

Involve Me: Increasing Involvement of People with PMLD in Decision-Making

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Louisa Whait is a national manager with the lead for PMLD in Mencap. She is managing the **Involve Me** project. Louisa has delivered training and presentations across England on the principles of **Involve Me** as well as managing the day-to-day aspects of the project. Louisa supports organisations as they start to think about how they can better involve people with PMLD in service planning and delivery.

Summary

Involve Me has a practical focus – aiming to increase the involvement of people with PMLD in decision-making and consultation. In the 3-year project, staff members who support people with PMLD receive specialist training in approaches to involving people with PMLD.

Introduction

Involve Me is a 3-year project funded by The Renton Foundation and partnered by Mencap, BILD (British Institute for Learning Disabilities) and Dr Nicola Grove. It aims to increase the involvement of people with Profound and Multiple Learning Disabilities, PMLD, in decision-making and consultation processes. **Involve Me** has a practical focus and we are working towards long-term change for people with PMLD. The PMLD Network describes people with PMLD as follows:

Children and adults with profound and multiple learning disabilities have more than one disability, the most significant of which is a profound learning disability. All people who have profound and multiple learning disabilities will have great difficulty communicating. Many people will have additional sensory or physical disabilities, complex health needs or mental health difficulties. The combination of these needs and/or the lack of the right support may also affect behaviour.

(Visit: <http://www.pmlidnetwork.org/>)

The practical element of the project is being evaluated by the Foundation of People with Learning Disabilities – led by Hazel Morgan (Associate Consultant and

former Co-Director of the Foundation). The evaluation is looking at what contribution is made by the different approaches to decision-making in different areas; day-to-day life, support and services, community provision, and national policy planning and development – and at what needs to happen to enable people with PMLD to participate.

The **Involve Me** project is crucial as people with PMLD are still amongst the most excluded from society. This project aims to show that, although people with PMLD are limited in their ability to express their opinions, choices or wishes, they can still be meaningfully involved in decisions about their lives. Their needs are not properly understood because they have complex communication needs and need specialised support in addition to what other people with learning disabilities need.

There has been positive change. The report, *Valuing People Now* (2009) (www.valuingpeople.gov.uk) highlights the need to ensure that people with complex needs, which includes people with PMLD, are included in changes to services. The Mental Capacity Act (2005) now places a legal obligation to ensure that people are not assumed to be unable to make decisions. The five basic principles of the Act are:

Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proven otherwise.

People must be supported as much as possible to make their own decisions before anyone concludes that they cannot make their own decisions.

People have the right to make what others might regard as unwise or eccentric decisions.

Anything done for, or on behalf, of a person who lacks capacity must be done in their best interests.

Anything done for, or on behalf of, people without capacity should be the least restrictive of the basic rights and freedoms.

(Visit: <http://www.publicguardian.gov.uk/mca/mca.htm>)

Preference, Choice and Decision-Making

The principles and ethos of **Involve Me** will enable a range of individuals and organisations to evidence how they have involved someone in a decision which affects them. Staff members are being actively encouraged to reflect on their own experiences and not let mere presumptions about any individual influence the experiences they offer them. For example, an attitude might be, 'This person hates coffee, they have always hated coffee so we will not give them coffee.' Instead, we are encouraging such questions as: Were different types of coffee tried? Was sugar used? Was it with or without milk? How long ago is it since the person tried a cup of coffee? Also, experiences should not be discounted for ever because our tastes change with time.

In order to effectively involve people with PMLD in decision-making it is important to be clear on the various components that contribute to it. Indicating preference, making choices and decision-making are interlinked and hierarchical – decisions are made from a range of choices based on preferences. Preferences tend to be unintentional and reactive. Making choices involves more intentional behaviour and has consequences – although they are short-lived. Decisions are much more concrete and long-lasting.

For many people with PMLD the opportunity to try out new experiences and re-visit old ones are limited. As a consequence, little may be known about their preferences which in turn inhibits the suitability of options offered and then influences how decisions are made.

What we know about how people communicate can help identify what preferences people have. A person may show strong positive reactions to lights. The reactions may be stronger with coloured lights or fairy lights. It is reasonable then to suggest that the person has a preference for lights. This preference can then inform the design of the person's bedroom and indicates a need for service providers to ensure the person has access to light-related activities. Options can be tried in different situations. It is important not to overload any person with things relating to one observed preference.

The Approaches Used

Involve Me is using a number of different approaches to working with people. All the approaches are centred around and led by the individual. Each of the approaches explores people's preferences and enables individuals to communicate them.

The approaches focus on communication and use the person's existing method of communication. Each approach promotes or supports choice, enables the development of relationships and is fun, interesting

and engaging. Each approach encourages creative listening, respects the person's own way of communicating and provides ways of collecting information in a way in which the person has control. An activity relating to each approach may last only five minutes or half an hour depending on how long the person wishes to engage for.

The experience of sharing information can be built up from working with someone who the person knows well. This could include an activity of sharing photographs. After that, with the person present, the same photographs are shared with a group of people the person knows well, then with a group the person does not know so well and finally, if appropriate, with people the person does not know at all. At each stage, the reaction of the individual is monitored. If they start to indicate that they are unhappy with the photographs being viewed the session is stopped. This stepped approach gives the individual some control over who has access to various aspects of their life.

The project is using the following four approaches:

1. Storysharing™
2. Multimedia Advocacy
3. Creative Communication
4. Peer advocacy

The facilitator of each approach is very experienced in the approach. Each approach has been selected on the basis that they are known to work and enable the engagement and communication of people with PMLD. The core principles of involving people with PMLD have been derived from analysing what the approaches have in common.

1. Storysharing™

Storysharing™ in **Involve Me** is facilitated by Dr. Nicola Grove. Nicola is the Director of Unlimited Storytellers. Nicola is a speech and language therapist and storyteller who has worked for over 30 years with people who have severe and profound disabilities. She is trained in sign language and the use of total communication.

We learn who we are by remembering and sharing what happens to us. People with severe and profound disabilities may not be able to do this for themselves but, if we can create some support systems, maybe they will remember the experiences they have enjoyed, or learn to deal with past experiences that are painful. Storysharing™ is based on a particular theory about the way in which narrative develops in childhood. The basic principles are that:

1. Stories are created around unexpected – or at least, non-routine – events
2. Emotion and feeling lie at the heart of the story

3. We learn to tell stories by participating in the act of storymaking and storytelling
4. We tell stories collaboratively with others – and at first, adults “scaffold” storytelling with children, by accepting and extending their contributions
5. Personal stories are repeated over and over again – we actively craft these little tales and roll them out at every social opportunity. This gives plenty of opportunity for practice.

Storysharing™ looks for what the person can put into the story and then scaffolds the story with the person, often in a group. A multisensory approach is used with props, music, and basic communication aids.

2. Multimedia Advocacy

Multimedia Advocacy in **Involve Me** is facilitated by the Rix Centre, a charitable organisation committed to realizing the benefits of new media technology to transform the lives of people who have learning disabilities.

Multimedia Advocacy uses digital photography, video, audio and computers to help people with learning disabilities to communicate more effectively. Using these tools they are able to articulate and express their preferences, choices, likes and dislikes, and have more of a say in how they are supported. In this way they can participate more actively in their communities. The Multimedia Advocacy process provides a framework for professionals and service users with learning disabilities to work together with friends and families, learn from each other and improve the exchange of information.

Multimedia Advocacy is a way of framing, organising, and implementing good advocacy practice. It provides a method for organisations to review the support that they provide and helps them to deliver services that are genuinely person-centred and inclusive. Multimedia Advocacy improves the quality of service provided for people with learning disabilities and frequently promotes positive cultural change for support organisations in the process.

3. Creative communication

Creative communication in **Involve Me** is facilitated by Kate Burns of CAN Communicate and Doncaster Advocacy. CAN Communicate is a training and consultancy organisation lead by Kate who provides training and consultation about how to listen to people who do not use traditional communication methods. Creative ways are used to establish an individual’s current communication skills, for example, how someone demonstrates happiness. A wide range of creative methods are introduced to individuals and their supporters such as art, music, movement & dance, drama, puppetry, film & multimedia and sensory activities. Any method the individual responds to is developed

further and adapted to suit their particular communication needs. Through user-led training and workshops the people in the individual’s life understand, respect and use this communication.

4. Peer advocacy

Peer advocacy in **Involve Me** is facilitated by Hammersmith and Fulham Mencap.

People with learning disabilities can use their experience of receiving services to speak up for people with PMLD. In the **Involve Me** project, a group of self-advocates are receiving support to advocate for partners with PMLD and to use their experience to provide a training resource for other peer advocates.

Training

Staff members at the sites that are taking part have had training on the aims and objectives of **Involve Me** and on communication with people with PMLD, and a day that provided an overview of the approach they are going to use. The facilitator of each approach then supports each site with additional training and workshops to support and encourage staff to use in their everyday practice the techniques they are learning.

Involve Me is looking at how we can develop a better understanding of who people are and their preferences and this will enable us to ensure people are involved in decisions which affect their lives. Common personal experiences can give important lessons for how services are planned and delivered. We will be producing an interactive DVD and an accompanying training guide based on the experiences of everyone who is part of **Involve Me**. People with PMLD and their supporters will be filmed while using the approaches to show real life practical examples of how they work in practice. We feel that not enough people know about different ways of communicating with or speaking up for people with PMLD. **Involve Me** and the DVD are intended to help with this.

For more information:

Involve Me

<http://www.mencap.org.uk/page.asp?id=12584>

BILD www.bild.org.uk

Unlimited Storytellers

www.unlimitedstorytellers.org.uk

Can Communicate can_communicate@yahoo.co.uk

Rix centre www.rixcentre.org

Hammersmith and Fulham Mencap

www.mencaphf.org.uk

PMLD Network www.pmldnetwork.org.uk