NHS Education for Scotland

Learning Byte

Breaking the barriers

Communication with people with profound and multiple learning disabilities

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Welcome to this Learning Byte!

This Learning Byte draws on information from a range of sources on the communication needs of people with profound and multiple learning disability (PMLD). It looks at the communication barriers they often experience and explores techniques and tools to support meaningful interactions.

What is a Learning Byte?

It's an alternative to a traditional, structured, beginning-to-end course that is available in bite-sized chunks in the workplace. You can access it in different ways – on a PC or mobile device, for instance – and at any time.

Who's it for?

We've developed this Learning Byte for students not only of learning disabilities nursing, but also those from all other fields of nursing – adult, mental health and children's. It will also be relevant for any staff who work with people with PMLD.

What will it give me?

The Learning Byte provides you with a brief guide to communication with people with PMLD. By the time you've completed it, you will:

- understand the different and highly individual ways in which people with PMLD communicate
- reflect on your practice and how you can develop skills to enable people with PMLD in different care settings to experience positive social interaction and maximise their communication potential
- understand how the communication skills of someone with PMLD can lead to him or her being socially disadvantaged and deprived of opportunities to communicate preferences and choices
- accumulate evidence to help you remove communication barriers and enable service users to be active participants in their care and support.

What is profound and multiple learning disability?

PMLD is commonly defined as applying to people whose intelligence quotient is under 20.[1] People with PMLD have very limited understanding of the world around them and live with impairments such as severe sensory and communication difficulties and significant motor problems.

What is the prevalence of PMLD?

In 2012, 26,236 adults with learning disabilities were known to local authorities across Scotland.[2] Estimates suggest the prevalence of people with mild to moderate learning disabilities in Scotland is around 20 in every 1000, and for people with PMLD in the region of 3–4.

The Royal College of Speech and Language Therapists estimates that about 80% of people with severe learning disabilities never acquire effective speech.[3] People with PMLD are among those with learning disabilities who are most likely to have some form of communication difficulty.

Pause for reflection

Using the above definition of PMLD and applying any additional knowledge you have about this client group, what can you infer about the impact of PMLD on someone's communication skills?

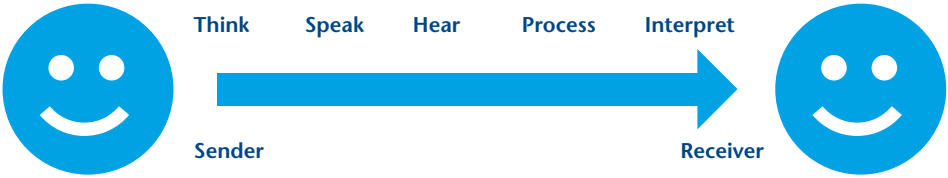
You may have mentioned that people with PMLD will have difficulties understanding spoken language and are likely to have problems processing written or visual information. You may also have made reference to difficulties in expressing themselves and commented on the impact of sensory and physical difficulties, such as visual or hearing impairment and movement restrictions, on their communication.

Perhaps you mentioned that this is a lifelong condition and, as such, people may have had limited opportunities to develop conventional communication skills and/or compensatory techniques.

All of these issues can have a significant impact on the communication skills of someone with PMLD. It's important that we're able to accurately assess their effects so we can identify and implement the most appropriate means of communication support for each individual.

What is communication?

Communication can be defined as a two-way process in which messages and information are sent and received. Sometimes it's shown as a chain, with each link representing an element that needs to be successfully completed for the information to pass accurately from person to person – something like this:



This shows the number of processes involved in a simple exchange of information. All of them require the speaker and receiver to have a "shared code" – a language they can each use and understand.

Other factors necessary for an exchange to be considered successful include the desire and opportunity to communicate and the exchange being pleasurable for both parties.

Pause for reflection

Reflect on links in the communication chain that may break down when one of the communication partners is a person with PMLD. Make a list of the broken links you've identified.

You might have referred to people with PMLD having problems with:

- receiving the message due to visual, hearing or attention problems
- understanding or interpreting the message because of cognitive impairment
- working out what information they wish to send (they find it difficult to correctly interpret their body's needs, such as hunger or thirst)
- expressing what they want or mean due to lack of speech and/or other means of getting their message across
- taking part in opportunities to communicate because they appear to choose to engage in repetitive self-stimulating behaviours rather than being sociable.

All of the above are potential areas of breakdown when communicating with someone with PMLD, but they are based on a value judgement of the skills of only one of the communication partners – the person with PMLD.

It's important when examining communication breakdown that we look at the relationship between the breakdown and **both** of the communication partners' skills, not just those of the person society might perceive as having the "problem".

Activity: Describing things differently

Take each of the accounts of communication breakdown identified above and think how they can be described differently by identifying the actions of the **non-impaired** communication partner (who could be you). We've completed the first "changed statement" to let you see what we mean.

Original statement	Changed statement
Difficulty receiving the message due to visual, hearing or attention difficulties	Difficulty receiving the message because the sender has not taken into account visual or hearing difficulties or ensured that the environment is suitable to the person's sensory/attention needs
Difficulty understanding or interpreting the message because of cognitive impairment	
Difficulty working out what information they wish to send (they find it difficult to correctly interpret their body's needs, such as hunger or thirst)	
Difficulty expressing what they want or mean due to lack of speech and/or other means of getting their message across	
Difficulty taking part in opportunities to communicate because they appear to choose to engage in repetitive self-stimulating behaviours rather than being sociable	

You'll recognise that although every link in the chain is open to breakdown, many can be mended **if** the communication partner facilitates the communication process effectively. Communication is a two-way process, but in this situation, responsibility isn't equally shared. The communication partner – **you** – must carry the greater responsibility if communication is to be effective.

What are communication skills?

So far, we've considered the communication difficulties people with PMLD might experience. Now we're going to look at the communication skills they possess.

Often we associate two-way communication with spoken and written words. Generally, people with PMLD can't use these routes effectively, but humans also communicate in many other ways.

Activity: Human communication

Watch two people having an informal conversation. Draw up a list of the attributes of communication they use, in addition to spoken words.

You may have included:

- non-verbal (paralinguistic) cues, such as intonation, tone of voice, gesture, facial expression and body language, eye contact or eye pointing, and touch
- vocalisations, such as shrieks of excitement or groans of despair
- additional resources, such as pictures or written words they refer to.

These are important aspects of communication. People with PMLD might not have (much) speech, but may be able to use the other aspects.

As you continue through this Learning Byte, it's important to remember that each person will be individual in their communication skills and styles. Any care plans you formulate for an individual should reflect this uniqueness.

How does communication develop?

We'll look now at interpreting information and understanding two key stages of communication development.

Activity: Identifying pre-intentional versus intentional communication

Consider the following statements.

- The behaviour doesn't have a communicative function for the person.
- The person understands that his or her behaviour gains responses from others and that different behaviours elicit different responses.
- The person isn't attempting to elicit a response from others.
- The person vocalises when activities start or when something is taken away but doesn't appear to direct them at anyone.
- The person is sending a planned message to gain a response from others.
- The behaviour has a communicative function for the person.
- The person's behaviour sends messages to others, but they are unintentional.
- The person realises that vocalising, reaching, gestures and such like have an effect on others.
- The person responds to physical discomfort by wriggling or becoming agitated: he or she is observed doing this even when not aware that someone else is present.

Now divide the statements into two groups in the appropriate columns overleaf according to whether you feel the behaviour has, or has not, a communicative function for the person.

The behaviour has a communicative function for the person	The behaviour doesn't have a communicative function for the person

Pre-intentional communication is a normal, very early stage of communication development and is a precursor to **intentional communication**.

At birth, babies are termed unintentional or pre-intentional communicators. They cry when they're hungry or wet, but initially do so without expecting or aiming to elicit a response from anyone – they are simply expressing what their body tells them they need. Adult carers assign meaning to the baby's cries – identifying the problem ("Oh, you must be hungry") and providing the solution and comfort ("There, that's better") when the baby is fed and has stopped crying.

The adult carer is solely responsible for interpreting the baby's vocalisations and responses during this period. But the baby is learning that when he or she makes a noise, someone responds. This baby is showing early signs of intentional communication, which usually happens consistently around the six-month stage of development.

It's important to say that we're not comparing an adult with PMLD to a baby. Rather, we're using what we know about the developmental process to help us understand how best to support adults we're working with at the stage of development they've successfully reached.

Many people with PMLD remain at a pre-intentional stage of communication. It would be easy to assume they don't have anything to "say" and aren't able to express their views about everyday experiences. The next section will help you decide whether this is true.

Activity: How do pre-intentional communicators share information?

Think about a service user who, based on the definition above, you believe is at a pre-intentional level of communication. If you can, try and answer the following questions about him or her.

Question	Answer
What is their favourite food?	
What is their favourite drink?	
Which music/singer do they prefer?	
What are their preferred activities – for instance, hand-massage, singing, having a bath?	
Which food do they dislike?	
Which drinks do they dislike?	
Which types of music are they not keen on?	

You'll probably have been able to answer at least some of these questions with confidence if you know the person well. But your responses need to be verified by evidence to be valid and helpful to the person and people supporting him or her.

Activity: Providing evidence

Complete the table again, but this time enter in the third column evidence to support your claims. What is it the person does that enables you to be sure of your responses? You will need to observe the person closely to collect this evidence. Be as detailed as you can: for example, don't enter "facial expression" as evidence; instead, you should write something like "his lip curled slightly and he made a grimacing face". Note down even the smallest reactions so you can see if they form a pattern of responses.

Question	Answer	Evidence
What is their favourite food?		
What is their favourite drink?		
Which music/singer do they prefer?		
What are their preferred activities – for instance, hand-massage, singing, having a bath?		
Which food do they dislike?		
Which drinks do they dislike?		
Which types of music are they not keen on?		

The more detailed the information you're able to produce about the person and his or her responses to items and experiences, the more meaningful and reliable your observations are likely to be.

You should compare your responses to your colleagues' and consider any differences. Identifying the way people consistently react when they like or dislike something can help you identify their feelings about a wide range of activities and experiences.

Activity: Evaluating the approach[a]

What difficulties might occur in using this approach to interpret someone's likes and dislikes?

You may have considered the following.

- Some of the responses you've captured may reflect what people feel at a given time. Just because they appeared not to like orange juice today doesn't necessarily mean it should never be offered to them again. Different feelings at different times might explain why you and a colleague perhaps recorded different responses. This emphasises the importance of collecting as much detail as possible about what you observe. And always be careful not to limit people's opportunities for experiences on the basis of a brief assessment.
- People's health may affect their responses on any particular day. Those in a post-ictal (after a seizure) state, for example, may find their sense of taste and general responsiveness altered.
- On occasion, caregivers can project their own likes/dislikes onto people: a caregiver's personal dislike of orange juice may have resulted in a negative face when offering it to a service user, and this may have been reflected in his or her response.
- You may simply have been expecting to see a certain response and that is what you observed – this is called confirmation bias.

You can see that critical self-reflection is required when carrying out this type of approach.

[a] *This activity is based on the assessment approaches found in the Pre-verbal Communication Schedule[4] and the work of Coupe O'Kane and Goldbart.[5]*

What is intensive interaction?

The principles of intensive interaction are based on observations of normal social communication development between parent and child. Intensive interaction provides much-needed social communication opportunities and offers people with PMLD a chance to develop their non-verbal communication and turn-taking skills in a naturalistic environment.

The approach works by carefully observing the person's regular behaviours, then linking with them by responding and joining in. It's a shared approach to communication led by the person's behaviours and responses rather than those imposed by others.

What is intentional communication?

Symbolic understanding develops with intentional skills.

Look at this list.

- a coloured photograph of a cup
- the written word "cup"
- a miniature cup
- a line-drawing of a cup
- a coloured symbol of a cup
- a black-and-white symbol of a cup
- a black-and-white photograph of a cup
- a real cup.

Activity: Symbolic development

Organise the list into a hierarchy, placing the item you think is most easily understood at the top and working down towards the one you feel requires most abstract thought to understand.

Compare your list to ours', which is in hierarchical order with the most concrete element at the top:

- a real cup
- a miniature cup
- a coloured photograph of a cup
- a black-and-white photograph of a cup
- a coloured symbol of a cup
- a black-and-white symbol of a cup
- a line-drawing of a cup
- the written word "cup".

Was your list different?

You perhaps felt that black-and-white items would be easier to understand than coloured ones, or that line-drawings would be easier than symbols? In fact, representations that look most like the real object are easiest to understand. Coloured pictures are therefore generally easier than black-and-white.

This development hierarchy can help us identify tools to augment or enhance communication for someone with PMLD. Always remember, though, that people are individuals: the development hierarchy is true for most people, but some may find particular items easier to understand because of, for example, visual difficulties.

We can use our knowledge that the real and miniature objects are easiest for people to understand to support someone to recognise what is going to happen next in their day. We call these items Object Signifiers, or Objects of Reference.

An Object of Reference is one that comes to represent a specific activity or event: a sponge, for instance, might become an Object of Reference for bath-time.

An Object of Reference must be used consistently to be effective and should be given to the person prior to the activity on each occasion. They should be identified for common activities, as the person will only be able to make associations if many opportunities to do so exist.

You need to consider an individual's preferences and experiences when thinking about which objects to choose. There's no value in selecting maracas to represent a musical group if the person regularly plays tambourine. Activities also need to be motivating for the person, so he or she can consider the system to be of value.

Real or miniature objects are the most effective signifiers for many people because they're the most concrete, but this is not always the case. Some activities, like trampolining, for example, don't lend themselves to real or miniature depictions. In cases like this, something less concrete can be identified, as long as it is used consistently.

Each object should be clearly labelled so everyone refers to it in the same way. A swimming costume may be selected as an Object of Reference for going swimming, but without clear direction, staff members may refer to the activity as “going for a swim”, “going to the pool” or “going to the baths”. Using a key word to consistently represent the activity will help to promote the person’s understanding.

Objects of Reference can enable people to use several senses, such as touch, vision and sound. Visual information might not be helpful for people with PMLD who have sensory impairments, so tactile signifiers may be more appropriate. Abstract items can be effective as long as they are used consistently.

Objects of Reference can give the person consistent and meaningful information about what is happening in everyday situations, providing a sense of security, potentially reducing challenging behaviour and, over time, enabling the person to make meaningful choices about day-to-day activities: he or she may, for example, learn to select a signifier from a choice of two to indicate a preferred activity.

How are health needs communicated?

How can you link what you've learnt about the communication skills of people with PMLD to supporting their physical, emotional and mental well-being?

You can verify the evidence you gathered from observing people's behaviours to support a better understanding of their health needs by using the Disability Distress Assessment Tool (DisDAT),[6] which is designed to capture the ways in which someone presents when feeling content and when distressed. Subtle changes in a person's presentation can alert us to signs of distress – DisDAT provides a way of objectively recording this information.

Activity: Using DisDAT

Click on this link
(or go to **http://www.stoswaldsuk.org/media/57806/DisDAT-20.pdf**) and complete a DisDAT chart for a person you know who has PMLD.

DisDAT is designed to capture the views of all the key people in the person's life, enabling consensus on what each behaviour signifies to be reached. You'll need to complete this activity with members of your team and family carers, friends and other key people.

Critically reflect on your own skills in drawing together the information and helping others to negotiate and agree the final completed form.

What are personal communication passports?

Personal communications passports were developed by Sally Millar of CALL Scotland in 1991.[b] They're widely used in home care, social work, education and health.

Communication passports make sense of formal assessment information and record important things about people in an accessible, person-centred way. According to CALL Scotland, passports aim to:[7]

- present the person positively as an individual, not as a set of "problems" or disabilities
- provide a place for the person's own views and preferences to be recorded and drawn to the attention of others
- reflect the person's unique character, sense of humour etc.
- describe the person's most effective means of communication and how others can best communicate with, and support, the person
- draw together information from past and present, and from different contexts, to help staff and conversation partners understand the person and have successful interactions
- place equal value on the views of all who know the person well, as well as the views of specialist professionals.

A personal communication passport is extremely beneficial for staff working with a person with PMLD. It makes communication much easier and enables staff to gain a better understanding of the unique individual they're working with.

The CALL Scotland website provides guidance on how to compile a personal communication passport for people with PMLD.[c] You should work in partnership with the person's speech and language therapist when doing so.

[b] *You can find out more about CALL Scotland by visiting: http://www.callscotland.org.uk/Home/*
[c] *Visit: http://www.communicationpassports.org.uk/Creating-Passports/*

Summary and conclusion

You've had the opportunity in this Learning Byte to consider some of the many ways in which someone with PMLD can communicate. You've also identified why they may choose to communicate. And you may have thought about opportunities people with PMLD are, or should be, offered.

The model of communication by Money and Thurman[8] below summarises the importance of these three areas – means, reasons and opportunities – being present to enable successful communication.

Money and Thurman's model of communication[8]

As you work with people with PMLD and come to understand more of their personal styles of communication, you might want to draw this information together in a way that's accessible to everyone who interacts with them.

Activity: Paper to practice

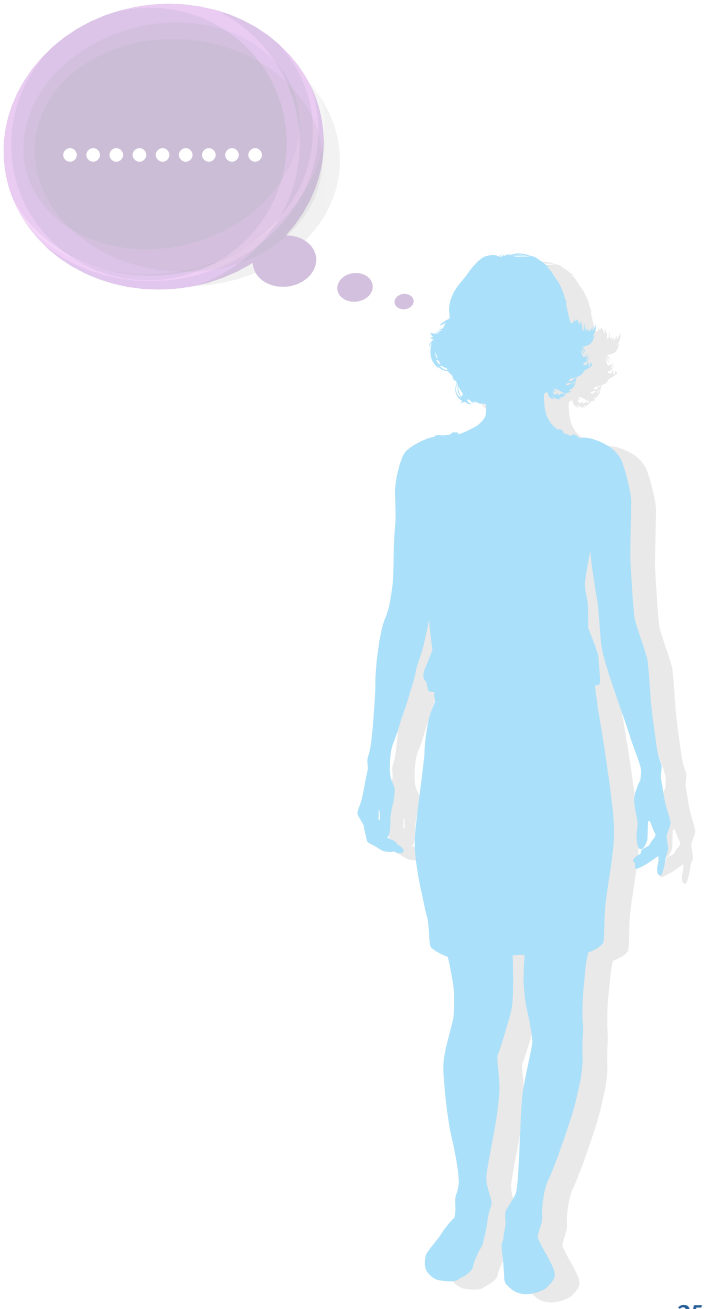
Well done for completing the Learning Byte!

Reflect on your learning. Identify five key areas in which your knowledge has developed, then write one objective for each, outlining how you can implement some of what you've learned in practice. It might be about developing yourself or your service to provide good care and support. Discuss it with your lecturer, supervisor, mentor or manager.

Key learning – I have learned about:	To develop this area of practice, I will:
1.	
2.	
3.	
4.	
5.	

References

1. Mansell, J. (2010). Raising our sights: services for adults with profound intellectual and multiple disabilities. Department of Health, London.
2. Scottish Consortium for Learning Disability (2013). eSAY Statistics Releases. SCLD, Glasgow.
3. Royal College of Speech and Language Therapists (2003). Communicating quality 3: RCSLT's guidance on best practice in service organisation and provision. Royal College of Speech and Language Therapists, London.
4. Kiernan, R. & Reid, B. (1987). Pre-verbal Communication Schedule. NFER-Nelson, Windsor.
5. Coupe O'Kane, J. & Goldbart, J. (1998). Communication before speech: development and assessment. David Fulton Publishers, London.
6. Regnard, C., Matthews, D., Gibson, L., & Clarke, C. (2003). Difficulties in identifying distress and its causes in people with severe communication problems. International Journal of Palliative Nursing 9(3): 173–6.
7. CALL Scotland (2015). Personal communication passports: about [website]. University of Edinburgh, Edinburgh (http://www.communicationpassports.org.uk/About/, accessed 27 February 2015).
8. Money, D. & Thurman, S. (1994). Talk about communication. Bulletin of the College of Speech and Language Therapists, 504: 12–3.



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