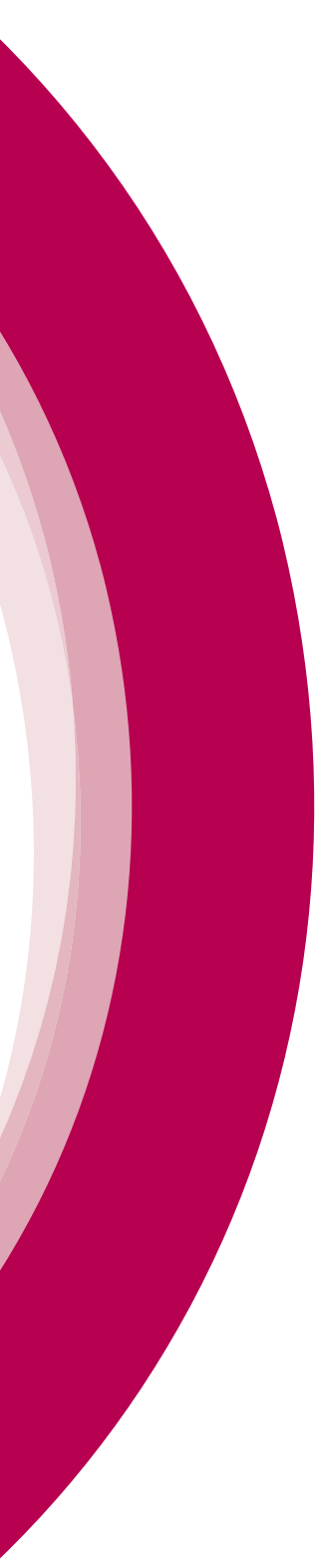



Your guide to

The arts and people with profound and multiple learning disabilities (PMLD)



About this guide

This guide has been written for professionals to outline the importance of engaging people with PMLD in the arts, and to explain the steps you can take to make the experience as enjoyable and productive as possible. It also contains useful information about additional resources and support that are available. Look for the **What next**  sign for things you can do.

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The arts and people with profound and multiple learning disabilities (PMLD)

Making sure that people with profound and multiple learning disabilities (PMLD) have the opportunity to take part in the arts is very important for many reasons.

Art is an integral part of the human experience, and it can help people to get involved in their community, find new ways to communicate, and increase their self-confidence.

As a professional, there are many things you can do to help people with PMLD get involved in the arts, and to make the most out of their experience. The information in this guide has been taken from a booklet which accompanies the DVD 'In the Moment', which demonstrates the use and power of many of the techniques described here. It also shows people with PMLD taking part in the arts and showcases some of the most exciting work in this area.

“Participating in arts projects is so important, to be visible and for people to be really valued for what they can achieve.”



For further information, and to get a copy of the DVD, please contact:

Mencap's trading team

Telephone: 020 7696 6993

Email: trading@mencap.org.uk

The DVD is priced at £15.00, including posting and packaging.

For more information you can also contact:

Gus Garside

Telephone: 01444 449089

Email: gus.garside@mencap.org.uk

Why is it important to make the arts available to people with PMLD?

- **Art is an integral part of the human experience**
Art is integral to life, both in terms of experiencing it and creating it. It should be made available to everyone, regardless of ability.
- **Access to the arts is a big part of community inclusion**
People with high support needs are often denied access to community activity. Much more needs to be done to help include them, and the arts can play a key role in this.
- **Participation may make people with PMLD more visible in society**
This is especially true if the projects they are involved with are accessible to the public. This is one way of encouraging a change in the way people value those with high support needs.

“The purpose of the work is to provide the opportunity for people who have special needs to engage with the world in a deeper and more profound way.”

- **Participation can help people express themselves non-verbally**
People who communicate non-verbally can be supported to express emotions and ideas through different art forms. The ability to express emotions, and to have them acknowledged in some way, is a big part of coming to terms with the way you are feeling.

- Participation in the arts increases self-confidence. This can be particularly relevant to people with PMLD, who may struggle to establish a sense of a valuable self. Using art to have an immediate and valuable effect on the space around someone can help increase their confidence.
- **Participating in the arts can be seen as a form of play**
For adults as well as children, play is a big part of how people learn about the world around them and develop new skills. Arts therapists see play at all ages and in its different forms as psychologically healthy.

“I think she just feels really empowered, happy.

It’s a place in her life that she doesn’t easily

get to on her own or in her usual day-to-day

activities. It’s a very unique and precious thing.”

- **Involvement in the arts can help someone to develop social skills**
The arts often provide an opportunity to work in groups. This encourages the development of useful social skills, such as taking turns, listening to others, eye contact and other forms of interaction. These skills form the basis of valuable and meaningful relationships.
- **Art can be a trigger for social change**
Throughout history, art has often been a trigger for social change. Involvement in projects that tackle issues or promote choices and needs can provide an opportunity for people with PMLD to be indirect self-advocates.
- **Participation can be fun**
Experiencing or participating in the arts can be extremely enjoyable and is a fun way to spend time.



Things to consider when working in the arts with people with PMLD

If you are a professional working with people with PMLD, there are some key issues that you need to consider:

- take time to watch, listen and learn
- think about other people
- make it clear why you're there
- prepare
- be flexible
- be multi-sensory
- focus
- work at close proximity
- make time for reflection
- be person-centered
- change the space
- take risks.

Take time to watch, listen and learn

The more time you have and the better you know each other, the richer the communication and therefore the experience. The longer you have to prepare for, and to actually work with, individuals with PMLD, the richer the experience will be for both of you. Work carried out over a whole day, or a week or a term, is likely to be far more effective than an hour-long performance – no matter how brilliant. Take time to get to know the individuals you are working with, and vice versa.

Think about other people

Most people will have a supporter or maybe even a member of their family with them. Use their knowledge of the person and how they communicate – the supporter may have ideas about how the person will join in or what they may get from a session.

It is also good to bear in mind that the individual may respond to you and to what they are doing in a way that their supporter may not have seen before. Equally, you may observe reactions and interaction that their supporter misses. This can be wonderful because it means that your efforts can lead to the people you work with being seen in a new light – freed, just a little, from the labels that are so often applied to them.

“By looking at small movements and sounds that the child made we could effectively help them to really take part in what was going on.”

Make it clear why you're there

If you are planning sessions over a period of time, can you give the person a clear indication that they are with you for a particular reason? For example, you may leave a card with your photo and something they can touch, like a paintbrush. They can then prepare for their time with you by looking at your photo and touching the brush while their supporter reinforces that “next we are going to be painting with X”.

Prepare

It is a good idea to have a clear idea of your goals for a performance or session, and a plan to show how you aim to achieve them. However, you must also remain prepared to depart from the plan in order to adapt to the different personalities you will work with.

Prepare your audience or participants, and the people who will accompany them, for the workshop or performance in advance. You can do this through a briefing, including training sessions, printed items, video, posters, session outlines and references to informative websites.

A great deal of work with people with PMLD takes place in the presence of others, so it is vital to develop the understanding and co-operation of family members, teachers and support workers. The attitude of these companions can have a significant influence on the reactions of the people with PMLD, and briefing them is a big part of getting their support. This can lead to suggestions for follow up activities, and ensure that a workshop or performance is not just a one-off event that is quickly forgotten. Rather, it can be the key that opens the door to other activities, providing the motivation people need to explore further.

Be flexible

- Any work you do should be readily adaptable to the needs of the different individuals you work with. Be observant, think laterally, and always be prepared to depart from the plan.
- Don't try and work with too many people with PMLD at a time. The larger the group, the more difficult it is to adapt to individual personalities.
- Always try to offer a choice of activities.
- Always look for consent.
- Take care not to push on with an inappropriate activity simply because the person involved is passive or compliant. Ask: is this really connecting? And, if not, then what would be? Activities with people with PMLD are most effective when they are about give and take – when they are truly playful.

“It doesn’t have to be verbal. It’s an outlet for people to be able to express themselves which they might not otherwise have.”

Be multi-sensory

Think about all the different ways people can engage in the activity. Can you incorporate all the senses? Think about touch, taste and smell, as well as sight and hearing. Look at ways to maximise involvement and engagement.

Focus

To get someone to focus on a particular activity, try to minimise any other distractions. Keep the periods of time that you need someone to concentrate short, but observe their engagement – if they want to carry on, adapt or change the activity and go with it.

Work at close proximity

It is important that work with people with PMLD takes place at close proximity. Any event, no matter how awesome, is unlikely to have any relevance to most people with PMLD if it takes place some distance from them.

Make time for reflection

Allow time for the person to respond. If they do not seem to be engaged, leave a little more time before you move on – people may need quite a while to engage and respond. Remember, you do not have to fill every moment with meaningful activity. It is helpful to allow time for everyone to reflect and take time out. How you manage this will depend on what you are doing together.

People with PMLD, as with all of us, have off days and may not want to join in. Indeed, joining in per se may not come easily to them. It is vital for your own confidence that you develop strategies for dealing with resistance or passivity. There is no single approach, but one example might be to allow the person to withdraw to another part of the room, keeping their space open and occasionally inviting them back into the activity. Allow the activity to draw them in.

It is also useful to get as much feedback as possible from your primary audiences – the people with PMLD. Such feedback might take the form of a video that you study and discuss to gauge reactions, provided you have got everyone’s consent. Of course, you must also obtain feedback from the secondary audience – such as support workers, family members and teachers. This might come in the form of debriefing sessions, interviews, feedback sheets, or an online forum. Each project should allow time for reflection, preferably facilitated reflection, so that you can further develop your practice.

“It doesn’t matter what you bring to the session, everything seems of value. Everyone’s got something to offer. It’s nice when we get these opportunities to feel part of a group.”

Be person-centred

Work from the point of view of the person with PMLD. Try to create work that is appropriate to the age, experience and modes of communication of the individual. At the same time, put yourself in their shoes – try to experience the activities for yourself. Then ask whether any aspect seems patronising, dull, or unpleasant. If this is the case, why should it appear any less so to a person with PMLD?

Change the space

Obviously it is important to make sure that the space where you are working is safe. For example, make sure that there is nothing to trip over or nothing that could fall over onto someone. Create a stimulating environment, with features to address each of the senses. This can yield astonishing reactions and needn’t be a complicated or expensive business. You can achieve a great deal with a suspended parachute or lengths of sari fabric, plus some appropriately placed lamps. Making changes to the look, feel and even smell of a familiar place can signal that something new and different is going to happen.

Take risks

Be prepared to do away with convention! You may have planned to do some painting with brushes, but if the person enjoys dipping their fingers or feet in the paint and working that way, go with it. We should, of course, pay the greatest attention to issues of health and safety, but it is also important to present work that is challenging. It is also essential to be respectful of the family members or professionals you are working with. Nonetheless, experience shows that the capacity of people with PMLD to concentrate and to react is frequently underestimated.

Sometimes, support workers think that their duties are discharged once the practicalities of feeding, changing and medication are taken care of – you can help them to understand that people with PMLD have as much right to take part in creative and imaginative activities as the rest of us. You can show that they frequently respond to these approaches in ways that challenge our preconceptions of them.

Working with wheelchairs

- Make sure that things are at the right height so that people in wheelchairs and those working from floor level can actively join in too.
- When working with wheelchair users it is good to work face-to-face as much as possible, and not tower over the person in the chair.
- It is great to get wheelchair users out of the chairs where possible. For example, you could work with them in foam blocks, or in hammocks, or in a hydro pool. Although this can involve hoists and the like, it can add to the sense of anticipation, excitement and certainly allows more possibilities for a face-to-face working relationship. It also contributes to overcoming the physical dangers that people with PMLD experience as a result of lack of movement.

Consent

No one should be filmed, photographed or recorded in any way without their consent, or the consent of someone who is their advocate.

- Read [Mencap's factsheet on consent for video and photographs](http://www.mencap.org.uk/consent) at www.mencap.org.uk/consent

The arts are an expression of who we are. They celebrate difference and flourish through unique voices and the expression of unique experiences communicated in fresh, original and often unexpected ways. All artists are part of a process of discovery, invention and communication. Working in the arts with people with profound and multiple learning disabilities challenges and rewards everyone involved profoundly.

Further help

- **Order a copy of Mencap's DVD 'In the Moment'.**
Contact Mencap's trading team at trading@mencap.org.uk or 020 7696 6993. The DVD is priced at £15.00, including posting and packaging.
- **Order Mencap's 'Doing Arts' booklets.**
The five booklets include **Doing Drama, Doing Photography, Doing Dance, Doing Visual Art and Doing Music**. For more information or to order contact **Gus Garside** at gus.garside@mencap.org.uk or call **01444 449089**.
- **Mencap's factsheet on 'Learning disability and arts therapies'** at www.mencap.org.uk/factsheets
- **The Unlimited Company**
Website: www.bild.org.uk/storytelling
- **Oily Cart**
Website: www.oilycart.org.uk
- **Project Art Works**
Website: www.projectartworks.org
- **Soundabout**
Website: www.soundabout.org.uk

Contacts

England

If you live in England and would like more information on learning disability, you can contact:

The Learning Disability Helpline

Telephone: 0808 800 1111

Typetalk: 18001 0808 808 1111

Email: help@mencap.org.uk

If English is not your first language and you would like access to a translation service, please contact the Mencap helpline and ask for Language Line.

Northern Ireland

If you live in Northern Ireland and would like more information on learning disability, please contact:

Mencap's Information Service

Telephone: 0808 800 1111

Email: mencapni@mencap.org.uk

Wales

If you live in Wales and would like more information on learning disability, please contact:

Wales Learning Disability Helpline

Telephone: 0808 800 1111

Email: information.wales@mencap.org.uk

Scotland

If you live in Scotland, and would like more information on learning disability, please contact:

ENABLE Scotland

Telephone: 0141 226 4541

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