



Good practice 2: Learning about ways in which you can communicate with people better

The ability to successfully lodge a complaint about something is closely linked to the ability to communicate effectively. Many people with learning disabilities face significant challenges in this area – particularly those with profound and multiple learning disabilities and those who have been labeled as highly challenging. **Jean Ware (2004)**¹ explores the problems faced when trying to obtain the views (defined as an opinion, belief, standpoint, notion or idea) of people with profound and multiple learning disabilities. She points out that:

A view about an event, is then, potentially different from a reaction to it. Consequently somebody communicating at a pre-intentional level who reacts to an event (ie someone who has no intention to communicate their reactions) is not, according to this definition, 'expressing a view'
Ware 2004 (p176)

She also points out the high degree of inference or guesswork required when interpreting such communication and suggests there is a need for honesty in acknowledging the limitations of what can be achieved when seeking to establish the views of people with profound and multiple learning disabilities. On the other hand Beamer (2001)² suggests that:

the starting point is not a test of capacity, but the presumption that every human being is communicating all the time and that this communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions. From this perspective, where someone lands on a continuum of capacity is not half as important as the amount and type of support they get to build preferences into choices.
Beamer (2001)

People who are labeled as challenging to services also face barriers in complaining. Their behaviour, which is often a form of communication, frequently remains unheard as people try to find ways to eradicate the behaviour without listening to what is being said through it.

The emergence of disruptive or destructive behaviour is often the person's way of communicating with an incomprehensible and non-responsive world.
McGee et al (1987)³



What do we mean by communication?

All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. All people have the following specific communication rights in their daily interactions.

Each person has the right to

- request desired objects, actions, events and people
- refuse undesired objects, actions, or events
- express personal preferences and feelings
- be offered choices and alternatives
- reject offered choices
- request and receive another person's attention and interaction
- ask for and receive information about changes in routine and environment
- receive intervention to improve communication skills
- receive a response to any communication, whether or not the responder can fulfill the request
- have access to AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
- have AAC and other AT devices that function properly at all times
- be in environments that promote one's communication as a full partner with other people, including peers
- be spoken to with respect and courtesy
- be spoken to directly and not be spoken for or talked about in the third person while present
- have clear, meaningful and culturally and linguistically appropriate communications

ASHA 1992⁴

Communication is a human characteristic and an important human right. The New Oxford English Dictionary defines communication as *“The imparting, conveying or exchange of ideas, knowledge, information etc – whether by speech, writing or signs.”* Communication involves not only the sending and receiving of messages but is also a means of establishing contact, influencing others and a way to build relationships.

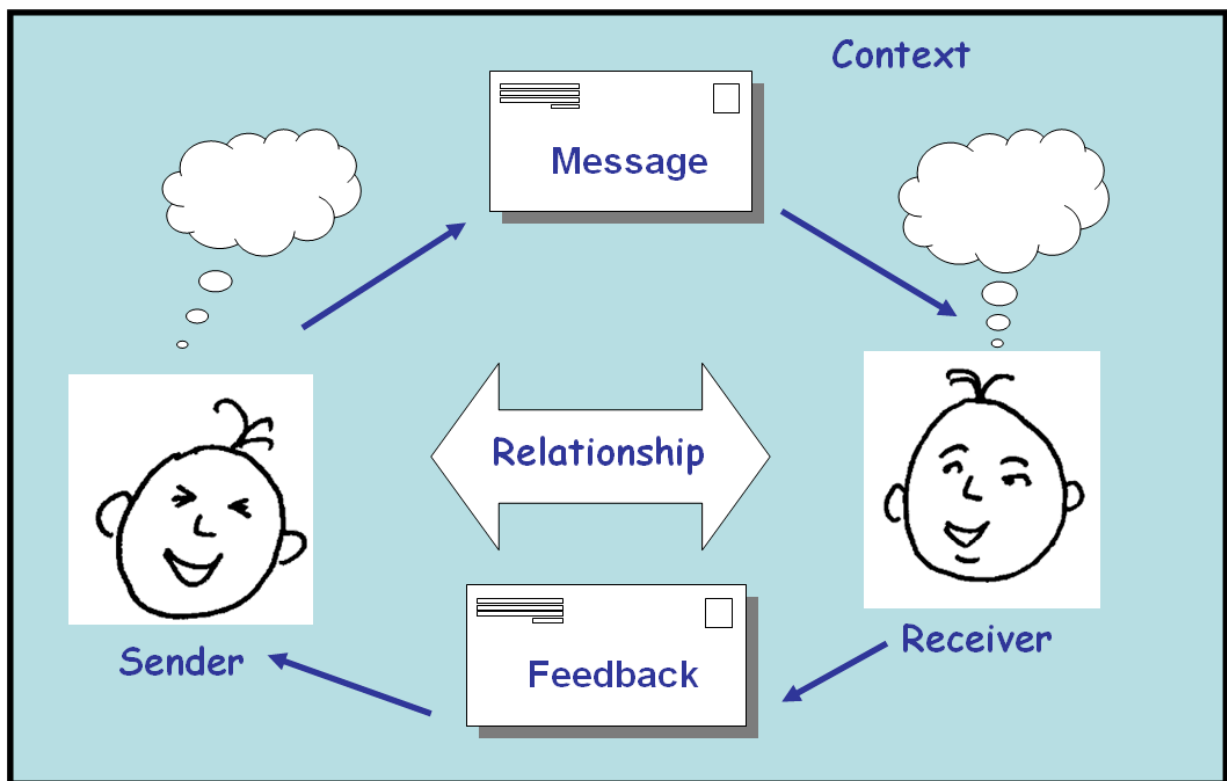
Communication and sociability are the human abilities which make the greatest contribution to emotional well being and they are also the basic tools by which all else is achieved.

Nind and Hewett (2005)⁵



Communication is the conduit between the individual and the world. It is the very cornerstone of identity formation, social engagement and human relationships. In this respect, people with profound intellectual and multiple disabilities are no different to the typically developing population. The real differences lie in the scope and level of sophistication of available skills and the role performed by significant others (the people who engage with them on a daily basis).
Karen Bunning (2009)⁶

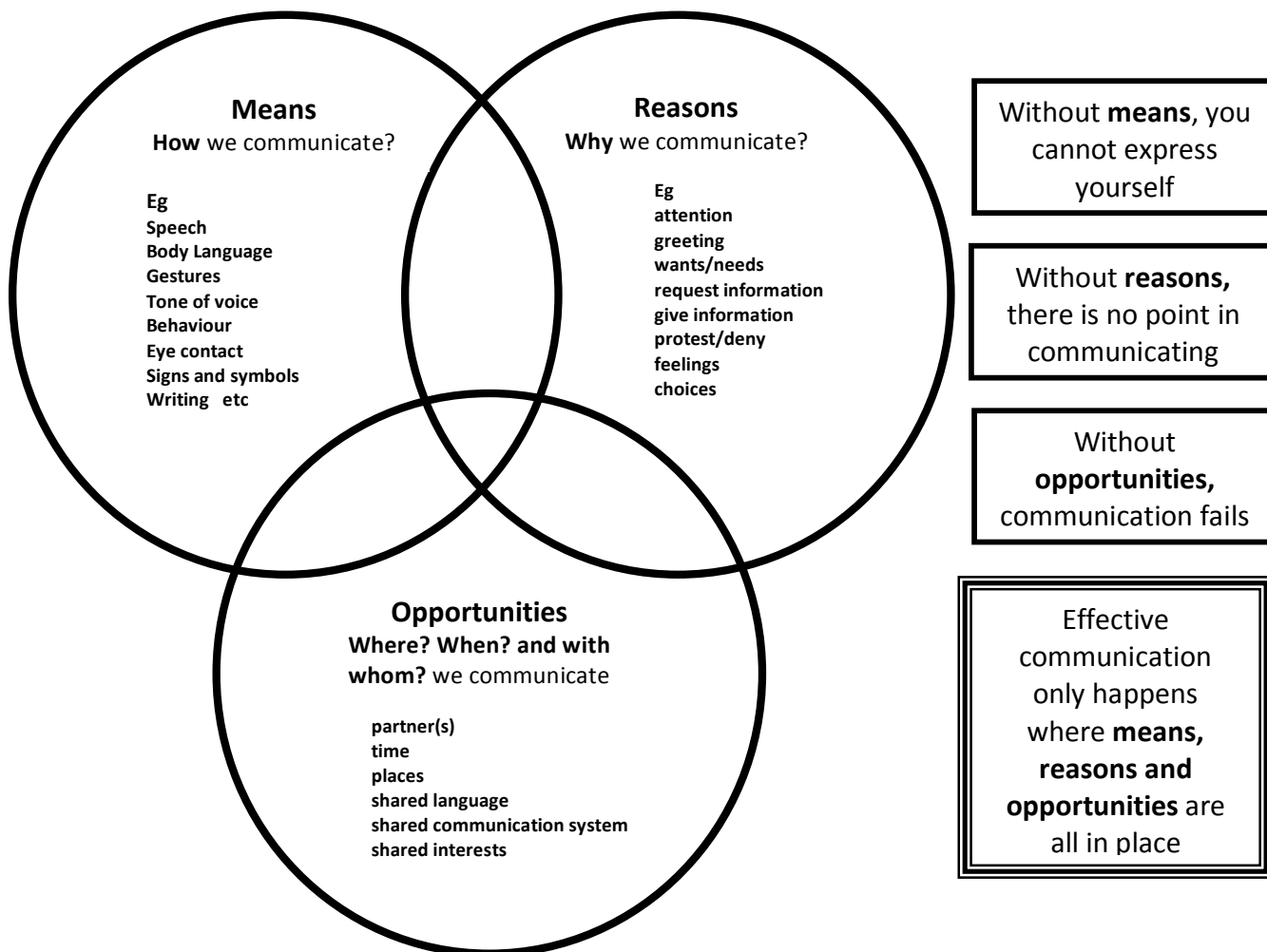
This is illustrated in a simple representation of the communication process below.



This illustrates the shared responsibility of not only sender and receiver in creating an effective communication partnership but also the impact of various factors such as relationships and context on the communicative exchange. In simple terms this means that for any individual with complex communication needs, there is a need to consider every aspect of the communication process in achieving meaningful exchanges – not just equipping the person themselves with the means by which they can express themselves.



An important framework for demonstrating the shared responsibility for communication is the means, reasons and opportunities model of communication.



Money, D. & Thurman, S. (1994) Talkabout Communication, *Bulletin of the College of Speech and Language Therapists*, 504, 12-13.

There are many reasons why people with learning disabilities require support with the whole process of communication if their views and wishes are to be 'heard' by others. One helpful distinction to draw is between those individuals who can be considered reactive communicators from those who are proactive communicators as this has a major impact on the type of communication support required.

Reactive communicators need to experience something in order to respond and are therefore only able to react to real life situations at the time they are happening. Someone else has to interpret the person's reactions. There is always a high degree of 'best guessing' in interpreting such communication.



Hence consistency of approach and sharing of pooled knowledge of a person and their communicative signals is essential. Some reactive communication is intentional whilst some is merely a reflex or a reaction to the person's circumstances and hence unintentional.

Royston has no formal means of communication by which he can tell you what he would like to eat. You offer him porridge. He spits it out. You conclude that he doesn't like the porridge through his **reaction** to it. He is a '**reactive communicator.**' However, you still don't know if he always dislikes porridge, he didn't want it on this occasion or he actually did want it but it was too salty.

Miriam cannot tell you what she wants to wear. You offer her a skirt and trousers. She stares at the skirt. You conclude she has 'chosen' the skirt. She is also a '**reactive communicator**' as she could only **react** to your offered choices. You do not know whether actually she would have preferred a dress or was staring at the skirt for a completely unrelated reason.

Proactive communicators can 'tell' you what they want before you offer it as they have both the understanding and motivation to do this as well as a way of expressing it. Although there is still some ambiguity, the person has more independence in their communication. They may still face barriers if the means and methods they use to communicate their messages are not readily accepted or understood by others (as is often the case when people's behaviour is their main means of communication)

Tamsin crosses the room, taking her communication book to a member of staff and points to a picture of swimming on a page which contains pictures of a number of activities (including a symbol for 'something else'). The member of staff promises to take her after lunch. She is able to spontaneously ask you for what she wants. She is a '**proactive communicator.**'

Effective communication is essential if we are to listen to those who are seldom heard. There are many communication strategies, tools and approaches that can be used to promote effective communication for people who are traditionally seldom heard. You can find information on some of these approaches in the resources accompanying this section (**resource one**). It is important to remember that none of these are appropriate for everybody and



there are no easy short cuts to finding out how someone may be feeling or what they may be telling you. It is always wise to seek advice from a Speech and Language Therapist in considering which approach is suitable for any individual.

As mentioned earlier, it is also important to consider the role of the communication partner and the environment in achieving successful communication partnerships. Communicating effectively with people with complex communication needs requires both creativity and reflection.

Some examples

Martin Goodwin (www.disabilitydice.co.uk) uses creative ways to listen and respond to people who do not use words to communicate. His **listening and responding poster** (see resource two) outlines steps that enable us to listen and respond to the experiences and possible views they may have about their lives or the services they receive. He will release a publication in September 2009 to explain this process further (for more information contact info@disabilitydice.co.uk). The report **I'm creative too** (see resource three) first published in PMLD Link Spring 2009, describes a creative arts and play project with children and young people with profound and multiple learning disabilities. The report describes approaches that workers used that enabled them to listen and respond to children and young people more effectively.

Sunny Arts (www.sunnyarts.co.uk, Info@sunnyarts.co.uk, 07796 005857) explored issues relating to how people with profound disabilities can be supported to make choices and how carers, staff and friends can support their choices. Their 30 minute DVD '**A Question of Choice**' can be purchased from them and covers areas such as communicating with people with profound disabilities, people's rights, person centred planning, advocacy, creative approaches, circles of support and latest technology

Challenging Behaviour Foundation (www.challengingbehaviour.org.uk) have produced a DVD '**Communication and Challenging behaviour**' which demonstrates the importance of finding different ways to communicate effectively with those who have been described as challenging.

Mencap (www.mencap.org.uk/inthemoment) have produced a DVD '**In the moment**' which illustrates the usefulness of creative arts approaches in promoting communication and emotional wellbeing for people with profound disabilities.



Further resources:

Communication approaches

Oxfordshire Total Communication website A fantastic website packed with information about different communication methods <http://www.oxtc.co.uk/>

Total Communication: Person centred thinking, planning and practice - a booklet on the subject available for download or purchase from www.helensandersonassociates.co.uk

Communicating with people with profound and multiple learning disabilities (a guide from Mencap) <http://www.mencap.org.uk/document.asp?id=9470>
Other guides are also available on PMLD and Intensive Interaction, PMLD and Multi Media Profiling and PMLD and consultation

Some communication tools and approaches that may be useful (see resource one)

Other work

MENCAP Involve Me Project

This 3 year project seeks to evaluate the role of communication in consultation and involvement of people with profound and multiple learning disabilities using 4 pilot sites (Multi-Media Profiling, Story Sharing, Getting to know you and Creative Communication).

For more information contact Louisa Whait, louisa.whait@mencap.org.uk
07944931433

Other organisations

PMLD Network c/o Mencap, 123 Golden Lane, London EC1Y 0RT **Tel:** 020 7696 5549E **mail:** pmldnetwork@mencap.org.uk **Website:** www.pmldnetwork.org

PAMIS Springfield House, 15/16 Springfield, University of Dundee, Dundee, DD1 4JE **Tel:** 01382 345 154 **Fax:** 01382 227 464 **Email:** pamis@dundee.ac.uk
Website: www.dundee.ac.uk/pamis

British Institute of Learning Disabilities (BILD) Champion House, Green Street, Kidderminster, Worcestershire, DY10 1JL **Tel:** 01562 723010 **Website:** www.bild.org.uk



Challenging Behaviour Foundation c/o The Old Courthouse, New Road Avenue, Chatham, Kent, ME4 6BE info@thecbf.org.uk **Family Support Line:** 0845 602 7885 **General Enquiries:** 01634 838739 www.challengingbehaviour.org.uk

Royal College of Speech and Language Therapists, 2 White Hart Yard, London, SE1 1NX **Tel:** 020 73781200 **E mail:** info@rcslt.org **Website:** www.rcslt.org

Your local speech and language therapy service should also be able to offer support and advice

Resources to accompany this recommendation

1. Some communication tools and approaches that may be useful
2. Listening and responding cycle
3. I'm creative too

¹ **Ascertaining the views of people with profound and multiple learning disabilities** British Journal of Learning Disabilities, December 2004, Volume 32 no 4 pp 175-179 (Ware J, 2004)

² **Making decisions - best practice and new ideas for supporting people with high support needs to make decisions** Beamer S Values into Action, London (2001)

³ **Gentle Teaching: A Non-aversive Approach to Helping Persons with Mental Retardation** McGee et al, New York: Human Sciences Press (1987)

⁴ **Guidelines for meeting the communication needs of persons with severe disabilities:** from the National Joint Committee for the Communicative Needs of Persons with Severe Disabilities. (1992). ASHA, 34(Suppl. 7), 2-3

⁵ **Access to Communication** Nind M and Hewett D (2nd edition) 2005 David Fulton publishers

⁶ **Making sense of communication** Bunning K (2009) in **Profound Intellectual and Multiple Disabilities: Nursing complex needs**, Edited by Jill Pawlyn and Steven Carnaby, Wiley-Blackwell 2009