

# PMLD LINK

sharing ideas and information

Sharing Perspectives

Spring 2017



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PMLD Link is a journal  
for everyone supporting  
people with  
Profound and Multiple  
Learning Disabilities

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## GUEST EDITORIAL

# Sharing Perspectives

It is always a pleasure to edit a sharing perspective edition of PMLD LINK as it allows us to consider a variety of topics. There is, throughout the edition, a vital underlying principle that bridges the gap between education, care and health for children and adults with PMLD. That is engagement. To live a fulfilled life adults and children with PMLD need to be able to engage with the environment around them, the community and the people within it. This issue includes articles about communication, changing legislation for schools, optimising environments, empowering people with PMLD to use music and the opening up of the community for students with PMLD, to name just a few.

The importance of interaction and communication for people with PMLD is explored within several of the articles in this issue. Having a voice and having the ability to communicate is a fundamental human right. Intensive Interaction empowers people to experience social interactions, whether that is within education, health or care. Amandine Mouriére challenges some of the misconceptions of Intensive Interaction within schools stating that the more we raise awareness and understand what is at stake, the more we are able to influence practice and culture. While, within her article, Shahana Pervin Kakoly discusses Intensive Interaction including how effective it is on challenging behaviour in adults. Rob Ashdown provides a guide to developing communication and interaction.

The case study that Claire Fraser-Tyler has written highlights the importance of fun, enjoyment and humour. As a music therapist she uses music to develop Elsie's feeling of self-worth and the sense of being valued. A fulfilled life that is fun is what everyone deserves. Carrie Lennard describes this empowerment and ability to have fun when she talks about using the improvisation approach with a young girl with PMLD. How better to have fun than to have a story. I had great fun sharing Peter Well's story from the Winter edition, Sheldon and the Hare, with my class. They loved the slime! In this edition he shares a sensory story about losing his granny's gnashers!

Educationalist amongst our readers are all to aware of the changes in assessment for our students with PMLD. The Rochford Review is explained by Richard Aird, who was a member of the independent group, established by the Minister of State for Schools in July 2015, to review statutory assessment arrangements for pupils working below the standard of national curriculum tests. The report recognises the importance of engagement. Martin Goodwin discusses the Rochford Review with a more comprehensive musing than mine. Flexibility within the curriculum enables teachers to be creative in their provision such as the community based curriculum Cathy Bradshaw discusses. School and education is a demanding place for any teacher and evidencing progress is a perpetual challenge. This is even harder for teachers of children with PMLD, who are also encompassing postural, personal care, medical and even nutritional needs. Amanda Brown shares her experience of the difficulty in balancing meeting the holistic needs with the pressures of Ofsted. She describes how she maintained the core values care, respect, perseverance, patience, enjoyment and aspiration during what was a difficult process.

The importance of environment can not be underestimated. For any person with a sensory impairment or sensory processing difficulty environmental triggers can potentially be a barrier to engagement or interaction. A room that is too bright, too loud, too hot, smells can be distracting, uncomfortable and even confusing. For autistic people it can even cause incredible anxiety. Richard Hirstwood provides an example of an environmental assessment as an example of how we evaluate the sensory environments.

There are all the usual sections on News, Books, Resources, Courses and other sources of information. Margaret Tyson and colleagues report the views of carers experiences of Annual Health Checks for people who have a learning disability, indicating that a proactive approach with health checking and health protection and promotion needs to happen. I hope all our readers find things which interest, excite, and help them in their day to day practice. Future Focus introduces the topic for the next issue 'Life as an Adult' and all the details for sending articles are given there. Finally, thank you to all the writers of articles for their contributions to this issue.

Wendy Newby and Jillian Pawlyn

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# Intensive Interaction in schools: tackling misconceptions

Amandine Mourière

I have been working with the Intensive Interaction Institute for about three years, whilst also working as a supply teaching assistant in special needs schools on an ad-hoc basis. One of my roles with the Institute involves delivering training courses on Intensive Interaction in schools.

Intensive Interaction was developed in this country back in the 1980's and has been disseminated for over 30 years in a wide range of settings, especially in schools. It is referred to and referenced as standard practice within the English national curriculum guidelines for planning the curriculum and teaching pupils with learning difficulties (QCA, 2009, pp.5, 20 & 45), the Routes for Learning (Welsh Assembly Government, 2006, p.14), and the Quest for Learning (Council for the Curriculum, Examinations and Assessment, 2009, pp. 69, 70, 73 & 99), and is regularly taught in Speech & Language Therapy and teaching degree courses. This naturalistic approach was developed partly by studying and learning from the research on the natural model of interaction development in infancy (Nind and Hewett 1994). The potential effects or expected outcomes of taking part in Intensive Interaction can be fitted in note form on one side of A4 paper, but should not be underestimated. They are called the Fundamentals of Communication (FOCs) (Nind and Hewett, 2001).

I would like to relate and challenge some of the most widespread misconceptions on Intensive Interaction here. Be reassured: my aim is not to berate staff, quite the opposite. I am hoping that by addressing the misconceptions that exist on Intensive Interaction, I will raise awareness of how crucial and fundamental it is in supporting, caring for, and teaching children with communication difficulties. The more we raise awareness and understand what is at stake, the more likely we are to influence practice and cultural change.

## **'Intensive Interaction...is that the thing where you imitate everything?'**

I have lost count of how many times I have heard this. I must admit, in the early days, I myself had this rather inaccurate understanding. The first time I encountered Intensive Interaction, I saw the practitioner following the child's lead, waiting for him to take the first turn, and then respond by using imitation. I assumed this was the core element of the approach, and the only way to respond to the child's actions/behaviours. It was only months later, looking back at videos of my early practice

that I realised imitation was not it. I was doing way too much, trying to imitate everything the child was doing. I even ended up with toys in my mouth! There are no rules by the way about whether you choose to put a toy in your mouth, or flap, or rock even. The questions that a practitioner must ask themselves are: Why am I imitating this behaviour? What is the purpose of it? and What am I trying to achieve by doing so? Copying what a child does is a very powerful way of helping them develop awareness of your presence, and of your intentions. It will also help them learn that they can influence the world around them, have a voice, and therefore develop a sense of self. It is therefore crucial to understand WHY we imitate. It is not about mirroring everything a child does, in a wooden, cold, removed way. It is about joining in with a behaviour the practitioner feels would be conducive to developing the child's awareness and interest.

## **Intensive Interaction is a lovely thing to do when you have some spare time**

Children with PMLD have greater communication difficulties than any of their peers, since their learning disability and physical disability further challenge their access to the social world. Children with PMLD have extensive brain damage, and therefore their





processing time is greater than what we may be accustomed to; it is basically as long as they need it to be. Being a communicator is about experiencing the social world in an active way. If the environment around a child with PMLD is not optimum, they are likely to remain switched off and therefore have very little awareness about themselves and the people around them. They are a number of attainments human beings need to learn in order to become successful communicators.

#### The Fundamentals of Communication:

- enjoying being with another person
- developing the ability to attend to that person
- concentration and an attention span
- learning to do sequences of activity with another person
- taking turns in exchanges of behaviour
- sharing personal space
- using and understanding eye contact
- using and understanding facial expressions
- using and understanding physical contacts
- using and understanding non-verbal communication
- using vocalisations with meaning
- learning to regulate and control an arousal level

Surely, working in these areas is the priority for people with PMLD, and should beyond all doubt be the central, most crucial aspect of their curriculum. Is it not self-evident, that lack of knowledge, experience and performance in these areas is a central aspect of a person with PMLD? Teaching children to be compliant only teaches them to be reliant, and to switch off. Surely, we want our learners to be passionate about their learning, and to be engaged with themselves and the people around them. 'In enhancing children's thinking, it is more important to aim at depth and not breadth. Deep understanding is more important than superficial

coverage' (Evangelou et al., 2009, p.4). Teaching is still conceptualised in a very traditional way. There is somehow this common belief that children need to be sat on their chairs in order to learn. I agree this is probably true for a lot of learning, and of course, the ability to take part in such learning comes with the ability to sit and concentrate on a task and therefore with a certain level of development. Children learn to do people first, before they can move on to do objects and shared activities.

#### **The practitioner is being directive and decides the content of the activity or It is about giving complete control to person**

**H**ewett and Nind (1998) point to three underpinning Intensive Interaction principles:

- The learner is an active participant – doing, thinking, processing, deciding, being creative.
- The learner shares control with the teacher, leads and contributes to all processes by mostly going first. The learner generates the content and is more or less in charge of the tempo of the activity.
- The learning activity is intrinsically rewarding and motivating. The reward for being in the activity is the interest and delight of taking part – the learner does not need to receive a sweet or even to be praised.

When we practise Intensive Interaction, we aim to promote a child's social-communication by helping them develop a sense of agency. Letting the child go first is crucial in the development of intentional communication.

Intensive Interaction practitioners learn how not to bombard, not to do too much, but just enough to help the other person be active and powerful, learn to decide, experiment, exercise curiosity. Intensive interaction techniques are about us holding back, waiting, allowing time and space for the other person to think, process, and act. To eventually do things to which we can then respond in order to develop the flow of the interaction. Learning to be a communicator is about learning how to have personal power and to how to use it (Hewett and Nind, 1998). Resisting the urge to prompt, to make something happen, or recreate something that previously happened between the two people. Minimalism we call it - is possibly the hardest skill to master in Intensive Interaction.

Having the confidence to wait will give the child time to think and be confident, and eventually take the first turn. Intensive Interaction enables people to independently and spontaneously access the world, and to have free thoughts. By not doing too much, not driving on, and



allowing the child to be in the lead, they can get a sense of control and feel empowered, communicate their needs and wants, and be part of the social world.

### **Intensive Interaction is effortless**

**T**he core technique of Intensive Interaction is tuning-in. It took me a while to be able to grasp the full meaning of this technique, and be able to explain it to others. The Macmillan Dictionary (2017) defines tuning-in as the ability 'to understand something such as a situation or someone else's feelings'. When we tune-in, we are fully present, in the moment, listening, reading, and interpreting all the signals the child sends. To do so, the practitioner must sensitively attune themselves to the child. It is only by tuning-in that the practitioner will know how to meet the child where they are at, and know how to respond accordingly. It is a highly demanding process, in which the practitioner must give all their attention and focus to read the child moment by moment.

### **Intensive Interaction can be done in Communication Group**

**I**ntensive Interaction is a one-to-one approach, and is based on joining the child, meeting the child at their level. Doing it in a group is therefore not an option, as the practitioner would then not be able to apply core techniques such as tuning-in.

Now, whether Intensive Interaction should take place away from the busy environment of a classroom, the answer is yes and no. It may be preferable in the early stages for the practitioner to go to a quieter area with the child they are working with. There are two reasons for this. Firstly, the practitioner may benefit from being in an environment in which they are not going to be disturbed, and in which they can build up confidence in the technique of Intensive Interaction. Secondly, this way of interacting may be new for the child, and a quieter environment therefore conducive to develop awareness and understanding.

Ultimately, the aim is for the child to receive a frequent supply of this type of interaction, many times a day throughout the day, in both planned and scheduled one-to-one times, but integrated into and flowing through all other activities (Hewett and Firth, 2012).

### **It is a nice thing to do but it's not really teaching**

**I**n Intensive Interaction, we often talk about a pleasurable time between the two people involved. Unless we know why we do Intensive Interaction, it is likely to remain this lovely thing we do but only when we get a chance. By taking part in Intensive Interaction, the child has the opportunity to rehearse the Fundamentals of Communication (Nind and Hewett, 2001).

### **Some don't like doing Intensive Interaction**

'We've tried, he doesn't like it.' Or even... 'He's not good at it'. Considering everything that has been said thus far, I think it will now become clear to you that there isn't such a thing. When we do Intensive Interaction, we sensitively tune-in to the child, and meet them where they are at. It may take some time to learn how to access someone, to get to know them and how to best join-in and respond to them. It may also take some time for a child to feel safe and secure with us, and with this new way of interacting. The reality is, we are the one applying the techniques of Intensive Interaction. We are the ones doing Intensive Interaction. We are the flexible ones, adapting our communicative style so that we can give a voice to those who can't access conventional ways of communication. To give opportunities for a child to take the first turn is not only empowering them as communicators, but is to give them the same opportunities to express and be heard, as any other human beings.

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### **Where to go for further information**

The Intensive Interaction Institute ([www.intensiveinteraction.co.uk](http://www.intensiveinteraction.co.uk)) provides training and support for organisations, practitioners, and parents.

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## Have you used the PMLD LINK Website?

The PMLD LINK website was launched in early 2016. It gives access to many back copies of the PMLD LINK journal and we are currently developing the resources section.

Some subscribers have told us they have difficulties accessing the member's pages of the website which carry the most recent issues. The reasons have been various, including:

- Their subscription has not been renewed at the end of the year
- They were trying to use the password for the former website which ceased to be valid
- They had forgotten or misplaced their user name and/or password
- Their details had been incorrectly registered on our database, sometimes as little as a misplaced dot or letter in an e-mail address

The main thing is that we can help you regain full access. If you are experiencing any problems with the website, please do not hesitate to contact Rob Ashdown who deals with subscription matters.

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## Elsie Finds Her Theme: A case study of Music Therapy with an 18 year old

Claire Fraser-Tytler

Music Therapy is a powerful medium of communication, especially for people with a diagnosis of profound and multiple learning difficulties (PMLD). When words are, for whatever reason, a challenge, emotions, needs and desires can be explored and expressed through the medium of shared musical experiences in a safe therapeutic environment.

In my job as a music therapist I work at a school for students with PMLD. My room is set up with a wide range of musical instruments, including tuned and untuned percussion, a keyboard and drums of various sizes. The clients also have use of a microphone and other handheld percussion instruments. I use my trumpet, a green plastic trombone and my trusty ukulele in order to have the wide range of timbres with which to match whatever sound the client wishes to express. When clients have little physical movement, they know that I am listening to them by playing to the rhythm of their breathing, the movement of their eyes or even the smallest twitch of a finger. When the client realises that I am matching their movements or vocalisations, it is a delight to see the joy in their face. Music Therapy can provide a much needed channel for the release of pent up emotions that may otherwise manifest themselves in

challenging behaviours. It provides a conduit for the exploration of feelings that have hitherto found no means of release.

Elsie (not her real name) is an eighteen year old student with a diagnosis of complex PMLD with additional medical needs. She is non verbal and a wheelchair user. Her education statement includes Music Therapy and she is a student I am working with on a long term basis. Her class team were keen for me to try and create a trusting and communicative relationship in order to help her develop ways of interacting with others. We began working together in January 2016.

Initially I saw Elsie on a weekly basis with three other class members. Each week she made a quiet yet valuable contribution. It was during these sessions I began to think



that by working with her on a 'one to one' basis, she would be encouraged to form her own musical identity. My hope was that this might add to her sense of self and self esteem. After the first term I began working with Elsie on her own.

For our first session together I intentionally set the room up differently so that there was a clear boundary between the group and the individual sessions. I did this by creating a horseshoe shape around her wheelchair, with keyboard, drums, cymbal and metalophone, all within easy reach. These were the instruments she seemed to like the most and my objective was for her to feel more comfortable and confident.

During our initial session Elsie seemed confused that the room looked different. She spent some time looking for the other members of our previous group and her teaching team. I explained simply that it was the two of us working together now and she would see the other members of her class later. As the realisation that she had my undivided attention came to the fore, she relaxed and began to enjoy the musical interactions that she was in control of. Music Therapy is a very client-led process and it was wonderful to watch her suggest the style, timbre and speed of each musical improvisation through her arm and torso movements, as well as her facial expressions.

Elsie has a great sense of humour and cheekiness. She loves, for example, when an instrument is accidentally knocked to the floor and my descending sliding 'ohhhhh no!' vocalisations that accompany it. The laughter and smiles that follow often morph into lighthearted musical conversation during which we take turns to vocalise. Elsie watches me intently throughout these exchanges and our musical connection is a privilege to be a part of.

Elsie loves the sound of the cymbal; she revels in the moments of shared musical to-ing and fro-ing as we pass the beater between us. The first time that we used the cymbal in session she gave me the beater so I could play it for her as I believe that she wanted the cymbal to be played loudly but didn't have the fine motor control to achieve the sound and timbre she wanted. When she touched the cymbal I struck it with a soft beater so that the sound reverberated around the room. Elsie was delighted and showed me this with big smiles, giggles and a twinkle in her eye. It was as if she was being heard musically for the first time, perhaps uncovering her long held desire to fill a room with her own musical identity? I felt her facial expressions dared me to play louder and when I did, using two beaters to create a cymbal roll, her excited vocalisations let me know that I had read her face correctly and she was fully engaged and invested in our musical experience.

Each week Elsie came and reached out to the cymbal, letting me know in no uncertain terms what her aims for the session were! As the weeks progressed we explored other instruments such as the metalophone and keyboard in greater detail but she always came back to the cymbal. Elsie accompanied the cymbal playing with her own triadic descending vocalisations whilst playing the piano with her right hand. I mirrored her vocalisations with my trumpet which, as the weeks past emerged to be 'Elsie's Theme'.

We have had success with the use of a Big Mac button, so that Elsie could play her name during her 'Hello Song', so I programmed the button enabling to ask for more. I modelled this for Elsie and she learnt that a press of the button meant that she could hear the trumpet, trombone, cymbal or whichever instrument her heart desired that session.

As the sessions progressed our trumpet and vocal improvisations evolved into 'Elsie's Theme'. It was a joyful melody that seemed to fit with her presentation in our sessions. At times when Elsie came to a session tired or a little under the weather her theme moved from the major to the minor key and was slower and more thoughtful, in keeping with the mood I felt she was trying to communicate. She acknowledged with smiles, seemingly genuinely pleased that I had correctly understood her feelings.

I wanted to develop 'Elsie's Theme' and create a piece of music that she could not only take pride in but something concrete she could take away and share with her class mates, her family and friends. We are currently in the process of recording her song on the iPad with garage band. I have programmed her song onto the Big Mac button so she can play it whenever she wants throughout the track. I have also created a backing track of drums and trombone, over which she can improvise, using chimes, piano or her beloved cymbal.

Giving Elsie a sense of musical identity, belonging and control over what is played within the track has given her confidence to play the cymbal herself with a beater and to use the microphone to ensure her vocal contribution is heard. I am hopeful that this increased sense of selfworth and value is transferable throughout other areas of her life and our continuing work together.

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To find a music therapist in your locality please visit [www.bamt.org](http://www.bamt.org) and click on 'find a therapist'

# Tierney the story of a girl with profound disabilities – the Improvise approach

Carrie Lennard

For people who have severely restricted movement, a touchscreen musical instrument plus specially composed backing tracks, give you freedom and direction.

Tierney has very restricted movement and complex learning needs and yet she can create music independently.

She plays along using the ThumbJam app in her own time, her own style and with her own backing band. It sounds good. She knows it and it makes her smile a lot!

Tierney's mum, Tracey, was introduced by Carrie Lennard (special needs music teacher/designer and publisher) to 'The Improvise Approach'. It makes music-making accessible to anyone with severely restricted movement, using an iPad.

The ThumbJam app is the music instrument and is available from the App Store. Everything else comes in The Improvise Approach ebook (available from the iBookstore) - all the instructions (with pictures) and 10 interactive music audio tracks are included in the ebook.

Mum is really happy that she can open up and develop Tierney's creative music-making potential so easily.

Everything Tierney plays is in tune. How? This is due to the way the ThumbJam app is beautifully set up (instructions in the ebook). Her repertoire includes jazz, reggae, classical, world, ambient music - all 10 music tracks play directly from The Improvise Approach ebook. (Music only is available as an album 'Improvise One' from iTunes).

Her teacher also uses The Improvise Approach activities in class and Tierney and her friends now have their own band - The Angelfish iBand! Check [www.improviseapproach.com](http://www.improviseapproach.com) for the video!

It took a couple of music sessions for students and staff to get started. Everyone could see how motivated the students were about making music by themselves, with minimal adult support. The improvise activities are intrinsically rewarding because what you hear is great sounding music. Everyone wants to join in!



Other important things are happening like improved hand-eye coordination, developing motor skills, growth of self esteem, establishing self-identity and group awareness, involvement and interaction with peers...the list goes on. And of course, these things cross over into other areas of the student's life.

If you'd like to know more, check out [www.improviseapproach.com](http://www.improviseapproach.com). The ebook is available from the iBookstore and it comes with simple picture instructions and the 10 music audio tracks, everything you need to break down the barriers and to empower another budding musician.

## Contact Details

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## A Special Measures Experience from the point of view of a PMLD Teacher

Amanda Brown

Prior to December 2013 I was a conscientious, hard-working, caring teacher who had developed a passion for teaching pupils with PMLD. I enjoyed the challenge of creating fun learning activities for individuals or for groups of pupils, drawing upon knowledge gained from the positive relationships my team of teaching assistants and myself worked tirelessly to develop with each and every pupil.

**W**e recognised the value of repetition within daily routines and also within lessons. I was never sure whether or not we were doing things 'right', but always looked for ways to adapt and improve my teaching approaches based on our observations and continually deepening knowledge of the pupils we taught. I used to moan about the limited time I had to do what often seemed like an overwhelming list of tasks, and even though I was always very generous with my time, things like record keeping regularly ended up at the bottom of

my priority list. My team and I considered the well-being of each pupil to be of uttermost importance, and the core values of care, respect, perseverance, patience, enjoyment and aspiration were central to our practice.

One day in December 2013 my school received the phone call saying that Ofsted would be visiting the following day. We hadn't thought that our inspection would be in the autumn term, so it was a bit of a shock. My immediate team and I received lesson grades that we

were proud of, and I personally enjoyed the dialogue with the Ofsted inspector about my lessons. She told me about elements of excellent practice that she had seen in other schools and gave us a couple of suggestions. We put these suggestions into practice the following week. It was clear that the Ofsted inspector had an understanding of PMLD, and I would have liked to have been able to learn more from her. I picked up through conversations about other teachers' feedback that learning time for each and every pupil needed to be maximised. This made perfect sense, as did the emphasis on individualised approaches to learning.

The Ofsted inspection deemed the school to be 'inadequate' and this is where the Special Measures journey began for my school. The spring term of 2014 was filled with uncertainty. My colleagues and I understood that what we had been doing wasn't good enough, but it felt like a long time before direction became clear. The feeling of wanting to support the school to improve, but not knowing how to, was frustrating to say the least.

Following on from the phase of uncertainty came an influx of external 'support' in the form of advisors from the Local Authority, head teachers and senior leaders from other schools, consultants and many other visitors. Everything and everyone within the school was 'interrogated', no stone was left unturned, and some of the visits left us feeling 'rotten to the core'. I had previously felt trusted as a teacher. It was clear that this trust had been taken away and I had the constant feeling that someone was trying to catch us out. Looking back, I know that many of the professionals supporting the school were doing so in a developmental, positive way and the part they played was important in the improvement of the school. At the time it was difficult to know whether people were trying to catch us out or be supportive, so I found it easiest to just assume that I needed to be wary of everyone. Along with the external advice, came the contradictory guidance e.g. 'Do laminate individual targets for the classroom wall.', 'Don't laminate because it looks like targets don't change regularly.', 'Produce a sheet showing an overview of class progress.', 'Don't produce a sheet showing class progress.' My colleagues and I continued trying to do our absolute best for the pupils while cyphering through this bombardment of confusing advice. The best days during this period were the ones when no visitors came to school and we could just get on with supporting the pupils to learn.

Some people who visited our classes or observed our lessons clearly had very little PMLD experience. This was evident in some of the comments made and questions asked. I joined external advisors on learning walks around school and became much more aware of what

someone sees when they step into a classroom and what judgements they make. This was pivotal for me because it made me realise I needed to make it really obvious to absolutely anyone coming into my classroom that learning was taking place. My colleagues and I knew that learning was taking place and we were all in tune with the small steps of progress our pupils were making, so I started saying out loud the learning that I was observing during lessons, and directing this to the pupils e.g. 'Pupil A, you stilled to that smell'. I would also use my comments to show that we were supporting the pupils to progress further e.g. 'Pupil A, can you turn your head towards the smell?'. While making these comments and asking questions I was mindful not to use too much language and of the need to maintain a quiet, calm classroom without unnecessary speech. It is unclear how much of what I said was understood by the pupils, but involving them in the dialogue I had in my head about their learning seemed like a natural thing to do. Touch Cues/Body Signing and/or Makaton signs would support my speech where appropriate. This approach worked for my class as we were still able to hold on to the core values held central to our practice while helping any observer to be able to identify learning. Lesson observations continue to feel like a performance to me, or a bit like a driving test where you need to make it really clear to the examiner that you are looking in your wing mirror.

As our journey towards 'good' progressed, I became involved in supporting some other teachers. A new head teacher was appointed and the way forward became increasingly clearer. I enjoyed working with leaders and colleagues to create clear, standardised paperwork and support consistent ways of working. I was particularly nervous about observing a lesson alongside the HMI inspector, but it turned out to be a positive experience, encouraging me to approach future discussions with inspectors or advisors with more confidence and self-assurance.

In November 2015 we officially became a 'good' school again. Since then we have amalgamated with another local special school, and have taken on their DFE number, so another Ofsted inspection is around the corner for us! We have a department based structure now and it has been exciting working within PMLD classes to further develop our provision for pupils with PMLD. We now use ImPACTS curriculum and assessment devised by Rosewood School, and are in the process of building stronger links with other PMLD schools, departments and teachers.

It sometimes feels like teaching lessons is such a small part of the role of a PMLD teacher. The time between lessons, routines, break and lunchtimes, toilet visits and transitions from one activity to the next are all highly



valuable learning times. Discussions with families, medical professionals, therapists, social workers, specialist teachers and respite care providers are all vitally important aspects of the role. I enjoy the variety associated with the role.

My team and I managed to hold on to the core values of care, respect, perseverance, patience, enjoyment and aspiration throughout the special measures process. We are now more confident that we are providing the pupils with a great education, and we have a solid basis for the creative discussions that are emerging about how to further develop the department. Lots of brilliant

colleagues who constantly go above and beyond their job descriptions, and supportive, encouraging leaders made the special measures process bearable and sometimes pleasurable. The real pleasure has come from each and every pupil in the department. They have been exceedingly generous with their interactions, acceptance, humour and curiosity, and I wish to thank them for this.

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### **Addendum Winter 2016: Health Matters Vol 28 No.3 Issue 85**

Apologies for the missing email contact for Lisa Donaldson  
l.donaldson@seeability.org (page 31);

Our thanks to Anna Marriott for contributing 2 items:

- LeDeR Programme update (page 52)
  - Information about the Reasonable Adjustments reports (page 54)
- To contact Anna, email: [anna.marriott@ndti.org.uk](mailto:anna.marriott@ndti.org.uk)

Due to lack of space some items of Health News were moved into this issue.  
See pages 40 and 41

## **Being Social #PMLDlink**



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<https://www.facebook.com/PMLD-Link-777526962325831/timeline/>

# Reflections On The Rochford Review Recommendations With Particular Regard To Pupils With Profound Multiple Learning Difficulties

Richard Aird

In 2015 the Department for Education (DfE) published the final report of the Commission for Assessment without Levels (CAWL) which reported that, “Assessing pupils with complex needs and those with very low attainment can be more complicated than assessing other pupils and implementing the principles of assessment may sometimes need to be approached differently” (DfE, 2015a, p.46).

As obvious as such a statement might appear to PMLD practitioners, its inclusion in the CAWL report helped prompt the Standards and Testing Agency (STA) to commission a more in depth review of pupils working below the standard of national curriculum tests (The Rochford Review) of which I was a permanent member. The terms of reference for the Rochford Review included a requirement to research and make recommendations about whether the so-called P scale levels (used by many schools to track progress of pupils towards national curriculum level 1) remained fit for purpose and consider how any proposed solutions to P level issues might:

- Recognise achievement and progress made by all pupils;
- Support the ambitions of the most recent SEND (special educational needs and disability) reforms (in particular Education, Health and Care (EHC) Plans);
- Assist with school inspection and improve accountability for SEND provision;
- Suggest wider implications for professional development.

The final report of the Rochford Review (Standards and Testing Agency, 2016) was published in October 2016 with public consultation on its recommendations set to end in April 2017. For sake of brevity this paper refers only to matters which are immediately relevant to the education of pupils with PMLD.

## The EHC context

Whilst considering whether P levels remained fit for purpose, the Rochford Review noted that the SEND Code of Practice (DfE, 2015b) and the Children and

Families Act (2014) came into force considerably after the requirement for schools to statutorily assess pupils by reference to the P levels. This new legislation set out additional requirements for how schools should assess pupils with SEND, e.g.

- Assessment should be used diagnostically and build in a ‘graduated approach’ (i.e., Assess, Plan, Do, Review);
- Assessment should be holistic and assess pupil progress in the wider areas of need;
- Assessment should consider progress relative to starting points alongside the nature of pupils’ learning difficulties;
- Assessment should contribute to the early and accurate identification of pupils’ special educational needs and any requirements for support and intervention.

These additional requirements were not only considerable in terms of their scope, but also the more formative, wide ranging assessment approaches being requested, were rather in contrast to the existing overarching statutory requirement for schools to focus on summative P level linear assessment (i.e. pupil progress through the 8 P levels towards subject-specific attainment at national curriculum level 1). The government offered little advice about how schools might be able to reconcile such differences and schools were left to interpret new assessment requirements in a climate where the Qualifications and Curriculum Development Agency (QCDA) “progression guidance” was still being applied during some school inspections. There can be little doubt that the absolute importance associated with P level performance data inhibited the

extent to which some schools have been able or willing to develop the kind of holistic assessment approaches required by the introduction of EHC plans which are at the heart of the new legislation, but currently struggling to fulfil the ambitions the government hoped would be realised via the EHC multi-agency strategy (Long, 2016).

### Pupils with PMLD and P scale levels

For a generation of pupils the DfE definition of PMLD has included the statement, "Their attainments are likely to remain in the early P scale range (P1-P4) throughout their school careers", demonstrating there has always been official recognition that these pupils are very unlikely to make linear progress. Inevitably this definition has resulted in ambiguity in the way practitioners have viewed the relative value of the linear aligned P level approach. The CAWL report stated that teaching had become too focussed on getting pupils through the next national curriculum level and 'depth and breadth of understanding were sometimes being sacrificed in favour of pace' (DfE, 2015a, p5). If this was the case for pupils working at subject specific standards then the Rochford Review was rightfully concerned about what negative impacts might also be being inflicted on pupils with PMLD. Learning is generally defined as the acquisition of knowledge classified by reference to different subjects. In keeping with this definition, the statutory assessment of pupils is traditionally undertaken by testing a pupil's knowledge against concise standards of what s/he is expected to know and be able to do at specific chronological stages. Pupils with PMLD work at cognitive levels below that which can be attributed to individual subjects, so attempting to rate their performance by reference to the linear, subject aligned P level approach was always bound to create confusion.

Midway during the Rochford Review, the DfE undertook a survey of teachers and other interested parties and asked the question whether P levels remained fit for purpose: 78% of respondents replied "no" and this was also the overwhelming view of the Rochford Review panel. Although there was general agreement that the P level approach was no longer appropriate for assessing pupils with PMLD, the panel had to identify an alternative that would not only satisfy the review's terms of reference, but that could also be viewed as being "inclusive". The Rochford Review spent a considerable amount of time debating what 'inclusivity' actually meant in respect to pupils with PMLD. The group came to the conclusion that ensuring everything is the same in statutory assessment does not mean such an approach is inclusive or able to provide equal insight into the standards of learning being attained by all pupils. Instead, the review agreed that sometimes approaches to statutory assessment have to be varied in order to provide equal insight into the standards being attained by pupils with PMLD.

### The Idiosyncratic Learning Styles of Pupils with PMLD

Pupils with PMLD have idiosyncratic and severely restricted behaviours that make it difficult to assess their learning. Multiple and often severe impairments to their cognitive, sensory, physical, communication and social/emotional abilities together with chronic health problems, often combine to form barriers which isolate pupils from engaging effectively in new learning. As a consequence, the way in which these pupils are taught needs to be informed by a sound appreciation of what motivates and empowers an individual pupil to engage in learning, together with an understanding about what things might serve as learning barriers without appropriate intervention being taken. Assessing how well pupils are making progress within the four EHC areas or domains of need is notoriously difficult, as the gains and losses which pupils make are often so subtle as to confound the ability of teachers to undertake evidence based assessment. Moreover, assessments are often undertaken by a number of different agencies including therapists, clinicians, social workers and visiting teachers who may not necessarily work closely enough to provide clear, overarching insight into how the impact of a pupil's profile of EHC related disabilities can be minimised in order to empower a pupil to learn more effectively. Teachers of pupils with these profound and complex needs have to be guided by accurate, formative and holistic information about what and how to teach in order to fully support pupils to succeed in their education and make a successful transition to adulthood. (DfE, 2015).

### Recommending an Alternative to P level Assessment

When the narrow historical focus of P level assessment was finally agreed to be untenable, the Rochford Review investigated a number of different assessment models, many of which were acknowledged as being of considerable worth. However, copyright issues and strict rules governing commercial schemes meant that the panel could not recommend any particular approach, even had they wished to do so. Instead a specific aspect of learning was identified that could be used to assess pupils with PMLD in a fair, inclusive way and that could also help support the ambitions of EHC plans - this aspect of learning was that of 'engagement'.

When used in this context, engagement represents variations in attention, interest and involvement which pupils demonstrate when they participate in new learning, enabling them to progress towards mastery in their acquisition of new knowledge and ultimately able to generalise new learning. Engagement is a crucial aspect of learning common to all pupils, as confirmed by Hargreaves (2006) who commented that without

engagement, there is no deep learning. Engagement is fundamental to the process of learning for all pupils, regardless of individual academic ability. Research undertaken by Iovannone et al (2003) had previously found that, engagement was the single best predictor of successful learning for children with learning disabilities. Because engagement is central to how pupils of all abilities learn, measuring the different ways and extent to which pupils engage in learning was accepted by the Rochford Review as representing an inclusive approach to statutory assessment that was particularly relevant to pupils with PMLD.

### Statutory assessing pupil engagement in cognition and learning

Research into engagement has been underway on an international scale since at least 2003 and various different aspects of engagement have been consistently identified. For example, the Welsh Assembly Government (2006) published their well respected “Routes to Learning” in which a number of “indicators” of learning were described and a research project on Complex Learning Difficulties and Disabilities (CLDD) (see Carpenter et al. 2015) noted seven aspects of engagement. Numerous discussions were held within the Rochford Review about how changes in pupil behaviour could be used to serve as reliable predictors of learning and members eventually agreed to accept the definitions of the seven aspects of engagement as published by the CLDD research project, with only very minor amendments:

- Responsiveness – Changes in a pupil’s behaviour that demonstrate s/he is being attentive to a new stimulus. This sort of assessment is important for establishing what differing stimuli motivate a pupil to attend and is particularly relevant for assessing pupils with multiple sensory impairments who have reduced and/or atypical sensory acuities and perception
- Curiosity – How a pupil is building on an initial, fleeting reaction to a new stimulus, perhaps by reaching out or scanning for the source of a new stimulus
- Discovery – Changes in the way a pupil is interacting or responding to a new stimulus, sometimes accompanied by expressions such as enjoyment and excitement
- Anticipation – How a pupil is able to predict, expect or associate a particular stimulus with an event which is important for measuring a pupil’s understanding of cause and effect
- Persistence – The extent to which a pupil is sustaining attention towards a particular item or action and thus beginning to develop conceptual understanding
- Initiation – The different ways and extent to which a

pupil is instigating an event in order to bring about a desired outcome

- Investigation – The extent to which a pupil is actively trying to find out more about an object or activity via prolonged, independent experiment

Having a sharp assessment focus on cognition and learning, facilitated by measuring pupil engagement, immediately offered an inclusive solution to statutory assessment and provided a way of supporting the ambitions of EHC plans. The CLDD project developed an Engagement Scale with which to measure variations in pupil engagement which international research has shown to be highly effective (Carpenter et al, 2015). Data about pupil engagement can be used formatively to inform personalised learning pathways and refine distinctive pedagogical approaches and also used summatively to report linear and lateral pupil progress. In keeping with the national trend towards flexibility within curriculum and assessment design. It will be up to schools how they choose to use the Engagement Scale to the best advantage of their pupils and it is reassuring there is a large, international body of research which schools may draw upon to inform their practise. The Rochford Review believes that adoption of the Engagement for Learning approach will provide schools with a flexible assessment system that is robust enough to inform a dialogue with parents, OfSTED, local authority commissioners and peer reviewers without the need to submit pupil performance data to the DfE.

### A Holistic Approach to the Statutory Assessment of Pupils with PMLD

“Cognition and learning” is one of the four areas of need as highlighted in EHC plans, the others being:

- Communication & interaction;
- Physical & sensory;
- Social, emotional & mental health.

“Routes to Learning” stressed the need for assessment to be sensitive to a pupil’s preferred sense modalities and ensure it bears in mind the priority needs and physical and sensory abilities of the learner. The Rochford Review very much supports the absolute importance of formative, holistic assessment in the education of pupils with PMLD and advocates that data about pupil engagement can be used to both interpret and complement information gathered from more clinically biased diagnostic testing in areas such as communication, behaviour, sensory and motor function. Assessment of pupil engagement is not just concerned with monitoring whether a pupil is demonstrating engagement in each of the seven aspects described above, it is also about measuring changes in the frequency and duration of engagement by reference to the following scale:



- No focus = 0
- Emerging or fleeting = 1
- Partly engaged = 2
- Mostly engaged = 3
- Fully engaged = 4

Pupil engagement in any targeted activity or intervention strategy can be base-lined and then the impact of any subsequent modifications in differentiation and/or teaching approach can be measured objectively via further application of the engagement scale. Data may then be used to demonstrate progress in a targeted concept/skill and also to evaluate the relative effectiveness of different intervention strategies in any of the EHC domains. Although the Rochford Review recommends statutory use of the Engagement Scale in the domain of cognition and learning, the additional requirement for schools to routinely report progress in all four EHC domains implies use of the Engagement Scale in the other three domains. It is implicit in the Rochford Review that pedagogy, curriculum and combined formative/summative assessment need to be closely inter-linked to ensure that pupils with PMLD have the appropriate:

- Motivation, support and access arrangements to engage effectively in cognition and learning;
- Personalised intervention strategies to improve functional abilities in all EHC domains;
- Opportunities to apply new concepts and skills in practical, functional ways;
- Long term outcomes that will be enduring and improve social inclusion in adult life.

The Rochford Review recommendations have been designed to help facilitate such outcomes and readers are encouraged to offer positive support during the DfE consultation exercise.

Readers wishing to know more about engagement for learning are strongly urged to visit [www.engagement4learning.com](http://www.engagement4learning.com) which offers a massive amount of practical advice and downloads.

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## Circles of Support

This research project is a collaboration between Manchester Metropolitan University; The University of Sheffield; The University of Bristol and Northumbria University as well as SpeakUp; Mencap; Foundation for People with Learning Disabilities; Pathways Associates; Manchester Learning Disability Partnership and Independent Living Advisors Pete Crane, Wendy Crane, Max Neill & Helen Smith.

**W**e ask: how are people with learning disabilities faring in a time of Big Society?

have a paid facilitator and funding available for facilitation is limited;

### Circles of Support

The research found that:

- Circles of support come together to work with a person is socially isolated or has been socially excluded;
- People tell us that circles can be a very powerful way of offering personalised support and ensuring that the person's wishes are heard;
- Circles are not a new idea, but there are still relatively small numbers in regional clusters around the country;
- There is debate about whether or not circles should

We suggest that:

- Circles offer a powerful form of 'co-produced' advocacy;
- Information about circles should be shared widely;
- Funding for facilitation should be made available to people who want it.

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## NEXT ISSUE

Summer Vol. 29 No. 2 Issue 87

### Life As An Adult

See page 38 for details

# I've lost my Granny's Gnashers!

Peter Wells

## Storyline:

- 1 I've lost my granny's gnashers, I stole them for a play,  
Now I don't know where I left them and I've been *everywhere* today!
- 2 I've lost my granny's gnashers, they were in a glass beside her bed!  
I used them to trim the hedges, in the garden by the shed!
- 3 I've lost me granny's gnashers, did I leave them in the dog?  
I thought they'd help him crunch his biscuits, the greedy little hog!
- 4 I've lost my granny's gnashers, or where, oh where could they be?  
I've been down to the beach today, did I drop them in the sea?
- 5 I've lost me granny's gnashers, this day was great but this'll spoil it,  
I hope I didn't dropped them, when I was sitting on the toilet!
- 6 I've lost my granny's gnashers, whilst giving them a clean!  
When she finds out she will be furious, she can be very, very mean!
- 7 I've lost me granny's gnashers, I gave them to the cat,  
To keep inside his mouth a while, there's nothing wrong with that!
- 8 I've lost my granny's gnashers! Did I leave them on the porch?  
It's starting to get dark outside, I'll have to find my torch.
- 9 I've lost my granny's gnashers, I put them on the table,  
Then I think I saw them picked up, by shortsighted Auntie Mabel.
- 10 I've lost to me granny's gnashers, I've searched all over the house!  
I think last time I had them, I was cleaning out my mouse.
- 11 I've lost to my granny's gnashes, this really is a drama!  
I think I remember using them to mash up my banana.
- 12 My granny FOUND her gnashers, please don't tell her where they've been!  
Because now they're back inside her mouth, and can't be very clean!

## Suggested Props!

(Feel/smell grass/hedges/  
soil)

(Taste biscuits/woof on  
BigMack)

(Feel sand/water)

(Flush/splash/toot on  
BigMack)

(Smell/taste toothpaste/  
mint)

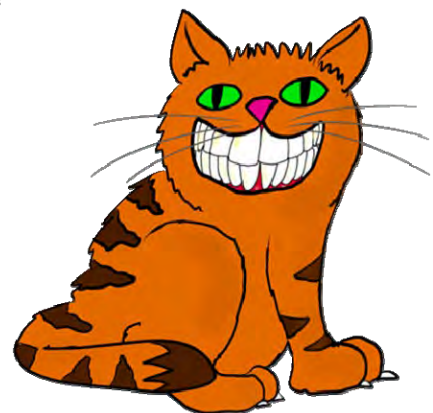
(Meow/feel cat, look at cat  
picture)

(Track torch/switch  
activated light)

(Smell perfume)

(Feel/smell animal  
bedding)

(Feel/taste banana)



Pete Wells has been teaching amazing children in Sunderland for over twenty years.

Pete works as creative lead for Ascent Academies Trust and can be reached at [pwells@ascenttrust.org](mailto:pwells@ascenttrust.org).  
You can find more of his sensory stories in the Resources section of <http://www.portlandcollege.org/>

# Guides to Developing Communication and Social Interaction

Robert Ashdown

This article includes some of the material which is currently being prepared for uploading to the PMLD LINK resources page of the website. The focus will be on providing a guide to texts and websites that offer useful information about teaching and assessing communication with both children and adults with PMLD.

**J**uliet Goldbart and Jean Ware (Goldbart and Ware, 2015) provide a short overview of communication and interaction in relation to children and young people with PMLD. They describe how communication typically develops and in what ways communication may develop differently in learners with PMLD. They identify approaches to assessment and some specific teaching approaches, including use of specialist switch technology, Intensive Interaction and the use of Objects of Reference. Peter Imray and Viv Hinchcliffe (Imray and Hinchcliffe, 2014) outline a 'communication curriculum' and their evaluation of a range of assessment and teaching approaches.

Online materials are also available. Juliet Goldbart and Sue Caton (Goldbart and Caton, 2010) produced a guide commissioned by Mencap which presents the evidence base for a range of communication approaches. They stress the need for further evaluation of the effectiveness of commonly used, but relatively unevaluated, approaches. Mencap and the PMLD Network have produced a series of Raising our Sights guides and videos which aim to help local areas meet the needs of people with PMLD. The third guide by Sue Thurman is about communication and focuses on what good provision looks like and what needs to be in place to meet the communication needs of people with PMLD. The ninth guide written by Penny Lacey focuses on accessing meaningful and interesting activities in places where the needs of adults with PMLD can be met and there is an associated film. The guides and films can be accessed online at: <https://www.mencap.org.uk/advice-and-support/pmld>

In 2012 the Department for Education produced online Training Materials for Learners with Severe, Profound and Complex Learning Difficulties. The training materials relate to teaching pupils with a wide range of special educational needs and disabilities but some elements are very relevant to assessment and teaching and the curriculum for learners with PMLD. The materials are presented in 16 modules but particularly relevant to communication and interaction are three modules: 2.2

Considering communication and interaction; 2.4 Assessment, monitoring and evaluation; and 3.1 Communication: augmentative and assistive strategies. The materials are supposed to be undergoing revision. They can be accessed online at: <http://www.complexneeds.org.uk/>

## Affective Communication

**O**ne approach to establishing intentional communication is called the 'affective communication method'. The several steps in this teaching approach may be summarised as follows. First of all, a variety of stimuli are presented to the pupil and their observable responses to each are noted. These stimuli may be auditory, visual, tactile, gustatory or olfactory or a complex combination of these, such as, human contact, specific sounds, tastes of specific foods, bright disco lights, and so on. The pupil must be given time to respond to each stimulus and a provisional interpretation of the meaning of the pupil's responses - vocalisations, facial expressions and/or body actions - has to be made in each case. The next step involves representing those stimuli that evoked the pupil's strongest responses. Checks are made for the consistency of the pupil's responses and the behaviours that may be interpreted as 'like' or 'dislike' are identified. The final step is to actually teach the pupil that behaving in certain ways will have an effect on the people who are doing these things to him or her. Situations are engineered which are known to evoke specific potentially communicative behaviour, i.e. the behaviour that can be said to communicate emotional reactions to the stimuli. When potentially communicative behaviour has been evoked, the teacher responds to the pupil's behaviour in a relevant and consistent way as though the pupil is intentionally communicating. If the pupil's behaviour indicates 'like', the interesting or pleasing item or activity is presented again. If the pupil's behaviour indicates 'dislike' the item or activity is stopped or withdrawn immediately. The assumption is that after sufficient experiences of this nature the pupil will come to realise that they can behave in ways that communicate desires or rejection of things or activities.



In such interactions are sown the seeds of simple communication and choice making by many pupils. The approach is described in several publications including Barber (2001), Coupe et al (1985) and Coupe-O’Kane and Goldbart (1998)

### Intensive Interaction

Intensive interaction is an approach to teaching the pre-speech fundamentals of communication to children and adults who are still at an early stage of communication development. Dave Hewett and Melanie Nind developed Intensive Interaction in the 1980s and their approach has become widely accepted. Dave Hewett and colleagues (Hewett et al, 2015) provide an overview of Intensive Interaction’s aims, potential outcomes, and intended processes and differentiate it from other approaches. Information about training and publications are available online [www.intensiveinteraction.co.uk](http://www.intensiveinteraction.co.uk).

Another practitioner, in Australia, is Mark Barber. He has various downloadable articles available online at: <http://www.drmarkbarber.co.uk/resources.html>. Two articles by Mark Barber have appeared in PMLD LINK (Barber, 2005; Barber, 2007). Jean Ware brings to our attention the importance of ‘creating responsive environments’ to promote communication and interaction (Ware, 2003). She stresses that practitioners should expect that all learners will respond to interaction and other stimuli but they must be given as much time as they need to process information and then respond at their own pace. Every response from a learner should be treated as communicative and responded to appropriately. Environments and activities should be carefully engineered to evoke responses from learners but also they should have opportunities to take the lead.

### Objects of Reference and Photos

The idea behind Objects of Reference is that the object (or even a smell or taste) has more significance for the learner at an earlier developmental stage than pictures or formal symbols (Ashdown, 2001; Ockelford, 2002; Park, 1997). Objects of reference have a number of uses. They can be used to signal to the learner what is about to happen, for example giving the learner a cup would show that is snack time. They are also used to offer choices; giving the learner a choice between a cup and a spoon to show their choice between a drink and a snack. A development on from this would be the use of a visual timetable with objects of reference for the activities that were available or due to happen during the morning. As well as this use of objects to help the learner make sense of what happens around them, the learner may learn to use the objects to request things or events. Good quality photos and True Object Based Icons (TOBIs) may be useful with some individuals. TOBIs can be any line drawing or picture that are cut out in the actual

shape or outline of the object they represent. With repeated use, the individual may learn to see the symbol and outline of the shape, and this will help in developing understanding of two-dimensional symbols. TOBIs are usually larger than typical two-dimensional symbols. For more details about TOBIs and other visual systems see Anderson et al (2016) and Lacey (2012).

A range of examples may be found in the Training Materials for Learners with Severe, Profound and Complex Learning Difficulties (see above) especially Module 3.1 Communication: augmentative and assistive strategies. Information about different visual systems is available online including at: <http://www.callscotland.org.uk/downloads/quick-guides/AAC/> <http://www.oxtc.co.uk>

### Personalised Technology for Communication

Switches and other cause-and-effect activities are ways of helping people with PMLD understand that their actions can make things happen. This is viewed as a step on the way to making things happen by communicating with other people. Some will learn that switches may be used to make and convey choices and attract the attention of other people. Some of the most helpful communication aids are simple touch-operated aids: for instance, Big Macks (a large button that can be used to play and record a message or sound effect) and similar devices may be used to gain the attention of other people for social contact; and talking photo albums. For people with a degree of eye-hand coordination 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. Then, of course, there is a growing range of sophisticated (and often expensive) technical devices to support communication. Ian Bean is a really good consultant and trainer: see his website (<http://www.ianbean.co.uk>). Some specialist centres provide online guidance materials and offer specialist expertise in communication and assistive technology. For instance, go to:

- <http://www.ace-centre.org.uk>
- <http://www.callscotland.org.uk>
- [www.thecommunicationtrust.org.uk/projects/what-works/](http://www.thecommunicationtrust.org.uk/projects/what-works/)

More details about communication strategies and approaches to facilitating genuine interactions plus information about assessment will also appear in the communication resources on the PMLD LINK website when these appear later this year. Watch out for the changes.

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## Get Involved!

We welcome any contributions to PMLD LINK. We are very flexible in our requirements and articles are usually between 1 and 4 pages of A4 single-spaced, regular font size. This usually equates to between 350-1500 words. However we are happy to accept shorter or longer pieces. Ideally, we want you to have the opportunity to discuss what you want, rather than tie you to a fixed number of words.

Our readers are family members, carers and a range of professionals working across child and adult services, so any specialist terms used should be clarified. Articles vary from those with a research/academic focus to those that are very practical in nature. It is useful to include references and contact details to enable readers to follow up information – and they do!

As this is the only journal dedicated to people with PMLD, it is important that your article is specifically related to them. If appropriate, give examples of the work in practice and how it could be applied elsewhere. We can include images, photographs or samples of materials, which will appear in black and white only, if this is appropriate and where relevant permissions are given. Please send a completed consent form with your article (downloadable from the PMLD LINK website).

We also welcome short informative pieces about new resources, books, websites, events, courses and news in general.

**Email: [info@pmlmlink.org.uk](mailto:info@pmlmlink.org.uk)**

# School's out! A community based curriculum for young people with PMLD

Cathy Bradshaw

Think of a school, any school, and you immediately have a picture in your head of what a classroom looks like. Now think of a classroom for young person with PMLD. There are differences, but ultimately it's still a similar picture, only this time with extra equipment and hopefully more floor space!

Classrooms are a safe environment for our young people. They are adapted to meet our learners' needs with an array of equipment, offering familiarity and predictability and opportunities to learn new skills.

Teaching and learning can take place in a controlled environment. This enables learners with PMLD to pick up the cues from sights, smells, sounds and textures that are familiar to them, giving them opportunities to develop communication and independence skills.

As our learners grow older, they may move to different classrooms, also purposely adapted; safe, but with different sensory stimuli. Students may begin to generalise skills in these new classroom environments and apply them in different contexts and to different stimuli.

Let's move forward in time to that exciting but often scary moment when our young person leaves education. They have learned a variety of skills in safe, predictable, familiar and specially adapted environments, however, ultimately this is usually a classroom.

As adults, our young people are no longer in schools. They find themselves suddenly based in the community, with its dazzling array of different sensory stimuli: unpredictable, exciting, sometimes daunting and hitherto only accessed at irregular intervals.

A community based curriculum is essential for preparing our young people for life after school. As they grow older and more secure in their skills, they need opportunities to make progress by practising these classroom based skills in the outside world.

Our Post-16 centre is part of The Shrubberies Special School. It is a purpose built centre, located approximately half a mile from the main school site, within easy walking distance of the local High Street and the surrounding countryside. It is called The Apperley Centre.

The main aim of The Apperley Centre is to develop our students' skills and so prepare them for adult life. We have our own minibus and a programme of community visits is offered which may include cafés, garden centres, access to the local countryside and local shops. Students also access community leisure facilities such as local leisure centres, fitness classes, gyms and parks and some may access local services such as the hairdressers or opticians. Students are given opportunities to develop work skills through work related learning at the centre and last year 77% of the students also accessed external work related learning in the community.

Communication skills learned in school with familiar young person are developed in shops, cafes and other community facilities with the support of school staff. Interactions with people in the community is the rule, not the exception.

Problem-solving and thinking skills that have been developed in the classroom, are practised in busier and ultimately highly stimulating and distracting environments, leading to increased confidence and independence.



Gardening in the local High Street.

Basic work skills, so necessary to engage our young people in the world around them, are developed where possible in the community through projects such as work in a local orchard, gardening at the community allotments or in community raised beds in the High Street. Other work related learning includes an Enterprise Project with the local Community Partnership, links with a local shop and a recycling project at a garden centre.

Such projects not only prepare our students for adult life, but also build links that can in some cases be sustained once students leave school.



Apple harvesting at the local orchard.

A community curriculum is vital for preparing our young adults for life beyond school. It can take time, patience and lots of networking in order to build it up, however the resulting levels of confidence and independence seen in our learners, makes it all worthwhile. It also leads ultimately to a more cohesive and inclusive community. Our role is to prepare our students for life beyond school and where better to do it, than in the outside world.

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## **NEXT ISSUE**

Summer Vol. 29 No. 2 Issue 87

### **Life As An Adult**

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**Copy date 29th May 2017**



# Effectiveness of Intensive Interaction in Adults with Profound and Multiple Learning Disabilities

Shahana Pervin Kakoly

This article has been derived from a much longer and more detailed review by the author of the literature relating to the practice and outcomes of Intensive Interaction approaches. The literature includes formal evaluations of Intensive Interaction and a wide range of professional and practitioner accounts of Intensive Interaction, as well as web-based resources.

**B**ellamy, Croot, Bush, Berry and Smith (2010) defined people with “profound and multiple learning disabilities” (PMLD) after conducting their research review as people with extremely delayed intellectual and social functioning, who may have limited ability to engage verbally, but respond to cues within the environment (e.g. familiar voice, touch, gestures). According to Professor Jim Mansell’s report Raising our

Sights, “people with profound and multiple learning disabilities have an intelligence quotient under 20 and therefore they have severely limited understanding” (Mansell, 2010, p.3). In an ‘average’ area in England with a population of 250,000 the number of adults with PMLD will be 78 in 2009 rising to 105 by 2026 (Mansell, 2010, p.3).

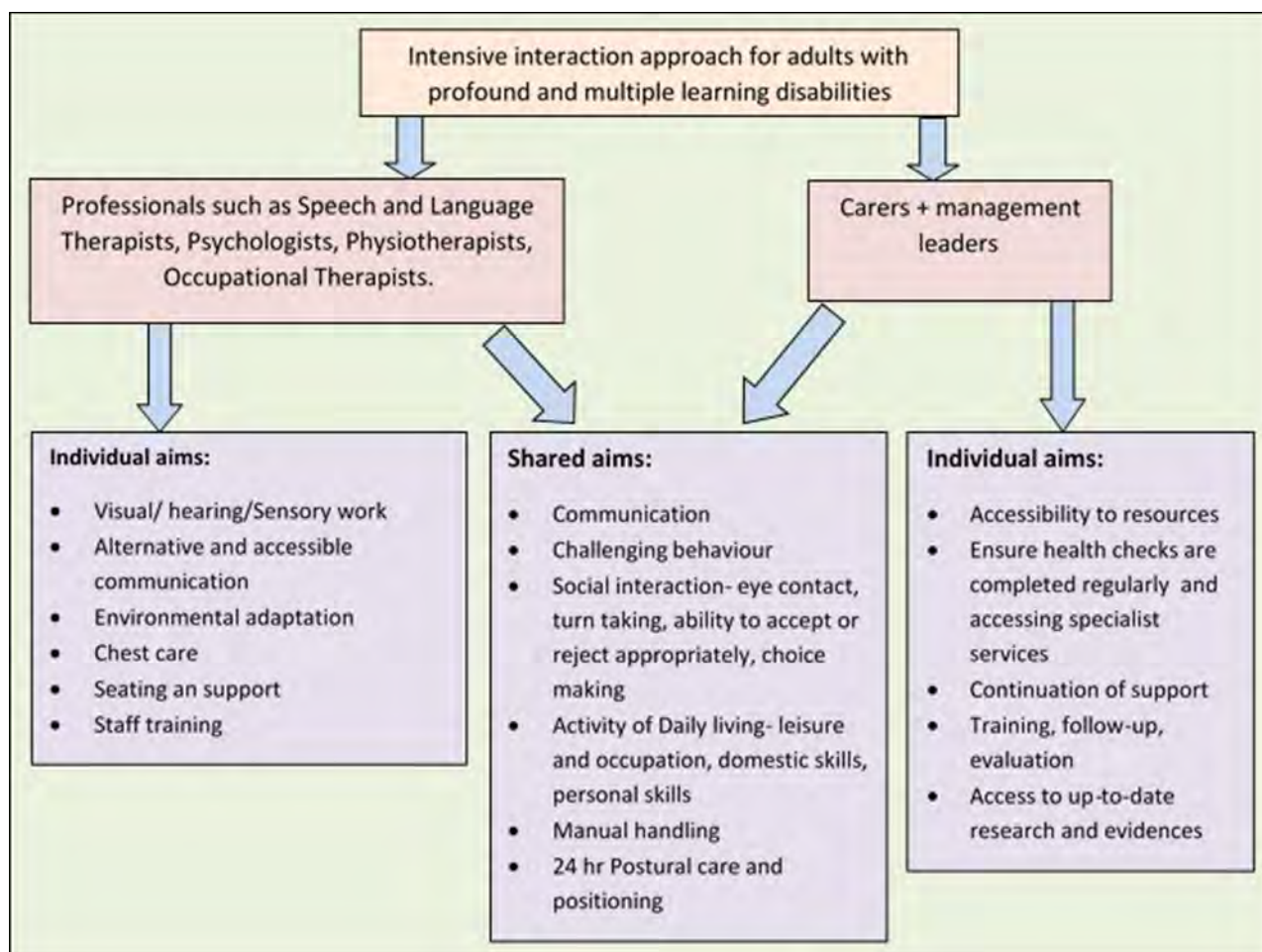


Figure-1: Aims of professionals and carers to achieve through intensive interaction approach for adults with PMLD. This table is based on Campbell, Ballard and Booth (2013).

Intensive Interaction has gained attention in over the past decade as a means of enhancing the social abilities of individuals with severe communicative impairment (Zeedyk, Davies, Parry and Caldwell, 2009). According to Goldbart and Caton's (2010) survey over 85% of speech therapists are using the Intensive Interaction approach for people with PMLD. Firth, Poyser and Guthrie (2013) defined the Intensive Interaction approach as a 'transactional approach' to developing improved communication for children and adults who have severe or profound learning disabilities and/or autism, and who are still in the early stage of developing communication. Another definition by Goldbart and Caton (2010, p.9) is that "Intensive Interaction is an approach to developing interaction and communication between people with complex communication needs and the people around them". They say that it is described primarily as a way of building up enjoyable interactions between people with complex communication needs and significant others. Any gains in communication or reductions in challenging behaviour would be seen as secondary.

The figure 1 (page 23) demonstrates the aims for professionals, carers and management leaders to achieve through the Intensive Interaction approach for adults with PMLD.

### Outcomes Reported In The Literature

Greater initiation in social interaction, eye contact, engagement in physical contact activities, vocalisation and facial signalling after implementation of intensive interaction intervention has been noticed (Firth, 2006). Intensive Interaction is a dynamic, highly enjoyable, active and interactive way to teach social interaction to people with PMLD (Hewett, 2007). Regular Intensive Interaction sessions with adults with PMLD within a flexible person centred approach is significant for service users to enable them to achieve social interaction with staff member and communicate basic needs (Kellett, 2000).

There is less evidence regarding the effect on challenging behaviours such as self-stimulatory behaviour and self-injurious behaviour (Hutchinson and Bodicoat 2015). One of the studies (Firth, 2006) suggested that there is no significant change in self injurious behaviour after using the Intensive Interaction approach. Another study (Leaning and Watson, 2006) discussed that clients were able to make a good progress in increasing positive behaviour and reducing challenging behaviour due to ongoing sessions of intensive interaction. Leaning and Watson (2006) emphasized combining ongoing Intensive Interaction with continuous supervision for staff members to achieve an effective result on challenging behaviour. A specified timescale is essential to meet the goals of any specialised intervention to address and change clients challenging behaviour (Pilling, Marcus,

Whittington and Murphy, 2015).

Leaning and Watson (2006) advised that, if the Intensive Interaction session can be made interesting, comfortable and enjoyable for participants, it would be an essential tool to provide access to meaningful contact and enhance the emotional world of participants. Involvement of key workers and key communication partners has an increased positive impact in carryover and sustains the communication approach (Goldbart et al, 2014). It is important to maintain the carer and client relationship to be able to communicate and express their choices (Scottish Government, 2012). To achieve the goals set, care staffs are required to facilitate movements and adjust positioning to enable service users to communicate effectively with their peer (Watson and Fisher, 1997).

Communication can become a flexible two way means mutual adaptation between carers and people with PMLD through Intensive Interaction (Barber, 2007). Therapeutic touch in an Intensive Interaction approach has increased communication skills, reduced challenging behaviour (Dobson, Upadhyaya, Conyers and Raghavan, 2002). The Intensive Interaction approach enables adults with PMLD to engage with others and communicate their needs or what they want, which is important, crucial to their well-being and development (Culham, 2004).

Intensive Interaction has to be characterised by person-centred, regular and frequent two way interactions between staff and people with PMLD to achieve an effective outcome and to improve communication and reduce challenging behaviour (Nind, 1999). Firth et al (2013) were unable to evaluate in their study if the incidence of challenging behaviour or self-injurious behaviour had reduced as there were no data collected to support this claim.

According to Goldbart et al (2014), to achieve effectiveness of the Intensive Interaction approach, managerial support, staff availability and commitment, staff training and research evidence availability also play an important role. Staff providing services to people with PMLD would benefit from national standards for training in specific areas (Scottish Executive, 2000).

The role of communication care staff and their training needs are important due to the complex communication needs of people with PMLD. Goldbart and Caton (2010) emphasized the need for training for staff involved in caring for people with PMLD and working to improve client's communication, challenging behaviour through Intensive Interaction sessions. Intensive Interaction is a collaborative work between professionals and carers (Culham, 2004).

## Conclusion

The studies considered in this review, mostly suggested that Intensive Interaction is effective at improving communication and social interaction. There is less evidence of the impact on challenging behaviour, so it is not possible to generalise widely and say that Intensive Interaction is effective in reducing challenging behaviour in all adults with PMLD. The views of care staff and other professionals are that intensive interaction will be effective for adults with PMLD with environmental adjustment, organisational support and staff training.

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# A Teacher's Musings on the Rochford Review Report: Towards Personalised Curricula and Pedagogy

Martin Goodwin

In this article, I take the opportunity to consider the Rochford Review Report (Standards and Testing Agency, 2016), writing from the perspective of a teacher of pupils with PMLD. The article explores the application of the Engagement Profile and Scale (Carpenter et al, 2016) and its potential for developing personalised learning for pupils with PMLD.

Since the introduction of education for pupils with PMLD the fundamental questions of what to teach and how to teach learners with PMLD have been raised by practitioners and academics. Of late, rather than following a 'content based' national curriculum, schools have had increasing freedom to develop their curriculum. A mixture of 'process based', 'skills based' and 'developmentally based' or 'content based' models are deployed (see Byers and Lawson (2015) for further information and debate). It is of concern that in some schools the curriculum has been driven by assessment with the aim of every student being able to pursue a broad set of skills - an approach which may not consider the most relevant and meaningful type of learning opportunities for the pupil.

The Rochford Review Report recommends the assessment of pupils not engaged in subject-based learning against seven aspects of cognition and learning (responsiveness, curiosity, discovery, anticipation, persistence, initiation and investigation) (Standards and Testing Agency, 2016: p. 14). Although the Rochford Review Report does not prescribe an approach for assessment, the Engagement Profile and Scale may offer an appropriate vehicle for the development of a personalised curriculum. Rather than imposing a pre-determined curriculum, the Engagement Profile and Scale may support teachers to investigate contexts and negotiate learning with PMLD pupils through process-based opportunities that allow them to discover suitable pathways for learning.

Curricula that utilise a linear model, based on atypical development, presented as a set of tick boxes and strands that relate to P levels, may not allow for individualised learning pathways that are developmentally appropriate and meaningful for the pupils. The Rochford Review Report criticises P scale based assessment frameworks:

'there is an in-built incentive for schools to encourage progression onto the next P level before pupils have acquired or consolidated all the elements of the previous P level.'

(Standards and Testing Agency, 2016: p. 14)

Crucially, within a linear curriculum model, learners often bypass much-needed consolidation of critical skills or processes; in the attempt to demonstrate progression PMLD pupils often do not receive enough time and opportunities for their learning to become secure. Alternatively, pupils' progress that is measured laterally enables us to demonstrate that learners have become increasingly less dependent, have increased fluency and can generalise the skill or process with other stimuli or with less familiar people (Sissons, 2010). For learners with PMLD, a broad and balanced curriculum has been embraced within many schools. However, a more refined, tightly focused concentration on critical areas of learning (such as communication and interaction, cognition, physical, personal and social wellbeing) and use of a curriculum and assessment model that does not neglect how a pupil with PMLD needs to learn, may present valuable opportunities for them to practise skills and acquire a more solid foundation of learning (Hewett, 2011). The Engagement Scale and Profile provides a measurement tool in which quantitative and qualitative assessment and progression can be demonstrated. Such a process can equally enhance the development of a curriculum which is based on the principle of a spiral-based model (for more information see Bruner, 1960) so that it enables continued reinforcement of valuable learning opportunities and engagement behaviours that are conducive to active learning.

Curricula that schools have chosen to implement may be incongruent with the philosophy and personalised pedagogy of the Engagement Profile. Care must be taken to ensure that engagement indicators are not simply

'bolted on', but that the curriculum and presented learning opportunities promote active listening and responding to the 'dialogue' that we are sharing with the pupil so that personalised pathways are pursued. The Rochford Review Report principally recommends the adjustment of assessment strategies so that they more suitably meet the learning needs of pupils with PMLD. This offers an exciting opportunity for transformation of an assessment system that has steadily received criticism.

In view of pupils' Education and Health Care Plans, a personalised curriculum that supports pupils with PMLD needs to be aligned to their long-term plans. The Rochford Review Report envisages that learners with PMLD will engage in non-subject based learning. Consequently, in devising a personalised curriculum for pupils with PMLD, the emphasis should be in establishing process-based targets that are meaningful, relevant and purposeful and in response to their plans for their future lifestyle. Areas of development such as attention and listening, as described in the case of Alfie by Carpenter et al. (2016), or a target of improving interaction skills may be crucial skills for a pupil to develop and underpin their future life options. Pedagogically, this will require that teachers have a firm grasp of appropriate and engaging pupil targets. The Engagement Profile embedded within a culture of active listening may support teachers to become aware of what a pupil with PMLD is interested in and develop person-centred opportunities that appeal to and motivate the learner.

Facilitating a personalised pathway may prove challenging, as it requires that teachers determine appropriate curriculum content and explore new, perhaps previously unused, pedagogy or innovative pedagogical approaches which may be unique to the pupil. Schools will need to ensure that they are able to offer a flexible and potentially eclectic range of pedagogical tools. This pedagogical approach additionally implies that teachers should be able to: understand what a pupil with PMLD may need to learn; can listen and respond to the individuals' aspirations; can appropriately shape learning opportunities by using a variety of appropriate pedagogical approaches that meet the distinct needs of learners (Imray and Hinchcliffe, 2014) and can effectively determine individuals' needs (Lacey et al, 2015). It will become necessary to evidence not only how the pupil has met a target, but to describe the approach of engaging a pupil. A process of inquiry-led learning where teachers investigate and over time evidence what works is envisaged (Carpenter et al, 2016) and the set of engagement tools have been carefully designed to support this process. A close examination of pedagogical practices through a process of inquiry, to determine effective pedagogy, is valuable. However, to deeply embed the process will require a culture change

within schools, where teachers are supported through mentoring, reflection groups or partners and, potentially, time allowance. Increased partnerships between schools and specialists or/and universities that aid action research processes may prove helpful and may increase the development of studies in this area (Carpenter et al, 2016).

Process-based teaching requires sensitive interactions with learners with PMLD that centre on building their strengths through motivating and engaging contexts and approaches. Successful learning requires the teacher to have knowledge about how a person with PMLD learns and the level of support that they need to actively engage. The Engagement Profile provides a pathway for questioning what works for students, a format for recognising signs of high and low levels of engagement and indicators of varying behaviours that define how a person has engaged in activities (Carpenter et al, 2011). In attempting to develop a person-centred curriculum, an embedded process and culture of listening and responding (Goodwin, 2013) is significant in harnessing the development of meaningful learning opportunities that are increasingly pupil-informed or initiated.

In teaching learners with PMLD, I have found that the Engagement Profile definitions are broadly helpful with understanding what the type of engagement looks like. However, it is not until the teacher focuses on what engagement may look like, with regard to the individual pupil, that more supportive definitions are formed. Unlike, the use of P levels it is not a case of a matching a best fit descriptor to the pupil's perceived or evidenced level of attainment; it requires that teachers undertake the challenging process of carefully observing and understanding a range of ways that they can demonstrate the range of engagement types and describe learning processes. Improved training in areas such as observation, facilitating pupil-initiated learning, understanding interactive approaches (Collis and Lacey, 1996) and indeed the Engagement Profile itself (available from Engagement 4 Learning at [www.engagement4learning.com](http://www.engagement4learning.com)) may support teachers in their application of this new pedagogical approach.

From a practitioner perspective, my experience suggests that there are some pupils at a very early stage of development whose level of engagement may not be precisely described by the Engagement Profile categories. Whilst the Engagement Profile is not a hierarchical tool, the indicator of 'responsiveness' is likely to be a precursor and underpinning step for pupils with PMLD towards other areas of engagement. For some learners with PMLD who may be at the very early stages of responsiveness, I question if the term appropriately encapsulates behaviours that are pre-intentional, particularly those at a 'reflexive level' (Coupe O'Kane and



Goldbart, 1998). At a reflexive level, pupils may encounter experiences by being passive or resistant, or show reflex behaviours (Coupe O’Kane and Goldbart, 1998). Through a process of imputing intentionality (Nind and Hewett, 2006) reflexive behaviours may be interpreted by adults as conveying inferred communication such as like or dislike, want or rejection (Goldbart and Ware, 2015). The Engagement Profile defines responsiveness as ‘shows awareness, acknowledgement or recognition’ and the guidance further suggests that this is the ‘noticing phase’ in which the teacher can ask ‘How does the learner demonstrate awareness/recognition of the activity?’ (Engagement for Learning, 2014, pp. 4-5). The step of showing awareness, where learners may demonstrate what P levels guidance (Department for Education, 2014) describe as ‘emerging awareness’, is deemed to be level P1(ii). Therefore, the earlier definition of responsiveness (Carpenter et al, 2016) would preclude the assessment of pupils with PMLD at a very early stage of development (momentarily described as P1i).

More recently, Richard Aird describes that minor amendments to the definitions took place during the Rochford Review which details responsiveness as ‘changes in a pupil’s behaviour that demonstrate s/he is being attentive to a new stimulus’ (Aird, 2016, p.5; and see Richard Aird’s article in this issue). Recognition of the reflexive stage, where pupils with PMLD may not be intentionally responding or reacting to stimuli is important, as for some learners it is an initial step towards the development of attention. Indeed, the QCA (2009) guidance represents the stage of ‘encountering’ as being prior to ‘awareness’ and ‘attention and response’ (cited by Fergusson and Byers, 2015). A further debate of the extent to which pre-intentional behaviour be judged as responsiveness and a wider definition of the responsiveness engagement indicator, that includes the step of ‘encountering’ may be needed.

The Engagement Scale utilises criteria that may allow measurement of what might be considered pre-engagement. Within the Engagement Scale, a score of 1 may be given for behaviours such as ‘fleeting or emerging’ which is described as ‘low or minimal areas of engagement, some evidence of awareness’ (Engagement 4 learning, p.19). The Scale may have the potential for measuring the engagement of pupils with PMLD who are working at a reflexive level, but wider definition may need to be considered. It would prove unsatisfactory if learners at this level could not score on the Scale or potentially be on a long term basis scored 0 (where pupils are considered to be having ‘no focus’ which is described as ‘being inattentive and unresponsive’) (Engagement 4 learning, 2014, p.19). Although this may be the case for any learner, a person with PMLD may potentially show higher scoring against the scale such as

being ‘partly engaged’ (emerging engagement but unpredictable) ‘mostly engaged’ (engagement occurring the majority of the time) ‘fully engaged’ (completely engaged) (Engagement 4 learning, 2014, p.19). Potentially, learning could be demonstrated for a range of learners within the typical PMLD range as denoted by the P scales. However, I am at this stage unsure whether the Scale and the Profile sufficiently and accurately capture engagement at a reflexive level, commonly and momentarily described through the P scales as being at P1i and/or working towards P1ii and indeed if this is to be defined as engagement. Since the Rochford Review proposals recommend engagement as a means of acknowledging learning by pupils with PMLD, the use of the Engagement Scale and Profile may permeate the education system. Further evidence-based inquiry into the application of the Engagement Profile and Scale regarding people with PMLD, particularly its relevance at very early stages of development, may be required.

Helpfully, rather than slotting a pupil with PMLD into a pre-determined curriculum, the Engagement Profile and Scale potentially allows for process-based interactions to become part of the day to day pedagogy of working with the pupil and a personalised curriculum to be organically constructed in response to their (the staff and the pupil’s) ‘dialogue’. For pupils with PMLD who may not follow a set pathway or due to their combination of difficulties may not follow a typical pattern of development, a person-centred pathway that responds to the uniqueness of individuals’ learning style seems justified and central to ensuring that their schooling is suitably responsive in meeting pupils’ needs. In conjunction with Education Health Care Plan targets, provides the opportunity to focus on what is relevant, meaningful and purposeful to the learner through observing and evidencing their engagement. There is an opportunity to revisit and assess the responsiveness of current curricular and pedagogy in meeting the needs and wishes of pupils and their families. The implementation of the Rochford Review’s proposals is an exciting development, and I hope that the opportunity to rethink our curricula and pedagogical approaches so that they are personalised, meaningful and responsive for PMLD pupils is embraced.

### Contact Details

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# Useful articles, reports and information with a focus on health

Jill Davies & Jillian Pawlyn

## Academic papers

Carey, IM et al (2016). **Do health checks for adults with intellectual disability reduce emergency hospital admissions? Evaluation of a natural experiment.** Journal of Epidemiology and Community Health.  
<http://jech.bmj.com/content/early/2016/06/16/jech-2016-207557.long>

Glover, G, Williams, R et al. (2016). **Mortality in people with intellectual disabilities in England.** JIDR.  
<http://onlinelibrary.wiley.com/doi/10.1111/jir.12314/full>

Marsden, D., & Giles, R. (2017). **The 4C framework for making reasonable adjustments for people with learning disabilities.** Nursing Standard.  
<http://journals.rcni.com/doi/abs/10.7748/ns.2017.e10152>

Seliner, B., Latal, B., & Spirig, R. (2016). **When children with profound multiple disabilities are hospitalized: A cross-sectional survey of parental burden of care, quality of life of parents and their hospitalized children, and satisfaction with family-centered care.** Journal for Specialists in Pediatric Nursing.  
<http://onlinelibrary.wiley.com/doi/10.1111/jspn.12150/abstract>

Young-Southward, G et al (2016). **What Effect Does Transition Have on Health and Well-Being in Young People with intellectual disabilities? A Systematic Review.** Journal of Applied Research in Intellectual Disabilities.  
<http://onlinelibrary.wiley.com/doi/10.1111/jar.12286/abstract>

Young, H., Hogg, J, and Garrard, B. (2016). **Making Sense of Bereavement in People with Profound Intellectual and Multiple Disabilities: Carer Perspectives.** JARID.  
<http://onlinelibrary.wiley.com/doi/10.1111/jar.12285/abstract>

Young, H. (2016). **Conceptualising bereavement in profound and multiple learning disabilities.** Tizard Learning Disability Review.  
<http://www.emeraldinsight.com/doi/abs/10.1108/TLDR-09-2015-0035>

## Reports

### **Cerebra and University of Cardiff: Problem solving toolkit for families**

The Toolkit is a comprehensive, practical and easy to use guide to help families resolve difficulties with their statutory health, social care and education support services. It aims to help unpick commonly experienced problems and to offer effective strategies for resolving them. The Toolkit:

- considers nine general categories of dispute, from inter-agency disputes and complex cases to delays and resource issues, and offers detailed advice for resolving them
- identifies key factors that can empower people to claim their rights and to challenge failures when they occur
- offers advice on preparing for, attending and following up on meetings
- sets out a series of template letters that families can use in a variety of situations.

<http://www.lukeclements.co.uk/wp-content/uploads/2016/02/Toolkit-draft-2016-04.pdf>

### **Contact a family: Short breaks for children with complex needs: new resources for forums**

The Short Breaks Partnership, which Contact a Family is a member of, recently launched new resources for parent carer forums working to improve short breaks in their local area.

<http://www.cafamily.org.uk/news-and-media/short-breaks-for-children-with-complex-needs-new-resources-for-forums>

### **IHAL: Making reasonable adjustments for people with learning disabilities in the management of constipation**

This report is about constipation, its causes and how it can affect people. It describes recent research findings about bowel management to avoid constipation and the management of constipation if it occurs.

<https://www.improvinghealthandlives.org.uk/publications/313922/>

[Making\\_reasonable\\_adjustments\\_for\\_people\\_with\\_learning\\_disabilities\\_in\\_the\\_management\\_of\\_constipation](#)

**Oxleas NHS Foundation Trust. For a range of personal health profiles free to download.**

<http://oxleas.nhs.uk/gps-referrers/learning-disability-services/personal-health-profiles/>

**Seeability: Children in Focus annual report**

Children with learning disabilities are 28 times more likely to have a serious sight problem than other children. In the last academic year (September 2014 – July 2015) SeeAbility provided eye care for 258 pupils, dispensed 87 pairs of glasses, and provided 261 sight tests. They found:

- Over half of children we tested had a vision problem
- 43% of the new pupils we saw this year had no history of eye care
- 85% of those discharged from hospital eye clinics had no follow up community eye care
- 75% of the children with no history of eye care were noted as having autism
- 36% of the children we saw needed glasses

[https://www.seeability.org/uploads/files/Children\\_in\\_Focus\\_campaign/CiF-full-report-2016.pdf](https://www.seeability.org/uploads/files/Children_in_Focus_campaign/CiF-full-report-2016.pdf)

**Tyson, M. et al (2017) The Views of Carers of Adults with Intellectual Disabilities on Annual Health Checks.**

This report presents data from a survey of carers about Annual Health Checks for people with learning disabilities.

<https://www.improvinghealthandlives.org.uk/adjustments/?adjustment=421>

## **Blog**

Alicia Wood: From placements to real places to live - new funding to create more adapted housing.

<https://socialcare.blog.gov.uk/2016/09/15/from-placements-to-real-places-to-live-new-funding-to-create-more-adapted-housing/>

Chris Hatton: Health inequalities and the 'hidden majority' of adults with learning disabilities. <https://publichealthmatters.blog.gov.uk/2016/10/04/health-inequalities-and-the-hidden-majority-of-adults-with-learning-disabilities/>

Sean McLaughlin: Personalising support for people living with autism <https://socialcare.blog.gov.uk/2016/09/07/personalising-support-for-people-living-with-autism/>

**National Elf Service**

The National Elf Service 'bloggers' make evidence-based research more accessible and usable for busy health and social care professionals. Find and follow your favourite elf!

<https://www.nationalelfservice.net/learning-disabilities/>

## **Websites and Apps**

### **'Help stop choking'**

This website and free app is now available for apple devices at [helpstopchoking.hscni.net](http://helpstopchoking.hscni.net). The app allows you to work offline, and people with learning disabilities have found the app easy to use and have loved being in control of their own learning. The app can be purchased via iTunes <https://appsto.re/gb/P6ml-i>

### **My health apps**

This website brings together the world's favourite healthcare apps – tried and tested by people who use the apps. Apps focus on a range of health conditions and the search function allows you to search by platform type as well as condition and tags.

<http://myhealthapps.net/>

### **NHS Choices Health tools library**

Collection of Interactive tools, smartphone apps and podcasts focussed on health

<http://www.nhs.uk/tools/pages/toolslibrary.aspx>

## **Services**

### **GM Primary Eyecare: Eye Tests Made Easy**

A new service has been launched in Greater Manchester to help people with learning disabilities get the right eye care. People with learning disabilities are 10 times more likely than others to have serious sight problems. Despite this, many people are still not getting the right eye care.

The free NHS-funded 'Eye tests made easy service' is for people who will find it hard to have a standard eye test and has reasonable adjustments such as a longer appointment and the use of an easy read reporting form. The benefits of good eye care include reducing preventable sight loss and improving vision with glasses <http://www.gmpec.co.uk/ld-services.html>

### **Contact Details**

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# A classroom environmental assessment

Richard Hirstwood

An environmental assessment will tell you how "autism/sensory impairment friendly" your room is. Many young people with autism experience sensory sensitivity, processing and perceptual differences. The assessment will also help other learners who don't have autism, but have multi sensory impairments, and share some of those sensory difficulties.

**W**hen we say 'room' this could be your classroom, your workspace, your play space or home space - anywhere where you are working or playing with individuals with autism and/or additional needs/sensory impairments.

You may consider completing one of these environmental assessments for each of the above spaces, or you may wish to target one specific space initially.

To complete the assessment you are asked to rate different aspects of the environment, giving each a score from 1 to 5, where 1 is the lowest rating and 5 is the highest. Ticking the relevant rating for each aspect you've assessed, will create an 'easy to interpret' graph. The more 'autism/sensory impairment friendly' your space is, the higher up the graph your score line will be. Areas for improvement will be easy to identify, with a target to achieve - i.e. the statement for description 5 for that environmental aspect.

Remember, this environment assessment may produce different results for the same space at different times of

the day or in different seasons.

## Let's get started!

Your blank chart to complete is below. Simply tick/star the score (1 - 5) for each environmental aspect (A to T) according to which of the statements below is most applicable. Which statement sounds most like your space? Each statement is accompanied by an explanation of what you are looking for - and a brief rationale for why.

This might be an ideal opportunity to assess your space as a team, to consider how it really works on all levels for you, as well as your learners!

### A. The glare from the windows.

5. Normal light evenly spread, with little glare;
4. Some glare, but manageable in most parts of the room;
3. Increased glare, unmanageable in most parts of the room;
2. High glare on sunny days;
1. High glare even on dull days.

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T
5																				
4																				
3																				
2																				
1																				



**B. How is your lighting? Older fluorescent lighting can become dull and have an increased rate of flicker, which has been linked to photic seizures & visual discomfort.**

5. We have no fluorescent lighting and the light in the room is pleasant/zoned well for activities;
4. We have no fluorescent lighting and the light is tolerable and partially zoned for activities;
3. We have bright fluorescent lighting which doesn't flicker & other lighting sources are available for zoned activities;
2. We have fluorescent lighting with good light but with an increased rate of flickering and some other lighting sources available for zoned activities;
1. Our lighting is fluorescent which is dull with a high rate of flicker, with no other lighting sources available for zoned activities.

**C. Does the light coming into the room create any distracting patterns? These could be shadows/reflections which may be deflected into other parts of the room.**

5. There are no distracting patterns or shadows;
4. The room has 25% distracting patterns or shadows;
3. The room has 50% distracting patterns or shadows;
2. The room has 75% distracting patterns or shadows;
1. Every surface has distracting patterns and shadows.

**D. Do you have light reflecting on objects such as metal or shiny surfaces? (This can be especially distracting on work surfaces in classrooms and kitchens.)**

5. There are no reflective surfaces;
4. There are 10% reflective surfaces;
3. There are 20% reflective surfaces;
2. There are 30% reflective surfaces;
1. There are 50% reflective surfaces.

**E. Visual clutter on the walls can be very distracting. We need to have clear wall spaces where learners can escape the bombardment of visual clutter.**

5. 20% or less of the walls have distracting pictures, charts or written materials;
4. 40% or less of the walls have distracting pictures, charts or written materials;
3. 60% or less of the walls have distracting pictures, charts or written materials;
2. 80% or less of the walls have distracting pictures, charts or written materials;
1. 100% of the walls have distracting pictures, charts or written materials.

**F. Colour contrasting surfaces help learners develop spatial awareness. A dark floor and light walls gives the strongest colour contrast.**

5. There is a strong colour contrast between the floor and the walls;
- 4.

3. There is a moderate contrast between the floor and the walls;

2.

1. There is no colour contrast between the floor and the walls.

**G. A cluttered floor space can be confusing for learners with autism or multi sensory impairments. With less clutter on the floor, mobility is easier and distraction is reduced.**

5. Our floors are clear with little visual clutter;
4. Our floors have some visual clutter in designated areas, where it is kept to a minimum;
3. Our floors have some visual clutter not in designated areas, where it is kept to a minimum;
2. Our floors have visual clutter, which is disorganised and hard to make sense of;
1. Our floors have a high level of visual clutter, which causes navigational difficulties and distraction.

**H. It helps our learners to have clutter free space to work or play. Without this they can become overwhelmed by the environment and other people.**

5. We have designated 'clutter free' work and play areas which are easily identified by our learners;
4. We have some designated 'clutter free' work and play areas which require greater identification;
3. We have designated work and play areas, which do have clutter;
2. We do not have designated work and play areas and all spaces have a moderate level of clutter;
1. All of our work and play space is cluttered.

**I. Learners with autism and/or a hearing loss can be distracted by external/extraneous sounds. Stop and listen to the sound in your room when it is quiet - listen for hums, buzzes and other distracting noises.**

5. There is no distracting sound;
4. There are a few sporadic distracting sounds;
3. There are a few, more constant distracting sounds;
2. There are moderate levels of distracting sounds;
1. There are high levels of distracting sounds.

**J. Learners with autism and/or a hearing loss can be distracted by the noise of people. Stop and listen to the sound in your room which is generated by other people.**

5. There is no distracting sound;
4. There are a few sporadic distracting sounds;
3. There are a few, more constant distracting sounds;
2. There are moderate levels of distracting sounds;
1. There are high levels of distracting sounds.

**K. Having a full view of your room with vulnerable learners may be important. Some spaces do not allow a full view, how is yours?**

5. The room setting allows a 100% view of all learners at all times;
4. The room setting allows a 75% view of all learners at all times;
3. The room setting allows a 50% view of all learners at all times;
2. The room setting allows a 20% view of all learners at all times;
1. The room setting allows a 10% or less view of all learners at all times.

**L. Hypersensitivity to smell can be very distracting, or in extremes cases, cause nausea or irritation for some learners.**

5. There are no detectable smells at any time of day;
4. There are some detectable smells at certain times of the day e.g. lunchtime;
3. There is a moderate level of detectable smell at certain times;
2. The room has a moderate level of detectable smell most of the day;
1. The room has smells which are strong and detectable all day.

**M. Some learners need to move at certain times of the day as periods of inactivity may be difficult to sustain.**

5. There is a space in the room, free from hazards, to allow a kinaesthetic learner to move;
4. There is a space close by, free from hazards, to allow a kinaesthetic learner to move;
3. There is a space in a nearby room to allow a kinaesthetic learner to move;
2. There is a space in a nearby room some distance away to allow a kinaesthetic learner to move;
1. There are no spaces available to allow a kinaesthetic learner to move.

**N. Some learners need to escape from an over stimulating space. Many schools/centres have a small room away from the main classroom, where learners can desensitise.**

5. We have a clutter free 'escape space' away from the teaching space where we can control the sensory stimulus to meet the needs of the learner;
4. We have a clutter free 'escape space' away from the teaching space where we cannot control the sensory stimulus to meet the needs of the learner;
3. We do not have a clutter free 'escape space' away from the teaching space. We have a designated 'desensitising space' marked by room dividers, where we can control the sensory stimulus to meet the needs of the learner;
2. We do not have a clutter free 'escape space' away from the teaching space. We use tents and umbrellas to

create a 'desensitising space' where we can control the sensory stimulus to meet the needs of the learner;

1. There are no 'escape spaces' nearby/within our main teaching room.

**O. Tools, toys and other objects stored on open shelving/in view can be very distracting. A good storage system, where these things are out of sight, can be essential.**

5. We have great 'closed' storage and rarely leave things lying in view which are not being used;
4. We have good 'closed' storage system, but items may be left in view and we should utilise storage more effectively;
3. We have a small 'closed' storage system, which is insufficient to keep all tools and so some need to be stored in view;
2. We have very little closed storage space and the room is moderately cluttered most of the time;
1. We have no closed storage space and the room is highly cluttered most of the time.

**P. Light switches and electrical sockets can be a dangerous distraction. Many sockets are at waist height for ease of access, but can be a hazard because it's the perfect height for poking. Extension leads are a definite hazard!**

5. All our sockets/light switches are covered or not accessible and no extension leads are required;
4. The majority of our sockets/light switches are covered or not accessible and no extension leads are required;
3. The majority of our sockets/light switches are covered or not accessible, and we use one extension lead;
2. Some of our sockets/light switches are covered or not accessible, and we use more than one extension lead;
1. Some of our sockets/light switches are covered but are at waist height and we use multiple extension leads.

**Q. Some learners find labels irresistible and highly distracting, others less so. However, the fewer labels, the better.**

5. Labels are kept to a minimum and are those that learners access and use on a daily basis;
4. Labels are kept to a minimum level and are those that learners and staff access and use on a daily basis;
3. Labels are at a moderate level and are those that learners and staff access and use on a daily basis;
2. Labels are at a moderate level and are those that learners and staff access and use on a daily basis, as well as some with little/no functional value;
1. There are a high number of labels, many with little/no functional value.

**R. Many of our learners with sensory loss or autism use various methods of communication. It's always great to know the following: 'who is with me?' and 'what do I do when I get there?'**

5. We use specific effective communication strategies which are appropriate to the learner, who is given plenty of processing time to understand;
4. We have varied effective communication strategies which are appropriate to the learner, who is given some processing time to understand;
3. We have varied effective communication strategies which are appropriate to the learner, which may be used inconsistently, with reduced processing time to understand;
2. We have varied communication strategies which may be appropriate to some learners, which may be used inconsistently, with little processing time to understand;
1. We use limited communication strategies, not specifically targeted to the learner, who is given severely limited/no processing time to understand.

**S. Clearly defined areas can be important for learners with autism/cognitive disabilities/multisensory impairments, enabling them to understand what happens where.**

5. We have clearly defined spaces for all activities;
- 4.
3. There are some clearly defined spaces for activities;
- 2.
1. There are no clearly defined spaces for activities.

**T. Computer screens, tablets and TV's can be a distraction, especially for those with autism/multisensory impairments.**

5. All touchscreens, computers and tablets are out of the room/hidden when not being used;
4. All touchscreens, computers and tablets are switched off when not in use;
3. One touchscreen, computer or tablet may be on constantly for the practitioner or parent to use;
2. All touchscreens or/and computers or/and tablets are left on for the majority of the day;
1. All touchscreens or/and computers or/and tablets are left on all of the day.

### Interpretation of the Environmental Audit Results

If your results look like the chart below, then you seriously need to think about some changes in your space. Your room is probably quite inappropriate and possibly a little dangerous.

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T
5																				
4																				
3																				
2																				
1																				

If your results look like the chart below you've done an incredible job with your room. I would not expect anybody to be able to score 5 all the way through. To be certain, I suggest you check your results with a colleague.

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T
5																				
4																				
3																				
2																				
1																				

If your results look like the chart below then you are doing okay there is room for improvement in some areas and you may have one or two problems in the room which need attention, however on the whole the room is probably a good place to be.

	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T
5																				
4																				
3																				
2																				
1																				

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## PMLD LINK is a '*not for profit*' charity

PMLD LINK is a 'not for profit' charity (UK Registered Charity No: 1121085) and its trustees and editorial board are all volunteers who give their services for free. All profits from the sale of the journal and all donations are used to maintain the production and posting of the journal, the development of the website and the management of Facebook and Twitter for networking and information sharing.

Any information about potential grant applications and any donations are welcome. Currently, PMLD LINK needs money to support its '*Far and Wide Project*' which aims to communicate with potential new subscribers to bring these services to the attention of families and carers, adult day centres, residential homes, and small self-help organisations that are harder to reach, as well as to schools and other charities.

Donations to PMLD LINK can be made via the 'donations welcome' button on the home page of the website (www.pmlmlink.org.uk). If you can offer support or want to make further enquiries, please contact us. Email: info@pmlmlink.org.uk

# Kyanninga Child Development Centre Equipment Appeal

Rosie Brister

As a teacher of primary aged children with PMLD in the UK, I spend much of my day meeting the physical needs of my students. With a host of equipment assigned to each individual, many are able to walk, stand, sit and lie in relative comfort supported by a wide range of positional equipment, splints and supports.

As each child gets older, we see them outgrow their equipment and get replacements. So what happens to the equipment that has become too small, or the older models that are replaced by more technologically advanced ones? The reality is that it is often disposed of. This is usually because the cost of refurbishing equipment coupled with the perceived threat of potential legal action if an item were to be faulty, puts equipment providers off finding a renewed purpose for it.

packing tape helped to provide a functional supportive seat.



Now, take a moment to consider what life would look like for the same group of students if they lived in Uganda. In stark contrast, they are unlikely to have any specialist equipment, no formal schooling opportunities and little, if any, medical input or assistance from therapists. In the absence of specialist equipment, families have to improvise. Without a standing frame, the only way that her family could enable Beatrice (Picture above) to stand, was to dig a hole in which she can stand for short periods of time. Hajjara (Picture right), is unable to walk independently, he was fortunate to be provided with a wheelchair. Blocks of foam and





In 2014, Kyaninga Child Development Centre (KCDC) was set up by a physiotherapist from the UK to try and combat the issues faced by young people with disabilities in the Kabarole District of Uganda. Since KCDC began its work, 483 children with disabilities have been assessed and treated. KCDC continue to work within these communities to raise awareness of disabilities, assess individual needs and endeavour to provide whatever they can to facilitate young people's independence. In order to help the children who access KCDC in Uganda, I have decided to collect unwanted equipment and then, once sufficient funds have been raised, have this transported to KCDC in Uganda. I have already had a great response to my appeal but would still like to gather a little more. Because of the scale of the whole operation, I cannot collect equipment but if it can be posted to me, I will be more than happy to include it in my shipment. The smaller items that I am currently looking for are Pedro™ boots, splints, gaiters, AFOs and protective helmets. Pacers, wheelchairs and standing frames are also in great demand but are sadly very

expensive to courier to our storage facility in North Lincolnshire.

If you think you have any suitable equipment that you would be willing to post, please email me at [rosiealice@hotmail.com](mailto:rosiealice@hotmail.com) with details of your equipment and I will get back to you as soon as possible. The deadline for sending equipment is the 31st May 2017, after which time I will prepare the items for shipment. If you don't have any equipment but would still like to support this project, please consider making a donation towards our shipping costs via my crowdfunding page [www.justgiving.com/crowdfunding/rosie-bristerforKCDC](http://www.justgiving.com/crowdfunding/rosie-bristerforKCDC)

If you would like more information on Kyaninga Child Development Centre, please check out the website [www.kyaningacdc.org](http://www.kyaningacdc.org)

### Contact Details

Rosie Brister  
[rosiealice@hotmail.com](mailto:rosiealice@hotmail.com)

## In the Next Issue Life As An Adult

The next issue of PMLD Link (Summer issue) will focus on 'Life as an Adult'. While all of our issues address topics relevant to adults with PMLD it is many years since we have dedicated an issue to this life stage. Life today as an adult with PMLD is framed by new laws and policies – such as the Care Act 2014, the Mental Capacity Act 2005 and the Deprivation of Liberty safeguards (soon, perhaps to be superseded by the Liberty Protection Safeguards). It is also, for many, constrained by a lack of funding to key support services, such as social care and social work services. More positively, expectations of what adults with PMLD can do have increased and they are being afforded opportunities that previous generations missed out on. In many places the late Jim Mansell's call to 'Raise Our Sights' has been heeded. Life can be good as an adult with PMLD in 2017.

In this Summer issue we hope to achieve a balance between illustrating the challenges and celebrating the joys of adult life. Can you contribute an article to help us do this? Articles can be anything between 300 and 2000 words. We would be delighted to hear from anyone with an idea for an article, however provisional, and stand ready to assist you to develop your idea.

The deadline for submission of completed articles is 29th May.2017 As social care is such a significant part of adult life for people with PMLD, we would be particularly pleased to hear from anyone working in social care or social work with adults with PMLD, and from families and friends of adults with PMLD about their experiences of social care and social work provision.

We look forward to receiving your contributions!

The Guest Editors:

Rachel Parry Hughes  
[rmparry@hotmail.co.uk](mailto:rmparry@hotmail.co.uk)

Becky Loney  
[becky.loney@gmail.com](mailto:becky.loney@gmail.com)

Rob Ashdown  
[rob.ashdown@ntlworld.com](mailto:rob.ashdown@ntlworld.com)

**Please send articles and other contributions by Friday 29th May**

## IN THE NEWS



### A flying start to the development of a national postural care strategy

**A**fter a highly successful Got My Back conference in September 2016, a working group was formed to develop a national postural care strategy. The group got off to a flying start as family carers, Changing Our Lives, professionals, including researchers, physiotherapists, health facilitators and equipment suppliers from a range of voluntary, statutory and private providers, came together in January 2017 to start work on this under developed area.

Rather than sitting round a table, which we all know encourages poor posture, the group stood up and brainstormed using flip chart paper on the walls. This fostered collaborative working and got everyone involved. The group was encouraged that the Learning Disability Professional Senate has endorsed the 'Got my Back' paper from the September conference. This paper clearly sets out the consequences of poor postural care and a commitment to improving postural care so that quality of life for both the disabled person and the family carer can be enhanced.

Everybody had a clear idea of the work that each member needs to complete before the next meeting in March. Group members are working on a range of areas needed for the development of the strategy, including:

- a survey for parents
- engagement with disabled people to ensure the strategy is coproduced
- gathering of best practice including an agreed definition of postural care and existing postural care pathways
- an overview of current training across England
- a summary of myths surrounding postural care
- an exploration of adding body measurements to the Cerebral Palsy Integrated Pathway which currently only includes hip measurements.

In addition, a sub group will submit an ethics application to Birmingham City University in order to conduct a small pilot study around the impact of postural care on quality of life.

If you want to know any more about this work, or offer any assistance, please email Jayne at [jayne@changingourlives.org](mailto:jayne@changingourlives.org)

PMLD LINK are represented on this working group.

### The Views of Carers of Adults with Intellectual Disabilities on Annual Health Checks

**T**his report presents data from a survey of carers about Annual Health Checks for people with learning/intellectual disabilities. The main aims of this study were to discover what factors cause the low uptake of Annual Health Checks (AHCs) by people with learning disabilities. For those who have had AHCs they explored the level of carers' satisfaction with these. This report presents data from a survey of carers. There is quantitative data from answers to standardized survey questions and qualitative data was also collected about carers' opinions and experiences. Findings identify, people with ID were more likely to have an AHC if cared for by a paid carer rather than by the family. The number of people with ID attending and being invited for an AHC needs to be increased. Increased training, awareness, advertising, correspondence and coordination of and between healthcare professionals, carer organisations and social services is necessary. A transformation from reactive responses to health change and health decline to a proactive approach with health checking and health protection and promotion needs to happen.

<https://www.improvinghealthandlives.org.uk/news/news.php?nid=2872>

# National Health Service in Northern Ireland

Northern Ireland operates a National Health Service in common with other parts of the UK. General Practitioners (GPs) provide free primary health care to a panel of patients mostly resident in their locality. There were 351 GP practices in 2015/16 with around 1,100 GPs employed in total. The average number of patients per practice was around 5,200 of whom 3,800 are adults aged 20 years and over. In addition Health Boards may contract with GPs to provide additional services to subgroups of patients such as those with learning disability and PMLD under what is known as Directed Enhanced Service (DES).

As in other parts of the UK, a DES for Learning Disability was introduced regionally in 2010 with GPs entitled to claim £75 for each patient with learning disability and PMLD who had a health check. Guidance was provided on the type of checks to be undertaken based on the Cardiff Health Check (Royal College of General Practitioners, 2010). This assessment is formatted in such a way as to capture any changes with the individuals health over the past year (symptom checker usually completed by a nurse) followed by a full physical examination which is usually conducted by the GP. In many cases the individual with PMLD is supported through this process by a formal or informal carer. Since 2010 over 10,000 health checks have been conducted on adults with learning disability and PMLD. Many GPs and Practice Nurses have been supported by the health facilitators to conduct a health check. McConkey et al. (2015) found that 84% of GP practices in Northern Ireland provided health checks covering an estimated 87% of the population with LD. Overall, 64% of people known to practices had received a health check which is significantly higher than comparable percentages of around 46% reported for England. As professionals within primary healthcare have become familiar and confident in the delivery of the DES, the focus of the health facilitation service has now shifted from supporting practices with the assessment process to:

- The development and integration of individual person centred health promotion action plans,
- The collation and utilisation of health check information to inform service development and
- The creation of partnerships with statutory and voluntary agencies to ensure that people with learning disabilities have equal and sustainable access to healthcare, health information and health promotion activity and are supported to partake in National Cancer Screening opportunities for example.

Throughout Northern Ireland a number of health promotion projects have been instigated by or in partnership with health facilitation these include: smoking cessation; weight management; mental health and well-being; bowel cancer awareness; breast examination and healthy lifestyle programmes. There has also been the development and delivery of health education programmes i.e. Heart Health programme which has been adapted for use with people with learning disabilities in collaboration with the Public Health Agency, British Heart Foundation and local council, the delivery of DESMOND ID which is a structured Type 2 diabetes education programme and the delivery of PEPE an epilepsy education programme designed specifically to meet the needs of this population. To promote access to services, health facilitators have also worked alongside mainstream health services in the development of easy read material i.e. bowel care, type 2 diabetes, health checks and Triple AAA screening. The forging of robust partnerships with agencies and organisations has raised awareness of the needs of people with learning disabilities which will be incorporated into future service planning.

People with PMLD may find difficulty in attending GP practices, but alternative support can be put into place. Some practices may require extra time per appointment so individuals can become familiar with their surroundings, allowing extra time to take bloods for example, and they may use a communication passport provided by the speech and language therapist. Once the nurse and doctor builds up a rapport with the patient and carer they will become more aware of their special requirements on each visit and therefore it will not feel like a challenge each time they visit. Some patients may request for their blood tests and vaccinations to be taken by the nurse in the comfort of their own home where they are more relaxed. The health facilitator may also do some desensitisation work on patients who find it extremely difficult to have bloods taken or blood pressure checked, which can therefore make it a lot easier for the patient prior to their health check.

By Dr Laurence Taggart Email [l.taggart@ulster.ac.uk](mailto:l.taggart@ulster.ac.uk).

Biography: Laurence currently works as a Lecturer in the Institute of Nursing and Health Research at the University of Ulster.

## References

- McConkey, Roy, Taggart, Laurence and Kane, Molly (2015) *Optimising the uptake of health checks for people with intellectual disabilities*. Journal of Intellectual Disabilities, 19 (3). pp. 205-214.
- Royal College of General Practitioners (2010). *A Step by Step Guide for GP Practices*. <http://www.rcgp.org.uk/learningdisabilities>

## Health News from Scotland

In 2013 the Scottish Government published 'The keys to life', outlining its 10 year vision for improving the quality of life for all people with learning disabilities in Scotland. A central goal of this strategy is to implement action to address the health inequalities experienced by people with learning disabilities. For people with Profound and Multiple Learning Disabilities the strategy is explicit in its commitment to health improvement and specifically to addressing premature mortality in the population, emphasising that good quality communication between family members, carers and health professionals is critical to achieving transformation in the quality of health and care that are required.

According to the Chief Executive of PAMIS, there are a number of key priorities that need to be addressed for people with profound and multiple learning disabilities including: postural care; invasive healthcare procedures in an integrated service; sharing of important health information - use of PAMIS digital passports; support for emotional and mental health including bereavement and loss and trauma; physical activity; communication and sensory integration. "Having all the pieces of the complex jigsaw are required in order to be able to really support and include a person with PMLD in an active and fulfilling life. This is reliant on an educated, informed, communicative and skilled health and social care workforce working in partnership with the real experts in care - the family carers."

Of course positive transformation in health and health care should also be informed by good quality evidence. The Scottish Learning Disabilities Observatory was established in 2015 with funding from the Scottish Government to support implementation of 'The keys to life' through the provision of evidence to support improvements in health and care of all people with learning disabilities. ([www.sldo.ac.uk](http://www.sldo.ac.uk)) ([www.pamis.org.uk](http://www.pamis.org.uk))

By Angela Henderson, Scottish Learning Disabilities Observatory

## Scruffy Targets, Meaningful Outcomes, Inspiring Legacy - Celebrating the life and work of Dr Penny Lacey

Location - School of Education (Building R19), The Vaughan Jeffreys Lecture Theatre

Date - Saturday 13th May 2017 (14:00-18:00)

Registration required: <http://www.birmingham.ac.uk/schools/education/events/2017/05/scruffy-targets-meaningful-outcomes-inspiring-legacy.aspx>

## New Sensory Learning Hub

NatSIP has created a new Sensory Learning Hub as a central resource for the sensory impairment community. It hosts trusted information about sensory impairment and a hub of discussion, shared ideas and resources.

It is aimed at the mainstream workforce (teachers, SENCos and Teaching assistants) as well as specialist practitioners (qualified SI teachers and therapists). We want the sensory impairment community to access the sensory learning hub to gain and share information. The hub has been designed to be interactive, a place to ask questions, share good ideas as well as tap into resources or access two new 'What works teaching and learning', and 'What works technology' databases.

The hub has been designed to follow four key areas of inquiry

- Develop – to find out about learning and development
- Know – to find out about our 'what works' databases
- Share – to access resources
- Interact – to find out about ways to interact with others

The Sensory Learning Hub is a new interactive resource for all things sensory – come and have a look and tell us what you think: [www.NatSIP.org.uk/SLH](http://www.NatSIP.org.uk/SLH)

## Being Disabled in Britain

In April, the Equality and Human Rights Commission published a report called Being Disabled in Britain: A Journey Less Equal, which offers a comprehensive and depressing analysis on how the rights of disabled people are protected in Great Britain.

The report finds that, despite legislation and much published guidance, disabled people in Britain are still experiencing significant disadvantages and details urgent improvements that are necessary. The report shows that disabled people are still not being treated as equal citizens and continue to be denied the opportunities and outcomes non-disabled people take for granted. This includes: a lack of equal opportunities in education and employment; barriers to access to transport, health services and housing; the persistent and widening disability pay gap; deteriorating access to justice; and welfare reforms significantly affecting the already low living standards of disabled people. Negative attitudes towards disabled people remain prominent in Britain.

Of course, this report is concerned with all people described as disabled but the report does refer to issues relating to people with 'learning disabilities'. Even so, in only a few places is there specific mention of 'profound and multiple learning disabilities' or 'severe learning disabilities'. Nevertheless, many of these issues have relevance for the much smaller and highly vulnerable group of children and adults with PMLD and their families and carers. The report and its key recommendations that the UK and devolved governments take concerted action to:

1. Reduce educational attainment and employment gaps for disabled people.
2. Ensure that essential services, such as housing, health, transport and justice, meet the particular needs of disabled people and support their independence and wellbeing.
3. Promote the inclusion and participation of disabled people in civic and political life.
4. Strengthen disabled people's choice, autonomy and control over decisions and services.
5. Improve existing legislation, policies, frameworks and action plans to better protect and promote the rights of disabled people.
6. Improve the evidence base on the experiences and outcomes of disabled people and the ability to assess how fair Britain is for all disabled people.

The full report can be accessed online at:  
<https://www.equalityhumanrights.com/en/disability-report-being-disabled-britain>

## Modernisation of North West learning disability services to improve care for patients and see closure of Calderstones Learning Disability Hospital

People with a learning disability, autism or both in the North West will be supported to lead more independent lives in their communities thanks to plans given the final go ahead today, which include the closure of Calderstones (now known as Mersey Care Whalley site) – England's last stand-alone NHS learning disability hospital.

See: <https://www.england.nhs.uk/2017/03/modernisation-of-north-west-learning-disability-services-to-improve-care-for-patients/>

## Supporting people with learning disabilities through flagging within the Bowel Cancer Screening Programme

This project developed a pathway that identified, flagged and offered support to people with learning disabilities prior to point of invitation to bowel cancer screening using the faecal occult blood test (FOBT). This enabled individually tailored work to support people with learning disabilities in making a choice about participation and being supported through the screening process.

The project has been really successful and they are now looking to roll out into other CCG areas as well as share our learning so other areas can look at the work and possibly copy/adapt. The full report is available to download.

For further information on the project, please contact Julie Tucker. Email: [Julie.tucker11@nhs.net](mailto:Julie.tucker11@nhs.net)  
Tel: 01138 249693  
<https://www.improvinghealthandlives.org.uk/news/news.php?nid=2866>



## People with learning disabilities should have annual mental health checks, says NICE

**P**eople with learning disabilities should have their mental health checked annually to ensure they are not living with undiagnosed conditions, the National Institute for Health and Care Excellence (NICE) has said. Mental health problems can be more difficult to diagnose for people with learning disabilities, as it can be harder for the person to explain how they are feeling and what help they would like. Data shows only half of people with learning disabilities received a health check in 2011/12. This is an improvement on previous years, but it is not clear whether these checks included mental health questions or only focused on the person's physical health.

NICE is recommending that everyone with learning disabilities receive an annual health check, which includes a review of their mental health.

NICE present a series of quality statements, including: People with learning disabilities who need a mental health assessment should be referred to a professional with expertise in mental health problems in people with learning disabilities. People with learning disabilities and a serious mental illness should have a key worker to coordinate their care. People with learning disabilities and mental health problems who are receiving psychological interventions (such as talking therapies) should have them tailored to their level of understanding. People with learning disabilities who are taking long-term medications, such as antipsychotic drugs, should have annual documentation on the reasons for continuing this treatment.

See: <https://pathways.nice.org.uk/pathways/mental-health-problems-in-people-with-learning-disabilities>

## Frozen Light

**E**xciting new production from Frozen Light. HOME immerses audiences with Profound and Multiple Learning Disabilities (PMLD) in a multi-sensory story of discovery. HOME is the latest bold and exciting production from Frozen Light. Recent review: <http://www.thereviewshub.com/home-the-northcott-theatre-exeter/>  
Tour dates: <http://frozenlighttheatre.com/current-production/home-tour-dates/>

## Family views of independent hospitals/ in-patient settings

**N**ew report based on the experiences of family members who have their loved ones with Autism and Learning Difficulties [Disabilities] in two independent hospitals. It shows what can go wrong when ordinary children loved by ordinary families go into a crisis. Bringing us Together (2016) <http://bringingusttogether.org.uk/wp-content/uploads/2017/01/Independent-Hospitals-Final-pdf.pdf>

## Helping people with learning disabilities get health checks

**T**he Public Health England Learning Disability Observatory is developing some guidance with NHSE about the important role social care providers can play in helping people with learning disabilities get health checks. We would like to include some good practice examples from social care providers about how they are doing this.

Please send any examples to [sue.turner@ndti.org.uk](mailto:sue.turner@ndti.org.uk)

## Inquiry into the housing needs of people with disabilities

**T**he Equality and Human Rights Commission (EHRC) has launched an inquiry into the housing needs of people with disabilities. They want to know whether the availability of accessible and adaptable housing and support services currently fulfils the rights of people with disabilities to live independently.

More information on the EHRC housing & disability inquiry. Easy read information on the inquiry. You can respond directly to the EHRC. Their call for evidence is open until 23:59 on Tuesday 18 April 2017:  
EHRC Housing Inquiry - Questions for Individuals

See: <https://www.equalityhumanrights.com/en/inquiry-housing-disabled-people/housing-disabled-people-have-your-say>

## Survey: Deciding for others - informed consent and decision making for research involving people without capacity

**A**t Cardiff University we are conducting a study to look at health and social care professionals' views and understanding of how decisions are made for people who are unable to provide their own informed consent for research, which may include those who have intellectual and developmental disabilities, or a condition resulting in cognitive impairment.

We are keen to include a wide range of health and social care professionals who are involved in research involving people with IDD, such as clinicians, psychologists, Allied Health Care professionals, and social care practitioners. The findings from the survey will help with the ultimate aim of the project which is to develop an intervention to support informed consent for research involving adults who lack capacity.

We are limiting the survey to those in England and Wales only as the mental capacity legislation is different in Scotland and NI. The survey takes 10-15 minutes to complete, and participants are able to download and keep a summary of the legislation governing proxy consent for research, and information about how the law applies to the scenarios used in the survey. So hopefully this will be an interesting, informative and useful experience for those kindly agreeing to take part!

The survey can be found at <https://cardiff.onlinesurveys.ac.uk/pilot-healthcare-professionals-understanding-of-legislat15>

All views are very important to us. If you have any questions, or would like more information about the study, please contact Victoria Shepherd, Cardiff University [ShepherdVL1@cardiff.ac.uk](mailto:ShepherdVL1@cardiff.ac.uk)  
Best wishes,  
Vicky

Victoria Shepherd  
NIHR Doctoral Research Fellow  
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Cardiff University  
CF14 4YS

## Inclusion Europe invite you to this year's Europe in Action conference "Love, life and friendship".

### Where and when?

**T**he conference will be jointly organised with Inclusion Czech Republic and will take place in Prague from 1 to 3 June 2017 (with associated meetings starting on 31 May).

### How can I register?

To register, please go to <http://europeinaction.org/category/registration/>

### Why this topic?

We chose this topic because finding friends and partners is important for everyone's wellbeing. However, people with an intellectual disability often face difficulties when establishing such relationships. Their families, on the other hand, might have hopes but also fears when it comes to this issue.

### What will happen at the conference?

At this conference, we will listen to people with first-hand experience on the topic: people with intellectual disabilities themselves and their parents. The event will be a space for discussion, for exchanging opinions and sharing experiences of how to overcome certain barriers and worries. We hope that through the diversity of speakers, the conference will be a good opportunity for opening up new perspectives, raising awareness of the importance of these themes, and for potential cooperation.

### Where can I find more information?

Please do not hesitate to visit the conference website for information about accommodation options, the beautiful city of Prague and the (constantly updated) list of speakers. <http://europeinaction.org/>

# RESOURCES

## The Needs of People with Learning Disabilities

**T**his booklet aims to highlight to all pre-registration nursing students what their programme of study should offer around the health needs of people with a learning disability, increasing the students' competence, regardless of what setting they work in.

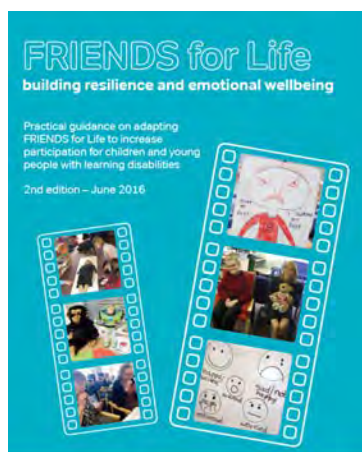
<https://www.rcn.org.uk/professional-development/publications/pub-005769>



## Friends for Life guide

**A**lthough children and young people with learning disabilities have higher rates of emotional and behavioural problems than their peers without learning disabilities, research shows they have less access to services and support.

The Foundation for People with Learning Disabilities has produced a guide on ways to adapt the internationally recognised and World Health Organisation-endorsed FRIENDS for Life programme to help children and young people with learning disabilities to manage their feelings better.  
See: <https://www.mentalhealth.org.uk/learning-disabilities/publications/friends-life-guide>



## Dysphagia Factsheets

**T**wo factsheets which explore dysphagia and learning disabilities: What do we know about dysphagia (difficulty in eating, drinking or swallowing) in people with learning disabilities? What do we know about supporting people with learning disabilities who have dysphagia (difficulty in eating, drinking or swallowing)?

[https://www.improvinghealthandlives.org.uk/publications/313917/Dysphagia\\_Factsheets](https://www.improvinghealthandlives.org.uk/publications/313917/Dysphagia_Factsheets)

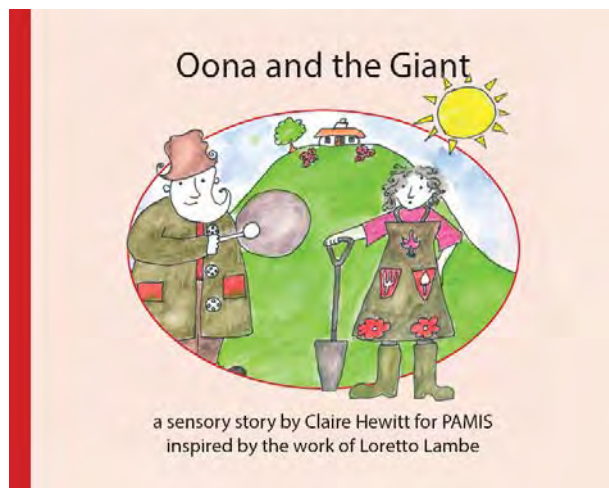


## How do I prepare my child with a learning disability for hospital?

**W**hat? why? children in hospital (WWCIH) have a video which helps children with learning disabilities and their parents with information, which can help to reduce anxiety around hospital visits:

How do I prepare my child with a learning disability for using healthcare. A video explaining ways of how to prepare your child for using healthcare services.

<https://our.choiceforum.org/t/video-how-do-i-prepare-my-child-with-a-learning-disability-for-hospital/4536>



## Launch a multi-sensory story resource

Inclusive communities was at the heart of all Loretto Lambe's work. At the PAMIS conference in June 2017 we will launch a multi-sensory story resource that has been created in her memory. This is a story resource that captures the spirit of inclusive communities. It is a resource where communities have come together to continue Loretto's storytelling legacy. People made this happen. Everyone worked together and everyone who wanted to help and be a part of it could be. Maureen Phillip [m.phillip@dundee.ac.uk](mailto:m.phillip@dundee.ac.uk)

## When I Grow Up: facilitator's handbook

This handbook is designed to help teachers raise the aspirations and employment prospects of young people with learning disabilities.



Across the UK, fewer than 5.8% of people with a learning disability have a job and many of those who are employed only work part time. Yet the vast majority of people tell us they want to work. This handbook was developed with schools and pupils and includes session plans and resources for 10 school workshops, along with some family workshops. <http://bit.ly/2orbfmX> (written by Jill Davies)

## Making reasonable adjustments for people with learning disabilities in the management of constipation

This report is about constipation, its causes and how it can affect people. It describes recent research findings about bowel management to avoid constipation and the management of constipation if it occurs. We also present a holistic approach to bowel care and management of constipation. The report has links to resources as well as descriptions of bowel management work by groups that sent them to us. Stories from family carers show very acutely the extent to which this apparently simple issue can blight some people's lives.

For more information: <http://bit.ly/2pxwuCS>

## People with learning disabilities

Since September 2016, NICE (National Institute for Health and Care Excellence) have published seven new resources focussed on the health and care of people who have learning disabilities.

<https://www.nice.org.uk/guidance/population-groups/people-with-learning-disabilities>

## Special Yoga for Special Children

Special Yoga Foundation (Registered Charity no. 1163374) was created to serve as many special children as possible through the medium of yoga. Offer a range of workshops and classes open to parents, children, health and education professionals, and anyone who wishes to participate. <http://specialyoga.org.uk/>

# SHORT COURSES & CONFERENCES

## May

Title:	Intensive Interaction with Dave Hewitt
Date:	4th
Location:	London
Provider:	Equals
Contact:	<a href="http://www.equals.co.uk">www.equals.co.uk</a>
Title:	Sensory stories
Date:	8th
Location:	Winchester
Provider:	Joanna Grace
Contact:	<a href="http://jo.element42.org/training">http://jo.element42.org/training</a>
Title:	Sensory stories
Date:	9th
Location:	Bath
Provider:	Joanna Grace
Contact:	<a href="http://jo.element42.org/training">http://jo.element42.org/training</a>
Title:	Sensory stories
Date:	10th
Location:	Cardiff
Provider:	Joanna Grace
Contact:	<a href="http://jo.element42.org/training">http://jo.element42.org/training</a>
Title:	Scruffy Targets, Meaningful Outcomes, Inspiring Legacy: Celebrating the life and work of Dr Penny Lacey
Date:	13th (2pm to 6pm)
Location:	University of Birmingham
Provider:	University of Birmingham
Contact:	<a href="https://goo.gl/nCCglw">https://goo.gl/nCCglw</a>
Title:	Sherborne Developmental Movement
Date:	18th
Location:	Derby
Provider:	Equals
Contact:	<a href="http://www.equals.co.uk">www.equals.co.uk</a>
Title:	Delivering a sensory curriculum
Date:	19th
Location:	Cardiff
Provider:	Hirstwood Training
Contact:	<a href="mailto:richardhirstwood@gmail.com">richardhirstwood@gmail.com</a>
Title:	Delivering a sensory curriculum
Date:	26th
Location:	London
Provider:	Hirstwood Training
Contact:	<a href="mailto:richardhirstwood@gmail.com">richardhirstwood@gmail.com</a>

Title:	Very Special Mathematics: With Les Staves
Date:	26th
Location:	The Bee Hive, NN2 8LR
Provider:	University of Northampton
Contact:	<a href="mailto:steve.cullingford-agnew@northampton.ac.uk">steve.cullingford-agnew@northampton.ac.uk</a>

## June

Title:	Delivering a sensory curriculum
Date:	6th
Location:	Edinburgh
Provider:	Hirstwood Training
Contact:	<a href="mailto:richardhirstwood@gmail.com">richardhirstwood@gmail.com</a>
Title:	Delivering a sensory curriculum
Date:	9th
Location:	Preston
Provider:	Hirstwood Training
Contact:	<a href="mailto:richardhirstwood@gmail.com">richardhirstwood@gmail.com</a>
Title:	Promoting Inclusion, Transforming Lives (PAMIS) International Conference
Date:	14-16th
Location:	Dundee
Provider:	PAMIS
Contact:	<a href="http://pitl.org.uk/">http://pitl.org.uk/</a>
Title:	Multi-sensory learning & environments for people with SEN: With Richard Hirstwood
Date:	15th
Location:	The Bee Hive, NN2 8LR
Provider:	University of Northampton
Contact:	<a href="mailto:steve.cullingford-agnew@northampton.ac.uk">steve.cullingford-agnew@northampton.ac.uk</a>
Title:	Technology for Inclusion, Physical meets digital: technology-enabled real world learning
Date:	22nd
Location:	London
Provider:	Equals
Contact:	<a href="http://www.equals.co.uk">www.equals.co.uk</a>
Title:	Delivering a sensory curriculum
Date:	23rd
Location:	Newcastle
Provider:	Hirstwood Training
Contact:	<a href="mailto:richardhirstwood@gmail.com">richardhirstwood@gmail.com</a>
Title:	Why sensory, and how to make amazing sensory stories
Date:	23rd
Location:	Plymouth
Provider:	Joanna Grace
Contact:	<a href="http://jo.element42.org/training">http://jo.element42.org/training</a>



Title:	Supporting mental well-being for adults with PMLD
Date:	27th
Location:	Leatherhead
Provider:	Joanna Grace
Contact:	<a href="http://jo.element42.org/training">http://jo.element42.org/training</a>

Title:	Develop your sensory lexiconary
Date:	28th
Location:	Leatherhead
Provider:	Joanna Grace
Contact:	<a href="http://jo.element42.org/training">http://jo.element42.org/training</a>

### August

Title:	Sensory stories
Date:	25th
Location:	Loughborough
Provider:	Joanna Grace
Contact:	<a href="http://jo.element42.org/training">http://jo.element42.org/training</a>

## NEXT ISSUE

Summer Vol. 29 No. 2 Issue 87

### Life As An Adult

Do you have any stories to share?

If so, contact the editors:

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[info@pmlmlink.org.uk](mailto:info@pmlmlink.org.uk)

**Copy date 29th May 2017**

## Promoting Inclusion Transforming Lives: PAMIS and Dundee University TCELT first international conference

15th and 16th June 2017

**W**hat is the conference about and what themes will it be focusing on?

We are delighted to be hosting a conference that will give a platform to discuss, debate, share practice and build networks. This is to enable us to consider how we build communities and practice to be inclusive across a whole life span of some of our most excluded people within our societies. We are bringing together a broad spectrum of practice that support these life transitions including those who need communities to be inclusive, their family carers, researchers, practitioners, planners, government officials, and students.

The conference is moving away from traditional programmes. We know that the most memorable and significant learning comes from listening to the voice of those who are at the heart of services and communities. We are, therefore, focussing the key notes on their stories and perspectives asking them to challenge the audience to think creatively and collaboratively in order to transform the way we help our communities to be inclusive. The collective wisdom about Inclusive Life Transitions and Inclusive Spaces will truly make an impact.

Supported by the Scottish National Inclusion Network (NIN) we have planned for inclusion with a range of accessible sessions and an accessible venue.

**Why do you think a conference on inclusion is timely?**

**W**e have just celebrated the 10th anniversary of the adoption of Convention on the Rights of Persons with Disabilities (2006 – 2016). This has led to a heightened awareness about the need to engage with those who use services - people with disabilities, children and young people, and family carers, to ensure

we build the communities which they value and can participate in.

The 25th anniversary of PAMIS – (Promoting a More Inclusive Society) this year seemed an appropriate time to reflect on the past 25 years and join with an international audience to share, debate, ponder and identify opportunities to collaborate on building communities that engage and care.

### **Why is Dundee an appropriate venue for such a conference?**

**D**undee is transforming – The emerging Victoria and Albert Museum of Design with fully inclusive facilities such as a Changing Place Toilet is a catalyst for inclusive living and a sense of place. There is a real appetite from the local agencies and businesses to get it right for those who require support to access their communities and we think that this conference will focus heart and minds on the ambition of being one of the most inclusive cities in Scotland. Dundee leads the world in aspects of research in healthcare, technology and culture. It is also the home of PAMIS headquarters and in our 25th anniversary year, where better to bring this focus?

The Dundee and Angus convention bureau, partners in the organisation of the conference, are driving the local Business Tourism community to consider the unique selling point of being totally inclusive. We know this will take time but there is a real appetite and we hope this conference will bring the expertise together to make this ambition a reality.

### **What kind of interest have you had in the conference?**

**W**e are thrilled to have attracted delegates from as far afield as Australia and Japan, as well as Europe and the UK. There are a number of family carers as well as those who use services and academics locally, nationally and internationally. We have representatives from the Scottish government, from health and social care and from the third/voluntary sector. And still room for plenty more!

### **Can you tell us about the BLETHERS preconference session on Wednesday 14th June?**

**H**annah Young, the research director in PAMIS, is leading a workshop that brings together those interested in exploring topics around profound learning disabilities. Hearing the voice of the person with profound learning disability and valuing the contributions they make to our lives is one area that will

be explored. The programme is open to participant's contributions/suggestions.

### **And what about the Transforming Childhood Symposium?**

**T**his exciting session will begin a dialogue that extends across professional and generational boundaries to identify how we can deepen participatory and inclusive practices with children and young people. Moving practice from adult –centrism that expects the child to engage in adult life to practices that respond to and are led by children and young people.

### **What format will the conference take?**

**T**here are four key notes all led by people who use services, both individually and as carers. We feel this embodies the ethos of the conference - learning from the experts, those who use the services. The plenary sessions are a mixture of workshops, themed papers and transformational practice sessions. There is a session for posters as well as an open space to enable further networking and the ability to take some of the work to the next stage opening possibilities of transforming practice through collaborations and sharing.

All the sessions will be underpinned with key reflections – what have I heard, what do I notice, what do I wonder and what will I do back in my practice/life?

There is civic reception to welcome everyone to Bonnie Dundee and begin the networking and collaborative nature of the conference. We will sing, share stories, encounter the amazing Scottish culture and hospitality and have the opportunity to experience the wisdom of our environment through a Street Wisdom session at the evening symposium and meal at Guthrie Castle. There will also be an emotional launch of Loretto's stories - a multisensory storytelling resource as a legacy to the late Loretto Lambe founder of PAMIS.

Action packed, exciting, stimulating but most of all an opportunity to make a difference through collaborative working, sharing and wondering about the possibilities.

Hope to see you in Dundee in June 2017.

For all enquiries please contact TCELT@dundee.ac.uk

# Future Developments of the PMLD LINK website

## A Survey of Your Views

The new PMLD LINK website was launched in early 2016. During the twelve months since then we have had useful experiences of using the website. We are now seeking to improve the website further, although a fundamental redesign is not possible. We wish to seek your views about what would make our website most useful to you.

We will soon be sending a survey to all subscribers, including guest subscribers. The actual questions are reproduced below so that readers who are not subscribers may be included in the survey

We would be most grateful to hear your views and hope that you will complete this simple survey and return it to us by 1st August 2017. It can be e-mailed to [rob.ashdown@ntlworld.com](mailto:rob.ashdown@ntlworld.com) or [info@pmlmlink.org.uk](mailto:info@pmlmlink.org.uk) or mailed to Rob Ashdown, PMLD LINK Treasurer, 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH.

1. Do you (or your organisation) have a member's subscription to PMLD LINK?
2. If not, have you logged on to the PMLD LINK website as a guest subscriber for free?
3. Do you find it easy to log in to the website?
4. What do you like most about our website?
5. What changes would most improve our website for you?
6. How often do you use our website?
7. How likely is it that you would recommend the website to others?
8. Overall, how satisfied are you with your experience of using our website?

We intend to develop the Resources page of the website by adding single page documents with links that can be accessed through buttons labelled with the following themes: Advocacy; Commissioning Services; Communication; Education; Families; Health; Housing; Legislation; Workforce.

9. Do you agree that these themes are important?

10. Would you like to see other themes included?

11. Are there any particular resources that you think the website should make available?

The website does not have a facility for interactive messaging, although it shows ways of contacting us. We use Facebook and Twitter for messaging and networking.

12. How often do you use Facebook?

13. How often do you visit the PMLD LINK Facebook page?

14. Do you find our Facebook page useful for sharing information and networking?

15. What changes would most improve our Facebook page?

16. How often do you use Twitter?

17. Do you find our use of Twitter helpful for sharing information and networking?

18. What changes would most improve our use of Twitter?

19. Do you regularly use other forms of social media for information or support around caring for/working with people with PMLD?

20. What is your interest in PMLD LINK ? (e.g. as a Parent or family member of a person with PMLD; teacher; nurse; carer; other professional)

Thank you for completing this survey. It can be e-mailed to [rob.ashdown@ntlworld.com](mailto:rob.ashdown@ntlworld.com) or [info@pmlmlink.org.uk](mailto:info@pmlmlink.org.uk) or mailed to Rob Ashdown, PMLD LINK Treasurer, 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH.

The results will be published in the PMLD LINK journal and on Facebook in due course.

**Subscription prices are:**

<b>UK:</b>	Personal	£20.00	Organisation:£30.00
<b>Non UK:</b>	Personal	£27.00	Organisation:£40.00

**Name of Subscriber:** .....

**Address:** .....

**Telephone No.** ..... **e-mail:** .....

**Place of work** (if applicable).....

**Contact name within organisation** (if applicable) .....

This is a new subscription / renewal subscription

I/we enclose a cheque for £ ..... (made out to PMLD Link)

I/we have set up a standing order for £ ..... with our bank starting on .....

How did you hear of PMLD LINK?..... Date: .....

**Please send this form with payment to: Rob Ashdown, 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH**

*If you require a receipt please enclose a stamped addressed envelope marked Receipt.*

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**PMLD Link** is an informal journal for practitioners and carers working with people with profound and multiple learning disabilities (PMLD), of all ages and in all situations. It covers a wide range of issues of interest and practical use in the day-to-day work of practitioners, parents and carers in schools, colleges, adult provision, in the home, and covers issues pertaining to all groups, including occasional articles by practitioners and parents from overseas. It enables readers to create networks, and provides a forum for contact with others involved in the field. The contributions may be short papers, information sharing, news of individuals, families or other groups or requests from readers for information.

## About Us

The editorial team is drawn from a variety of settings and currently includes:

<b>Rob Ashdown</b>	Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
<b>Jeanne Carlin</b>	Retired Disability Consultant and a parent of a young woman with PMLD.
<b>Helen Daly</b>	Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
<b>Jill Davies</b>	Research Programme Manager for the Foundation for People with Learning Disabilities. Jill recently completed a Dept. of Health project on Meeting the needs of children with complex health needs. She facilitates the UK Health and Learning Disability Network.
<b>Ann Fergusson</b>	Annie is a senior lecturer in the SEN & Inclusion team at the University of Northampton, teaching on undergraduate and postgraduate courses relating to severe, profound and multiple learning disabilities. Her research interests relate to person-centred working, meaningful participation and the voice of the individual in promoting positive mental health and wellbeing. She works one day a week in a special school with a role for training and looking at impact. Annie has a brother with a learning disability. She is a family member of the Learning Disabilities Mortality Review Programme Advisory Group.
<b>Martin Goodwin</b>	Martin is a teacher of pupils with PMLD and a Regional Tutor/Visiting Lecturer for the Severe and Profound Multiple Learning Disabilities course at the University of Birmingham. Martin has specialised in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities. Martin has experience of working in play and leisure, education, residential and advocacy.
<b>Rachel Parry Hughes</b>	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
<b>Becky Loney</b>	Becky has a background in running creative services for adults with PMLD within the voluntary and statutory sector and she established the Lambeth Mencap Carousel project. Becky is passionate about intensive interaction and sensory storytelling, and spreads the word by training staff teams in high quality activities and creative approaches.
<b>Wendy Newby</b>	Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
<b>Jill Pawlyn</b>	Jillian Pawlyn has a background in Learning/ Intellectual Disabilities Nursing and is an enthusiast and advocate of Technology Enhanced Learning. During her years as a registered nurse Jillian has developed a specialist interest in the health needs of people with a learning/ intellectual disability in particular those individuals who have Profound Intellectual and/or Multiple Disabilities (PIMD/ PMLD). She is a member of both the national and local PMLD Networks
<b>Sue Thurman</b>	Former NHS Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. Now writes and trains about communication and is a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts.
<b>Bella Travis</b>	Policy Lead, Mencap

**Disclaimer:** Views expressed by contributors to **PMLD Link** are their own and do not necessarily reflect the policies and opinions of the editorial team



sharing ideas and information

PMLD Link is a journal for everyone supporting people with profound and multiple learning disabilities.

Visit [www.pmlmlink.org.uk](http://www.pmlmlink.org.uk)

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