



Involve me

Increasing the involvement of people with profound and multiple learning disabilities (PMLD) in decision-making and consultation

Summary



What is Involve Me?

Involve Me is about ways of involving people with profound and multiple learning disabilities (**PMLD**) in decision-making and consultation.

It looks at different ways of working with people who often get left out because we find it difficult to understand their communication or worry about 'getting it wrong'.

Involve Me looks at ways to use what we learn from people with PMLD to involve them in different types of decisions about:

- everyday life and regular daily choices
- their own support and services

- community involvement with day services, house meetings or their local area
- national policy and planning for people with PMLD.

The materials pull together what we learned from people working creatively to support communication, understand preferences and involve people with PMLD.



What are the Involve Me materials?

The **Involve Me** materials consist of:

- this short booklet, which gives you a summary of the project, the eight key Involve Me messages and what's on the **Involve Me** DVD
- the practical guide, which consists of the interactive DVD with lots of information and resources, including video clips, downloadable/printable resources and the **Involve Me** film.

There is also a PDF version of the guide to download and print at www.mencap.org.uk/involveme

We will also be sharing information and updates through **Involve Me** training, our website and other events.

Words highlighted in **bold** in this booklet refer to information that is covered in more detail on the DVD, or to specific DVD sections.



What do we mean by PMLD?

In thinking about who has profound and multiple learning disabilities (PMLD), we have used the definition developed by the **PMLD Network**. It 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.



What do we mean by choices and decisions?

It can be very confusing when we think about choice, decision-making or consultation in relation to people with PMLD.

The **Choice, decision-making, capacity and consent** section on the DVD discusses this in more detail. It also talks about the importance of the key principles in the **Mental Capacity Act** for people with PMLD.

It is perhaps easier to use the word preferences to describe the things people like or 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.



Using Involve Me

Involve Me is about real people in real services and what we can learn from them. The DVD has information about the **project sites** and the **creative approaches** they used. It includes video clips of the different approaches in action and comments from people involved. The **Act on what you learn** section has examples of how a person's preferences might be used to influence bigger decisions or policy changes.

Eight key Involve Me messages came out of this work, and we hope they will give more people the confidence and tools to challenge the fact that people with PMLD are so often marginalised and excluded.

We have used these messages as headings for the different sections of the DVD, and you can download a graphic showing these from the **Downloadable resources** section of the DVD.



Who is Involve Me for?

Involve Me is for everyone:

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

We can all act on what we learn to ensure people with PMLD are more involved.

The **Key messages for...** section of the DVD draws on the Involve Me evaluation report and suggests what different people might need to think about.

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

This practical guide is designed as an interactive resource that you can dip in and out of, use in staff training or turn to when you feel in need of a bit of support or inspiration.

We understand the demands on your time and have included a **Quick start guide** on the DVD with suggestions of how to get the most from the **Involve Me** practical guide – no matter how little time you have!

Involve Me – eight key messages

Involve Me found that, whatever *approach* you use to involve people with PMLD, there are consistent messages about *how* to do this.

Things like sharing interests, having fun, consistency, interaction and staff support are an essential part of the four approaches we looked at.

The four sites and Different creative approaches sections of the DVD and **What the approaches have in common** information sheet have more information about what should underpin all approaches to involving people with PMLD in decision-making and consultation.

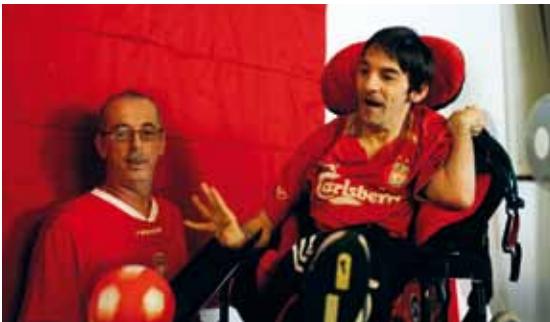
This learning is summarised in the **eight key Involve Me messages**. While it is useful to know about different approaches to involving people with PMLD, the most important thing is to ensure that everything you do is underpinned by these:



1. Know the person really well

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

- 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.



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.



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.

Involve Me provides 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.

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.

5. Be creative and try out new ideas



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 form part of an ongoing process, 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.



6. Learn from what the person 'tells' you



In each **Involve Me** site, people were interested 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 done *with* them.

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 you learn.

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 something we do continuously rather than just once, 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.

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.





What's on the DVD

1. Who is Involve Me for?
2. More about Involve Me
3. The four Involve Me sites
4. Different creative approaches to involvement
5. Policy and people with PMLD
6. Choice, decision-making, capacity and consent
7. Downloadable resources
8. Video clips and the Involve Me film
9. Know the person really well
10. Take lots of time
11. Don't make assumptions
12. Be responsive to the person
13. Be creative and try out new ideas
14. Learn from what the person 'tells' you
15. Act on what you learn
16. Help the person recall and share things about their life
17. Information about the Involve Me funders and partners
18. Where to find out more
19. The Quick start guide
20. Downloadable version of the Involve Me practical guide

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

Foundation for People with Learning Disabilities

Website: www.learningdisabilities.org.uk

Telephone: 020 7803 1100

Email: mmattingly@fpld.org.uk