



**Raising
our Sights**

How-to guide 3 communication

For people with profound and multiple learning disabilities



Raising our Sights guide to communication

Raising our Sights, by Professor Jim Mansell, was published in March 2010 with recommendations that aim to make sure people with profound and multiple learning disabilities (PMLD)¹ and their families get the support and services they need, and do not miss out on opportunities for more choice and control over their lives.

Some local areas have started to carry out recommendations from the report. However, many areas have yet to begin and have asked for further guidance on how to do this.

Now that local health and wellbeing boards are starting to lead the commissioning of health and social care services, it is a good time to think about what good support for people with PMLD looks like. It is an opportunity to make sure the right services are commissioned to meet the needs of a group of people who have so often been left out.

These how-to guides were commissioned by the Department of Health, and produced by Mencap and the PMLD Network, to help local areas implement the *Raising our Sights* recommendations, which are aimed at the local level. It does not focus on recommendations aimed at government and national bodies.

About this guide

This guide to communication is one of 11 guides designed to help local areas implement the *Raising our Sights* recommendations. It is for both families and commissioners.

For more information about *Raising our Sights* and to download all the guides, go to:

www.mencap.org.uk/raisingoursights

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¹ Read the PMLD Network definition of profound and multiple learning disabilities at www.pmldnetwork.org

1. What Raising our Sights says about communication

There are four recommendations:

Recommendation 18.

The government should decide whether funding the provision and repair of communication aids for adults with profound and multiple learning disabilities (PMLD) is the responsibility of the NHS or Local Authority social care services.

Recommendation 19.

The Department of Health should commission the SCIE (Social Care Institute for Excellence) and/or NIHCE (National Institute for Health and Clinical Excellence), to review and disseminate the available research and practice on the use of communication aids and assistive technology for adults with PMLD.

Recommendation 20.

The Department of Health should fund research and demonstration projects in each region (perhaps through the Health Technology Assessment programme of the National Institute of Health Research), to identify opportunities for increasing the quality of life of adults with PMLD through the use of communication aids and assistive technology.

Recommendation 21.

The Department of Health should commission organisations such as Communication Matters and HFT, which have expertise in this area, to advise families and agencies about new opportunities presented by these communication and control aids, to offer opportunities for people to try out different equipment, and to train staff.

The government's plans for people with a learning disability in Valuing People Now made limited reference to communication. However, in order to achieve any of these plans, it is vital to ensure good communication is in place, promoted and enabled for and with people with a learning disability. Nowhere is this need more obvious than with the group of people described as having profound and multiple learning disabilities (PMLD).

Four of the *Raising Our Sights* recommendations are about **communication aids and assistive technology**. However, good communication support is not just limited to assistive technology. Professor Juliet Goldbart was asked to look specifically at the communication needs of people with complex needs (including those with PMLD). Her report, *Communication and people with the most complex needs: what works and why this is essential*, provides commissioners, service providers, families and researchers with information about communication approaches that work, and highlights the importance of staff training and further research. Her main conclusion is that positive relationships are central to good communication with people with PMLD.

“Communication with people with the most complex needs is most successful with familiar, responsive partners who care about the person they are communicating with.”
(Goldbart and Caton, p1)

All the *Raising our Sights* recommendations about communication are aimed at the national level, but there are many things to do at the local level to ensure the communication needs of people with PMLD are met.

This how-to guide focuses on what 'good' looks like and what needs to be in place to meet the communication needs of people with PMLD.

2. What does ‘good’ look like?

Meeting the communication needs of a person with profound and multiple learning disabilities (PMLD) is highly individual. Each person is unique and what works for one person may not work for another. However, the key elements are highlighted in Professor Goldbart’s report and elsewhere.

Acknowledging communication as a basic human right

Everyone supporting a person with PMLD must acknowledge the importance of communication as a basic human right. They must also know how to support them to understand and express their thoughts, preferences and choices as far as they are able. This includes respecting that a person who might be unable to communicate intentionally has the right to be listened to and communicated with in ways appropriate to them.

Communication support that works

Services should be creative and open to using whatever form of communication works for a person. For some people that may involve music, art or any of a range of multi-sensory approaches. This will take time to learn, and information gained about an individual must not be lost as they move from one service to another – especially during the transition from child to adult services. Person-centred thinking tools, such as learning logs, are particularly useful for helping people to reflect on what communication approaches are effective for each individual.

Some areas have adopted **Total Communication** strategies. Total Communication is a nationally recognised process of using and valuing all forms of communication (for example, body language, facial expression, actions, objects, photos, pictures, symbols, speech, writing and drawing as appropriate) for people to understand and express their needs, wants, feelings and preferences in effective two-way

communication. It is important that these strategies include people with the most complex communication needs who may not use formal means of communication such as words, signs or symbols.



Scenario 1: Being involved through simple technology

Megan lives in her own house with her own support team. She and her mum are involved in selecting staff and providing their initial training. A simple ‘talking book’ presentation in PowerPoint on her computer explains how she likes to be supported, and includes photos and video clips. Megan and her mum show this to the staff as part of their training. It is Megan’s job to start the presentation using a switch which she presses with her foot. She sometimes giggles and enjoys making everyone wait before she does this!



Scenario 2: Learning from a mistakes

A young man with PMLD was sent to a consultation workshop with a supporter who had never worked with him before. The leaders of the workshop had no idea how to include him in the meeting as they had no information about his communication methods. When one leader showed him some of the cause and effect apps on her iPhone (where tapping a screen causes something to happen, like a noise), he became very animated and demonstrated that he could use a simple touch screen to create sounds and moving images. His support team realised that in future they should ensure his communication was better supported. They developed a communication passport identifying his communication preferences, and used money donated by a local charity to buy him an iPad on which they installed the apps he enjoys.

3. What needs to be in place to meet the communication needs of people with profound and multiple learning disabilities

A well-trained workforce

Goldbart recommends that staff training should include Intensive Interaction, communication passports, objects of reference and the use of switches for cause and effect. Training should be ongoing and constantly updated because there are always new developments, particularly in the area of technology. Ongoing support, for example from speech and language therapists, is needed if the learning from this training is to be implemented or effectively supported.



Scenario 3: Making sure staff have suitable training

A charitable donation enabled a residential care home to furnish a sensory room with a variety of interactive equipment, including a sound beam¹. After a couple of years, a new manager arrived and noticed that this expensive piece of equipment was never used. Staff told her that the person who knew how it worked had left and nobody knew where the instructions were. The manager arranged for the staff to be trained, and made sure a clear care plan for its use was developed and maintained.

Access to speech and language therapy services

Goldbart found that many families of people with profound and multiple learning disabilities (PMLD) had not seen a speech and language therapist (SLT) for many years, if at all.

It is important that this changes and that this group of people are prioritised for speech and language therapy assessment and monitoring. Speech and language therapists also play an important role in supporting families and workers to successfully respond to, enable and promote communication.

¹Soundbeam is a device that uses sensor technology to translate body movement into digitally generated sound and images:

<http://www.soundbeam.co.uk>

Listening to families and carers

Families should be involved in thinking about how best to support the person's communication as they are the natural experts. Everything that is known about a person's communication should be documented and made readily available to anybody they come into contact with. **Communication passports** are an excellent way to achieve this. Speech and language therapists can valuably help review and update these.

"The communication passports described to us were generally on paper, card or laminated paper, and made by hand or using some of the excellent web-based resources. There is an overlap, however, with multimedia profiling and it is likely that in the future, communication passports could include video and audio files, giving a rich and detailed view of the person in different settings."

(Goldbart and Caton, 2010)



Scenario 4: Sharing knowledge about communication approaches

Greg's foster mum had found good ways to communicate with him, using his sounds and body movements. She was, however, reluctant to use them when the social worker visited, because they had previously told her to "talk to him like a grown-up". A speech and language therapist explained that the communication style Greg's foster mum used naturally was actually based on the principles of Intensive Interaction, and encouraged her to continue. This gave her the confidence to challenge the social worker's views about communication. Greg was able to be involved in decisions about his life through the use of respectful and appropriate communication. The social worker learned about Intensive Interaction and was able to use this in her work with others.

Involve people with PMLD in planning and consultation

More people with a learning disability are speaking up about the things that are important to them, but people with PMLD are often left out due to their complex communication needs. Local areas must find innovative ways to make sure people with PMLD have a voice in planning and commissioning services, including having champions who can speak on their behalf where necessary.



Scenario 5: Including people with PMLD

A local partnership board realised they did not always include the needs of people with PMLD in their plans. They appointed the father of a young man with PMLD to be their ‘PMLD champion’. He introduced a ‘day in the life’ event to increase the board’s awareness. This saw members of the board spending a day with a person with PMLD to experience life from their perspective. The board members spent their next meeting sharing their experiences and identifying lessons they had learned that would influence their future plans. They agreed they would repeat this activity regularly to make sure people with PMLD weren’t forgotten.



Scenario 6: Feedback to commissioners.

A local speech and language therapy service was dismayed to hear that local commissioners had under-estimated the number of people with the most complex communication needs in their area. They carried out their own survey of local need, including speaking to families and service providers, and presented their findings to the commissioners. This led to recognition of the need for additional training and support for staff working with PMLD, and resulted in a series of funded projects to promote the use of Intensive Interaction.

Assistive technology is an umbrella term used to describe any equipment or system that helps people to do things that might otherwise be difficult or impossible. Sometimes called **personalised technology**, it can enable, maintain or increase independence. It includes aids to mobility, such as walkers and wheelchairs, as well as ways to access computers or other equipment. Some technology is ‘low tech’, such as baby monitors used to enable a carer to hear when a person is distressed and needs assistance, while other technology is more ‘high tech’, for example using global positioning systems to monitor where somebody is at any time. Organisations such as **HFT** are exploring the use of assistive technology for people with a learning disability. We still need to find out more about how different types of technology might help people with PMLD. For example, using switches can help some people access simple computer programmes to learn about cause and effect, or simply for pleasure in their leisure time.

“Such technological aids offer the prospect of enabling people to communicate with others and to control aspects of their environment such as where they are. For people often dismissed as unable to communicate, the possible impact on the attitudes of others is at least as important as the direct effect on the person’s quality of life.”

(Mansell, 2010)

Communication aids help people to communicate more effectively with those around them. These range from simple switches and objects of reference, to sophisticated pieces of electronic equipment and computers. For most people with PMLD the most useful aids are not complex or sophisticated. In deciding whether a communication aid would be useful it is important to take into account the person's individual characteristics. Can they physically operate the device? Do they understand pictures or objects? Do they understand (or can they learn about) cause and effect? How would a communication aid help them to communicate or be included more?

Some of the most helpful communication aids are simple touch-operated aids, such as Big Macks (a large button that can be used to play and record a message or sound effect) and smaller, cheaper versions like Big

Point or talking photo albums (where short messages can be recorded underneath a photo.) For people with some hand control there are a growing number of apps and simple communication aids available for iPads, smart phones and netbooks, and other widely available non-specialist technology. You can learn more from the work of Richard Hirstwood and Flo Longhorn (see the Links to more information and resources section at the end of this guide).



Scenario 7: Joining in using technology

Adam is a member of a weekly story sharing group at his residential home. Each week people gather to share stories about their lives. Although Adam cannot speak, he is able to operate a Big Mack switch with his hand. He shares in the telling of his stories with his key worker by activating the switch to produce a suitable sound effect during the story.

It should probably be stressed that however exciting the technological advances to independence and communication, **people** will always remain the most important communication aid for people with PMLD. They need communication partners who value all communication, whether intentional or not, who take the time to really listen and respond and who are willing to nurture relationships.

“As nice as all those things are – he doesn’t really need them – what he needs is people who will give him time.”

(Lesley, mother of Stuart)

The *Raising our Sights* commissioning guide has more information about how to achieve these things.

4. How do people get their communication needs met, including accessing communication aids and technology?

Most speech and language therapy services have an open referral system. You can contact them directly and possibly complete a referral form. You can get information about your local service from your GP, community learning disability team or care manager. There will probably be a prioritised waiting list. You should be told roughly how long you might have to wait for a therapist to be allocated. It will help if you are very clear about the help you require for the person with profound and multiple learning disabilities (PMLD).

The funding for communication aids and technology for adults varies from area to area. Some health or social care departments have a budget for this but many adults have to buy

their own, raise money or borrow equipment from charities. There is more advice about funding, including a directory of charities that can help, on the **Communication Matters** website (see the Links to more information and resources section at the end of this guide).

Law and policy which can help

It is useful to know about any relevant laws and policies which can be used as a lever to help ensure a person with PMLD can access support and services to meet their communication needs.

“Although there is no formal legal right to communication, it can be argued that communication is a basic human right.”
(Thurman 2009, 2011)

The Mental Capacity Act 2005 says people who lack capacity in relation to a particular decision should be involved as much as possible when a decision is made in their best interests. This includes supporting people to express their preferences and views as much as possible. In doing this, those who are most familiar with, or work with, the person should find out how they communicate and facilitate this.

The Equality Act says public organisations such as local authorities and health trusts must involve and consult people about services, including people with PMLD and their families. This requires creative approaches to consultation and involvement.

If the person can't access the services they need

If the person with PMLD you support, or other people with PMLD in the local area, are not getting their communication needs met you may want to challenge or campaign.

Your local Learning Disability Partnership Board (LDPB) can be a good place to get advice or support and link up with other people to campaign. Many now have a PMLD champion or PMLD sub-group. Carers groups, local Mencap groups or advocacy organisations can also be good places to bring people together to support each other and campaign.

Challenging

Sometimes you may just be trying to change things just for the person with PMLD who you support rather than trying to get wider change.

Some tips:

- Use the information in this guide, including what ‘good’ looks like, legal rights and policy information, to support your challenge.
- If the person’s needs are not being met, say so in a letter to the lead person at social services or the Clinical Commissioning Group (CCG). Let them know you will campaign publicly against their decision if they do not listen to what you have to say.
- Get your local councillor or MP involved. You could ask them to write a letter of support.
- If you are not listened to, you might want to make a complaint or seek legal advice.
- If there are other people with PMLD in the area facing similar issues you may want to get together to campaign publicly!

Campaigning

If a particular issue is affecting more than one person with PMLD in your area, you may want to work with others to raise awareness about this and campaign publicly for change. An example of an issue that many local areas have successfully campaigned against is the lack of appropriate changing facilities for people with PMLD. Thanks to campaigning, many local areas now have Changing Places toilets.

Some tips:

- Organise a campaign for people in your area to send an email or letter to their councillors.
- Launch a petition explaining what you are campaigning for.
- Hold a public meeting to tell people about the campaign and how they can get involved. You could invite a local newspaper or radio station along to cover the story.
- Organise a rally by inviting members of the public to a significant place, such as a town hall, to publicise the issue. Again, your local media might want to cover this.
- Gathering real stories and using photos and film can be very powerful. Social media can be a useful tool to share these.
- Don’t forget to plan your campaign!

To help you challenge or campaign, see:

The Challenging Behaviour Foundation information sheet **Ten Top Tips**, by **Luke Clements**, which sets out the legal rights to community care services, has a template letter to follow if you want to challenge a community care decision. See <http://www.thecbf.org.uk>

Mencap’s Know your rights local campaigns guide (this is specifically about cuts, but it has some useful general information about campaigning). See www.mencap.org.uk/node/14506

The **KnowHow NonProfit** website, which is part of the National Council for Voluntary Organisations, has lots of useful ideas about campaigning, including how to plan a campaign. See <http://knowhownonprofit.org/campaigns/campaigning/planning-and-carrying-out-campaigns/planning/planning>

Complaints or legal action

Some people may choose to go down the complaints or legal route if their challenging or campaigning is not successful.

Complaints

See our factsheet about making a complaint.

It includes some specific information about making complaints in relation to each of the topics in the *Raising our Sights* how-to guides. See: <http://www.mencap.org.uk/raisingoursights/complaintsfactsheet>

Legal action

Getting legal advice can be helpful. It is useful to do this sooner rather than later as some sorts of cases, such as Human Rights Act and Equality Act cases, have time limits on them. It doesn't necessarily need to cost you anything because you might be entitled to legal aid or be able to get a law firm to take on your case for free. For further information, or to find a solicitor, contact the Disability Law Service on **020 7791 9800** or email advice@dls.org.uk

5. Detailed case study

Eleanor

Eleanor is a young woman with profound and multiple learning disabilities (PMLD) who lives in the north east of England with her mum, dad and younger brother. She has a range of complex physical and learning needs. She does not use recognisable speech but communicates with those who know her well through body language, facial expression, vocal sounds and her special love of music.

Following spinal surgery at the age of 14, she is no longer able to walk and relies on others to push her wheelchair. Adaptations have recently been completed to provide a ground floor annexe so Eleanor can be close to the heart of family life, but also have her own private space. She takes a little time to get to know new people. Once she does so, she has a wonderful smile and inquisitive nature and it is a delight to spend time with her.

Eleanor had attended a special school since the age of two but, over time, her parents began to question whether this was right for her secondary education.

When Eleanor was six, her mother attended a **Partners in Policymaking** course, which introduced her to the social and medical models of disability. The family became convinced that Eleanor would benefit from a more inclusive environment. A couple of years later, Eleanor was welcomed into a youth choir alongside children without disabilities. Both these positive experiences of inclusion led Eleanor's parents to fight for a place in a mainstream secondary school. They achieved this and it proved to be a highly rewarding experience for all concerned.

For Eleanor's education after the age of 16, her family made imaginative use of direct payments to put together a home-based education plan, rather than taking up a college placement or returning to the special school. A team of six part-time personal assistants work with Eleanor's mother to involve her in personalised activities. The team meet every half term to review her progress and share what they have learned from Eleanor's reactions and participation in the sessions. So far, this has included one-to-one music lessons, physiotherapy, cooking, pottery, painting and swimming.

The team uses **person-centred thinking tools**, such as learning logs, to reflect on the sessions.

<http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/person-centred-thinking-tools.aspx>

These logs tell them what has gone well, what has not gone so well and what they believe Eleanor feels about the activities. Video clips of her sessions are also used so others can learn from her reactions.

Eleanor's communication has always puzzled people. There have been differences of opinion between professionals and her family about how much she can understand and what methods of communication work best for her. A variety of methods including picture symbols and objects of reference have been tried with little success. Her family has always believed that her love of music and singing holds the key to her communication and are keen to explore this further using her person-centred activities.

Some of Eleanor's personalised budget has been spent funding technical support and training sessions at a local education resource called **Space 2 Learn**. Although not specialist in the needs of people with a learning disability, the centre is highly skilled in the use of technology to create interactive areas. The plan is for Eleanor and her staff to experiment and learn in the **immersive room**, an activity room that responds to contact and movement. This uses the latest computer and lighting technology to project images on to three walls and the floor, which can be programmed to respond to movements from people in the room. For example, the images may move and make sounds if the person touches them or moves around the room.

The staff at the centre will work in partnership with Eleanor's family and music teacher to develop a six-week training course for Eleanor and her supporters to experience their range of interactive technology. She will be provided with a personalised iPad with suitable software and apps. Her learning will be linked to other weekly activities, for example the coloured lights she can switch on and off with arm movements will be

matched to the colours she has been using to indicate her favourite songs.

It is recognised that Eleanor will take much longer to become familiar with everything the technology could potentially offer, so learning logs will be kept and monitored to learn what works well and what can be built on at the end of the six weeks. Including her supporters in the sessions means they too will be able to learn how to use the technology and develop further ideas to explore with Eleanor outside the centre.

The team will also contact specialists in the use of technology and interactive approaches for people with PMLD to gain ideas as to how best to explore cause and effect, and simple communication with Eleanor using the technology at Space 2 Learn.

One of Eleanor's personal assistants has attended a course on developing **communication passports** and it is hoped one will be compiled soon, based on everyone's shared understanding of Eleanor's communication. This will be updated and expanded as more is learned from this ongoing approach to supporting Eleanor's wellbeing and communication.

Everyone around Eleanor is committed to finding out about, supporting and helping to develop her communication skills. It is partnership work that places Eleanor at the centre and includes her family, supporters, person-centred thinking, use of a personalised budget, and innovative use of technology and available local community resources.

Note: Since this case study was written many of the aims outlined in it have now been achieved and Eleanor's life is becoming more and more fulfilled.

6. Film

The Involve Me project, carried out by Mencap and BILD (British Institute of Learning Disabilities), looked at creative ways of communicating with people with profound and multiple learning disabilities (PMLD), and involving them in decision-making.

Watch the Involve Me film clips at
www.mencap.org.uk/involveme

7. Frequently asked questions

Q: My son or daughter has never seen a speech and language therapist. How do I arrange for them to see one?

A: You can approach your local community learning disability team for an assessment. In most cases you can request this yourself - there is no need to have a medical referral. If you have difficulty, the Royal College of Speech and Language Therapists can offer advice.

Q: Who pays for any communication aid or piece of assistive technology my son or daughter needs?

A: Sadly, there is no simple answer to this as there is still no agreed responsibility for funding. This is one of the actions recommended by *Raising our Sights*. Your son or daughter's care manager, speech and language therapist or occupational therapist should be able to advise you on the local situation. You can get further advice from Communication Matters (see the Links to more information and resources section at the end of this guide).

Q: What is the best communication approach to use with my son or daughter who has profound and multiple learning disabilities?

A: There is not a single answer to this as it depends on their individual communication needs. You should ask for a speech and language therapist to assess your son or daughter. They should then be able to offer you advice and support to find out about and use, whatever approach they recommend. You could also look in the resource list in this guide for links to useful approaches.

Q: I know how to communicate best with my son or daughter. Why does nobody ask me?

A: They should do! You have the legal right to be consulted in decision making for your son or daughter if they cannot do this for themselves. You may need to remind professionals of their obligation to do so under the Mental Capacity Act.

Q: How does a commissioner know if they are commissioning a good speech and language therapy service?

A: They should talk to the speech and language therapy team. Ask whether their service plan includes people with profound and multiple learning disabilities (PMLD). They should also read the Royal College of Speech and Language Therapists' position paper on adults with a learning disability (this can be found on the RCSLT website – the link is at the end of this guide). Listen to what families and other champions for people with PMLD say about the service.

Q: Should commissioners be prioritising people with PMLD? It all seems very expensive.

A: Commissioners have a responsibility to provide for this group. People with PMLD have faced prejudice, discrimination and low expectations in the past. This is not acceptable. We should be working towards a better quality of life for this relatively small but most disadvantaged group of citizens.

Professor Mansell (p34) said:

“Hard times should, however, dictate the pace at we can achieve these objectives, not the nature of the objectives themselves... our obligation is to work towards achieving progressively the full realization of the rights of this group of disabled people.”

Q: What communication approaches should be used in services in our area?

A: Ones that work for the people who use the service! This may be one of a number of communication approaches, with or without the additional use of communication technology. A good start would be to ensure all staff working with people with PMLD receive training on Intensive Interaction and communication passports. Make sure this training is implemented and that all people with PMLD have up-to-date communication passports that go with them wherever they are.

The most powerful communication aid, however, is always a familiar, responsive partner who cares about the person they are communicating with. The biggest investment should therefore be in the people who support and care for people with PMLD, family and paid carers.

8. Share good practice!

We know there is already good practice out there and some examples are referred to in these *Raising our Sights* how-to guides. But we would like to hear of more examples and share them so other local areas are inspired to develop good support and services for people with PMLD too.

Please tell us about any good practice in your local area relating to support or services for people with PMLD:

Email pmldnetwork@mencap.org.uk
Call **020 7696 5549**



The Lambeth PMLD project

This project aimed to show what life was like for people with PMLD in Lambeth, and use the information to better plan to meet their needs. It was initiated by family carers of people with PMLD on the Lambeth learning disability partnership board and run in partnership with Lambeth Council, NHS Lambeth, 'I Count' Register Services, National Mencap and Lambeth Mencap.

The project identified people with PMLD on the learning disability register using criteria developed from the PMLD Network definition. Information was also collected through surveys and interviews with families and support staff.

Priority areas for change were identified and, two years on, there is an active PMLD sub-group committed to take these forward. The focus is currently on developing meaningful activities for people with PMLD in Lambeth. There is a case study and film of Lambeth's work on

meaningful activities work in the *What people do in the day* guide.

For more information about the Lambeth PMLD project see:

www.mencap.org.uk/Lambethpmld

9. Links to more information and resources

ACE centre

Provides specialist expertise in communication and assistive technology.

<http://www.ace-centre.org.uk>

Call Centre

Provides specialist expertise in communication and assistive technology (primarily in Scotland).

<http://www.callscotland.org.uk>

Communication for Involvement

Jane Jones and Sue Thurman worked with BILD (British Institute of Learning Disabilities) and the Rett Syndrome Association UK to develop a communication toolkit.

<http://www.rettuk.org/rettuk-public/rettuk/Family-Support/information-summary/Information-A-Z.html>

Communication Matters

Communication Matters campaigns for people who find communication difficult, provides information and resources on different methods of communication, and advises on various communication aids and technology.

<http://www.communicationmatters.org.uk>

Communication and people with the most complex needs: What works and why this is essential.

Professor Juliet Goldbart.

This guide was commissioned by Mencap in partnership with the Department of Health.

<http://www.mencap.org.uk>

Communication passports

These involve a process of gathering, sharing and making explicit information about a person and their communication in order to help less familiar people recognise and make sense of the person's communicative behaviour.

<http://www.communicationpassports.org.uk>

Hearing from the Seldom Heard

This recommends six areas of good practice in listening to people with profound and multiple learning disabilities, including links to a range of communication approaches in the communication section.

<http://www.bild.org.uk>

HFT

This organisation provides advice and training in using personalised technology with people with profound and multiple learning disabilities.

<http://www.hft.org.uk>

Intensive Interaction

<http://www.intensiveinteraction.co.uk>

<http://www.usinabus.org.uk>

<http://www.phoebecaldwell.co.uk>

The Hanging Out Programme

http://www.clickspecializednz.com/doc/approach/02_intens/res/Hanging%20Out%20Programme%20written%20notes.pdf

This doesn't need training! The basic principle is to give 100% attention for 10 minutes per day to quality interaction with the person with PMLD.

Involve Me

A project aiming to increase positive involvement of people with PMLD. A resource pack, inspiring DVD and links to creative approaches to communication and consultation are available.

<http://www.mencap.org.uk/involveMe>

Is communication a human right for people with profound and multiple learning disabilities?

Thurman Sue (2011). PMLD Link Vol. 23 No. 1 Issue 68 p 10-14

Multi-sensory approaches

You can learn more from the work of Richard Hirstwood and Flo Longhorn.

<http://www.multi-sensory-room.co.uk>

<http://flonghorn.squarespace.com>

Oxfordshire Total Communication

A useful site with a wealth of information on different communication approaches.

<http://www.oxtc.co.uk>

Partners in Policymaking

Leadership training courses for disabled adults, parents and carers of disabled children, professionals and other service providers working in education, health and leisure.

<http://www.in-control.org.uk>

Person-centred thinking tools

Ways to help carers listen and learn about what really matters to a person in order to take action together to make sure these things become part of their lives.

<http://www.helensandersonassociates.co.uk>

PMLD Network

A group of people committed to improving the lives of people with PMLD.

<http://www.pmldnetwork.org>

PMLD Link

A journal that shares ideas and good practice in supporting children and adults with PMLD.

<http://www.pmldlink.org.uk>

Royal College of Speech and Language Therapists

The professional body for speech and language therapists has a national network of therapists working with people with a learning disability.

Call: **020 73781200**

Email: info@rcslt.org

Got to: <http://www.rcslt.org>

Soundbeam

A device which uses sensor technology to translate body movement into digitally generated sound and images.

<http://www.soundbeam.co.uk>

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