Guidelines on Involving People with Profound and Multiple Learning Disabilities in Planning and Commissioning Services

Supported and developed by

Leicestershire Learning Disability Partnership Board
Leicester City Learning Disability Partnership Board

Speech and Language Therapy transforms lives

November 2012
Introduction

These guidelines have been put together to help everyone communicate with and involve people who have profound and multiple learning disabilities. They are part of the Communication Plan for Adults with Learning Disabilities for Leicester, Leicestershire and Rutland.

To write these guidelines we have used the PMLD Network definition to help us understand the needs of this group of people.

Definition of people with profound and multiple learning disabilities

People who have profound learning disabilities have severely limited understanding and often have

- More than one disability such as problems with seeing, hearing and movement.
- Other problems like epilepsy and autism.
- Complex health needs.
- Great difficulty communicating, with understanding limited to the situation and with their expression usually interpreted through their behaviour and/or a few signs and gestures.
- Sometimes people have challenging behaviour such as self-injury.

(PMLD Network)

However, the key thing to remember when thinking about communication and involvement for this group of people is that each person is unique and a personalised system of communication will be needed.

Due to the long term, personalised approach required to involve people with profound and multiple learning disabilities, services often find it difficult to make the adjustments required to gain their views. This means that the views of this group of people are often not heard.
Good practice in relation to communication is required if people with profound and multiple learning disabilities are to be enabled to form relationships, express their views, make choices and increase the control they have over their lives and the type of personalised services and support that they receive.

**Aim of these guidelines**

To support services and individuals to find out the views of people with profound and multiple learning disabilities and enable them to express these views in order to inform service planning and commissioning.

This paper sets out the principles to improving communication and involvement and then gives some more specific tips and guidance.

**Principles and basic facts**

Communication is a basic human right and any guidelines will be based on the Communication Bill of Rights (National Joint Committee for the Communication Needs of Persons with Severe Disabilities). People communicate in many different ways and we need to make sure all ways of communicating are equally valued.

People with complex needs communicate about the same things as everyone else such as their feelings, their needs, their likes and dislikes. The way they communicate however, is not usually with words. Their communication is usually personal to them and harder for people who do not know them well to understand.

There should be a presumption that every human being is communicating all the time and that communication will include preferences. Preferences can be built up into expressions of choice and these into formal decisions (Beamer 2001).
Gaining the views of people with profound and multiple learning disabilities can involve a lot of guess work. This means we need to be honest about the limitations of what can be achieved (Ware J. 2004).

Many people will need to experience something in order to respond and can only therefore react to real life situations at the time they are happening. This means someone else has to interpret the person’s reactions. It is therefore very important that there is a consistent approach and sharing of knowledge about how the individual communicates and the best ways of helping them to understand.

As people with profound and multiple learning disabilities vary in the extent to which their messages are intentional and their communication is through personalised systems there is a need for skilled communication partners.

It is important that family carers are treated as experts and that the individuals' “circles of support” are used.

**Top tips for communicating with people with profound and multiple learning disabilities**

There are many communication strategies, tools and approaches that can be used to promote communication for this group of people. None of these approaches will be appropriate for everyone and there are no easy short cuts to finding out how someone may be feeling or what they may be telling you.

It is helpful to seek the advice of a speech and language therapist when considering which approach is suitable for any individual. It is also important to remember that the person’s family and their regular carers will be the experts on the individual’s communication.
Many of the approaches used to improve communication have not been fully researched; therefore evidence has been gained by asking family carers and people who work with people with profound and multiple learning disabilities. (Goldbart and Caton 2010).

These tips are divided into 3 parts
- Building the views of people with profound and multiple disabilities into service planning and commissioning.
- Involving people in their day to day life and care.
- Gaining consent to use pictures and recordings.

There are also 2 appendices one on local resources and expertise and the other on national resources and useful references.

1. Building the views of people with profound and multiple learning disabilities into service planning and commissioning

The basic idea underpinning this section is that all people with profound and multiple learning disabilities will have preferences about how services are delivered and how they are cared for. These preferences will be expressed mainly through their day to day behaviour and skilled communication partners, including their main carers, will be required to interpret and record these preferences.

Overtime these preferences can be built up to give expressions of choice and then into formal opinions. The final stage is for individuals to be facilitated to express these views in a variety of ways to key people who are planning and commissioning services.

The basic framework for achieving this is set out below but it is important to remember that the exact process will need to be personalised for each individual.
**Step 1** in the process is to make sure that there is a clear record of how the person expresses their preferences. How do they show what they like or dislike, what they want or don’t want?

It is also important to have information about the best ways of helping the person to understand information. This information would normally be part of their Communication Passport and part of their Person Centred Plans/One Page Profile.

**Step 2** will be to build up a picture of the person’s preferences around the most important things in their lives. This may already have been done as part of their Person Centred Plan. This step will require talking to the people who know the person best and recording what is already known about their preferences and by carrying out observations. These observations will provide information about the types of things that the person enjoys, are important to them, they want to happen in their life and how they want people to support them.

Depending on the level of information already available this stage can take a long time particularly if the person does not always have clear responses. It is also important that this information is checked and updated on a regular basis to reflect any changes in the individual’s preferences.

Some tools that might be useful are:

- Sensory assessment
- Preverbal communication schedule
- Observation checklists
- Person centred plans and approaches

**Step 3** is helping the person to communicate their views to people who plan and commission services. Based on the work of the Mencap Involve Me project and local examples of good practice these are some of the ways that people’s views can be heard.

- People can demonstrate their views using a range of approaches such as music, art, drama, sensory stories or
social stories. These can be filmed and taken to the key people (see section on consent) or to people invited to attend events.

- Special events can be arranged to support people to express their views
- Key people can be linked to families and key organisations who can pull these views together
- Key planning and commissioning meetings can be dedicated to hearing the views of people with profound and multiple learning disabilities
- The Learning Disability Partnership Boards can build up a record of people’s views which can then be considered when any topic is being discussed – a champion for people with profound and multiple learning disabilities could be responsible for this, feeding information into any appropriate consultations.

**Step 4** would be feedback from people who plan and commission services that show how the information provided has affected their decisions.

Alongside this the information gained can be used to set standards and expectations for services which can be checked through evaluations and audit.

**2. Involving people with profound and multiple learning disabilities in their day to day life and care**

- Information to support service planning and commissioning can only be gained if people are involved as activities occur and their preferences recorded and shared. This section aims to pull together the ideas about how this can happen.
Information needs to be captured about the best ways of communicating with each individual. This is usually done by developing a Communication Passport with the key people who know the individual well. This information should also include details about the person’s hearing and vision. Information may also be found in the person’s Person Centred Plan/One Page Profile.

Everyone needs to be clear about the best ways of helping the person to understand and to express themselves.

**Ideas that may be worth considering are:**

- Intensive interaction
- Cause and effect, including the use of switches
- Objects of reference
- Music and other creative arts based approaches
- Narrative and related approaches such as sensory stories
- The use of symbols, pictures and visual time tables/low tech augmentative and alternative communication
- Signing

The acknowledgement that gaining the views of people with profound and multiple learning disabilities is a long term, ongoing process and not based on a one off assessment. The person’s preferences then need to be recorded and changes made in their lives and care based on their views and wishes. The person’s preferences will then need to be checked regularly and records updated.

There needs to be a way of pulling together people’s views and communicating these to people who are planning, commissioning and evaluating services.

The most critical aspect when improving involvement and communication for people with profound and multiple learning disabilities is the quality of their relationships. Trained and responsive communication partners are essential.
3. Consent to the sharing of information and the use of video or photographs

We will base our practice on the guidance produced by Mencap which can be found on http://www.mencap.org.uk/sites/default/files/documents/2008-04/Consent%20for%20videos%20and%20photos%20of%20people%20with%20PMLD.pdf

Organisations need to sign up to this guidance.

For further information:

Jane Parr
AHP Lead and Speech and Language Therapy Clinical Lead
Learning Disability Division
Mansion House
Leicester Frith
Groby Road
Leicester
LE3 9QF

Email: jane.parr@leicspart.nhs.uk
Phone: 0116 2255250
References

1. PMLD Network  www.pmldnetwork.org


Appendix 1
Local expertise and resources

Appendix 2
National expertise and resources
Appendix 1
Local expertise and resources (to be developed further as part of the local PMLD network)

Leicestershire Learning Disabilities Partnership Board
The website of the Partnership Board has links to other websites and information about work at a local level.
www.betterlives.co.uk

Leicester City Partnership Board
Contact Kavita.Dholakia@leicester.gov.uk

Sensory Plus Equipment
Multi sensory equipment designed to be set up and used in your home, residential care settings or day service on a free 2 week loan basis.

- **North Leicestershire** based at Melton (including Charnwood and North West Leicestershire) contact Alison Keighley or Heather Guiney on 0116 30 53852
- **South Leicestershire** based at Wigston (including Oadby, Wigston & Blaby and Harborough and Hinckley) contact Sarvijit Kalarai on 0116 28 11922

Open Museums
The Held in the Hand pilot project commissioned 13 artists to make 13 small sculptural objects that can be picked up and “held in the hand”. This first box has been extremely popular, and proved particularly successful with SEN schools due to the tactile and multi-sensory stimulus the objects offer.
Follow the link for further information
http://www.leics.gov.uk/index/leisure_tourism/museums/open_museum/artworks/heldinthehand/heldinthehand_sen.htm
Touch tables is an exciting, innovative new art resource for people in the later stages of dementia or with more severe learning disabilities. The Touch Tables contain interactive art in the form of "Touch Tiles". The tables make art accessible, encouraging interaction and response to visual and touch stimulus. The tables are height adjustable to allow wheel chairs to be wheeled under, and they can be tilted like an easel so users can come into close contact with the artworks.

Follow the link for further information
http://www.leics.gov.uk/index/leisure_tourism/museums/open_museum/artworks/touchtables.htm
Or contact Lisa Webb on 0116 3055536
Lisa.webb@leics.gov.uk

Bag books
Bag books are a method of story telling using a bag of props, puppets and pictures to tell a story. The aim is to promote attention and listening skills, social inter-action through active listening. Bag books are for loan at your local library.

Follow the link for further information

Music therapy
Music therapy is an established clinical discipline which is widely used to help people whose lives have been affected by injury, illness or disability.
Follow the link for further information www.bamt.org
or contact Jo Gravestock on joyviolingirlie@yahoo.com

Hastings Road Day centre promote independence and help quality of life for adults with physical, sensory and/or learning disabilities in Leicester City. For more information follow the link to
http://www.leicester.gov.uk/your-council-services/social-care-health/adults/services-for-adults-and-older-people/day-centres
Glebe House is an independent charity that supports adults and children with learning disabilities. Based in Loughborough, we provide a wide range of day services for people of all ages, which are all aimed at improving the lives of the people we support. For further information follow the link www.glebehouseproject.org.uk

Leicester College have a series of general and specialist learning spaces, including a Performing Arts classroom, Art room, Dining room, high specification sensory rooms and an external sensory garden specially designed to cater for the needs of learners with PMLD.
For further information follow the link to
Or contact fwilliams@leicestercollege.ac.uk

If you want to be part of this good practise, join the local PMLD network.
Appendix 2
National expertise and resources

1. Involve me: Involving people with profound and multiple learning disabilities in decision making. www.mencap.org.uk/involveme


3. Intensive interaction: a way of communicating with people who do not use words or more formal methods of communication. www.intensiveinteraction.co.uk

4. Sensory stories: how to involve people with PMLD in storytelling. www.bagbooks.org

5. TACPAC communication through touch and music www.tacpac.co.uk

6. BILD Good Practice Guide: Learning about ways in which you can communicate with people better. www.bild.org.uk