Involve me

Independent evaluation report

By Foundation for People with Learning Disabilities
Acknowledgements

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Executive summary

Introduction

The aim of Involve Me was to explore how people with profound and multiple learning disabilities (PMLD) can be involved and consulted in creative ways about decisions that affect their lives. Four sites took part in the project. A different creative approach to involvement was used at each one.

The participants were supported to express their wishes and to be involved and consulted not only in decisions about everyday matters (for example, what to wear, what to eat and drink, daily activities) but also in decisions that would have a wider impact – on services and policies locally. It was hoped they would also get the opportunity to influence national policy.

Impact of Involve Me

Participants

Participants have been able to express their likes and dislikes in creative ways and to be involved to varying degrees in decisions and consultations about their lives. Sometimes the changes have been the result of people spending time with them and observing their expressions, sounds and body language and were not the direct result of the particular creative approach. Additional communication tools, such as the Big Mack and Talking Photo Albums, have enabled participants to express themselves and helped some to be involved in decisions.

The project demonstrated the importance of appreciating the uniqueness of each individual and of finding the best way of communicating with each person.

Participants have been involved in creative ways in decisions that have brought changes in everyday matters and how they spend their time. They are gaining in confidence and some are gradually participating more. Directly or indirectly they have begun to influence services and policy, but this is at an early stage. This takes time and is ongoing.

Staff

Staff working on the project were enthusiastic about adopting innovative approaches. They were also keen to hear what people were saying without words and to translate their wishes into actions that would have an impact on their lives. This has contributed to job satisfaction and enabled staff to have a more exciting and rounded view of their role beyond personal care.

Families

Parents, siblings and other family members have welcomed initiatives that they hoped would improve their relatives' lives. They have wanted others to see their family member as they themselves see and understand them. They have appreciated opportunities to work in partnership with staff.

Peer advocates

Peer advocates have learned about communicating with people with PMLD and have a better understanding of their lives. They have increased in confidence and are telling people about peer advocacy and what they have learned about the needs of people with PMLD.
Services

Involve Me has worked particularly well where management is actively engaged in supporting the project. The sites now have more resources for communication, which should increase involvement in decision-making. Services are placing greater emphasis than they did previously on involving people with PMLD in decisions and consultations and have begun to change internally, with a shift towards empowering people with PMLD.

A wider impact

The project sites have started to influence some other services and policy-makers locally – through learning disability partnership boards, for example. To date it has not been possible to involve people with PMLD in national decisions and consultations, but there is potential for this to happen in the future using the learning from the project.

Challenges

Understanding the Mental Capacity Act 2005

Ongoing reference by managers and staff to the Mental Capacity Act 2005 is more limited than would be expected, given the act’s centrality in decision-making for those who may lack capacity for a particular decision, whether large or small.

For service managers

Sites were affected by reorganisation to varying degrees. Low expectations needed to be challenged. There was also some scepticism about some approaches initially, but this was overcome as understanding grew.

It is helpful to have continuity in staffing so that strong communication partnerships are established. Health issues affected some staff, peer advocates and participants. Staff shortages meant that staff could not always be available for one-to-one support or released for training. Often, training had to take place while working with participants. This had some advantages because it demonstrated what could happen, but it did also mean there was insufficient time for reflection.

It was problematic for some managers to find the time to understand the approach and consistently give support to frontline staff. Yet their continued involvement amid their busy schedules will ensure that the voices of people with PMLD are heard across their services and that the values underpinning Involve Me are upheld. It can be difficult for services to find the time to engage with family members, friends and support staff in other services to share learning and achieve a consistent approach.
For staff

Staff needed to be aware of the dangers of making assumptions about a person’s preferences. They also needed to have the confidence to adopt new approaches; using technology was a barrier for some. It was important that staff understood the underlying values of the approach, and of the tools, so they used them appropriately. All staff members needed to be similarly motivated.

Staff were often unable to find the time to record what was happening to share with others, which meant that continuity of approach might be difficult to achieve. After using creative ways to find out about people’s preferences in a way that is appropriate for them, the challenge is then to enable people to have the real experiences in the community which they have indicated that they might like.

For a peer advocacy service

It can take time to set up a service from scratch. It can be a challenge to find a way of working with advocacy partners that enables them to meet with their peer advocates in a variety of settings. When peer advocates represent the wishes of advocacy partners it will be important to establish how they too can be engaged in a way that is appropriate and in an environment that is comfortable.

External challenges

There were obstacles in the local environment that created barriers to the implementation of wishes expressed by participants. These included buses that were not accessible for people in wheelchairs, transport arriving late, a lack of Changing Places toilets and lack of access – for example, a building where a lift was not working. Public attitudes could also be a barrier – for example, bar staff refusing to serve someone and bank staff appearing disparaging when asked about opening an account.

Overview of recommendations

The 16 recommendations on pages 8–10 are based on the evaluation of the contribution of Involve Me to enabling people with PMLD to be involved in decision-making and consultations in creative ways, and on the identification of the challenges in making this happen.

The recommendations aim to ensure that involving people with PMLD in decisions and consultations about their lives is accepted at all levels. They are directed at government departments and agencies, local policy-makers, services, advocacy organisations and staff. Listening to what people with PMLD are saying without words in imaginative and creative ways enables those who work directly with them to involve them in decisions about their daily lives. Those making policy locally and nationally need to be willing to spend time with people with PMLD and those who support them, to find out about their wishes so that they are involved directly and indirectly in wider decisions and consultations that affect their lives.
Recommendations

The evaluation of Involve Me has shown how people with PMLD can be involved in creative ways in decisions and consultations. This gives insights to those who support them, service providers and those who work at a strategic level. They can then act on these recommendations to improve the lives of people with PMLD.

Government departments

1. Government departments should 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.

2. Government departments should ensure, in their consultations and in developing initiatives, that they take notice of the wishes of people with PMLD. 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 (DH) should ensure that the importance of involving people with PMLD in decisions about their lives is emphasised in its ongoing guidance about the personalisation agenda.

The Equality and Human Rights Commission (EHRC)

3. The Equality and Human Rights Commission should 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, it should consider how people with PMLD can be involved in demonstrating the barriers they experience in everyday life.

The Care Quality Commission (CQC)

4. The Care Quality Commission should ensure, in its focus on involvement, that it uses the learning from Involve Me about supporting people with PMLD to have a voice. It should ensure that the services it regulates do the same.

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

5. 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.

6. Commissioners and providers of services should ensure that these 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.

7. 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 that 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)

8 Service managers should use the learning from Involve Me to prioritise listening to the voices of people with PMLD in creative ways, both to find out about each individual’s preferences and to aggregate the learning to inform the development of their services. It should be part of the overall culture.

9 Service managers 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, using the learning from Involve Me.

10 Service managers should note the satisfaction shown by staff in Involve Me in enabling those they support to express their wishes, likes and dislikes. They should use supervisions, staff meetings and training to encourage staff to find creative ways to engage with those they support to enable them to be involved in decisions and consultations.

11 Service managers should ensure that focusing on communication is an integral part of the role of support staff, and that communication is incorporated in all aspects of each person’s support and embedded in the culture of the organisation. They should prioritise investment in communication training that includes using creative approaches.

12 Services should 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. They should take advice about what is appropriate for each individual, recognising that communication aids are part of an overall approach to communication.

13 Service managers should 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. They should seek the necessary training and guidance. This should also be offered to families and others who know and care about the person.

14 Services should work in partnership with families and others who know and care about the person to learn from them about the person’s individual ways of communicating and their likes and dislikes. These should then be recorded and used to achieve 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

15 Staff should communicate consistently with those they support in the course of personal care and other activities, enabling people with PMLD to express their wishes in a two-way communication. They should also take the time to find out in creative ways each person’s wishes for different aspects of their life.

Advocacy services

16 Advocacy services should plan to establish peer advocacy, to contribute to providing a service that caters for people with PMLD. They should ensure that they have 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.
1. Introduction

The Involve Me project

Involve Me is a project that considers how to involve people with profound and multiple learning disabilities (PMLD) in decision-making and consultation. Using four creative approaches, the emphasis has been on how people can be involved and how this involvement leads to an influence on decisions. People with PMLD have been supported to express preferences that can have a direct outcome for them personally. Sometimes they have been involved indirectly, and those ‘listening’ to people with PMLD sensitively are then better placed to ensure wider decisions accord with their wishes.

People with PMLD and staff in four pilot sites have taken part in the project. Each site focused on one of the following creative approaches to involvement:

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

People have been supported to communicate in a way that best suits them. The sites have also been given communication tools that may be useful to some individuals, such as the Big Mack and Talking Photo Albums.

Why the project focused on people with PMLD

The definition of PMLD used in this project was developed by the PMLD Network:

People with profound and multiple learning disabilities:

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

People with PMLD are among the most excluded in our society. There is continuing evidence that this is the case:

• The Joint Committee on Human Rights reported that in the evidence it received from people with a learning disability, ‘even those who felt that they had a say in decision making themselves felt that “people who have complex needs often do not because people do not know how to communicate with them”’. (People with PMLD are included in the definition of complex needs.)
• Professor Jim Mansell, in his report Raising our sights, received evidence from families of ‘prejudice, discrimination and low expectations’.

The Involve Me project was expected to show how people with PMLD could have more say over what happens in their lives.

Rationale behind the project

It is estimated that there are just over 16,000 people with PMLD in England. They may be at different points in developing communication: most have no meaningful speech and very limited
or no understanding of words. Some express themselves through their reactions, some make choices between two or three options and others are able to make some decisions, particularly on everyday issues. Through communicating with each individual in a way that is appropriate for them, it should be possible to find out their likes and dislikes and to involve them in decisions and consultations.

Over recent years, many people with a learning disability have been able to make more decisions about the kind of lives they want to lead. In contrast, people with PMLD have had few opportunities to influence what happens for them. They are rarely involved in self-advocacy groups, in having a say in their services or in local policy through membership of learning disability partnership boards and do not participate at a national level through the National Forum of People with Learning Difficulties. It is therefore crucial to find ways in which they can be involved. They need to be listened to as they are supported to show their likes and dislikes in creative ways, whether they are communicating their own particular needs or information that can be used to influence services and policy locally or nationally.

Progress has been made over recent years in thinking about creative ways of enhancing communication, with a focus on creating communication partnerships through:

• recognising ways in which people are already communicating
• finding ways of communicating that meet individual needs: using gestures, facial expression, sounds, sense of smell, photos, pictures, objects of reference, signs and symbols, and drama and art
• harnessing technology to enable people with PMLD to express themselves
• ensuring the environment in which the communication takes place is favourable – for example in a place and at a time that is comfortable for the person.

The policy and legislative framework

• It had been expected that all people with a learning disability would benefit from the principles of rights, independence, choice and inclusion in Valuing People. This was not the case for many people with PMLD. This failure was recognised in the consultation Valuing People Now.6
• In 2009 the three-year strategy Valuing People Now7 prioritised people with complex needs. This strategy aims to be ‘inclusive of those groups who are least often heard and most often excluded’.
• The report Raising our sights8 points the way towards personalisation. It argues that this is the way for people with PMLD to get the individual support they need. Involve Me was expected to have a different focus in its exploration of the ways people can be involved in decisions and consultations and have influence over what happens in their lives.

With reference to legislation, the key principles of the Mental Capacity Act 2005 include the following:

• All adults should be assumed to be able to make a decision unless it can be shown that they are unable to make it.
• A person should not be considered unable to make a decision before all steps possible have been taken to enable them to make that decision. The person should be in surroundings where they feel comfortable. The information should be provided in a way that the person prefers, such as in pictures or photographs, or using sign language.

• An action or decisions made on behalf of someone who lacks capacity must always be in their best interests.

If someone is assessed as unable to make a particular decision, they should be involved as far as possible in making the decision. The Mental Capacity Act 2005 covers everyday as well as bigger decisions.

In addition, Article 8 of the Human Rights Act 1998 sets out the right to respect for private and family life, home and correspondence. This means people with a learning disability should not face restrictions on making personal choices and decisions – for example about day-to-day activities and participation in recreational activities and community life.

Meanwhile, the Equality Act 2010 targets discrimination.

The evaluation

The evaluation asked:

• What contribution is made by the different approaches to involvement in decision-making?

• What are the barriers/challenges to enabling people with PMLD to participate and be involved in decisions in the different areas? (These could be in everyday decisions, decisions about support and services, and decisions about the local community or national policy – either directly or, in the case of local or national policy, indirectly.)

This is not an evaluation of the different creative approaches. (See appendix 1 for evaluation guidelines for the sites.)
2. The four sites

Overview

At four sites in England a small number of people have been supported to express their wishes in different ways. It was planned that there should be between six and eight participants at each site. It was clear from participants’ profiles and baseline visits to all the sites that the participants used a range of non-verbal approaches to communicate. Some could say a few words and use some signs, and may be on the borderline of being described as having PMLD. Most had no speech and communicated mainly through facial expression, body language and sounds. A few could make some everyday choices; some could select from two or three options; others expressed preferences through their reactions. Generally, participants were involved in decisions about things such as food or sometimes clothes. Some were involved in decisions about activities and leisure, such as holidays. Their supporters hoped that being part of Involve Me would give participants more say over their lives.

At three sites the project was scheduled to run for between nine and eleven months:

- a local authority day centre
- the service provider
- the advocacy scheme.

At the fourth site, the multimedia centre and a day opportunity provider, the work was scheduled to run over five months.

A local authority day centre – creative communication

Creative communication

This approach is the use of creativity to enhance and develop communication and consultation. Individuals and their supporters are introduced to a wide range of creative methods, such as art, music, movement and dance, drama, puppetry, film, multimedia and sensory activities.

Any method the individual responds to is developed further and adapted to suit their particular individual communication needs, by creating effective communication tools to support inclusion (see appendix 2a).

The Coronation Centre is a local authority day centre in Ellesmere Port. It had recently used photography, drama and other media as a way for people to express their feelings and wishes. It was keen to be part of Involve Me, pioneering creative communication in the setting of a day centre. At the centre, five participants have used creative communication to tell others about their preferences.

Kate, the facilitator, introduced the approach to staff and participants. After several sessions introducing different ways of communicating creatively, she found it was best to work with each of the participants in a designated session and a follow-up session. She focused on the interests of each individual, engaging them in expressing their preferences in creative ways. At least three other participants were usually involved. Each individual was to
have a Talking Photo Album, a short film and an item that related to their session, such as a piece of art or object of reference. These items allowed each individual to be able to tell their own story in a way that is creative and unique to them. Those listening were able to understand what is important to the person, not only through the items but also by seeing the person’s reactions as they watch the film with them and engage with them in looking at the Talking Photo Album and other items.

Tanya is a young woman who likes sensory experiences. In discussion with staff who support her at home, it was suggested that Tanya might enjoy a session in a white room including butterflies, feathers, lights and projected images. Tanya liked the feathers, particularly when dropped onto her from behind, giving an element of surprise. Kate 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. Taking this as an indication that she wanted the blowing of feathers to continue, Kate resumed. This was thought to be a new sound for Tanya and an intentional one that, it is reported, she has continued. Tanya now has a film, a Talking Photo Album and a sensory box so she can tell others about her preferences. In the box are things she enjoys, including butterflies made from silver paper in which she can catch her reflection, a mirror, feathers and chimes. She and a staff member went to a learning disability partnership board outside her area with her film to show them how creative communication works. This enabled the board to see how she valued communicating her likes, and how people can then listen to her.

Being part of Involve Me has had a significant impact on Tanya’s life. It was working with Tanya that provided “the biggest learning curve for staff” (day centre manager). Through her creative session it became clear that Tanya likes surprises. Previously it had been thought that she liked peaceful activities – ‘soft things’ – but she enjoyed a noisy, active music session designed for another group member. If Tanya became upset it had been thought that she was in pain; it has become apparent that she was expressing boredom. It is important to build on these experiences and staff are now considering how Tanya could attend an event involving hot air balloons. She has also shown by her body language that she likes being supported by young women who share her love of fashion.

The service provider – sharing stories

Storysharing™

This approach is about sharing stories about the experiences of people with PMLD and what is important to them. Stories are shared in a group in a sensory way with objects and sounds, and the person with PMLD is supported to join
in. Storysharing™ enables people to remember together, entertain, make links with other people, make sense of the world, create meanings, create a shared history and develop an identity. By being involved in sharing stories, particularly about choices, people are better equipped to be involved in future decisions (see appendix 2b).

Sharing stories is an integral part of our communication as human beings. It is how we learn about one another, make sense of our experiences and have a basis on which we can make future decisions. How can this happen for people who do not use words? Nicola, the communication facilitator, has pioneered Storysharing™ for people with PMLD, and Turning Point, a service provider in Salisbury, agreed to participate.

There were three locations:

• Two participants, Tim and Dave, were in supported living.

• People from a residential home also took part. Initially two, Josh and Katie, were involved. Subsequently all eight people in the home were supported to engage in sharing stories as a way of identifying what is important to them, to inform future decision-making. Two of the people in the home used words and were ‘story catchers’ in the sessions, helping their friends to tell stories together.

• Additionally a weekly arts group of about 12 people supported by Turning Point in various residential settings locally has engaged in sharing stories. Some of this group also used words.

Nicola and staff have supported people to tell stories about a range of incidents and events, which may increase involvement and participation. Telling stories may in turn enable people to be more involved in making decisions about their lives. For example, it was hoped that creating activities and telling stories about shopping and exchanging money for goods would be translated into greater understanding and involvement for people when they go out to buy things.

Tim and Dave both like being outdoors. As they are tenants in a first-floor flat within a house in quite a large piece of ground, staff thought they might like to be involved in developing a garden. Nicola, and Tim and Dave's support staff, worked with them to look at pictures, make visits and tell stories about gardens, to create a basis on which to find out about their likes and dislikes and involve them in decisions. Dave goes to the arts group, where members told stories about gardens, and came to supper with Tim and Dave to tell them about his garden. He also went around their garden with them to help them decide what was rubbish, so they could take it to the tip.

Tim and Dave looked at pictures of plants and gardens. They were supported to make a collage of what they liked. They visited a care home’s garden and Dave liked the wind chimes and water in the fountain. Tim and
Dave visited a garden centre that was going 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 birdseed. They have both played football in the garden and painted gnomes.

Through looking at pictures, making visits and sharing stories about gardens, Tim and Dave are in a better position to indicate their preferences and make choices about what is grown in the garden. The decisions about what they would like in the garden are not just theirs; they have met with tenants in the two other flats to talk about ideas. Turning Point is planning the landscaping but will arrange for the designer to meet with them to find out what they like.

The multimedia centre and a day opportunity provider – multimedia advocacy

Multimedia advocacy

This approach involves the use of digital photography, digital video, microphones, computers and assistive devices (for example switches and different types of keyboard) as tools to capture people’s communication, preferences, choices, likes and dislikes. The multimedia advocacy process offers the opportunity for staff and people with disabilities to work together, learn from each other and document the day-to-day life of the person. Together they make person-centred plans that celebrate achievements and communicate choices, aspirations, likes and dislikes.

Multimedia advocacy is a way of framing, structuring and implementing good advocacy practice. As such, it provides a method for organisations to review their support for people and help deliver services that are person-centred and inclusive. Multimedia advocacy work thus frequently represents a cultural change for service provider organisations (see appendix 2d).

(Information from the Rix Centre.)

This site was a late addition to the project when another site withdrew. It is a partnership between the Rix Centre and Eastway Care, which provides day opportunities in four sites in London. Wayne and Michael and their supporters have completed a 12-week course on multimedia advocacy at the Rix Centre. People with a learning disability attend on alternate weeks. Wayne and Michael have been supported to complete the portfolios they started at the Rix Centre during their day activities at Eastway Care and to continue using multimedia approaches. They have been visited several times by Gosia from the Rix Centre, to provide additional support. A third person subsequently joined the Involve Me project.
Wayne was already involved in decision-making on a daily basis – for example choosing his food and drink, or indicating if he wished his support worker to help him phone his parents. At the Rix Centre he and his support worker engaged in developing his life story and photo stories so he can communicate with others about his likes and dislikes, choices and preferences. He indicated pictures he wanted to include and people he wanted to feature in his portfolio.

Wayne uses *talking mats* and objects of reference, such as his phone. He has been able to press the yellow button as his support worker moves the cursor on the computer. He enjoys using the microphone and headphones. When the course finished, Wayne was supported to complete his portfolio at his day centre, so that people can understand his current preferences and help him to plan his activities accordingly.

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**The advocacy scheme – peer advocacy project**

**Peer advocacy**

The defining factor in peer advocacy is some sort of shared experience. In this context, peer advocacy is where one person with a learning disability advocates for another person with a learning disability. For Involve Me, it is about advocating for a person with PMLD and is influenced by the work of Mencap’s *Getting To Know You* project (see appendix 2c).

At Hammersmith and Fulham Mencap, advocacy is well established, but the organisation had not developed a peer advocacy scheme. Involve Me provided the opportunity to establish one.

Peer advocates and their advocacy partners communicated in a range of ways – for example, using body language and facial expressions.
“You know where they’re coming from... You know at first hand what the problems are... You know at first hand what it is like having a learning disability.”

(Leroy Binns, peer advocate and campaigns assistant, Mencap)

Alexa was recruited to set up a peer advocacy scheme. The process of setting up a new service has been challenging, taking longer than originally planned. There has been considerable learning from this ‘pilot phase’. Over recent months Alexa has been working with five peer advocates recruited from the borough. She has supported them in advocacy partnerships with several people who attend a day service. During this phase the advocacy partners have met the peer advocates there. The exception is Jonathan, who was supported by a day service outreach team.

Jonathan’s peer advocate was Martin, who has described his meetings as “joyful” and “good fun”. He continues to find out how Jonathan likes to communicate: “Jonathan smiles and reacts. I’m learning, still learning”.

Martin was initially supported by Alexa but now goes to see Jonathan independently. They have met at his family home and at his respite centre. He also hopes to visit Jonathan at college. The activities Martin and Jonathan have engaged in together include swimming, going to the park, listening to music and bowling.

Martin was invited to attend Jonathan’s review. As a result he is going to support him in more social activities in the evenings. Martin said he will “gladly support him”, adding that “[Jonathan] seemed to like that idea”.

Martin has been learning about Jonathan’s preferences. Jonathan can gain wider experiences and have a friendship with Martin as a result of the peer advocacy project. This has the potential to develop. In the future Martin may be able to speak up for him on wider issues.
3. Impact of Involve Me

Impact on participants

Through the introduction of different creative approaches to involvement, participants have been able to express their likes and dislikes to varying degrees.

Participants have been able to reveal more of their personalities, likes and dislikes to those who support them. This is leading to changes in their lives. For example, some staff at the Coronation Centre have learned more about Robert. His designated session focused on cooking and his love of food. He chose the drink for the recipe for his bread. He showed a great sense of fun, which was communicated to others who saw his film. Robert has one-to-one support and so is not known by all staff.

“[It was] so nice to get on film how happy he can be and what good company he can be...”
(Staff member)

Robert has indicated that cooking is something he enjoys.

Being able to express preferences has led to changes in people’s lives and enhanced their wellbeing.

Terry’s designated session at the Coronation Centre focused on his love of football. He was then involved as the centre manager wrote a letter on his behalf to Liverpool Football Club with photographs of the session to demonstrate his interest. Terry received a certificate for being a ‘Number 1’ fan and a signed photograph. He has been involved in many conversations in the centre about being a fan and plans to go to football matches. Creative communication was the catalyst for taking action.

At Eastway Care it has been shown that multimedia approaches can enrich a person’s life and give them more control if, for example, they can use a switch to activate a video or music.

There have been changes in everyday matters and how people spend their time.

A young woman who attends Eastway Care has also attended the Rix Centre and is being supported to develop a portfolio. Recording her life in different environments highlighted an inconsistency in how she took her drinks – on a spoon or from a cup. She is now always being offered a cup as she seemed to prefer this.

In Salisbury, sharing stories and looking at pictures in holiday brochures contributed to making a decision about going on holiday. Josh and two of his housemates went to Eurodisney. Dave went to a seaside resort in Dorset. Tim was supported to apply for a paid cleaning job at a day activities centre. Telling and recording in photos a story about cleaning helped in planning his interview. He took along a photograph of himself voluntarily vacuuming up a pile of dust that had been spilt on the carpet. This demonstrated his ability to meet the job requirements.

Some approaches were more suited to one person than another, and sometimes were adapted to increase involvement.
Michael is a young man who enjoys swimming and hydrotherapy, music, television and being around his friends.

In the multimedia advocacy course at the Rix Centre, intensive interaction was used to help develop his communication. It enabled him to instigate communication. The focus has been on supporting him to make the connection between cause and effect using pre-recorded switches. The Big Mack gave him the opportunity to engage with a sound that he could activate himself. In time it is hoped that he may be able to use this to indicate ‘yes’ and ‘no’. In partnership with Michael and his family, his support worker is creating a portfolio during sessions at Eastway Care and reading the words to him. Michael has learned to use switches to play music and the microphone to vocalise.

Additional communication tools have enabled participants to gain attention and helped them express their wishes.

Additional tools were used widely. For example, Richard’s creative session was built on his love of horses. It involved using sounds, and Richard had a Big Mack with the sound of horses’ hooves recorded on it. He used the Big Mack to gain attention and this meant he was more involved with others in activities in the Coronation Centre.

The Big Mack has also helped those in the home in Salisbury to participate in meetings and to be involved in bigger decisions. Josh took part in his review of where he lives and, by using the Big Mack and body language, indicated that he wanted to remain there. Tim and Dave have also been supported to use Talking Photo Albums to communicate their experiences and what they like.

Sometimes the changes have been the result of people spending time with participants with PMLD, and observing their expressions, sounds and body language, and not the direct result of the particular creative approach.

One of the most striking examples was provided by Chelsea at the Coronation Centre. Chelsea indicated that she liked being with men when she had a young man to support her and when she was out and about. She showed this through raising her head and being alert. She now has male support for some of her activities. It was because of the focus on people with PMLD that her likes could be established.
People are gaining in confidence and gradually participating more.

This has been particularly apparent with two people in different sites who like to be on the periphery. The changes for Robert at the Coronation Centre are small but significant. Unlike his fellow participants he had his session on his own, with his supporters, as he does not like being with many people. However, through the project he has at times demonstrated a willingness to be included on the periphery of events (for example, at a coffee morning for family and friends halfway through the project), which is a step forward for him.

Katie, in the residential home in Salisbury, often remained apart – an observer. Gradually, she began to engage sometimes. For example, she joined in the activity about shopping to an extent that surprised her support staff.

Others have shown their films at external meetings, which has enhanced their confidence.

Directly or indirectly, participants have begun to influence services and policy but this is at an early stage. In all sites Involve Me is expected to be ongoing.

Participants have been involved in influencing services and policy to a small extent. Ways of influencing services take time to develop. At the Coronation Centre, commissioners and local councillors, along with family, friends, supporters and professionals from other organisations, were invited to a sharing event where they saw participants showing their films and could observe their reactions. This enabled those present to learn what is important to people with PMLD and to think about how this might affect how they configure services.

“It was a real eye-opener.”  
(Local councillor)

Tanya’s reactions expressed her pleasure at being able to communicate what she likes.

Impact on support staff at sites

Staff have been pleased to be able to improve the ways in which they listen to those they support, using their site’s approach. This has contributed to job satisfaction and enabled staff to have a more exciting and rounded view of their role beyond personal care, in enabling people to have more say about their lives.

Staff have welcomed the opportunity to interpret what they know of a person, check this out and either have it validated or find a new way of seeing what the person likes.
“It makes you think more.”
(Staff member at Coronation Centre)

“A massive success”; “I jumped on board – it’s fantastic”; “[Using the Big Mack is] very inspirational to me.”
(Staff in the home in Salisbury)

Staff in supported living said they are moving beyond “respectful guesses”. Several showed a keenness to empower the people they support.

“Everything with stories is going to help identity and growth. Once you talk about what has happened you increase their sense of power.”
(Staff member)

Staff involved in the project at Eastway Care had an interest in multimedia approaches but the course introduced them to further possibilities and ways of using technology.

“A video says a million words.”
(Staff member)

Impact on families and support staff from other settings

Families have welcomed initiatives that they hoped would improve their relatives’ lives.

Wayne’s and Michael’s families attended their graduation from the course at the Rix Centre. Michael’s family has been actively engaged in the development of his portfolio so that clips of his home life could be included.

Jonathan’s mother has welcomed his friendship with peer advocate Martin.

“Martin can come whenever he wants.”
(Mother)

Families have appreciated that others have an opportunity to see their family member as they themselves see and understand them.

At the sharing event at the Coronation Centre one mother said proudly: “That’s my son,” as she watched his film. Another parent, when interviewed at the start of the project, said she wanted others to understand her daughter as the family does.

“She does ‘speak’.”
(Mother)

Several relatives have been amazed when they have been greeted by their relative intentionally using the Big Mack.

This was an emotional moment for several family members in Salisbury, as they were greeted by their adult relative in a way that has never happened before. There were some questions about how far it was understood by their relative. Therefore an explanation was given about how the Big Mack can be a useful tool for some to foster anticipation and encourage participation.

There have been opportunities to engage in partnerships with families and support staff from other settings.
Staff from Terry’s supported living house in Ellesmere Port have gone with him to a live concert, as through Involve Me Terry’s interest in bands has been noted. Chelsea’s family went with her to a pantomime, building on her love of colour and music.

Impact on peer advocates

They have learned about non-verbal communication.

They have learned to cut down on words, to interpret the non-verbal communication of their partners through their body language and sounds. “Hands”, “moves head”, “grin”, “thumbs up”, “happy noise”, “screams” (peer advocates).

They have a better understanding of the needs of people with PMLD.

Peer advocates have discovered that their advocacy partners may be in situations where they are bored – that they may be restricted in their opportunities.

“It is all about learning from each other.”
(Peer advocate)

Peer advocates have increased in confidence and are beginning to tell people about peer advocacy and what they have learned about the needs of people with PMLD.

At a recent meeting of the PMLD sub-group, Kimmy commented on a mapping report carried out by the local psychology team about the needs of people with PMLD in the borough. From the perspective of the peer advocacy project, he made points about four recommendations: what people do during the day, evenings and weekends; improving the workforce; involving carers; and transport.

“It is giving a real self-worth.”
(Manager)

Impact on services

Involve Me has worked particularly well where management is actively engaged in supporting the project.

Where this happens consistently it has been evident that these approaches are more likely to be embedded.

Services have begun to change internally, with a shift towards empowering people with PMLD.

House meetings in the residential home in Salisbury have been transformed through sharing stories. In the past, the two people living there who use words had been the main contributors while others might drift away; now, however, others press the Big Mack. Katie now sometimes presses the Big Mack gently. The level of understanding is hard to gauge, but there is clearly a greater sense of participation and belonging when people are planning together. Residents are now also involved in selecting staff.

People with PMLD in the Coronation Centre have a higher profile than they did previously. Other people attending the centre are interested in what the
participants have been doing. As a spin-off from the Involve Me project, everyone decorated a t-shirt to reflect what was important to them and then held a fashion show. Some of the interests of others in the show are being followed up, too: one person is now doing dog-walking.

At Eastway Care, there is an opportunity to further develop the use of portfolios in person-centred reviews, to enable people with PMLD to have more say over what happens in their lives. For the Rix Centre, Involve Me was an opportunity to review how it supports people with PMLD and to think about ways of addressing the range of needs within that group.

The work of the peer advocates has been an “impetus” to planning at the day centre where most partners are based. A manager reported that it has helped them as they were thinking about introducing greater choice in the timetabling and in terms of who supports people. Staff appear to have welcomed the peer advocates.

“A nice development for individuals.”
(Staff member)

The peer advocates held two art sessions as a way of getting to know people better. They are speaking with a consultant who is reviewing the day service.

At Hammersmith and Fulham Mencap, the peer advocacy service is being established as an important strand of their work. The pilot phase has given the service a lot to think about. It took time to set up a service. Going to talk to people about being a peer advocate proved to be the best way to recruit. At a recruitment day the applicants heard a presentation, took part in a discussion about being a peer advocate and commented on a role-play involving a person with PMLD, suggesting what was wrong in the situation. These all helped in the selection process. Peer advocates were involved in drawing up their contract with the service. The coordinator has supported partnerships in setting up meetings, accompanying the peer advocates in early visits, making follow-up notes and holding monthly meetings with all the peer advocates together. In the future such a time commitment for the coordinator may not be possible. There may be opportunities for peer mentoring. The peer advocates have reviewed the service and checked what they are doing against the advocacy charter.

The scheme has been working closely with Safety Net, the self-advocacy group at Hammersmith and Fulham Mencap. People with PMLD are being supported to attend some events. Self-advocates will then know more about the lives of people with PMLD. The scheme is ongoing and two more people have recently been recruited as peer advocates.

The centres have more resources for communication, which should increase involvement in decision-making.

The Coronation Centre has the Big Mack and Talking Photo Albums. It has two multisensory rooms – one light, one dark – set up during the creative sessions that can be used by outsiders as well as those attending the centre. The centre has gained
funding for an interactive whiteboard which, with appropriate programmes, will enable them to explore other ways of communicating.

In Salisbury the whole organisation has low-tech augmentative communication devices including Big Macks, bought with advice from the speech and language therapist. This purchase was helped by an award from the local Sainsbury’s. John, from the residential home, was part of the bid and used the Big Mack in the presentation to the company.

**Participants are being supported to explore further preferences.**

In Ellesmere Port, staff are looking for a musical Chelsea would enjoy. They have been clear that the learning gained in the centre should be used to enable people to participate in the community.

The services see Involve Me as ongoing.

Staff at the Coronation Centre have identified others who would benefit from the approach. Staff in Salisbury have described sharing stories as ongoing.

“**A living project**”; “**It is not going to stop**”; “**It’s what we do.**”

(Staff members in Salisbury)

The peer advocacy project at Hammersmith and Fulham Mencap is moving into its second phase and recruiting more peer advocates.

**Wider impact**

A start has been made in influencing other local services.

The influence may be in the broader organisation or beyond it, in the community. One staff member moved from supporting Tim and Dave to another house in Salisbury and took the learning with him. Staff in other settings are becoming more aware of sharing stories. They support people who are attending the arts group. A library session in Salisbury that uses interactive multisensory storytelling is attended by people from the residential home and from other organisations, who can all bring their stories to and from the sessions.
Chatterbox, the meeting point for representatives from different Turning Point homes, is now more inclusive of people with PMLD. Josh and Dave have been able to increase their involvement and used the Big Mack.

In Ellesmere Port, other groups and organisations want to hear about creative communication and are looking to the centre for advice. Links are also gradually being made outside the community. The local community police officer attended the centre’s sharing event where participants showed their films and communicated what is important to them. This made a strong impression on her:

“There are barriers and walls between us and them and these need to be broken down. I am going to come here regularly.”
(Police officer)

A start has been made in influencing policy locally – for example, through learning disability partnership boards.

The peer advocacy project has placed emphasis on the peer advocates making managers and local policy-makers aware of the needs of people with PMLD. The peer advocates are seeking to influence both the local authority and the learning disability partnership board on behalf of people with PMLD. The learning disability partnership board is to consider issues for people with PMLD at a future meeting, which peer advocates will be involved in.

Alexa and Kimmy gave a presentation to a housing association. Alexa also spoke about peer advocacy to a Speaking Up group in another London borough and at a national conference. Others will be able to learn from the project.

In Ellesmere Port, Chelsea’s mother is a member of the sub-group of the local learning disability partnership board, which was set up recently. When Tanya showed her film to a partnership board outside her area, it made an impression:

“A lot of people saw that she does have a voice. We need to get out and about more.”
(Staff member)

To date, ways of potentially influencing national developments have been limited.

Two parliamentary candidates became more aware of the lives of people with PMLD through an invitation to visit residents in Salisbury before the 2010 election. People with PMLD greeted them using the Big Mack and communicated with them about the difficulties some were experiencing in trying to open a bank account. One candidate described his visit as an “education”.

The peer advocates are helping in an analysis of questionnaires about Changing Places, the campaign for accessible toilets and changing facilities, in order to have information to present to their borough. They may also use the findings to support the national campaign.
4. The challenges

During the evaluation, the sites were also asked what worked less well. This section explores the challenges and barriers that needed to be overcome or that continue to have a negative impact. Overall, the time span for the projects was not long enough to bring about all the anticipated changes. The activity on the sites is ‘work in progress’.

Understanding the Mental Capacity Act 2005

• Professionals did not always refer to the Mental Capacity Act 2005. Families may not have heard of it. However, because of its requirement to involve people as far as possible if they lack capacity for particular decisions, this legislation is crucial.

• In the initial stages of recruiting participants, if people could not give consent they needed to be involved as far as possible. Those close to them needed to be consulted to ensure they believed that taking part in research would not be harmful – engaging in activities such as Storysharing™, for example, had to be in their best interests. There was confusion; sometimes there were conversations that seemed to imply that families were giving consent, which under the act, of course, they could not.

• In evaluating Involve Me it has been clear that ongoing reference by managers and staff to the Mental Capacity Act 2005 is more limited than would be expected, given the act’s centrality in decision-making for those who may lack capacity for a particular decision, whether large or small, although their actions were in line with the spirit of this legislation.

For service managers

• Sites were affected by reorganisation to varying degrees. The most dramatic impact was in the creative communication site in the north west, where the local authority boundaries were changed and day services reconfigured. Changes in the day service in Hammersmith and Fulham also had an impact. One potential multimedia advocacy site had to drop out of the project altogether, partly because of the reorganisation of the service.

• There was some scepticism about some approaches initially, but this has been overcome as understanding has increased.

• Low expectations needed to be challenged.

“[People with PMLD] were always getting missed… They get left behind.”

(Manager)

• Health issues affected some staff, peer advocates and participants. This has sometimes had a negative impact on the project.

• Staff shortages meant staff could not always be released for one-to-one support or training. Often, training had to take place while working with participants. This had some advantages because it demonstrated what could happen but it did also mean there was
insufficient time for reflection.
• It is helpful to have continuity in staffing so that strong communication partnerships are established.
• It was problematic for some managers to find the time to understand the approach and consistently give support to frontline staff. Yet their continued involvement and support for staff will ensure that the voices of people with PMLD are heard in their services and that the values underpinning Involve Me are upheld.
• Managers can find it difficult to apply the principles of Involve Me consistently across all aspects of the organisation.
• Services needed to engage with family members, friends and support staff in other services to share learning and achieve a consistent approach. It can be difficult to find the time to do this effectively.

For staff
• The individuality of each person’s communication needed to be appreciated and assessed, in order to establish ways of enabling them to be involved in expressing their preferences in the best way possible for them. Professional advice from speech and language therapy services might be needed.
• Staff needed to be aware of the dangers of making assumptions.

“ ‘It’s easy for me to put words into [his] mouth.’” (Staff member)

“One needs to empower by genuinely and creatively finding his wants without projecting one’s own [...] preconceptions.” (Staff member)

• Staff were often unable to find the time to record what was happening to share with others, which meant that continuity of approach from different people in the person’s life might be difficult to achieve.
• All staff members needed to be similarly motivated.

“ ‘Does he know which staff are worth persevering with?’” (Staff member)

• In using creative approaches to find out about people’s preferences in a way that is appropriate for them, the challenge is then to enable people to have the experiences in the community that they have indicated they might like.
• It was important that staff understood the underlying values of the creative approach to involvement and the tools. For example, people needed to appreciate how the Big Mack is used for participation in sharing stories and other settings, to ensure it is not used inappropriately.
• Staff need to have the confidence to adopt new approaches. They may have felt they could not match the dynamism of several of the communication facilitators, but over time it became clear that they were ready to implement the approach independently.
• Use of technology can present barriers if staff are not confident in this area.
“Coming into the 21st century is quite scary.”
(Manager)

• Overall, the challenge is to understand that there is no ‘one size fits all’ solution. People need a range of ways to communicate, but some ways are more appropriate for some than for others. Empathy, creativity and imagination are helpful in breaking down barriers.

In developing a peer advocacy service

• It can take time to set up a service from scratch. It is a lengthy process: recruiting peer advocates and advocacy partners, training peer advocates, obtaining CRB checks and supporting the peer advocates through the early stages of their advocacy partnership.
• It is important to establish appropriate processes for selection of potential advocates and matching partners.
• The contract that is developed with peer advocates needs to be robust so they can offer consistent and regular support as far as possible. If peer advocates are unable to do this, there needs to be a clear process by which they will be released from their role.
• It can be a challenge to find a way of working with advocacy partners that enables them to meet with their peer advocates in a variety of settings.
• When peer advocates represent the wishes of advocacy partners it will be important to establish how they too can be engaged in a way that is appropriate and in an environment that is comfortable.
• There have been discussions about seeking funding to pay the peer advocates – a move that would, understandably, appeal to them. “[It] would help” (peer advocate). This needs further discussion and careful consideration of the implications for altering the relationship with advocacy partners.

External challenges

There were, and are, obstacles in the local environment that create barriers to the implementation of wishes expressed by participants. These include:

• buses that were not accessible for people in wheelchairs
• transport arriving late
• lack of Changing Places toilets
• lack of access – for example, a building where a lift was not working
• public attitudes – for example, bar staff refusing to serve someone; bank staff appearing disparaging when asked about opening an account.
5. Positive outcomes

Sites were questioned throughout the project about what worked well. The following contributed to successful outcomes:

- responsiveness of participants
- enthusiasm and empathy of staff
- enthusiasm and empathy of peer advocates

“You get a feel for what it’s like out there.”
(Peer advocate)

- creativity of approaches
- the quality of the training and support to staff at the sites from communication facilitators and Mencap coordinators

“[Attendees] saw the light going on... It opened people’s eyes to the opportunities there are around us.”
(Site manager)

- availability of additional tools such as the Big Mack and Talking Photo Album
- support from management
- staff supporting one another
- peer advocates supporting one another

“It’s about team work. We are there to support one another.”
(Peer advocate)

- support from other professionals (speech and language therapists, occupational therapists, physiotherapists and psychologists) when particular expertise was needed
- partnerships with families and also with staff supporting participants in other areas of their lives
- local people learning about how people who do not use words can communicate and contribute to their community with support – for example, police officers, young people who have not previously met a person with PMLD and local councillors.
6. Conclusion

“"I don’t think the people [with PMLD] who come here know how inspirational they are to us."
(Service manager)

Involve Me has shown that people with PMLD can express their preferences and be consulted and involved in decisions about their lives when people spend time with them and listen creatively to what they are saying without words. This takes time. The involvement may be in decisions that have an immediate importance for their lives, such as food, drink, clothes, support, and everyday and leisure activities. With close attention, creativity and imagination they can also be heard and involved in decisions and consultations about where to live and how they wish to spend their time. As each person expresses their preferences, the learning can be aggregated.

In listening to what is important to individuals, there has been limited opportunity for this learning to influence services and policy locally because of time constraints. Nonetheless a start has been made. Meetings of participants (including peer advocates) with local policy-makers and learning disability partnership boards have enabled them to better understand the lives of people with PMLD. This can then influence decisions in a way that will be responsive to the aspirations they have heard and seen. It can take a long time, and there will be ongoing learning about how people with PMLD can be involved in decision-making and consultation, directly and indirectly, which should eventually also have an impact on the national agenda.

There are barriers and obstacles that make it difficult for people with PMLD to have their voices heard, but these can be overcome. There need to be new priorities and ways of thinking so that the importance of hearing what people with PMLD are saying is not overlooked.

“"They should be treated the same as us."
(Peer advocate)

In exploring the impact of the work at the four sites and identifying the challenges and positive outcomes, we have been able to draw up recommendations that, if implemented, should enable people with PMLD to have more influence over what happens in their lives.
**Glossary**

**Advocacy** supports people in expressing their views, preferences and decisions on an equal basis. It does not make choices or decisions for people who receive advocacy support. It avoids the potential conflicts of interest when professionals or families speak up with someone.

**Big Mack** is a simple portable communication device that allows a single message/sounds of 20-second duration to be recorded. Touching a large coloured target area activates the recorded message. It can be highly motivating as a means of helping people participate when they are unable to do so in other ways.

**Intensive interaction** is ‘a way of being with people with PMLD… and a way of reaching those who are hard to reach… Intensive interaction teaches the pre-speech ‘fundamentals’ of communication…’. It is a simple practical approach to interacting with people with PMLD through using their own way of communicating, whatever that may be.

**Objects of reference** are objects used as a means of communication. Objects can be made to represent people, events or activities – for example a plate for a meal; a cup for a drink. They are selected to be appropriate for each individual.

**Personalisation** is a term coined in the Green Paper *Independence, Well-being and Choice* and refers to a new way of thinking about public services and social care: one which starts with the person with social care needs, rather than with the social care service. It could be described as the policy direction or approach.

**Self-advocacy** is speaking up for and representing your own interests. A self-advocate may need varying degrees of help to do so. This is often provided by a group which self-advocates organise and run.

**Talking mats** are mats with picture symbols. They can be used as a basis for communication, for example about preferences for activities. People who can successfully use a talking mat must be able to recognise pictures or symbols and use them to represent ideas and feelings. This approach requires a level of understanding and thinking that not everybody may have.

**Talking Photo Albums** are ‘flip-style’ albums. Voice messages and sounds can be recorded and activated next to each photograph.
6. Appendix 1

**Evaluation of Involve Me**

These guidelines were given to the four sites. We received profiles of all participants and some diary summaries and self-audits. The evaluation in the event focused mainly on the three visits made to each site, and related telephone interviews. We also received some reports and film clips.

**Introduction**

We are looking at how the people with PMLD in the four sites are involved in decisions about their lives using the different site approaches of Storysharing™, peer advocacy, creative communication and multimedia advocacy.

We want to find out:
- what is working well
- what is working less well
- what you would like to happen differently another time.

We are looking at different areas where people are involved in decisions

1. My everyday life
2. My support and services
3. Community involvement

These areas were described in the Involve Me concept training.

**Ways of evaluating**

1. Profiles of participants at the start
2. Summaries of diaries every 3 months – or before a visit if 3 months have not elapsed
3. Three visits to each site
4. Telephone interviews
5. Self-audit tool for monitoring participation in decisions using the approach in your site – in the different areas
6. Any additional materials that sites can provide, including monthly site reports and site facilitators’ reports.

**Working together**

We want to make the task of providing information as useful as possible to the sites. We know you will want to look at how people are involved in decisions and at what works. We are happy to discuss with you the format that is best for you in producing the summaries of diaries and the self-audit tools so that it helps both you and us. (Please see below.)

**The visits**

We will visit three times. The first visit will be in the first 2–6 weeks after the Involve Me concept training and your first approach training session.

We will need to receive the profiles at least 10 days before the first visit.

The second visit will be in mid-term and the third at about 8 months.

In Ellesmere Port and Salisbury our visits may have to be over 2 days – eg from lunchtime to lunchtime or over one day. In London they will be over one day. We will liaise with the site coordinator about dates and who we would like to see.
We hope that over the three visits it will be possible to meet all the participants and spend some time with them and their supporters. It will be helpful to know if there are one or two family carers who would be happy to talk with us on visit 2 and/or 3.

For either visit 2 or 3 we hope to observe an opportunity for participant(s) to be involved in a community or national decision-making opportunity.

On each occasion we would like to have **face-to-face interviews** with several people on the site.

At the end of the three visits we would like to have talked with:

- a sample of family carers, paid and unpaid supporters, peer advocates and advocates
- a sample of leading members of partnership boards, service managers and commissioners as appropriate on visits 2 and/or 3
- Involve Me project staff.

Please can you arrange for us to have a suitable place for face-to-face interviews?

For participants – we would like to spend time with them in a place and/or at a time that will be most comfortable for them.

We will also be able to do **telephone interviews** with a sample of the above people.

For the interviews – whether face-to-face or on the phone – we will use semi-structured interviews, ie we will have questions to ask, but they will enable interviewees to elaborate and give us a broader picture. We may take notes or, with interviewees’ permission, record our conversations.

**Personal profiles**

As part of the project the sites will be providing personal profiles of the participants. We will look at these before we visit so that we know something about the people we will be meeting.

**Summaries of the diaries**

You will be keeping diaries for each participant. The diary will provide a snapshot on a particular day of the communication between the participant, supporter and maybe others – the ways in which communication took place, how the person participated in decisions, what worked well, what worked less well, whether any changes resulted and what you would like to happen differently another time. The diary is the reflective diary that was shown to you at the Involve Me concept training.

We would like to receive summaries every 3 months or 10 days before a visit if 3 months have not elapsed. Please develop a way of providing a summary that is useful for you. We hope that you will find it helpful to look back – and to the future – every 3 months and to reflect on what has happened.

You may want to use a form or you may wish to produce a DVD with a commentary that we can use. You may have other ideas. It would be good if we can check these out together before or on our first visit.
We will want to know **with respect to the different areas where the person has been involved in a decision**, as appropriate:

- What kind of decisions the person has been involved in over the three months
- The way the person has communicated their wishes and how this may have changed, with particular reference to the approach in 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
- What has changed in the person's life/what outcomes there have been
- What has worked well both in the process and getting an outcome
- What has worked less well in the process and getting an outcome
- What you would like to happen differently in the future. NB This might be something you can change in the way you communicate together – or something that needs to change in the external environment (eg a partnership board having a different way of working).

If we need to get a fuller picture we may ask if we can see the diaries.

**The self-audit tool**

While the diary summary is an opportunity to review what has happened for the individual with PMLD, the self-audit is a chance to review what is happening with your site and the approach you are using, with respect to the different areas of involvement in decisions.

You will need to decide about the process:

- What do you need to audit?
- How often do you need to audit your processes?
- Who needs to be involved?
- Is it robust?

We would suggest every three months as a minimum – or before visit two and three if three months have not elapsed – but you may decide to do it more often. You will have questions you would like to ask yourselves – for example, in the time under review:

- What did you say that you would do?
- What was on your ‘tin’? (The ‘Ronseal Test’)
- Did you do it? If not, what did you do differently, and why?
- What difference did you expect the communication approach in your site to make in people's participation in different areas of decision-making?
- Can you see this difference?
- Has something else happened that you didn’t anticipate or expect?
- What evidence do you have that links what you did to the difference that you are able to perceive?
- What barriers and obstacles did you experience and how would you like to organise things differently in the future?

Please let us know what your self-audit tool is going to look like so that we can check it also meets our needs. We are happy to talk about this with you if you wish to get in touch, or we can talk at the first site visit.
Appendix 2

The approaches

The communication facilitators provided information about their approaches at the start of the project.

Appendix 2a: Creative communication

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<th>Name of approach</th>
<th>Creative communication</th>
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<tbody>
<tr>
<td><strong>Definition – what it is</strong></td>
<td>The use of creativity to enhance and develop communication and consultation.</td>
</tr>
<tr>
<td><strong>Aims – what do you aim to do?</strong></td>
<td>To develop methods of communication appropriate to an individual’s needs.</td>
</tr>
<tr>
<td></td>
<td>To enable people with profound and multiple learning disabilities (PMLD) to participate in the decision-making processes affecting their lives via their creative communication.</td>
</tr>
<tr>
<td></td>
<td>As a personalised approach, its direction is guided by the individual – the aim is to create interactions and opportunities that expect and encourage individuals with disabilities to participate as full communicative partners with all other people.</td>
</tr>
<tr>
<td>Name of approach</td>
<td>Creative communication</td>
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<tr>
<td><strong>Process – what actually happens when you are implementing the approach?</strong></td>
<td>Creative approaches are used to establish and record an individual's current personal communication skills and communicative behaviour. A wide range of creative methods are introduced to individuals and their supporters. For example, experience-based sensory activities (accessible art, music, movement and dance, drama and puppetry) and inclusive film, multimedia and technology. Any method the individual responds to is developed, personalised and adapted to suit their particular individual communication needs. By working together, communication tools are created that an individual can share with others and use to interact and be included. Supporting the individual to share helps to ensure the people in the individual's life understand, respect and use this communication.</td>
</tr>
<tr>
<td><strong>What equipment do you use?</strong></td>
<td>Anything and everything! A wide and varied range of materials is used. Keep an open mind – even the most simple, everyday items can be used creatively to aid communication. The workshops involve the use of tools, equipment and materials such as fabric, art items (paint, card, paper, etc), camera and computer equipment, musical instruments, parachute silk, bubbles, Talking Photo Albums, theatre masks, recycled items, items from nature and various other sensory items relating to touch, sound, smell, taste and sight.</td>
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<tr>
<td>Name of approach</td>
<td>Creative communication</td>
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</tr>
<tr>
<td><strong>Working principles and assumptions that underlie the approach</strong></td>
<td>Everyone has the right to control their existence through the recognition and meeting of their communication needs. Different ways of communicating should be equally valued and accepted, by people acknowledging the communication and by using the appropriate means. People with a learning disability don’t have one recognised tool for communication and are often dependent on professional intervention to develop a tailored communication plan. As outlined in the Mental Capacity Act 2005, people must be assumed to have capacity and supported to understand and communicate their wishes in any way needed. Creativity is the ability to think up and design new inventions, produce works of art, solve problems in new ways, or develop an idea based on an original, novel or unconventional approach. Creativity has been associated with a wide range of behaviours such as curiosity, flexibility and unusual uses of familiar objects. It shares principles with ‘intensive interaction’, such as mutual pleasure, imputing intentionality and contingent responding.</td>
</tr>
</tbody>
</table>

<p>| How is communication defined? | Communication is a basic human right. It is the way we make choices and gain independence. It is the way we build relationships and express our feelings, thoughts and emotions. Communication works through a two-way process by which we make sense of the world around us. Shared communication is what includes us in society. |</p>
<table>
<thead>
<tr>
<th>Name of approach</th>
<th>Creative communication</th>
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</table>
| **Any theory or research that is relevant?** | Jan Hawkins – *Voices of the Voiceless*  
Augusto Boal – *Theatre of the Oppressed*  
Edgar Dale – *Dale’s Cone of Experience*  
Donald Winnicott – *Playing and Reality*  
Herbert Lovett – *Learning to Listen: Positive Approaches and People with Difficult Behavior*  
Daniel Pink – *A Whole New Mind*  
Penny Lacey and Carol Ouvry – *A Collaborative Approach to Meeting Complex Needs*  
Peppy Hills – ‘physical listening’ – an inclusive approach to dance  
Steve King – inclusive music  
Trestle Theatre Company – mask theatre  
Phoebe Caldwell, Dave Hewitt and Melanie Nind – intensive interaction  
Dr Nicola Grove – Storysharing™ |

| How does it support decision-making and consultation? | People can be dependent on others to interpret their needs and choices through observing and responding to their communicative behaviour.  
The problem is that often, people who provide a service to people with PMLD can try to impose pre-designed communication methods on them, to find out what we want to know and what we consider important. |
<table>
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<tr>
<th>Name of approach</th>
<th>Creative communication</th>
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</thead>
<tbody>
<tr>
<td><strong>How does it support decision-making and consultation?</strong> (continued)</td>
<td>You build on known preferences to explore choices and decision-making and to support consultation – but be prepared to have past assumptions challenged.</td>
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<td></td>
<td>This approach aims to increase knowledge and awareness of non-verbal communication. It allows a method for establishing how an individual shows likes and dislikes so that we can respond to and encourage individuals with respect.</td>
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<td></td>
<td>It is a way of people feeling empowered or motivated to use their ‘voice’, whether it is via verbal or non-verbal means. People won’t develop isolated skills that they have difficulty using in different situations. Instead they are highly motivated to practise and develop their communication abilities because this is enjoyable and meaningful.</td>
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<td></td>
<td>It supports the individual to share information important to them in a way that creates an environment of shared enjoyment.</td>
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<td></td>
<td>This information is presented by the individuals to ‘decision-makers’. This is a way of sharing and celebrating individual achievements and seeing communication for communication’s sake being valued – without the pressure of ‘outcomes’ set by someone other than the individual.</td>
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<td></td>
<td>This encourages agencies and organisations to listen to the people involved and take them seriously, putting the person in control so it’s their priorities that are important.</td>
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<td></td>
<td>Creativity is of value in its own right. Creativity becomes communication when it is shared with others. This creative communication becomes consultation when it is shared by the individual with the people who can make a difference to their lives.</td>
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<td>Name of approach</td>
<td>Creative communication</td>
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<tr>
<td><strong>What would you expect staff to learn through its use?</strong></td>
<td>To be able to work with a variety of creative methods in order to develop and understand an individual’s communication.</td>
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<td></td>
<td>To have an understanding of the skills needed to implement different forms of creative communication techniques and solutions.</td>
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<td>To be able to identify the barriers experienced by people who use non-verbal communication.</td>
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<td>To feel empowered and to have the confidence to use their pre-existing creative skills and to develop new ones.</td>
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<td></td>
<td>To understand the potential issues with sensory communication.</td>
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<td>To understand the importance of choice, advocacy and communication and the responsibility we have to enable all people with a learning disability to uphold their rights and opinions.</td>
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<td>To appreciate that something we all have in common is senses, and sensory experiences should extend beyond the sensory room.</td>
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<td>Name of approach</td>
<td>Creative communication</td>
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<tr>
<td><strong>What would you expect a person with PMLD to learn?</strong></td>
<td>That their action will get a reaction – it is worth communicating!</td>
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<tr>
<td></td>
<td>To build on their basic skills of communication, such as turn-taking, establishing purpose and intention.</td>
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<td>To develop curiosity and exploration, choice and discovery, confidence and a willingness to take risks.</td>
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<td>To build motivation, especially internal motivation.</td>
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<td></td>
<td>To discover ways to gain the attention of others.</td>
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<td></td>
<td>To enhance creative sharing skills.</td>
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<td>Name of approach</td>
<td>Creative communication</td>
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<tr>
<td>What would you see as successful outcomes from the approach? Note: generally rather than specifically in this project</td>
<td>That people have had fun!</td>
</tr>
<tr>
<td></td>
<td>For individuals to be treated with respect and dignity when communicating.</td>
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<td></td>
<td>For individuals to have access to necessary alternative communication.</td>
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<td>That individuals will be creatively involved in communication exchanges about themselves when they are present and be able to interact by sharing their creative communication tools.</td>
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<td></td>
<td>To see communication for communication’s sake being valued – without the pressure of ‘outcomes’ set by someone other than the individual.</td>
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<td></td>
<td>For people to have their voices heard and to have their opinions, needs and hopes taken seriously.</td>
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<td>That the individual and the people around them relate better to each other and enjoy each other’s company.</td>
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<td>An atmosphere of collaboration and working with individuals rather than for them.</td>
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<td>That the individual and the people around them recognise their abilities and work towards achievable outcomes.</td>
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<td></td>
<td>That the resources and skills of people are valued and developed.</td>
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<tr>
<td>Name of approach</td>
<td>Creative communication</td>
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</tbody>
</table>
| **What organisational issues have to be resolved/in place for the approach to be successful?** | The staff to individual ratio – having staff with time to spend ‘just being’ with individuals enables the intricacies of the individual’s complex communication style to become familiar to the staff member. This enables consistent long-term partnerships to be developed between staff members and individuals – if the same people work together over a period of time (assuming it is a positive experience for both) a deeper understanding of communication preferences can be developed.  

Staff need to work alongside individuals as a partnership – shared enjoyment and fun is key!  

There needs to be emotional safety – sessions need to be facilitated so that individuals’ and staff’s contributions are valued.  

Creative use of space – having an appropriate space, which can be changed or adapted for the creative work. |
<table>
<thead>
<tr>
<th>Name of approach</th>
<th>Creative communication</th>
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</thead>
<tbody>
<tr>
<td>What might prevent the approach working?</td>
<td>The inhibitions of the supporter – people may feel uncomfortable with some of the unusual creative ways of working.</td>
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<td></td>
<td>Issues of ‘age appropriateness' may make some staff reluctant to be involved.</td>
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<td></td>
<td>If individuals often have a lot done for them and to them. This approach needs to be with them and by them.</td>
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<td></td>
<td>Individuals can have highly complex and individual ways of communicating. One communication style is not going to be accessible for all people in one group.</td>
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<td></td>
<td>If observations are not recorded and information is not shared between staff. A lack of records may mean seemingly inconsequential interactions (that could be the key piece of a bigger communication picture) may get missed and it is sharing information that enables continuity of practice and a consistent approach to communication.</td>
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<td>If opportunities are not available for individuals to share their work with ‘decision-makers’.</td>
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<td>If there is not a culture of seeing fun as a valuable part of work time.</td>
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<tr>
<td></td>
<td>If people impose their priorities of what is important upon the individuals and the process.</td>
</tr>
<tr>
<td>Anything else?</td>
<td>Don’t be afraid of ‘getting it wrong’. The key to creativity is shared enjoyment and interaction. If the individual and those around them are enjoying themselves and interacting, there is no ‘wrong’. Just have a go and have fun!</td>
</tr>
</tbody>
</table>
## Appendix 2b: Storysharing™

<table>
<thead>
<tr>
<th>Name of approach</th>
<th>Storysharing™</th>
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</thead>
<tbody>
<tr>
<td><strong>Definition – what it is</strong></td>
<td>A means of developing the recall and sharing of personal experiences.</td>
</tr>
<tr>
<td><strong>Aims – what do you aim to do?</strong></td>
<td>Enable people to participate actively in the social recall of a reportable experience.</td>
</tr>
<tr>
<td><strong>Process – what actually happens when you are implementing the approach?</strong></td>
<td>A reportable experience is brought to mind.</td>
</tr>
<tr>
<td></td>
<td>It is told collaboratively as an anecdote to a responsive audience.</td>
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<td></td>
<td>The person with PMLD is supported to take an active part in the retelling, however they can.</td>
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<td></td>
<td>It is told over and over again for the purposes of entertainment, making sense of, or coming to terms with, an experience.</td>
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<tr>
<td></td>
<td>Non-directive responsive conversational strategies are used.</td>
</tr>
<tr>
<td><strong>What equipment do you use?</strong></td>
<td>Big Mack.</td>
</tr>
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<td></td>
<td>Key object that might be involved in the story.</td>
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<td>Any communication devices used.</td>
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<tr>
<td>Name of approach</td>
<td>Storysharing™</td>
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</tbody>
</table>
| **Working principles and assumptions that underlie the approach** | That our identities are formed through reportable experiences and our reactions to them.  
That feeling is at the heart of the story.  
That autobiographical memory develops through shared telling.  
That the skills of narrative are developed through repeated, active, scaffolded participation. |
| **How is communication defined?** | A dynamic process whereby intentions, feelings and experiences are shared through active expression and inferencing by others. |
| **Any theory or research that is relevant?** | Vygotsky – social constructionist development  
Bates, Coupe and Goldbart – early communication  
Sperber and Wilson – relevance theory  
Labov, McCabe and Peterson – social models of narrative  
Katherine Nelson – autobiographical memory  
Caldwell, Nind and Hewett – intensive interaction |
<p>| <strong>How does it support decision-making and consultation?</strong> | At any one point, our decisions and choices are based on a memory of past decisions, and predictions of consequences. We actively talk through key decisions with others. Socially scaffolded recall of experience, making reactions and feelings explicit, should help people to take a more active role in decisions at the 4 levels. |</p>
<table>
<thead>
<tr>
<th>Name of approach</th>
<th>Storysharing™</th>
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</table>
| **What would you expect staff to learn through its use?** | To provide a range of experiences that are worth recalling and sharing.  
To provide opportunities to tell the stories together.  
To know how to support people to tell and to listen.  
To value and recognise the expression of feelings. |
| **What would you expect a person with PMLD to learn?**    | How to take a role in a collaborative narrative.  
How to listen actively and respond to others.  
How to reflect and consider something that has happened. |
| **What would you see as successful outcomes from the approach?** | People have a richer life with more varied experiences.  
People are enabled to take part in collaborative recall.  
People are supported to draw on their experiences when they are considering a decision.  
People are more aware of each other as peers or friends. |
<table>
<thead>
<tr>
<th>Name of approach</th>
<th>Storysharing™</th>
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</table>
| **What organisational issues have to be resolved/in place for the approach to be successful?** | Being prepared to take some risks, in allowing people to face challenges – novel or difficult experiences.  
Providing time for shared telling.  
Providing staff and some resources for the recording and sharing of stories.  
A culture that values imagination and creativity.  
A culture that supports staff development and actively problem-solves.  
A clear commitment to valuing different ways of communicating. |
| **What might prevent the approach working?** | Staff are not given time and space to develop the approach.  
Not all staff receive training, so it is seen as exclusive.  
Services are provided to the person, rather than actively with the person.  
Poor practice in information-sharing – failure to record what is going on when.  
A ‘whatever’ attitude. |
| **Anything else?** | |
## Appendix 2c: Getting To Know You – peer advocacy

<table>
<thead>
<tr>
<th>Name of approach</th>
<th>Getting To Know You – peer advocacy</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Definition – what it is</strong></td>
<td>In this context peer advocacy is where one person with a learning disability advocates for another. The defining factor in peer advocacy is some sort of shared experience. For people with a learning disability the shared experience is having a learning disability.</td>
</tr>
<tr>
<td><strong>Aims – what do you aim to do?</strong></td>
<td>Enable people with a learning disability to advocate for people with PMLD. The peer advocates will develop their self-advocacy skills, spend time with their advocacy partner and work with the support available to enable the person with PMLD to influence choices. The advocate will spend time getting to know how the person communicates, find out their likes and dislikes, and speak up on their behalf in a variety of situations.</td>
</tr>
<tr>
<td><strong>Process – what actually happens when you are implementing the approach?</strong></td>
<td>The peer advocate will receive training to develop their understanding of communication. Advocates are matched with people with PMLD with whom they may have something in common – eg leisure activities, age, using the same centres. The peer advocates, with support if needed, will spend time with their advocacy partner, talk with people who know their advocacy partner well and attend meetings about them. The advocate may decide to use a variety of resources to represent the individual – photos of the person doing something they enjoy, for example.</td>
</tr>
<tr>
<td><strong>What equipment do you use?</strong></td>
<td>Recording templates may be used to ensure that information gathered is accurate. An agreement may be made as to who will have access to any documentation related to advocacy. As far as possible, efforts should be made to ensure the advocacy partner is aware of what information the advocate has.</td>
</tr>
<tr>
<td>Name of approach</td>
<td>Getting To Know You – peer advocacy</td>
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</tbody>
</table>
| Working principles and assumptions that underlie the approach | The guiding principles of Advocacy Standards – Action for Advocacy.  
There will be common experiences between the advocacy partners.  
Professional and family support will respect what the advocate has to say.  
A relationship is formed between the advocate and partner.  
*The advocate is not directly responsible for providing services or making decisions but will form part of a wider team as applicable.*  
*A voice of their own: a toolbox of ideas and information for non-instructed advocacy – Annie Lawton.*  

How is communication defined? | Using an evidence-based approach, the advocate will present preferences for options. At times a best interest approach is used, based on what is known about the individual. Experiences are encouraged to enable the advocacy partner to express preference for a particular situation. |
<p>| How does it support decision-making and consultation? | The advocate can ask questions based on their knowledge of the advocacy partner and their own experience of using services. The advocate acts as the ‘voice’ of the person with PMLD. The advocate can spend time with the individual, sharing experiences with them. |</p>
<table>
<thead>
<tr>
<th>Name of approach</th>
<th>Getting To Know You – peer advocacy</th>
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</table>
| **What would you expect staff to learn through its use?** | How services are viewed through the eyes of a service user.  
People with a learning disability are effective advocates.  
The capacity to spend quality time, learning communication and respecting the individual can reap huge benefits in terms of exploring different experiences and preferences.  
Decisions and choices can be made within the ‘constraints’ of services. |
| **What would you expect a person with PMLD to learn?** | Forming relationships.  
Broader range of experiences and exploring preferences. |
| **What would you see as successful outcomes from the approach? Note: generally rather than specifically in this project** | The advocate is seen as the voice of the person with PMLD. Others learn from the advocate about how to view preferences and consider the needs and preferences of the person with PMLD. A long-standing, positive relationship is formed between the advocate and advocacy partner. |
| **What organisational issues have to be resolved or in place for the approach to be successful?** | Staff training in peer advocacy and its benefits.  
Development of a peer advocacy resource training pack.  
There is currently little training in existence. |
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<tr>
<th>Name of approach</th>
<th>Getting To Know You – peer advocacy</th>
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</table>
| **What might prevent the approach working?** | Professionals not respecting what the advocate has to say.  
Inappropriate support to record visits by the advocate.  
Inappropriate support to collect information.  
Advocate sent information on behalf of the partner which is written in an incorrect format. |
| **Anything else?** | 
**Appendix 2d: Multimedia advocacy**

<table>
<thead>
<tr>
<th>Name of approach</th>
<th>Multimedia advocacy</th>
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<tbody>
<tr>
<td><strong>Definition – what it is</strong></td>
<td>The way of conveying preferences and viewpoints using pictures, sounds, video and text.</td>
</tr>
<tr>
<td><strong>Aims – what do you aim to do?</strong></td>
<td>To engage people with PMLD in creating their own person-centred plans.</td>
</tr>
<tr>
<td></td>
<td>To empower them to present their own ideas and viewpoints.</td>
</tr>
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<td></td>
<td>To allow them to take an active role in decision-making processes.</td>
</tr>
<tr>
<td><strong>Process – what actually happens when you are implementing the approach?</strong></td>
<td>The support member of staff works together with an individual, firstly to establish their preferred communication.</td>
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<td></td>
<td>Next, a range of tools and approaches is introduced, tried and tested – for example, symbols, pictures, objects of reference, etc.</td>
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<td>The interactions are video-recorded, reviewed and analysed, and the tools that best meet the needs of the individual are identified.</td>
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<td>The preferred method of communication and useful tools are shared with other members of staff to ensure consistency of practice.</td>
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<td>The individual is supported to develop their multimedia advocacy portfolio using their preferred method of communication.</td>
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<td>During the training, the person whose portfolio is being created develops a better understanding of their rights to communicate, becomes more confident and, with appropriate support, is able to better advocate on their own behalf.</td>
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<tr>
<td>Name of approach</td>
<td>Multimedia advocacy</td>
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<tr>
<td>What equipment do you use?</td>
<td>A range of equipment can be used. This starts with pictures, images, symbols, objects of reference and talking mats, and moves on to digital cameras, microphones, video cameras, headphones, computers, switches, game controllers and more. Creativity plays a big role in the multimedia advocacy approach so staff are challenged to be creative and use tools and equipment that work for the individual they support.</td>
</tr>
<tr>
<td>Working principles and assumptions that underlie the approach</td>
<td>The working principles of multimedia advocacy are those of person-centred work. Each individual is born with some gifts and abilities. Every human being has the right to be independent, autonomous and self-determining. The basic human rights apply to everyone equally so people with a learning disability also have the right to: have a family; have a voice; education; employment; independence; and inclusion. People with a learning disability are not always allowed to make these decisions for themselves due to their complex communication needs. The aim of multimedia advocacy is to discover the individual’s communication and enable him/her to advocate for themselves. Everyone has an intention to communicate. Our role is to: find out what the person’s communication is; recognise this communication; capture it using multimedia; share it with others; value it; and use it. Once a person’s communication is being recognised and valued, new opportunities to communicate arise. The more opportunities to communicate we create, the better the person’s communication will be.</td>
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<td>Name of approach</td>
<td>Multimedia advocacy</td>
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<tr>
<td><strong>Working principles and assumptions that underlie the approach (continued)</strong></td>
<td>Do not have any assumptions about the person you support; speak to them, be creative, find out, document and share your findings.</td>
</tr>
<tr>
<td><strong>How is communication defined?</strong></td>
<td>Communication is a complex two-way process. It is a way of expressing our emotions, thoughts and viewpoints. It can be successful or unsuccessful. When thinking about communication, we must consider the environment, the message, the medium and time:</td>
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<tr>
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<td>Environment – responsive and quiet.</td>
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<td></td>
<td>The message – what is the message? Do I need to know something else in order to understand it? Do I need to have a specific experience? The message must be clear and simple.</td>
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<td></td>
<td>The medium – how can I communicate the message? Speech, body language, facial expression, sounds, actions, pictures, objects, symbols, signs, etc.</td>
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<tr>
<td></td>
<td>Time – communication is a complex process and it requires a communication partner to receive the message from the sender, decode it, understand it, think of an answer, code the answer and send it to the original sender, who is now a receiver.</td>
</tr>
<tr>
<td>Name of approach</td>
<td>Multimedia advocacy</td>
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<tr>
<td>How does it support decision-making and consultation?</td>
<td>Multimedia advocacy takes advantage of user-friendly technologies as well as other approaches and tools, eg person-centred work, total communication, intensive interaction, talking mats, objects of reference, signs and symbols. People with a learning disability are involved in making the multimedia advocacy portfolio, which includes a range of information including: ‘About me’, ‘My life’, ‘My likes, dislikes, wishes and dreams for the future’, ‘My friends’, ‘What I do’, ‘Where I go’, ‘How I like to be supported’, ‘What is important to me’, ‘Where I live’, etc. All the information is recorded using pictures, video and sound. For those whose communication is difficult to understand, video ethnography is used. The person’s interaction with the environment and other people is carefully recorded and their behaviour discussed and agreed with their circle of support and people who know the person well, and it is then shared with relevant people. This ensures that everyone understands the person, what is important to them and how they communicate so they can support the individual with respect. Multimedia advocacy aims to train the staff who support people with a learning disability to learn to really listen and recognise each individual’s strengths and abilities. It also aims for staff to recognise the power and control that are shared within any relationship and how they can consciously share this power to empower the person they support.</td>
</tr>
<tr>
<td>Name of approach</td>
<td>Multimedia advocacy</td>
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<td><strong>How does it support decision-making and consultation? (continued)</strong></td>
<td>During the process, the person with the learning disability is meaningfully involved, informed and listened to. Their choices and wishes are recorded and they can choose to present their portfolios to communicate their messages in various meetings and social settings. This approach helps to put individuals at the centre of their planning process and allows them to be actively involved and listened to.</td>
</tr>
</tbody>
</table>
| **What would you expect staff to learn through its use?** | Better understanding of communication processes and person-centred approaches to care, advocacy, empowerment and inclusion.  

The ability to reflect on their own practice, notice their interactions and have the knowledge and understanding of how this can be improved.  

The ability to identify various forms of communication, including body language and non-verbal behaviours, and understand the meaning of these communications.  

The ability to support their clients using multimedia tools. The process will give them a great sense of empowerment and satisfaction and it will be fun.  

Staff will also develop technical skills and confidence that will help them personally and professionally. |
<table>
<thead>
<tr>
<th>Name of approach</th>
<th>Multimedia advocacy</th>
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<tr>
<td><strong>What would you expect a person with PMLD to learn?</strong></td>
<td>That their communication is recognised and acted upon. This, in turn, will give them motivation to communicate more as they know they will be listened to. The more this takes place, the bigger the learning – if people are given opportunities to communicate and their communication is valued and responded to, they are more likely to ‘speak’ again and, in the process, become skilful communicators.</td>
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<tr>
<td><strong>What would you see as successful outcomes from the approach? Note: generally rather than specifically in this project</strong></td>
<td>The person is valued, included, respected and involved. They are given a chance and have their voices heard. Staff recognise that each individual has some potential and intent to communicate; all they have to do is listen and respond.</td>
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<tr>
<td>Name of approach</td>
<td>Multimedia advocacy</td>
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<td><strong>What organisational issues have to be resolved or in place for the approach to be successful?</strong></td>
<td>Some of the biggest barriers are around time and attitudes.</td>
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<td></td>
<td>Managers need to give staff one-to-one time with people with PMLD to allow them to get to know each other and develop a relationship that is safe and mutual.</td>
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<td>Allow people to take risks – ‘Nothing ventured, nothing gained’.</td>
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<td>Create working environments that support creativity and various ways of working.</td>
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<td>Staff having time to reflect and share information and their thoughts with each other, allowing them to learn from and support each other.</td>
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<td></td>
<td>Commitment from organisations to change existing practices and recognise that people with PMLD have the same human rights as everyone else, including the right to be involved. They should be involved and have access to activities that involve them on their terms, not ours.</td>
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<td><strong>What might prevent the approach working?</strong></td>
<td>Negative attitudes.</td>
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<td>Time constraints.</td>
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<td>Not enough staff to support the number of clients.</td>
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<td>Lack of training.</td>
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<td><strong>Anything else?</strong></td>
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</table>
Endnotes

1 See www.pmldnetwork.org


8 See 3.


11 See www.intensiveinteraction.co.uk


13 See www.bild.org.uk/docs/05faqs/Factsheet%20Advocacy.doc

14 See 11.


16 See 13.
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

This report was written in March 2011