Adam – is working with Tim and Dave to identify their preferences and use these to decide how the garden should look.



- Could you adapt or use this approach to consult people you support?





This can feel daunting or simply idealistic when you are supporting someone with PMLD who may have no formal means of communication and depends on others to interpret all their daily needs. But the important word in this project, and in all the approaches used, is *involvement* – we are not talking about independent choice or decision-making.

9. Involvement in choice and decision-making, capacity and consent

- Involvement in choice and decision-making
- Everyday life and regular daily choices
- Support and services
- Community involvement with day services, house meetings and the local area
- National policy and planning for people with PMLD
- Capacity and consent
- Consent to using images

Involvement in choice and decision-making

People with PMLD should be involved in all decisions and consultations that affect their lives.

The emphasis of Involve Me has been not just on how people with PMLD can be involved in activities, but also on how this involvement can influence decisions and consultation.

Chelsea may not know it but she's 'choosing' who supports her.



The creative communication sessions gave Chelsea the opportunity to experience being with different people. This included a male member of staff. She clearly indicated that she liked being with men through the way she responded to and engaged with activities, and concentrated for longer. Chelsea now has male support for some of her activities.

It is perhaps easier to use the word 'preferences' to describe the things people like, dislike, choose or refuse. Some people might only make these preferences known through their behaviour or reactions. Others might point, look or choose from two or three options. The Involve

Me materials show how people can be supported to move along this continuum if others start to listen to, learn and act on their preferences.

In many examples people have been involved indirectly in a choice or decision that might have previously been thought too complex for them. This happens when other people 'listen' to them and use what they learn to ensure wider decisions are made in line with the person's preferences.

Because people with PMLD are so dependent on others to interpret what they want, there can be conflicts of opinion about what their communication or behaviour might mean. Everyone must be prepared to be open and honest and share 'evidence' of why they think the person might be expressing a particular preference. See *What I Mean* (see reading list on page 67) is a really useful resource that can encourage this open approach and help everyone take a more objective view of what the person might be expressing.

The Involve Me project shows creative ways to build on preferences to involve people with PMLD in all types of decision-making, ranging from small individual choices to bigger decisions about the local community and national policy.

Everyday life and regular daily choices

In all four sites the biggest impact for individuals has been on how they spend their time or the types of activity they are involved in. People with PMLD have been supported to express preferences that can

have a direct outcome for them personally:

- Through creative communication staff discovered that rather than liking peaceful 'soft things' as they had always assumed, Tanya likes surprises and activity. This has changed the way people work with her and the activities she is offered.
- Through stories Josh shared his experiences of trying to open a bank account. The group has been learning more about handling money through modelling shopping experiences and then going out and handing over money for things they buy. Staff have learned about the barriers Josh encountered and are working to support him and others to have bank accounts.
- Staff working with a young woman supported her to develop a multimedia advocacy portfolio at the Rix Centre. By recording her life in different environments, they noticed an inconsistency in how she took drinks, on a spoon or from a cup. She seemed to prefer the cup and is now always offered this first.
- Wayne has been supported to develop a multimedia profile that he can use to communicate his likes and dislikes.
- Martin is Jonathan's peer advocate. He attended his review and is supporting him to expand his activities in the evenings.

In all of these examples the person gains more control through having a means to express their preferences. This happens no matter how large or small the choice might be. For example, in **video clip 16**, by choosing to hit the switch in his multimedia advocacy session, Michael has complete control over whether the music starts to play or not. This concept of ‘cause and effect’ underpins decision-making at all levels.

Support and services

Where would you prefer to live? How do you like to spend time? You cannot ask people with PMLD questions like this directly. But if you know them well enough and understand their preferences you can find out what their answers might be.

Directly or indirectly, participants in the four sites have begun to influence services and support:

- Creative communication gave Chelsea a connection with fashion students at the local college. Staff are hoping to support her to go to college one day a week instead of the day centre.



- Sharing stories and using the Big Mack has given people tools to increase their

involvement in decisions and meetings. Josh took part in a review of his placement and used a Big Mack and body language to indicate that he wanted to continue living at the residential home. Tim and Dave use Talking Photo Albums to communicate their experiences and what they like.



- Multimedia advocacy portfolios are being developed as part of person-centred reviews and give people with PMLD more say over what happens in their lives.



- The work of peer advocates is starting to have an impact on services and support. One manager reported that this has helped him think about how to offer greater choice in support and timetables for people with PMLD.
- Peer advocates are to speak to a

consultant who is reviewing the day centre.

- Robbie's film (**video clip 9**) shows how seeing actions such as spoon-throwing as part of his communication, rather than as a disruptive activity, helps staff develop a more positive relationship with him. They clearly enjoy working with him in this session. He in turn is able to enjoy and remain engaged in the activity for much longer as the whole session is built around his preferences.

Community involvement with day services, house meetings and the local area

This part of the project looks at involving people in issues such as consultations about what services should be in the local community.

In the sites, local policy-makers, managers in different learning disability services and others from the community have heard about Involve Me and want to know more. Those who are in positions of influence are learning more about the lives and needs of people with PMLD. The evaluation of Involve Me believes that 'this is a beginning and has potential':

- Some people have attended learning disability partnership board meetings and communicated their preferences using film they developed through creative communication or the Big Mack and sharing stories.
- Peer advocates are representing their advocacy partners' wishes and raising the profile of people with PMLD in local

meetings and at the learning disability partnership board. The partnership board plans to talk about issues for people with PMLD at a future meeting and peer advocates will be involved. Peer advocates are also contributing to a council review of the day service based on their observations and the experiences of their partners.

- People with PMLD are being supported to attend some events run by the Hammersmith and Fulham Mencap self-advocacy group. This will help self-advocates know more about the needs of people with PMLD.
- Two parliamentary candidates became more aware of the lives of people with PMLD when they were invited to visit the residential home. The residents greeted them using the Big Mack.
- Through sharing stories, visits and activities Tim and Dave were involved in planning changes to the garden at the flats where they live.
- **Video clip 18** shows how the director of adult social care who went to the Involve Me event at Ellesmere Port learned more about the needs of people with PMLD.

National policy and planning for people with PMLD

This part of Involve Me looks at involving people in issues such as government consultations and national campaigns.

Directly or indirectly, people with PMLD in the four sites have begun to influence services and policy. This work is at an early

stage but is ongoing. Because of the length of the project, there are fewer examples of people with PMLD influencing national policy than there are of their involvement in choice and decision-making in their own lives and services.

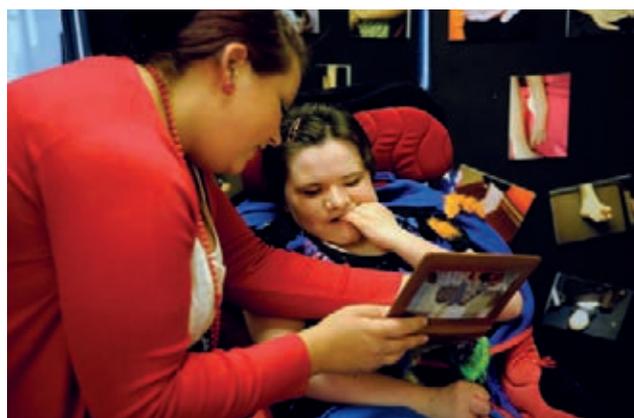
However, all sites have raised awareness of people with PMLD:

- The Getting To Know You project has started to make local policy-makers aware of the needs of people with PMLD. Peer advocates are helping analyse questionnaires about Changing Places toilets and suitable facilities for people with PMLD in their borough. They may use the findings to link to the national Changing Places campaign.
- In three of the sites, Involve Me has resulted in a greater influence on other services through representation to learning disability partnership boards.
- The visit by the parliamentary candidates has raised their awareness of this group of constituents.

Since the project finished, Storysharing™ has been used to involve people in campaigning about the cuts to the Disability Living Allowance (DLA) for people in residential homes. Members of the group made a jigsaw puzzle of their minibus, and each person was given money and asked to contribute a piece to the jigsaw in exchange for their money. They told stories about how people are using the DLA and made a DVD which they sent to their local MP, asking him to visit them to hear these stories.

Another Storysharing™ group has picked up the theme of problems with opening bank accounts. They organised a public meeting with their MP in Frome and 11 people told him their stories. They used music, drumming and a karaoke version of the song 'Money, money, money' to get their point across very successfully.

In Ellesmere Port the learning disability partnership board PMLD subgroup is going to make use of the idea of Talking Photo Albums used in the creative communication sessions to collect stories from families.



Involvement in policy and planning is at an early stage but we hope this guide will provide suggestions and resources to take the work forward in other areas.

Capacity and consent

The Mental Capacity Act 2005 protects the rights of people who lack capacity to make their own decisions.

In the past, people have been confused about when and how to make decisions for people with PMLD. The Mental Capacity Act 2005 clarifies the rights of people who lack capacity to make their own decisions and,

used properly, can be a powerful tool to:

- empower people with PMLD to make their own decisions wherever possible
- involve people with PMLD as much as possible in the *process* of reaching a decision, even if the person lacks capacity to make that decision themselves.

The principles of the Mental Capacity Act 2005 move away from previous blanket definitions of capacity to a process that ensures the person is involved as much as possible in decisions that affect them.

Involve Me shows how creative approaches to involvement can help you to learn about a person with PMLD and meaningfully *involve* them, even when someone else is making a decision in their best interests.

The Involve Me evaluation report suggests that professionals and families need a better working knowledge of the Mental Capacity Act 2005. Although people were following the spirit of the law in using the different approaches to involve people in making decisions, the report concludes that for many people this legislation was not ‘on the radar’ and they were not consciously following the act.

The **Where to find out more** section of the DVD has links to booklets about the act for unpaid carers, staff in health or social care and advice workers.

Consent to using images

There was a real challenge to establish that professionals and families understood the importance of the Mental Capacity

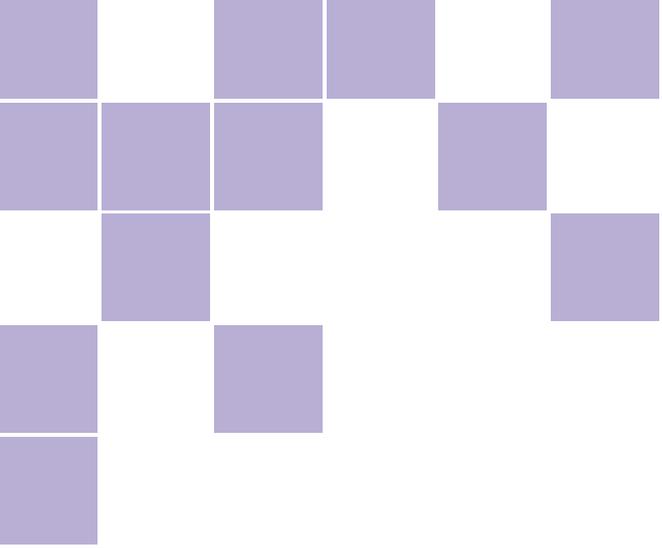
Act 2005 in the process of recruiting participants for Involve Me. If people could not give consent, they were involved as far as possible and those close to them were consulted to ensure they believed that taking part in research would not be harmful. Decisions about taking part in activities such as sharing stories had to be made in their ‘best interests’ but some people felt that families could give consent, which, under the act, they could not.

Video and photographs are very effective tools to help others learn about the lives of people with PMLD. However, debates over gaining informed consent can bog the process down and risk people losing their ‘voice’ and the opportunity to influence policy or practice.

The Involve Me sites used the commonsense approach outlined in a Mencap fact sheet about gaining consent to show people’s images. This is in the **Downloadable resources** section of the DVD.

Of course, we have to do everything possible to make sure people are happy for their photo or video clip to be used, but the reality is that we are asking people to agree to something very abstract. If you are sure someone is not able to give clear consent to the use of their images you can involve people who know them well in making the decision.

The Mencap guidelines can be given to a relative, carer, friend or advocate of the person to help them decide whether or not it would be in the best interests of the person with PMLD for you to show their photo or video clip.



10. What you can do

Involve Me has important messages for:

- families
- frontline staff
- advocates – including peer advocates
- service managers
- people who plan and commission services.

Families

- Partnerships with families were really important in some of the Involve Me sites. They gave staff and advocates the opportunity to find out about other areas of a person's life.
- Be open to new ideas – this might sound like just another new 'fad' but parents welcomed the fact that the different approaches to involving people meant others were getting to know their family member better.

Watch **video clip 19** to hear what John, a family carer, has to say.

Staff and advocates

- Persevere! The enthusiasm of staff and peer advocates has been a vital part of Involve Me. There have been lots of other pressures and demands on their time but all have been excited and 'energised' by the opportunities to listen to people with PMLD and give them a voice.
- You will find out more about the preferences of a person with PMLD and how to use them to influence what happens in their life if you:
 - appreciate the different ways people communicate
 - recognise the importance of your own role in communicating
 - spend time with the person.
- Communicating with each person in a way that is appropriate for them should be an essential component of support – a part of personal care or everyday activities – and not an add-on.
- Try to find time to engage with families and others in the person's life to learn from them and ensure you all communicate and work consistently.
- Don't make assumptions and be prepared to be surprised.
- However busy you are, find the time to record what you are doing or learning and share it with others.
- Be respectful of communication aids like Big Macks or Talking Photo Albums and make sure they are not used

inappropriately or in other settings where they are not valued.

Peer advocacy services

- Allow time to set up a service. It will involve recruiting peer advocates and advocacy partners, training advocates, obtaining CRB checks and providing additional support in the early stages of the advocacy partnership.
- Establish a process for selecting and training peer advocates and matching partners.
- Have contracts with peer advocates that set out what is expected from them in terms of commitment and a clear process for releasing them from their role if they are unable to fulfil this.
- Peer advocates may need support to represent their advocacy partner, particularly if the meeting or setting is intimidating.
- Resources to help you set up a peer advocacy service and train people to become peer advocates can be downloaded at www.mencap.org.uk/involveme

Watch **video clip 5** to hear Kimmy talking about peer advocacy.

Service managers

- Involve Me has worked particularly well where management is actively engaged in supporting staff to use the approaches to involving people. Where this happens, approaches are more likely to be embedded in practice.
- It might be difficult to consistently find time to understand the approach, support the staff who are using it and apply the principles of Involve Me across your organisation. However, this is the way to ensure the voices of people with PMLD will be heard.
- The evaluation of Involve Me found that managers and staff did not refer to the Mental Capacity Act 2005 as much as would have been expected. The law is central to decision-making with those who may lack capacity for a particular decision. Training on the act needs to ensure that everyone has a good practical knowledge of how to apply it in their work with people with PMLD.
- Staff also need relevant and practical training on communication and time to reflect on how to apply this.
- Think creatively about staffing – being short-staffed is one of life's realities. Staff in the project sites could not always be released for training but, rather than cancelling the training, it took place while working with participants, and staff and people with PMLD learned together.
- Involve Me had a huge impact on support staff in each site. This has implications

for staff development and retention. In empowering the person with PMLD, staff have also been empowered and excited by the opportunity to improve the ways in which they 'listen' to those they support. It can contribute to job satisfaction for staff working with people with PMLD and gives them a more exciting and rounded view of their role beyond personal care.

- Use recruitment, supervision and appraisal to ensure communication and involvement is an integral part of the role of support staff. Communication with the person should be incorporated in every area of their support and part of the culture of your service.
- Don't leave staff to do it all on their own. Each Involve Me site had support initially from an experienced communication facilitator who gave staff and peer advocates the confidence to use the approaches and work more independently.
- Be prepared to call on this type of support or the support of other professionals (speech and language therapists, occupational therapists, physiotherapists and psychologists) if you think you need it.
- Try to access additional tools like the Big Mack or Talking Photo Album.
- Find ways to build links with family members, friends and support staff in other services to share learning about the person's individual ways of communicating, their likes and

dislikes, and make sure everyone uses consistent approaches. These should then be recorded and used. This is not just another mantra about partnership working but a very practical plea – a Big Mack can be great but if your staff are supporting John to use it to say “I'm tired” and staff in the respite unit are using the same noise to say “I'm hungry”, things are going to get very confusing!

- Think about how you could use multimedia approaches to support people to be involved in review meetings or decisions about their lives. Would your staff want to build their confidence in using technology or need any training and guidance?
- Use creative ways to find out about individual preferences and then identify key themes that you can build on and expand.
- Run a training session for staff on Involve Me. Download a template Involve Me session plan from the **Downloadable resources** section of the DVD.

In **video clip 20**, Marie talks about her experience of creative communication.

People who plan and commission services

- Ensure services have policies and practices that enable people with PMLD to be involved in decisions that affect their lives. Expect a culture of engaging with people consistently.

- Communication is everyone's responsibility but health commissioners should ensure there is enough speech and language therapy provision to train and support staff who work with people with PMLD. This can help ensure they can use communication resources appropriately and consistently with people with PMLD and maximise their involvement in decisions about their lives.
- Find out and keep track of the number of people with PMLD in your area and the types of service and support they need and want.
- Listen to the voices of people with PMLD in creative ways – what do you need to

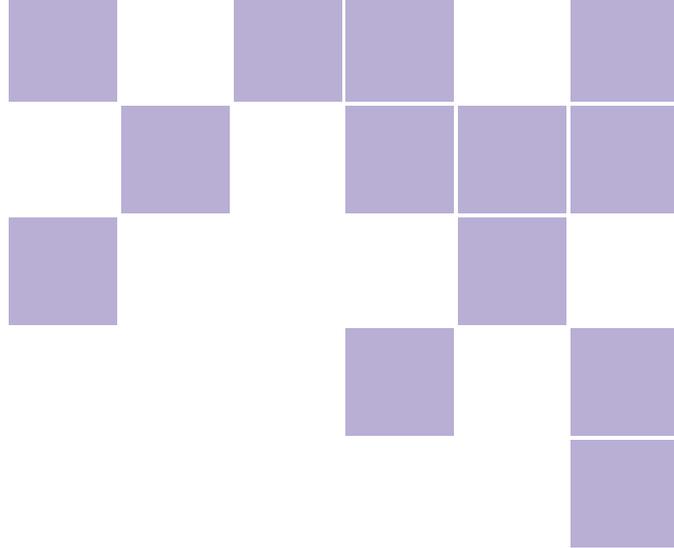
change about your meetings to make it easier for them to get involved? Identifying a local PMLD 'champion' would be one way to ensure this happens. Take a look at our suggestions for a session to get everyone thinking about this in the **Act on what you learn** section.

In **video clip 18**, Steve outlines the messages for people who commission services.

In **video clip 21**, Debbie, a partnership board rep, talks about her hopes for Involve Me.







11. The Involve Me messages

The information from the Involve Me sites and independent evaluation report can be summarised in eight key messages:

- Know the person really well.
- Take lots of time.
- Don't make assumptions.
- Be responsive to the person.
- Be creative and try out new ideas.
- Learn from what the person 'tells' you.
- Act on what you learn.
- Help the person recall and share things about their life.

This section looks at each of these in more detail.

1. Know the person really well

As part of the work around *Valuing People Now*, the Department of Health and Mencap commissioned a guide aimed at including people with PMLD (*Communication and people with the most complex needs: What works and why this is essential*). One of the key messages is:

'Communication with people with the most complex needs is most successful with familiar, responsive partners who care about the person they communicate with.'

Involve Me demonstrates how the different approaches to involvement can help you work with someone you know well to:

- find a starting point from which to suggest or explore new activities
- build on known preferences to support choice, decision-making and consultation
- get to know the person better or understand different aspects of their personality
- support the person to share this information with others.

Find a starting point from which to suggest or explore new activities

All the approaches started by focusing on something that was important to or had meaning for the person.

We all need a starting point from which to make choices or decisions and this usually means thinking about what we know or have experienced. With people with PMLD it is really important to establish a starting point in terms of their communication, understanding and interests and not to make assumptions about what they might like or how much they can understand or

are interested in. For example, **video clip 30** shows Nick working with members of the multimedia advocacy group at the Rix Centre to find out how much they understand about what is going on, if they know who else is in the room and whether they are using switches intentionally or recognise images of themselves or other people.



Build on known preferences to support choice, decision-making and consultation

Multimedia advocacy pulls together information about what is important to the person, creative communication starts with a 'known like', sharing stories develops stories around significant events, and peer advocates observe and learn about what their advocacy partner likes or dislikes. In these ways, each approach was able to reveal more about the person and see what these preferences might mean in terms of decision-making and consultation.

Richard's music session (**video clip 22**) is built around his known interest in horses but provides opportunities for staff to find out about other things he likes, such as quiet or loud music or taking a lead. This new information can be used to suggest other things Richard might like or dislike doing and to make sure any decisions take account of his known likes and dislikes. The giggling in the background as members

of the group decide what materials they want to use suggests that others are also enjoying elements of Richard's session. Staff can observe this and learn more about the person and perhaps find they have something in common with Richard and could share other activities with him.

Get to know the person better or understand different aspects of their personality

Robbie's film (**video clip 9**) showed a different side of his personality. In the past his behaviour had sometimes been seen as a problem but the clip captures his sense of mischief and infectious humour. The film was shown at his review meeting, which everyone felt was the most positive they had ever been to. Staff are now asking to work with Robbie and are far more aware of how he can respond if he is in the right environment and knows he can leave if things get too much for him.



This greater awareness led staff to suggest that Robbie was upset by the noise and increased activity around 3.15pm each day when transport arrives to take people home from the centre. He is now picked up at 2.30pm when things are quieter and is far happier. Staff have also learned that it is rain, not water, that Robbie loves. In the past they had tried to cover up his arms

and hands but now they know it is the feel of the rain on his skin that he loves.

Support the person to share this information with others

Involve Me is about involving people with PMLD in decision-making and consultation. To make this happen, we have to support the person to share what is important to them with people who can make a difference.

In Hammersmith and Fulham, peer advocates are contributing to their advocacy partners' person-centred reviews. As they observe and spend time with their partners they learn more about them and have helpful information to contribute about things such as day activities or the need for accessible toilets in the area.

Sharing stories has been used to say what is wrong with Mark's wheelchair (**video clip 6**) or how Tim and Dave want their garden to be. Tanya showed her film to a partnership board and made them think about the importance of finding creative ways to listen to people with PMLD.

In **video clip 23**, Dave explains how Nazia uses video to make sure staff hoist her properly and in a way that ensures she feels comfortable. This is far more powerful than written guidelines and emphasises the fact that Nazia is a unique individual who is perfectly happy to be hoisted if staff take the time and care to do this in the way that is right for her. Paperwork can be impersonal but these messages are more powerful as they come directly from Nazia.



2. Take lots of time

Involve Me demonstrates the importance of:

- spending time with people with PMLD
- taking your time, using every opportunity to develop involvement in choice, decision-making and consultation
- being honest and open about the time it takes to involve people with PMLD.

Spending time with people with PMLD

Many people with PMLD spend their time in busy environments, surrounded by people but with few opportunities to just spend time with others and build relationships. Interactions often focus on personal care or other tasks, rather than looking for opportunities for communication and involvement. In **video clip 24**, Kate talks about the importance of spending time and 'just being' with people.

Core elements of all the approaches were working together to build an understanding of each other, consistency of approach and 'ownership' by the individual. All of these can only be achieved by spending time with the person.

Taking your time, using every opportunity to develop involvement in choice, decision-making and consultation

We have highlighted the need to spend time involving people with PMLD but this doesn't have to be a big event and can be built into everyday activities and interactions with people. The fashion show where people modelled T-shirts representing their hopes and dreams was built on lots of everyday interactions which helped staff build up a picture of the person's likes and dislikes and suggestions of how they could explore these further. While the fashion show was an important way to share this information with others, it would have been irrelevant without this groundwork.

The group of people in the residential home all lived together but never really interacted or knew much about each other.

Video clip 25 shows how staff can use sharing stories as a way to bring people together around a table and share events that are significant to them. Once staff are confident with the principles of sharing stories, this activity could become a natural part of the day. This clip also demonstrates the importance of giving people time to respond, in this case by pressing the Big Mack. The temptation to jump in and take over to move the story on must have been very strong at times but people are given time to get involved at their own pace.



Being honest and open about the time it takes to involve people with PMLD

In **video clip 5**, Kimmy talks about being a peer advocate and is very clear about the length of time it will take him to really get to know Serena. Even when advocates had been meeting with their partners for six months, they still only knew a limited amount about them. The evaluation report records how another peer advocate, Martin, spent time finding out how his partner likes to communicate: "Jonathan smiles and reacts. I'm learning, still learning".



Peer advocacy relationships develop slowly and Jonathan gained wider experiences as a result of the project. This has the potential to develop and in the future Martin may be able to advocate for him on wider issues.

The same is true of all the other approaches; none of them can be rushed. Involvement means focusing on the person's interests, working at their pace to learn more about them and thinking about how to use what you learn to make sure they are involved in decision-making and consultation.

At a time when resources are scarce and staff are stretched, the examples from the pilot sites highlight the importance of embedding these approaches into practice and show how they can be incorporated

into many day-to-day activities. One of the most important messages for service managers is to think creatively about staffing – for example, staff in the project sites could not always be released for training but, rather than cancelling it, the training took place while working with participants, and staff and people with PMLD learned together.

3. Don't make assumptions

One of the greatest barriers for people with PMLD can be the attitudes of others. People make assumptions about their communication, levels of involvement and quality of life. This can limit the opportunities available to them.

These assumptions are not only made by society in general but can often come from within services or families as well. Involve Me provided the tools and opportunity to be open-minded, see the person with PMLD through fresh eyes and:

- be surprised
- see things differently
- learn new things about the person.

Be surprised

Each of the approaches gave different people involved in a person's life the opportunity to share all the things they know about them. Families appreciated that others have an opportunity to see their family member as they see and understand them. One mother watched the film at the Ellesmere Port celebration event and said with pride: "That's my son".

Another mother said she wanted others to understand her daughter as the family does and realise that "She does 'speak'".

Sharing stories introduced people to using a Big Mack and it was an emotional moment for several families when their son or daughter used this to say hello. For many, this was the first time they had ever received any form of intentional greeting.

See things differently

This was one of the biggest challenges for peer advocates, particularly for those whose partners attended the day centre. Many had previous negative experiences and had to use this experience constructively and separate it from what was happening for their advocacy partner.

Peer advocacy is starting to challenge the assumptions people make about representation on partnership boards and within self-advocacy groups. The advocates themselves challenge people's ideas about relationships between people with a learning disability.

Involve Me has shown how people with PMLD can gain confidence in their communication, have greater control and reveal more of their personality, and their likes and dislikes to those who support them.

Staff see the real Robbie through his cookery session



Robbie does not like being with lots of people. His behaviour was often seen as a barrier to relationships and, because he has one-to-one support, a lot of staff never get to know him as an individual. He had his creative communication sessions on his own with his supporters but the film of the activity (**video clip 9**) demonstrates his great sense of fun. His activity focused on cooking and his love of food. He chose the drink for the recipe for his bread. One staff member said it was “so nice to get on film how happy he can be and what good company he can be...”.



Other things are changing for Robbie. He appears more comfortable to sometimes be included on the periphery of events such as a coffee morning for family and friends. This is a significant step forward for him.

- Do you work with anyone whose ‘negative reputation’ always seems to go before them?
- What are the things you like and value about that person?
- What can you do to help others see the person you know?

Learn new things about the person

The real challenge is for staff, families and other supporters to approach this new information in an open-minded way, think creatively about ways to explore the person’s preferences and share what they learn with others. A good example is the T-shirt project in Ellesmere Port that resulted in a fashion show for family and friends (**video clip 35**). Each person modelled a T-shirt that illustrated a ‘dream’ activity. Many of these were not what people might have expected.



Throughout the Involve Me project, Terry’s activities and enthusiasm had centred on football and it would be easy to assume that any new activity would follow on from this. However, staff took the lead from his responses and identified that he might like to go to a Bee Gees tribute concert.

In the same way, Richard’s interest in horses suggested to staff that he might like to look at films of other animals. He particularly enjoyed the film of monkeys playing together. This prompted his family to plan to explore his enjoyment of nature and animals further, starting with a trip to a monkey sanctuary.

It is sometimes easy to focus on the end product – the ‘event’ – rather than the important process by which staff reached

this stage and how they take the work forward:

- Staff worked with people at their own pace, using activities and the internet to identify individual preferences.
- Staff explored these with people to think about new things they might like to do.
- This information was recorded on a one-page plan to be shared with others.
- T-shirts were created with an image representing each person's 'dream' activity.
- This was not seen as an end in itself – staff and families continued to observe and learn from people's responses to this work and to the new activities.

Staff get to know a very different Tanya (video clip 26)

Page 17 of the evaluation report describes how working with Tanya provided “the biggest learning curve for staff” and demonstrates the value of giving people the opportunity to try different activities through participating in other people's creative communication sessions. Previously everyone thought Tanya liked peaceful activities, and ‘soft things’, but she enjoyed Richard's noisy, boisterous session about horses.

Through her creative communication session it became clear that Tanya likes surprises. Staff knew Tanya likes sensory

experiences and suggested she might enjoy a session in a white room including butterflies, feathers, lights and projected images. She liked the feathers, particularly when they were dropped down on to her from behind, giving an element of surprise. Kate, the facilitator, also blew feathers from her hand onto Tanya's face. When Kate was doing something else, Tanya made a sound like a raspberry being blown. Kate took this as a request to blow the feathers at Tanya again and it was very clear this is what Tanya wanted. This was a new sound for Tanya and an intentional one that she has continued to use.



By watching Tanya carefully, staff also felt they had misunderstood why she became upset. This has totally changed the way people work with her. They had treated her as a ‘delicate flower’, assumed her wails were due to pain and would lie her down and rub her stomach. They have now realised it is Tanya's way of expressing boredom and do something to shock or surprise her instead!

... and the footballer loves feathers!

- When you are looking at this video clip, as well as looking at Tanya's reactions to the different sensory

experiences, take a look at Terry and Richard. Staff would probably not have chosen a poem about butterflies as an activity for either of them but, by joining in with Tanya's session, they have the opportunity to show that they too enjoy quieter, gentler activities.

- This is a world away from Terry's messy football pitch but his face says it all!

4. Be responsive to the person

People with PMLD are usually excluded from decision-making and consultation because people assume they have nothing to say. Some of the most powerful messages from the Involve Me sites come about when people learn about control, and cause and effect – they do something and in response to this:

- other people share the experiences of people with PMLD
- people with PMLD gain more control
- people with PMLD are more involved and others become aware of what is important to them.

Other people share the experiences of people with PMLD

Video clip 28 shows the Involve Me presentation day at Ellesmere Port. Terry, Tanya, Robbie, Richard and Chelsea have already shown their films and everyone in the audience is given a 'sensory goody bag'. Each person shows their film again and

the members of the audience are asked to share the experience of something they like. They let off party poppers and share Terry's excitement at the point in his film when he scores the last penalty and blow feathers at Tanya to experience her newly discovered love of surprises.



When people with PMLD are so often ignored, it is a very powerful image to see a room full of people responding to things that are important to them.

People with PMLD gain more control

Having identified things that might be important to the person, Involve Me demonstrates how you can use a known like to start building a sense of direction and control over choices.

Richard uses a Big Mack with the sound of a horse neighing to conduct his music session in **video clip 29**.



Everyone has something to use to shake or rattle to make a noise but Kate asks them to wait quietly until Richard presses the Big Mack. Before they start to move around the room, Kate asks them to practise this, asking everyone to wait to see if Richard wants to do it again.

At the Rix Centre, Michael found he could start the music by hitting the switch and did this each time the music was switched off. When Kimmy stands back and observes his advocacy partner in the cookery session he learns that simple changes like a table and old clothing would make the session more enjoyable for her. Tim and Dave use sharing stories to gain more control over decisions about their garden.

People with PMLD are more involved and others become aware of what is important to them

When Tanya showed her Involve Me film at a partnership board meeting, people learned about the things that are important to her. It was important for Tanya to be there at the meeting as people were able to learn from the way she responded to the film as well as from the film itself.

All the different approaches in the Involve Me project start by focusing on something that is important to the person and then respond to and learn from this. The person with PMLD leads at every stage because even suggestions made by others are based on what they have learned about the person.

This is demonstrated at its simplest level by one of the peer advocates who is a quiet person and really good at picking up

on signs from her advocacy partner and responding to them. For example, she can tell when her partner wants to dance, if this is making her happy and when she gets tired and wants to stop.

This same process of observing and responding to behaviour led staff to suggest that Robbie would be much happier if he went home from the centre before the afternoon rush.

Kieran and Chelsea had not worked together before the Involve Me project. Chelsea had always been read to by a female member of staff and would concentrate for about ten minutes before losing interest. When Kieran read to Chelsea, staff were amazed at how her interest was held for 25–30 minutes. In town she looked around and became very animated at the sound of a man's voice. Staff shared their observations and wondered if this meant Chelsea preferred the sound of a male voice. They are going to explore this further by using an audio book read by a man to see if the male voice, rather than a specific individual, holds her interest.

A key part of this process is the way staff have observed, been responsive and shared what they think they may have learned about Chelsea. Staff are now far more aware of her enjoyment of male company and are looking for ways to give her more male support for activities that do not include personal care, such as help with her lunch. They are beginning to appreciate that, as a young woman, it is natural for Chelsea to enjoy some male attention, regardless of her disability.

5. Be creative and try out new ideas

Involve Me focused on ways to *creatively* involve people with PMLD in decision-making and consultation.

The word 'creative' can be misleading and might suggest simply using music, art or craft. While some sessions were based on this type of activity, in this context 'creative' means using original and unusual ideas to involve people with PMLD. This includes:

- finding a starting point from which to explore or suggest new activities
- exploring different ways for people with PMLD to take control or share what's important to them
- working in ways that put the person with PMLD at the centre of the decision-making or consultation process.

These creative approaches must be part of an ongoing process and not just a one-off event. They will only become *communication* if they are shared with others and only involve people with PMLD in *decision-making* or *consultation* if they are shared with someone who can make a difference.

Finding a starting point from which to explore or suggest new activities

One of the peer advocates is supporting his partner to visit a local club night, as he knows he enjoys music but has never been to this club night before. This is a chance to observe his responses to a real experience, rather than present abstract choices. Once he has observed how his partner responds

to the club night, he might be able to suggest other activities he might enjoy or have a clearer idea of the environment in which he likes to listen to music.

In **video clip 30**, Nick sets up the session with the multimedia advocacy group. He uses a simple web camera and encourages group members to 'play games' to find out who else is in the room and say hello. When they press the switch, the image of a different group member appears on the screen and Nick watches how people respond to this. This creative way of introducing people to the sessions and to each other also allows Nick and the staff to gauge how much people are able to understand and whether they recognise images of themselves and others.



Exploring different ways for people with PMLD to take control or share what's important to them

Some of the communication tools used in Involve Me have enabled participants to gain attention and express their wishes. For example, Richard's creative session was built around his love of horses and involved a Big Mack with the sounds of horses' hooves recorded on it. Richard pressed this when he wanted everyone to start shaking or rattling their instruments. He is now using the Big Mack to gain attention in other situations and this means he is more



involved in sessions at the day centre. Tim's support workers notice that he is really good at spotting dirt and cleaning up. **Video clip 31** shows how Tim used a Talking Photo Album to go for an interview for a cleaning job. Talking Photo Albums were also used to capture what is important to people involved in the creative communication sessions. They can be used with people with PMLD in many situations to give them control over what people do and to make sure others understand their preferences or what is important to them. Following Tanya's presentation, the carers' rep on the partnership board is planning to use them to capture the experiences of families of people with PMLD.

Techniques for sharing stories were used to involve Tim and Dave in a 'goodbye meeting' with a member of staff who was leaving. This really helped with the transition and Tim was able to express his views clearly. Sharing stories is also being used for long-term work on financial awareness with Tim and Dave.

Working in ways that put the person with PMLD at the centre of the decision-making or consultation process

Although organisations like Mencap and the PMLD Network lobby nationally to improve the lives of people with PMLD, this can distance people with PMLD themselves

from the process. Involve Me showed that people with PMLD could be supported to 'speak' more directly to policy-makers.

In reality, most consultations do not support this type of communication or involvement. They are often structured in a way that excludes people with PMLD or means their involvement is merely tokenistic or in order to 'tick a box'. Involve Me demonstrates what happens when we begin to think more creatively about consultation. The focus moves from formal meetings and one-off opportunities to a process that evidences the preferences of people with PMLD through filming or photography work done with familiar people over a longer period of time:

- Multimedia advocacy portfolios are being developed and shown in person-centred reviews to give people with PMLD a greater presence at meetings and more control over decisions about their lives and services.
- Peer advocates are to speak to a consultant who is reviewing the day centre to ensure the needs of their advocacy partners are taken into account. They are starting to have an impact on services and support. One manager feels this has helped him think about how to offer greater choice to people with PMLD.
- At the presentation day, people with PMLD presented their films before inviting people to share things that are important to them. **Video clips 18 and 21** show the impact this had on local policy-makers and practitioners.

- Sharing stories and using the Big Mack have increased the involvement of people with PMLD in decisions and consultations. Josh used a Big Mack and his body language in a review of his placement to indicate that he wanted to continue living at the residential home. Sharing stories has also been used to challenge cuts to the mobility allowance for people in residential care. These people sent a DVD of the session to their local MP asking him to visit them to hear their stories.

Involve Me has given many staff skills and confidence to think about ways to creatively involve people with PMLD in decisions and consultations. Many have adapted the approaches in different ways and see the work as ongoing: “A living project”; “not going to stop”; “it’s what we do”. For many, the process has been energising as they find new ways to empower the people they support. One member of staff talked about the “energy” of sharing stories and how it increases a person’s identity and sense of power when they are supported to share meaningful events with others.

6. Learn from what the person ‘tells’ you

In each Involve Me site, people were interested in and open to learning from people with PMLD. This represents a huge culture change from a model where things are often done *to* or *for* people, rather than *with* them.

The project shows how relationships change when people with PMLD are seen as the experts in their own lives. When this happens, the role of others is to:

- start with small steps and learn together
- find out what the person understands
- think about how to use what they have learned about the person with PMLD.

Start with small steps and learn together

Video clip 32 shows a support worker sharing Dave’s story in a music and sharing stories session. He tells how Dave’s old clothes were thrown away and then how Dave went out of the gate and into the bin to get them back. The phrase ‘in the bin’ is recorded onto a Big Mack and repeated lots of times during the story. Dave’s contribution is to pull his old clothes out of a black bin bag and, although his expression shows how important they are to him, Nicola acknowledges that this input can look a little tokenistic.



However, every contribution is valuable. The idea is to start with one small thing the person can contribute and work together from there. The result is that other people become more aware of the person and listen and respond to them and their story.

The story is also a chance for Dave to express a choice or preference and make other people realise that things they might dismiss as ‘rubbish’ are really very important to him.

The peer advocates are all starting by spending time with their partners and learning to read their reactions and body language. This is a new skill for most of them.

Find out what the person understands

Video clip 33 shows one of the activities used to help tenants get involved in decisions about redesigning their garden. Dave is asked to select a photograph showing a particular part of the garden. This is a good way of establishing how much a person understands. Nick works in a similar way at the start of multimedia advocacy sessions. This observing and checking is an essential part of finding out what interests a person with PMLD and what has meaning for them. Without this it would be very difficult to engage with them and build their involvement.



In **video clip 17**, Nicola talks about the fact that you might sometimes appear to be imposing your own taste while you are trying to find out what things mean for someone with PMLD. In discussions about the garden Nicola and Adam referred to rubbish as “yuck” and described flowers as “beautiful” in order to establish a sense of what the garden is like – some is rubbish that needs to be thrown away and other things are beautiful and should stay. In

time, they will learn more about Dave and might discover that, like the previous tenant, his idea of beauty might lie in things that other people want to take to the tip.

Think about how to use what you learn

Having used the different approaches to learn more about people they support, the next step in all the sites was to use this to ensure people became more involved in decisions and consultations. It is important to make sure people with PMLD have the opportunities to share information about what they like with people who can change things for them. At the Involve Me presentation day, the audience had the chance to watch people’s films and then experience some of the things that are important to them. In **video clip 34**, Kate talks about the importance of sharing this with others. The director of adult social care says he has learned a lot and talks about using this to make sure people with PMLD have the same chances as others to be part of their communities.

Whenever you find out something new about a person with PMLD it is really important to think about how you can use this and who you need to share it with to make sure they are involved in decision-making or consultation. This includes sharing information across your staff team or service. One member of staff moved from supporting Tim and Dave to another house and took what he had learned about sharing stories with him. Staff in other settings are now more aware of this approach to involving people.

7. Act on what you learn

When you use creative ways to find out about a person's preferences, the challenge is to then enable people to have the real experiences in the community. It is important to see this as an ongoing process rather than a one-off event and to be aware of the issues that might be raised:

- the 'journey' – working out what people might like
- shifting power from services to the people they support.

The 'journey' – working out what people might like

In all the sites, people with PMLD have been able to express what is important to them or build on their current interests. In **video clip 35**, we learn about the 'journey' from learning more about the person to suggesting what dream activity might be recorded on their T-shirt. One Involve Me participant described this as moving beyond "respectful guesses". Staff worked with people at their own pace, using activities and the internet to identify individual preferences. They then explored these to think about new things each person might like to do. The information was recorded on a one-page plan to be shared with others and on the person's T-shirt.

Terry's creative communication session (**video clip 11**) focused on his love of football, but staff explored his love of music and identified that he seemed particularly interested in the 1970s and might like to go to a Bee Gees tribute concert. They realised that Robbie likes listening to stories as well

as music and suggested Tanya might like to go to see a hot air balloon because of the way she responds to the wafting of the parachute in dance sessions.



Chelsea's creative communication session (**video clip 7**) was built around her interest in colour and fashion. It focused on producing a piece of art based on materials on a tailor's model with fluorescent cloth in a dark room. Just as she did in the T-shirt fashion show where she was alert and clearly aware that people were talking about her, Chelsea indicated her involvement by raising her head and by her expression. As a result of her interest a link has been made with the local FE college fashion department that could lead to Chelsea attending some college sessions next year and the students designing clothes for people with PMLD.



Tim and Dave both like being outdoors. They are tenants in a first-floor flat in a house with relatively large grounds, so staff thought they might like to be involved in developing a garden. Using the sharing stories approach, Nicola and their support

staff worked with them to look at pictures, make visits and tell stories about gardens so they had a basis on which to find out about their likes and dislikes and to involve them in decisions. Dave goes to an arts group and members there also told stories about gardens. John, who likes gardening, came to supper with Tim and Dave to tell them about his garden. Tim and Dave looked at pictures of plants and gardens and were supported to make a collage of what they liked. They visited a care home's garden, where Dave liked the wind chimes and the water in the fountain. Tim and Dave visited a garden centre that wanted to donate a game for the garden. Dave tried several games and chose giant dominoes. He also chose green gloves and a green watering can. Tim wanted to buy bird seed. They have both played football in the garden and painted gnomes.

Kimmy watches his advocacy partner in a cookery session and sees how difficult it is for her to balance the bowl without a table. He is also aware that she doesn't want to get her clothes dirty. He acts on what he learns by talking to her support worker about what changes could be made (**video clip 27**).



Other peer advocates suggested that the activities at the day centre were not interesting enough for their advocacy

partners. They came up with ideas for other activities, including art sessions.

Shifting power from services to the people they support

In **video clip 36**, Nick talks about issues for organisations when they start to listen to people with PMLD and work creatively to involve them in decisions and consultation. Making sure information about people with PMLD is recorded and shared in ways that have meaning for them brings about a power shift, away from paid staff and towards the people they support. Nick also raises issues of staffing but suggests that, as with all the approaches, this is less of a problem if it becomes embedded and incorporated in the working day, and not seen as a special activity. Kate covers similar issues in **video clip 24**.



The messages for service managers in this guide and the DVD suggest that supporting staff to act on what they learn from people with PMLD has a positive impact on staff development and retention. In empowering the person, staff have also been empowered and excited by the opportunity to improve the ways in which they 'listen' to those they support. It can contribute to job satisfaction for staff working with people with PMLD and enable them to have a more exciting and rounded view of their role beyond personal care.

The evaluation report recommends that managers should use recruitment, supervision and appraisal to ensure that communication and involvement is an integral part of the role of support staff. Communication with the person should be incorporated in every area of their support and part of the culture of the service.

8. Help the person recall and share things about their life

A large part of the lives of people with PMLD seem to be lived 'in the moment'. The focus is often on dealing with current issues or personal care tasks that need to be completed, rather than reflecting on what has happened or looking forward to what is to come. Involve Me demonstrates how supporting people with PMLD to recall and share things that are important to them can enrich their lives and experiences by:

- involving people in building up knowledge about them
- sharing stories, particularly about choices, to support people to be more involved in future decisions
- recalling and sharing memories and experiences to help others understand how to support the person.

Involving people in building up knowledge about them

So much information about people with PMLD is collected in ways that have no meaning to the individuals themselves and so exclude them from the process of sharing it with others. In **video clip 37**, Nick and Kate talk about the importance of sharing

information as part of decision-making or consultation. The creative activity is just the start and can help people to recall events, experiences or people. They are then supported to communicate this information with others through film, Talking Photo Albums or other objects. When this is shared with people who can change things, it becomes consultation.



People are more likely to feel engaged in or comfortable at meetings when they can contribute in creative ways that have meaning for them. If they are not there, Nick suggests that decisions made about the person are often much more focused on the things that are important to them when information is presented in this way. When Robbie showed his creative communication film at his review, his mother felt this was their most positive meeting yet.

In Hammersmith and Fulham, peer advocates have been helping facilitators to do the preparation work for person-centred reviews. They spend time with their partners to learn about their lives and experiences and then share this with people who can change things.

At times of crisis, having a body of information about what is important to the person can help others follow the principles

of the Mental Capacity Act 2005 and make decisions that are in their best interests. It can also remind us of the things we need to try to maintain for the person if other things around them are changing.

Sharing stories, particularly about choices, to support people to be more involved in future decisions

Consciously or unconsciously, we all refer to previous experiences when faced with a decision about what to do. Stories provide something to think back to, helping us make sense of the world, and we can use them to make future decisions. Involve Me showed how sharing stories can increase the involvement of people with PMLD in choices about their garden or what they would like to do.

Sharing stories helped residents deal with bereavement. Through stories, staff were able to help them understand that two of their friends had died and would no longer be around in the home. Both were active participants in sharing stories; one helped to lead sessions and always had a story to share. The other took part through repetition, showing her awareness of the story. Everyone said goodbye in their own way and in their memorial services people remembered their stories and their personalities.

In **video clip 25** you can see how recalling and sharing a story about catching a crab in a net brings the group of residents together socially. Cath describes them as eight individuals who lived together but had nothing in common and who now interact with and reach out for each other.

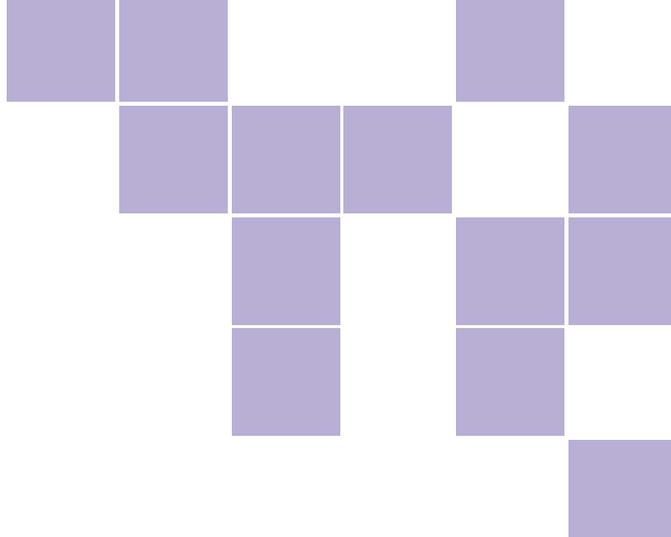
Recalling and sharing memories and experiences to help others understand how to support the person

People with PMLD are often supported by a range of different people. Each could have a different view of the person and what is important to them. **Video clip 38** shows Dave introducing us to Nazia using her film. Multimedia advocacy has been used to find out and share information about how Nazia likes to be massaged and the different sensory experiences she might enjoy. Dave uses the film to recall experiences Nazia has enjoyed, such as a sensory garden or an exhibition at the Tate Modern where she felt a hairy spider.



Robbie's film (**video clip 9**) reminds people of his sense of fun and enjoyment of the cookery session and suggests how he should be supported to get the most out of activities. It also provides a reference point for staff to see how he is enjoying other activities and to think about what they need to change to make him feel this comfortable and relaxed.



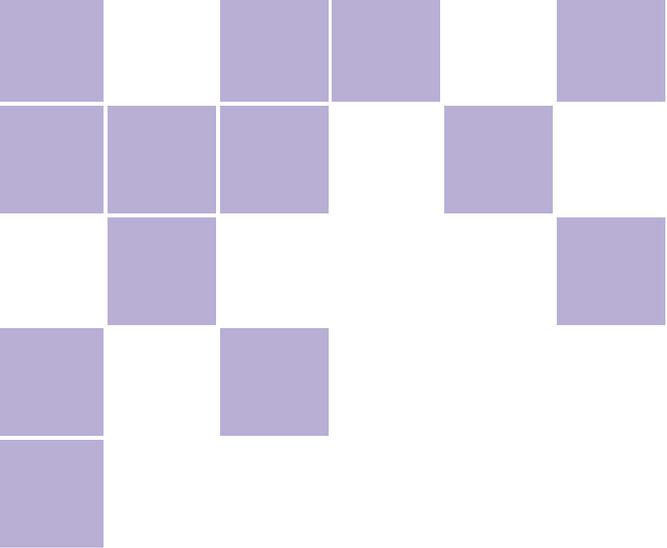


Additional material

12. Downloadable resources

These documents are available to download and print from the DVD:

- BILD advocacy fact sheet
- BILD intensive interaction fact sheet
- CALL Centre guide to using Big Macks
- CALL Centre guide to using Etran frames
- CALL Centre guide to using objects of reference
- Involve Me communication toolkit
- *Communication and people with the most complex needs: What works and why this is essential*
- *Help with managing money – if you or someone you care for lacks mental capacity*
- Information about the Involve Me approaches from the communication facilitators
- Involve Me key messages graphic
- Involve Me session plan
- Involve Me session plan – PowerPoint presentation
- Involve Me independent evaluation report
- Mencap’s guidelines on gaining consent for showing images or video clips
- Mencap’s multimedia profiling fact sheet
- Mental Capacity Act guidance on making decisions about your health, welfare or finances
- Mental Capacity Act guidance for family, friends and other unpaid carers
- Mental Capacity Act guidance for people who work in health and social care
- Mental Capacity Act guidance for advice workers
- Easy-read guide to the Mental Capacity Act (large file!)
- The Independent Mental Capacity Advocate (IMCA) service
- PMLD Network consent form
- PMLD fact sheet
- PMLD Network submission to the Joint Committee on Human Rights
- Summary of the PMLD Network response to *Valuing People Now*
- Top tips for partnership boards
- What the Involve Me approaches have in common



13. Where to find out more

Projects

Mencap's Getting To Know You project encourages self-advocates with a learning disability to become peer advocates and speak up for people with PMLD.

Sense's three-year Capacity to Communicate project provided training and information, harnessing best practice around communication and advocacy issues for people who lack capacity and have little or no formal communication, including deaf and/or blind people. The project has produced a number of resources that can be downloaded, including a summary report, advocacy toolkit and family toolkit. These (and accessible versions) are also available from the **Where to find out more** section of the Involve Me DVD.

DICE (Disability, Inclusion, Community, Education)'s I'm Creative Too project enables children and young people with complex, profound and severe learning disabilities to explore and express ideas and choices in a safe environment using art, movement, music and drama. It also aims to develop mechanisms for listening and responding to these individuals.

Openstorytellers runs book clubs, active

citizen clubs and courses for people with severe and profound disabilities, as well as training courses for professionals. Its active citizen project is designed to involve people with profound disabilities in community action and consultation.

Resources

The PMLD Network has a comprehensive list of resources with links to websites and publications.

Communication

Ockelford, A. (2002) *Objects of Reference*. Available from <http://onlineshop.rnib.org.uk>

Using Etran frames

The CALL Centre guide to using Etran frames is in the **Downloadable resources** section of the Involve Me DVD.

Using objects of reference

The CALL Centre guide to using objects of reference is in the **Downloadable resources** section of the Involve Me DVD.

www.ace-centre.org.uk
www.totalcommunication.org.uk
www.sense.org.uk

Using a Big Mack

The CALL Centre guide to using a Big Mack is in the **Downloadable resources** section of the Involve Me DVD.

Using signs and gestures

If you need to learn or check a sign, you

can find films of over 400 signs at:
www.britishsignlanguage.com

For more information see:

www.totalcommunication.org.uk
www.makaton.org
www.signalong.org.uk

Where to order communication aids

There are many different suppliers, and you can find a list at:

www.communicationmatters.org.uk

Inclusive Technology Ltd
Riverside Court
Huddersfield Road
Delph
Oldham OL3 5FZ

Tel. 01457 819 790
www.inclusive.co.uk

Liberator Ltd
Whitegates
Swinstead
Lincolnshire NG33 4PA

Tel. 01476 552 930
www.liberator.co.uk

Mental Capacity Act 2005

Mental Capacity Act booklets

The Office of the Public Guardian has a number of very useful booklets. Copies of these are in the **Downloadable resources** section of the DVD.

- OPG601 – *Making decisions ...about your*

health, welfare or finances. Who decides when you can't?

- OPG602 – *Making decisions. A guide for family, friends and other unpaid carers.*
- OPG603 – *Making decisions. A guide for people who work in health and social care.*
- OPG604 – *Making decisions. A guide for advice workers.*
- OPG605 – *Making decisions. An Easyread guide (large file!).*
- OPG606 – *Making decisions. The Independent Mental Capacity Advocate (IMCA) service.*
- *Just the facts about help with managing money: If you, or someone you care for, lacks mental capacity.*

Sharing stories

Grove, N. *The Big Book of Storysharing: at home, in school.*

Available to purchase from the Institute of Education: SENJIT (www.senjit.com)

Grove, N. *Learning to tell – a handbook for inclusive storytelling.* Charge applies: download order form from BILD website (www.bild.org.uk). Please note: This resource is not aimed at people with PMLD but at people with good verbal skills who want to become community storytellers. However, it could help staff or people with a learning disability to build their confidence and understanding of storytelling in order to support people with PMLD to share stories.

Websites

BILD

www.bild.org.uk

CALL Centre

<http://callcentre.education.ed.ac.uk/>

Changing Places

www.changing-places.org

Creative Communication

www.can-communicate.co.uk

Foundation for People with Learning Disabilities

www.learningdisabilities.org.uk

Getting To Know You

www.mencap.org.uk/gettingtoknowyou

Inclusive Technology

www.inclusive.co.uk

Liberator

www.liberator.co.uk

Mencap

www.mencap.org.uk

Openstorytellers

www.openstorytellers.org.uk

PMLD Network

www.pmldnetwork.org

The Renton Foundation

www.mencap.org.uk/therentonfoundation

The Rix Centre

www.rixcentre.org

Reading list

Department of Health (2001). *Valuing People: A new strategy for learning disability for the 21st century*. London: Department of Health.

Department of Health (2009). *Valuing People Now: A new three year strategy for people with learning disabilities*. London: Department of Health.

Emerson, E. (2009). *Estimating Future Numbers of Adults with Profound Multiple Learning Disabilities in England*. Lancaster: Centre for Disability Research.

Grove, N. *See What I Mean – guidelines to aid understanding of communication by people with severe and profound learning disabilities*. Charge applies: download an order form from the BILD website (www.bild.org.uk).

Mental Capacity Act 2005 – summary
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Bulletins/the-week/Chiefexecutivebulletin/DH_4108436

Department of Health (2007). *Making experiences count*
http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Consultations/Closedconsultations/DH_075652

Mansell, J. (2010). *Raising our sights: services for adults with profound intellectual and multiple disabilities*
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114346

Government response to *Raising our sights*
www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_124252

Mencap briefing on government response to *Raising our sights*
www.pmldnetwork.org/resources/briefing_Government_%20response_Raising_sights.pdf

The Equality Act 2010
www.equalities.gov.uk/equality_bill.aspx

Top tips for partnership boards: How to include people with profound and multiple learning disabilities (PMLD).
Available from www.mencap.org.uk

Joint Committee on Human Rights – Seventh Report.
Available from www.parliament.uk



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Bella Travis	Information and policy officer for profound and multiple learning disability	Steering group	Mencap
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Keith Smith	Chief executive	Project partner, steering group	BILD
Rachel Fyson	Associate professor	Steering group	University of Nottingham
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Evaluation			
Name	Job title	Involve Me role	Organisation
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Molly Mattingly	Assistant director, development	Evaluation	
Dr Paul Swift	Independent consultant	Evaluation	
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Jane Jones		Critical friend – Evaluation	
Jean Willson		Critical friend – Evaluation	
Victoria Willson		Critical friend – Evaluation	
Resource production			
Name	Job title	Involve Me role	Organisation
Peter Salisbury	Communications manager	Resource production	BILD
Steve Shaw		Film maker	Isha Films
Ross Clutterbuck	Independent consultant	DVD designer and programmer	BigRedBongo
Annie Lawton	Independent consultant	Practical guide author	

The Involve Me sites and creative approaches

Name	Job title	Involve Me role	Organisation
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Gaynor Roe	Community-based adviser	Site coordinator	Mencap
Amanda Henman	Partnership officer	Site coordinator	Mencap

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Cathy Birrell		Sharing stories site staff	Turning Point

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Nick Weldin		Technology consultant	The Rix Centre

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Creative communication

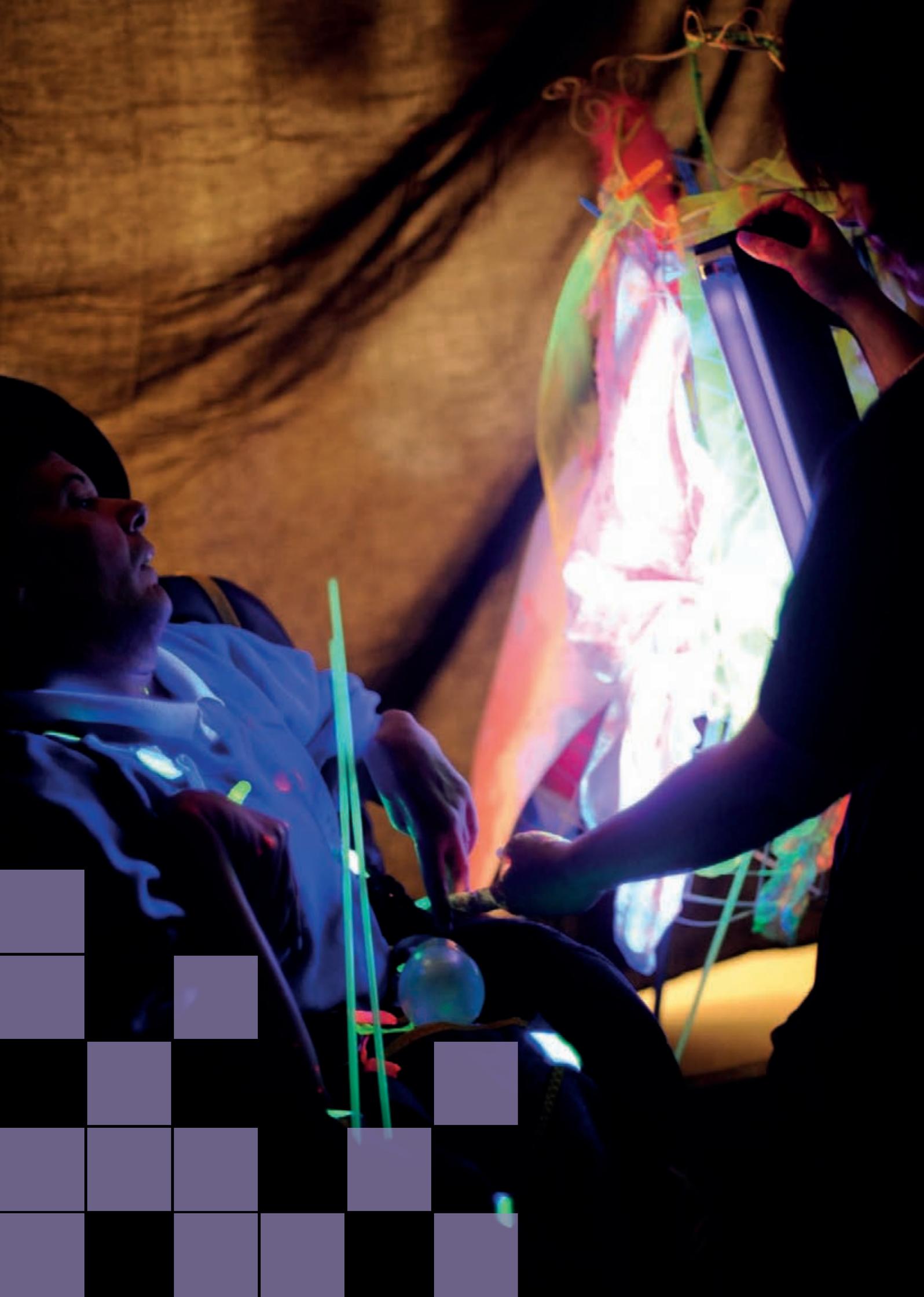
Name	Job title	Involve Me role	Organisation
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Sandra Pattinson	Unit manager		
Senga Threlfall	Support worker		
Baden Pugh	Support worker		

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Barbara Galibwa	Peer advocate	Peer advocate	
Leroy Binns	Peer advocate	Peer advocacy trainer	Mencap

And everyone else who was involved in helping us learn about peer advocacy and people with PMLD.





For further information please contact:

Mencap

Website: www.mencap.org.uk

Telephone: 0808 808 1111

Email: info@mencap.org.uk

British Institute of Learning Disabilities (BILD)

Website: www.bild.org.uk

Telephone: 01562 723 010

Email: enquiries@bild.org.uk

The Renton Foundation

Website: www.mencap.org.uk/therentonfoundation

Telephone: 01923 776 757

Email: rentonfoundation@mencap.org.uk