

Communication Inclusion: Barriers and Facilitators

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Profound Intellectual Impairment and

Visual (often cortical): 85% (van Splunder et al, 2003)
Hearing: 25-35% (Evenhuis et al, 2001)
Epilepsy: 50% (Lhatoo & Sander, 2001)
Mental health problems: 11- 52% (Cooper et al, 2007)
Self Injurious Behaviour: 5% of adults with ID (Cooper et al, 2009) and likely to be higher in those with profound impairments (Oliver et al, 1987).
Increased prevalence of motor impairments and health complications.

Communication

People with profound and multiple learning disabilities are likely to have significant communication difficulties. (Lacey, 1998)

What does this mean in practice?

- High dependency on others' interpretations
- A level of awareness of their own intentions which is low or difficult to determine;
- A level of comprehension which is low or difficult to determine;
- Limited, if any, independent ability to use a formal linguistic code in any modality;
- Inconsistent ways of communication leading to ambiguity of meaning;
- Inability to contradict an interpretation.

(adapted from Grove et al, 1999, p.190-191)

...or put more positively

- The person has a range of behaviours that can be interpreted by other people.
- They may have some goal directed behaviours we can interpret as meaningful.
- They may have some gestures, signs or symbols they use to communicate.

(Coupe-O'Kane & Goldbart, 1997; Iacono et al, 2009)

and in understanding:

- The person is likely to respond emotionally to the emotional tone of other people's messages.
- They may be able to extract meaning from other people's intonation and facial expression.
- They may have some understanding of language in context ("situationally-cued"). (Coupe-O'Kane & Goldbart, 1997; Iacono et al, 2008)

This suggests ...

The skills of communication partners are crucial to the inclusion of people with pmlD.

- Familiarity
- Access to background information
- Willingness to allow time
- Responsiveness
- Expressiveness
- Ability to use contextual supports.

Barriers to Inclusion

- Within the physical environment
- Within the individual
- Among people in the environment

What can we do?

- A. Improve knowledge and awareness in the wider community,
- B. Enhance the skills of key communication partners, including staff,
- C. Improve the communication skills of people with pmlD.

A. Community Facilitators 1

- “‘community’ is founded upon relationships rather than a place or an activity.” (Wightman, 2009)
- Skilled and responsive communication partners promote and model community engagement, AND plan for it.
- Community based experiences need to be both *physically* and *intellectually* accessible.

Community Facilitators 2

- Targeted work with community organisations can expand the pool of communication partners.
- Interaction with unfamiliar people can be supported by [communication passports](#).

Communication Passports

- “A positive way of supporting people with sensory and communication disabilities who cannot speak for themselves by collecting together important information about them and making this accessible to others with whom they may interact” (Millar, 1997)
- www.communicationpassports.org.uk/Home/



Key things you need to know about me...



1. I need
2. I mustn't
3. I like
4. I don't like

From CALL Centre page 1



How I communicate

- Understanding other people
- Getting my own message across

From CALL Centre page 5



How you can help me with communication

- Please DO
- Please DON'T

From CALL Centre page 6

Communication Passports

- The process of collecting and organising the information should involve all relevant people, including the person with pmlD.
- The process of making the passport acts as a training activity.
- As yet, there is little formal evaluation, but there are many useful articles and web-based resources.

B. Communication Partners

Key communication partners for many people with pmlD will be paid and informal carers.

Attributes identified above:

- Familiarity
- Access to background information
- Willingness to allow time
- Responsiveness
- Expressiveness
- Ability to use contextual supports.

What do we know about staff?

- Under and overestimate comprehension,
- Underestimate the extent of hearing loss,
- Use more language and less NVC than they think,
- Have difficulty in identifying nonverbal signals, and
- See positive changes in communication as resulting from changes in clients rather than in themselves.

(Purcell et al, 1999; Bradshaw, 2001)

Training

- Familiar people, including parents, should be involved in training. (Goldbart & Caton, 2010)
- Training involves attitudes (willingness to allow time, responsiveness) as well as skills.
- One-off teaching sessions from “experts” tend to be ineffective (Bradshaw, 2008).
- Combined hands-on and formal input is viewed as more successful.
- Evaluated examples e.g. Bloomberg et al (2003) and Chadwick and Jolliffe (2008).

C. Facilitators for people with pmlD

Why do we have greatest expectation of change from people with most difficulties?

Intervention approaches with SOME research evidence

- Switching
- Intensive interaction
- Objects of reference
- Creative arts: e.g. music, story-telling, narrative approaches
- Environmental modification

Switch-based approaches

(e.g. Lancioni et al, 2009)

- Small actions or vocalisations result in desirable consequences, thus developing intentionality as a precursor to intentional communication
- e.g. activating a switch by action or sound to operate a tape recorder, fan, toy.
- a good evidence base and strongly advocated in Mansell's (2010) report: *Raising our sights*.

Intensive Interaction

(e.g. Hewett & Nind, 1998; Nind & Hewett, 2006)

- Based on the highly responsive, individualised interactions between babies and their caregivers.
- Primarily a way of building up enjoyable interactions between people with complex communication needs and significant others, increasing sociability.
- Gains in communication or reductions in challenging behaviour are secondary.
- A growing evidence base.

Objects of Reference

(Sole source of evidence: Jones et al, 2002)

- Objects which are used to represent people, situations or events in order to support communication.
- Aim for increased awareness of associations between the objects and people, activities, etc., leading, eventually, to expressive use.
- Used to signal what is about to happen, to aid memory and for communication.

Creative Arts

(modest evidence from references cited)

- **Multi-sensory drama/sensory stories** (Grove & Park, 1996; Mitchell & van der Gaag, 2002)
Multisensory input and the heightened arousal involved in drama or story telling are used to facilitate access the story
- **Music therapy** (e.g. Graham, 2004). Similarities between speech and music, in, e.g., intonation pattern and turn-taking are used to develop interaction and communication..

And finally, for community inclusion,

Having a positive communicative repertoire, such as a smile and recognisable greeting is always helpful.

And not just for the person with pmld!

Contact me for reference list

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Many resources are listed in the communication guide at:

www.mencap.org.uk/communication