PMLD LINK

sharing ideas and information

Communication

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Jenny Buckland

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GUEST EDITORIAL
Communication

Communication is a human right. Article 19 of the Universal Declaration of Human Rights states "Everyone has the right to freedom of opinion and expression … to receive and impart information and ideas through any media". It is essential, therefore, that we enable people with PMLD to have a voice. The Core and Essential Service Standards recognise the importance of communication. In this issue Rob Ashdown outlines where communication fits into the Standards, highlighting the need for a responsive environment. It is vital that the upmost is done to identify the strengths and needs of people with PMLD. Felicity Court, in her article, links the Standards to the Royal College of Speech and Language Therapists' 'Five Good Communication Standards'.

The Core and Essential Service Standards also sets out the need for meaningful relationships. Breaking down the barriers and giving people with PMLD a voice can transform their lives. Dave Hewett and colleagues capture the passion and determination that is needed to promote meaningful communication for people with PMLD. They describe how crucial it is to have the techniques to facilitate communication and how Intensive Interaction can provide access to this. Emily Woolman shares her story about her relative Rose. The use of Intensive Interaction has transformed her life from being socially isolated into what she describes as a 'social butterfly'. Intensive interaction has given her the means to communicate. Standard 1 for individuals highlights the need for a means of communicating, a reason to communicate and an opportunity/availability of a communication partner. Throughout this issue we can see examples of these standards being met in creative and innovative ways. The use of eye gaze with her son Thomas has led Lucy Williams to believe how important it is to never assume they can't and won't do it. Jenny Buckland describes an exciting journey where students within a mainstream school have formed meaningful relationships and communicate with their peers who have PMLD. Leigh Wharton uses assistive technologies to allow her students to have a voice within real world situations. What a wonderful experience for all the children involved.

There is an underlying 'can do' attitude to the work that is described in all of the articles. This is only possible if the practitioners, carers and families have the appropriate training and resources. The organisation standards set this out in Standard 3. Dave Hewett and his colleagues describe how important it is for staff, carers and parents to have the skills to connect. It is wonderful to be a communicator.

We would like to thank all of the contributors for sharing their experiences. We hope that you enjoy reading the articles in this bumper issue! Hopefully the ideas shared here will inspire you to try something new, to try a new take on something you already do or why not try and see where there is evidence of The Core and Essential Service Standards being met within this issue. If we have encouraged you to be innovative - please write and tell us about your experiences or contact us via the website.

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Losing control

Rachel Wright

One of the first things to evaporate, when parenthood to a child with complex needs arrived uninvited, was my sense of control. That and sleep – sleep became a long distant memory. Foolishly I once thought I was the master of my own destiny. With rose tinted glasses I can fondly remember a time when, if I needed some groceries, I could pick up my wallet, keys and walk out the door. I remember a time when cleaning a midnight tide of poo and wee would have turned my stomach rather than be a normal Monday night.

Caring for a child with complex needs, meant my life and my diary was skewed by a growing list of professionals and their lengthening to-do lists. While my home became a collecting ground for specialist (and often ugly) equipment.

Loss of control is the same for anyone hearing the carefully crafted words of bad news.

In the beginning, there is a life-changing diagnosis or trauma. This defining moment splits life into before and after. Everything changes; perspective, hopes, dreams and expectations for the future.
Suddenly you are in the middle of a whirl wind of activity you barely understand, never mind determine. The best option becomes hunkering down in the eye of the storm as people buzz around like bees on illicit drugs. All the while, life ticks by with the slow monotonous pace of a midnight clock; relentless, persistent and unfazed by tragedy.

Then comes the invasion. Professionals, therapists, specialists and practitioners (even your sister's hairdresser), walk into your life to give advice, instructions, options and varying levels of fear or hope. In the midst of overwhelming change, you are left standing in the present.

The rope of life once clung on to, ruthlessly slips through fingers, no matter how tightly it is gripped by hands. Instead of climbing, slump to the ground deflated and tired, hands raw and throbbing we look up to watch everyone continue to climb.

The past seems so immaterial and the future uncertain. Professionals swarm about using language and rules not fully understood, like playground friends who have written a new code they aren't letting you in on. A rabbit warren of disability jargon and medical liturgy slowly builds a dark and impenetrable maze that I like to call the vulnerability labyrinth.

Soon the complexities of disability swell and consume, out sprinting the simplicity of ordinary life.

In the wee small hours of the night, Google flicks from ally to arch enemy. One minute a lifeline of hope is caught with a therapy, drug or personal story. But before long the stark truth flashes up in front of my eyes whether I am prepared to see it or not. Compounding this sense of confusion is the lingo, language, secret policies and protocols that frame the social, healthcare and educational world.

"This life changing therapy can't happen until you've seen Doctor Important."
"You can't access this opportunity until you've got this diagnosis."
"Yes, you need to see this specialist, but that professional has to refer you and they have a three-month waiting list."

As a parent, or simply someone trying to determine their own destiny, contributing to a decision could feel liberating. I don't necessarily want the weight of responsibility to lay heavy on my shoulders. Rather parents like me long to be part of a team of specialists determined to make the best decisions. Like everyone one else on this planet we simply want to be seen and heard, to belong and have purpose.

Thankfully there is hope. There actually is a magic wand that can help loosen the fear of the vulnerability labyrinth and bridge the gap between families and practitioners.

Effective communication

Practically every professional body, clinical guidance and credible research related to those with profound and multiple learning difficulties, recognises the importance of effective communication with families (National Institute of Clinical Excellence, 2017; Jones et al., 2014; Nursing and Midwifery Council, 2010; Learning Disability Professional Senate, 2015; and Ofsted, 2018). A parent's perception of the quality of care their child is receiving will be directly related to effective communication and the quality of relationship they have with a professional (Konrad, 2008). Effective communication allows the opportunity for relatives to engage in the lives of their loved ones. It is an essential ingredient for partnership and co-production (Stephens, et al., 2008). But first we must recognise the natural gap between each individual's priorities and perspectives whilst acknowledging parents and practitioners are experts in their own right. Relatives and carers are experts by experience, with the skills and knowledge necessary for 'best practice' to be provided. But the gap needs to be bridged with effective communication.

Sometimes information will be hard to hear. Sometimes hard conversations need to happen.

Trust between parents of children with additional needs and professionals can be difficult to build for many reasons (Avis and Reardon, 2008). In addition, communication can be emotional and tiring for parents (Young, et al., 2013). The professional/parent imbalance of power means the family is expected to reveal every little detail of their life whilst the professional maintains boundaries which prevent them from sharing simply where they live. Although there are very good reasons for this, the gap and imbalance it creates must be recognised in order for effective communication to flourish.

Small things can make a big difference.

But the way a professional builds trust, supports and listens will directly impact the feelings a person, parent or relative has when they leave a conversation. One small detail that can make a very big difference is using a parent's chosen name. Simply using 'Mum' or 'Dad' rather than a parent's name doesn't foster the attitude of partnership most professionals are keen to employ. Looking someone in the eye, saying, "Hello my name is …. and you are?" initiates an atmosphere of reciprocal respect and engagement.

In many instances, as the parent of a child with complex needs, I might not like what is being said to me. But if I feel heard, if I build trust with the person speaking to me, if I know they have me and my loved one's best interests at heart, then the sting of hard news is easier to bear.

I am passionate about dispelling the shadow of the vulnerability labyrinth with effective communication and co-production.

Simple practices like 'Don't call me Mum' demonstrates a practitioner's determination to communicate effectively, promote partnership and co-productive working.

As the parent of a child with complex needs and a nurse, I have experienced the positive benefits from both sides when all parties are heard and work in partnership. That is why my work is now focused on helping parents and professionals understand the impact of a family's story, their perspectives, priorities and the impact of effective communication. Through parent workshops, training professionals and speaking at conferences I believe we can learn to hear each other and bridge the gap. With effective communication and co-productive working, together we can change the lives of those with profound and multiple learning difficulties and their families – and it doesn't cost a penny.

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Rachel Wright is a nurse, writer, public speaker, trainer and mum living in Essex with her husband and three sons; one of whom has severe disabilities. Through her website, Born at the Right Time, you can read her blog and find out more about her training for professionals and workshops for parents. Her three passions are communication, community and facing life's challenges.

Website: https://www.bornattherighttime.com
Photographs by Nicola Parry Photography'

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Apology for Angelika Hild

We try very hard to ensure that what we print is correct. Unfortunately, within the winter issue, Health and Wellbeing, a mistake was made. We would formally like to apologise to Angelika Hild, who with Guillaume Jacquinot wrote the article on a new task force on people with complex support needs, for the misspelling on her first name within the winter issue. This mistake will be corrected in the online winter issue on our website.

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The PMLD Standards and communication

Rob Ashdown

In 2017, the PMLD Standards were published and details were disseminated in 2017 and 2018 at the two national conferences titled 'Raising the Bar'.

There are two main components to the standards. The first set of standards aims to give guidance and support to organisations on how to provide high quality care to people with PMLD (p.24). A second set of standards (p.28 to p.30), focuses on the individual and their specific needs.

The standards can be read in their entirety on the Resources page of the PMLD LINK website (http://www.pmldlink.org.uk/resources/#pmld-standards)

Standard 5 for Organisations: Communication

Organisations are challenged to comply with the following:

- Ensure effective and consistent communication with each person, by supporters who develop warm and trusting relationships with the person/s they support.
- Ensure staff are trained in appropriate total communication approaches to maximise expressive and receptive communication.
- Appropriate communication aids, including assistive technology and concrete routine and environmental cues, are in place to promote communication and decision making in the persons best interest, acknowledging their perceived wishes and known preferences at all times.

Note that the emphasis is on what people at all levels and ranks of an organisation's structure should contribute to ensuring effective communication with each person with PMLD. A range of possible evidence that organisations are meeting these standards is detailed.

Standard 1 for Individuals: Communication

Organisations are asked to self-assess against these aspects of the communication standard and to identify actions to improve the quality of the support they provide for each individual.

- Communication, in its entirety, with the individual is developed, considering the individual, and staff are equipped with appropriate training, knowledge and resources.
- Communication should be a collaborative activity, it has to be a two-way exchange; reciprocal and responsive.
- A means of communicating (that is acknowledged), a reason to communicate and an opportunity/ available communication partner are crucial - all three aspects are needed for communication to be effective.

Organisations are asked to provide evidence that the utmost is being done to identify each individual's strengths and needs, taking into account their preferences and interests. The organisations should offer a responsive environment wherein the emphasis is on developing effective two-way communication between the individual and their supporters. The development of the communication skills of the individual is important but so too is recognition of and appropriate response to their communication acts, intentional or otherwise, whatever form they might take.

Guidance from PMLD LINK and others

There are downloadable documents covering appropriate communication approaches and assessments on the Resources page of the PMLD LINK website, especially in the Communication and Education sections. A starting point for readers would be the overview called 'Communication and Interaction'.

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Five Good Communication Standards

Felicity Court

The publication of the PMLD Core and Essential Standards in 2017 was very welcome for all parents/carers and practitioners in this field. Section five of this document focuses solely on communication standards and ‘from the top’ reference is made to the Royal College of Speech and Language Therapists’ ‘Five Good Communication Standards’ (2013). PMLD Core and Essential Standard 5:1 requires services to evidence how the communication standards embed these into their quality frameworks. There follows a brief resume of the communication standards, with a PMLD focus and a ‘Positive Indicator’/example of ‘what good looks like’:

Standard 1:

There is a detailed description of how best to communicate with individuals

Sometimes referred to as communication passports or guidelines, these should be written simply and clearly. For people with PMLD they are likely to include information around understanding of nonverbal language, response to routines, hearing and vision, use of vocalisations, facial expressions and body language, consideration of whether communication and behaviour is intentional, best times of day, people and environment (noise, space, sensory information), use of Interactive Approaches, Objects of Reference, use of simple AAC (alternative and augmentative communication systems), sensory resources such as sensory stories.

Positive Indicator: An up to date passport/guideline is readily available, referenced across care plans and staff are aware of a person’s communication support needs – and are prepared to adapt their own communication/use the appropriate resources to meet these needs.

Standard 2:

Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.

Careful detailed observations, use of, for example, objects of reference, and involvement of family members/carers all help to build up a picture of the likes/dislikes of a person with PMLD. This information can then be used to inform decision making around certain everyday choices, e.g. mealtimes and activities. NB - it is important to recognize that preferences may change over time.

Positive Indicator: A person’s preferences are established and recorded in this way, thus contributing, albeit in a small way, to multi-agency ‘best interest’ decision-making under the Mental Capacity Act (2005).

Standard 3:

Staff value and competently use the best approaches to communication with each individual they support.

Good learning and development programmes should exist to support staff working with people with PMLD to develop and refine the appropriate communication skills. Staff supporting people with PMLD across different settings must recognise that it is incumbent on them to change their communication level, style and methods. For example, learning to simplify their language, being prepared to use more non-verbal communication, observing and responding to an individual’s behaviour. They also need to be aware of the critical roles of hearing, sight and sensory processing. Good staff create opportunities for positive communication; over and above simply meeting a person’s basic needs.

Positive Indicator: People with PMLD are supported by staff who truly try to communicate with them in their ‘own language’.

Standard 4:

Services create opportunities, relationships and environments that make individuals want to communicate.

It is critical that people with PMLD enjoy a good quality of interaction, which will in turn lead to emotional wellbeing, and a sense of belonging and inclusion – all of which impact on good mental health. For someone without formal language, Interactive Approaches are a way of 'being' or 'spending time with' another person. Meaningful contact can be made with people who may be considered 'hard to reach'.

Positive Indicator: It is apparent to families, friends, professionals and all visitors when warm and genuine interactions are clearly observable – and not just functional exchanges.

Standard 5:

Individuals are supported to understand and express their needs in relation to their health and wellbeing.

It is particularly difficult for people with PMLD to communicate about their health and/or show that they are in pain. Staff need to be aware of how each individual communicates this information and how ill health can lead to changes in behaviour. All of this information should be clearly documented e.g. in a Health Passport.

Positive Indicator: Reasonable adjustments have been considered prior to a medical appointment and should include consideration around the appointment venue, time, duration and staff member providing support.

The Five Good Communication Standards can be used to help organisations work towards best practice through self-assessment against each standard. There are also links to other publications and relevant resources alongside each of the five standards – so well worth another look!

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PMLD LINK Issue 68, Spring 2011

Issue 68 was a themed issue on communication containing significant articles by Johanna Bilingsley, Sheridan Foster, Penny Lacey, and Janet Gurney which challenge us to ask whether, when we are directly engaged in communicating with people with PMLD, we are really listening. They show how attention to detail and challenging assumptions can change whole experiences. Also, Sue Thurman reminds us of the importance of the importance of communication as a human right, what communication rights should look like and the practical implications.

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Communication, human rights and Intensive Interaction

Dave Hewett, Julie Calveley, Jules McKim and Amandine Mourière

Isn't it wonderful to be a communicator? For all of us, surely, the best, most joyful thing in life is to chat, interact, connect, relate, have relationships. Think about how much time you spend talking to others about the weather, what was on television last night, what you did at the weekend, who should be playing in the next England team, who should be voted out of a 'reality' show, gossiping about friends and relationships, just laughing and joking, discussing what is happening on social media or spending time 'relating' on social media.

Communication is wonderful

If you think about it, nearly all of us do a huge quantity of this every day, simply in order to enjoy the social connections – no particular outcome, just the gossip, the chit-chat. Well, perhaps we should say there are outcomes, big outcomes, but they are not visible, practical, functional ones where something tangible happens as a result of what was said. The outcomes of these lovely, normal, pleasurable interactions are something big and important happening inside us.

Of course, yes, as we will describe below, human communication is also highly effective practically, instrumentally, functionally – it can make things happen, achieve goals, make the machinery of society work, enable us to have buildings, banking, economic systems, the EU, houses, streets, towns. Our communication abilities enable us to get things. It is possible to say something important like 'want drink'.

However, in this brief article our intention is to emphasise the awareness that most human communication is actually simply chit-chat with no particular consequence except the crucial, 'hot air of human companionship'. We will be proposing that this realisation should have an everyday, but profound and continuing effect on our practices and service delivery for people with PMLD.

The importance of Intensive Interaction

For years now, Intensive Interaction has been bringing this ordinary, normal joy and fulfillment of true human contact and relationship to the most communicatively disadvantaged people. Many people with PMLD are likely to remain communicatively disadvantaged, if not, let's be blunt, communicatively and socially isolated, unless an Intensive Interaction practitioner can be available to make expert contact and enable the person's true social participation. How many of us think back to the pupils or service users who remained severely socially isolated, before we knew how to do Intensive Interaction?

Many people with PMLD have such profound impairments that we need most positively to acknowledge that yes, they can be genuinely difficult to reach communicatively. In order to reach them, it is necessary to enact Intensive Interaction techniques in an even more careful and focused manner than might be necessary with many more active people. We have been explicit about the techniques of Intensive Interaction in this sense, in particular, recently re-emphasising issues of tempo, waiting and pausing, don't do too much - minimalism, tuning-in, if not micro-tuning (see Calveley, 2017, 2018; Hewett, 2018; Mourière and McKim, 2018).

In a sense, Intensive Interaction doesn't do anything particularly remarkable, it simply enables us to be a communication partner who is simple enough and perhaps unhurried enough for the other person to successfully connect. In particular, good technique slows us down enough for a person who may take fifteen seconds or more to process cognitively, nonetheless to take part in communicative turn-taking.

Then, the people we care about, can become in that moment, no longer disadvantaged, can take up their rightful, ordinary, normal place in the social world and the social to-ing and fro-ing that the rest of us enjoy without really thinking about it. In fact, our many experiences of establishing meaningful communication connections with the most profoundly disabled people, gives rise to an inevitable perspective. If we are teachers or carers for such a person and we do not have these requisite communication techniques, then we are a considerable feature of that person's disability.

Most of us writing for and reading this journal have an education or social care orientation to the communication development of the people we care about. We want them to succeed, to develop, to flourish. Teachers especially (like Dave) can become highly focused on progress, outcomes and record keeping. All laudable. But we need to remember the simple truth that the first outcome of an Intensive Interaction activity, is the interaction (see Firth, 2008). Let's now technically focus therefore on some studies of the wider purposes of human communication.

The purposes of communication for all of us.

Texts on the psychology of communication categorise human communication facilities in all sort of ways. Here, we refer to some texts on communication theory which lead us to divide communication into only two, but two crucial, categories. We have written about this previously (e.g. Hewett, 2012) and since that time have worked to integrate this knowledge about human communication into our standard course delivery, as an aspect of the crucial nature of the employment of an Intensive Interaction approach.

The two categories have already been described above, but let's set them out again:

Communications with a Concrete Aim or Outcome (CCAOs)

> Requesting and getting things, making things happen, achieving a practical tangible outcome. Examples:
>
> "Pass the salt please." "Return to Paddington please". "May I have an overdraft?" "Just put it down there yeah?" "Come on let's go". "Want drink".

Chit-chat communications

> No tangible outcome, no particular objective, things that don't really need to be said. Examples:
>
> "Oh, it's clouded over again." "Who do you fancy for the premier league this year?" "Did you see it last night? Did you vote him out?" "Did you have a good holiday? Tell me about it" "I think those two are a bit more than friends actually."

Now of course, you have already worked out that we are attempting to help you practitioner readers into realisations about the crucial importance of chit-chat communications. This does not mean we are downgrading the importance of CCAOs. Where a person has the functional ability to request, they should have the tools available. However, we would argue that our field has a history of tending to focus communication efforts on the deployment of CCAOs and a tendency to neglect the wider nature of what is actually human communication. "If we just focus on functional communication we are in danger of helping people to manipulate the world but we are not helping them to share it." (Nind, 2009).

Consider this. What would you be like as a person if your communications with everyone were limited only to CCAOs? No chit-chat at all, just concrete aim and outcome stuff. How would you be? Limited? Boring? Bored? Unfulfilled and flat? Emotionally and psychologically not very well?

Anthropologist Bronislaw Malinowski (1923) coined the term 'Phatic Communion', later modified to 'communication', which:

> "serves to establish bonds of personal union between people brought together by the mere need of companionship and does not serve any purpose of communicating ideas'. (p.316)

Miller (2015) says, Phatic Communication:

> 'is used to express or maintain connection with others in the form of shared feelings, goodwill or general sociability, rather than to impart information exchange', (p.3).

Burton and Dimbleby (1995) argue the critical role of communication in establishing and maintaining a sense of self, that an attractive self only becomes apparent when it communicates with others. Further, that one's sense of self-image must be 'in a dynamic relationship with the outside world' and that the 'link with the outside world is communication.'

Adler and Rodman (2006) are even more emphatic, asserting that 'personal communication is essential for our well-being' and it may be that this is the 'primary goal' of human existence. Again, consider how you would be, if you did not participate every day, in a huge quantity of apparently pointless chit-chat. In fact, what is the ratio between CCAOs and chit-chat communications for all of us in most everyday circumstances?

The studies here are actually somewhat limited. However, Dunbar (1996) and Emler (1992) found that around 65 per cent of speaking time was taken up with talking about social experiences of one sort or another. When we discuss these figures in courses, most people seem to have a "gosh that's right" sort of a moment and will often then offer that 65 per cent chit–chat actually seems a bit low. We suggest that we have to put into the mix here the amount of time spent on social media. How much of that is actually CCAO communication? It is interesting to watch practitioners have these realisations and to then follow the thought process into the implications for what we do in our practices.

It's important to remember isn't it, that for many people we are thinking about here, phatic communication, their version of chit-chat, may manifest as exchanging prolonged touch, or very simple turn-taking behaviours, or shared meaningful gaze. It is the fulfilling human connection that is the thing - 'simply being responsive, in any way, to others' adjustments in spatial-orientational positioning sends a message of engagement, another function of phatic communion' (Al Qinai, 2011: p.35).

Concluding discussion – what is the 'good life'?

There is available an array of literature and theorizing on the nature of the 'good life' for people with learning disabilities (see particularly Hughes et al., 2018). Whilst much is made of obviously positive features of the good life such as status, community presence and participation, we hope we (and e.g. Adler & Rodman) have successfully made the point, that for all of us, the 'good life' has as its absolute bedrock, the ability to be a true social participant, to connect, interact, receive and give human contact. People with profound impairments may be able to make little or no access to this underpinning aspect of the good life, unless services and practitioners have both the outlook and the expertise that makes human connection available to the person in recognition of this bedrock priority. It can seem as though getting these realisations about the nature of human communication into the general consciousness of our work can be a slow process, but the last few years show the issue becoming gradually more illuminated (e.g. see RCSLT, 2013). More recently and pertinently, the 'Core & Essential Service Standards' (Doukas et al., 2017) asserts that each person must have available:

"Supporters who develop effective and consistent communication with each person, by supporters who develop warm and trusting relationships with the person/s they support" (p.24).

But let's go further. Are we not now advanced into the stage where we recognize that this need for basic, meaningful human connection and interaction, a sense of social belonging, is so prominent, that it is practically an abuse of human rights if services fail to provide members of staff with sufficient expertise for making human communicative contact with service users who are very 'difficult to reach'. These rights have surely already been internationally recognised (Article 21, United Nations 2006). If you are an accomplished Intensive Interaction practitioner, you must already be aware, that nobody needs to remain isolated, everybody is reachable. It may take the dedicated, micro-tuned technique as described earlier, but everybody can have true social participation – and surely, as of right.

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A transformation from socially isolated into a social butterfly through using Intensive Interaction

Emily Woolman

This article is a personal reflection of the Intensive Interaction journey I have had with my family member over fifteen months as I trained to become an Intensive Interaction Coordinator. My relative, Rose is 53 years old, has PMLD and lives in a local authority trust. I am a special needs teacher and I have a Masters in Severe, Profound and Multiple Learning Difficulties. Rose is the reason why I am passionate about Intensive Interaction and is why I have chosen to work within the field of SPMLD.

What is Intensive Interaction?

Intensive Interaction (II) is an approach developed in the 1980's by Dave Hewett and Melanie Nind. It is an approach to;

'…teaching the pre speech fundamentals of communication to children and adults who have severe learning difficulties and/or autism who are still at an early stage of communication development' (Hewett, 2019).

The principle of II is based on the literature about parent-infant interaction and focuses on the teaching and development of what Hewett and Nind (2001) called the Fundamentals of Communication (FOC). The FOC are basic, non-symbolic communication skills and concepts that should be the first communication learning that a person should be expected to undertake, these skills are the important foundations of communication. As Hewett describes it: *'II is a conversation whose content is almost entirely decided upon by the emergent communication partner'* (Hewett, 2018: p.12-13).

Furthermore, II is based on the natural model of communication, the interaction between infants' and mothers'. Imitation or mirroring, known by II practitioners as joining in, is one of the techniques of II. Mirroring taken literally can be seen as a cold, hard, removed reflection, whereas for II mirroring is about joining in with a behaviour to develop communication sequences and tuning in. Nind and Hewett (1994) describe how caregivers respond to an infant and make their worlds predictable by imitating or mirroring elements of their behaviour. It is important to note that imitative exchanges are not acts of copying but moments of sharing. Firth and Barber (2011) describe II for a person with a social or communicative impairment as a way of reflecting back a response that is very similar or closely linked to the behaviours of a person, also known as echoing the person's behaviour simultaneously.

After filming solo videos of Rose and watching them back, I was able to choose some behaviours to respond to and join in. There are some movements that Rose makes that I believe are communicative, for example when I arrive, she bangs her right arm on her thigh, this is her 'hello and welcome' gesture and means, she is ready to communicate and have a chat. However, there are other movements that are involuntary or self-regulating behaviours, therefore, I would not join in with those movements or respond to them.

My Aims for the Coordinator Course

As my Intensive Interaction Coordinator journey was a personal one, the only aim that I had at the beginning of the course was to be able to bond with Rose and enhance the relationship that we already had. However, through trusting the process of II and tuning into Rose with all of my senses, the progress and development of her FOC became quite evident through her increased vocalisations, laughing, physical movements and facial expressions. It is important to note that I see Rose very regularly and our journey has been over 15 months. The information below is just a snapshot of our journey and it is important to remember this when reading.

Rose and Emily's Intensive Interaction Journey

First II session -January 2018

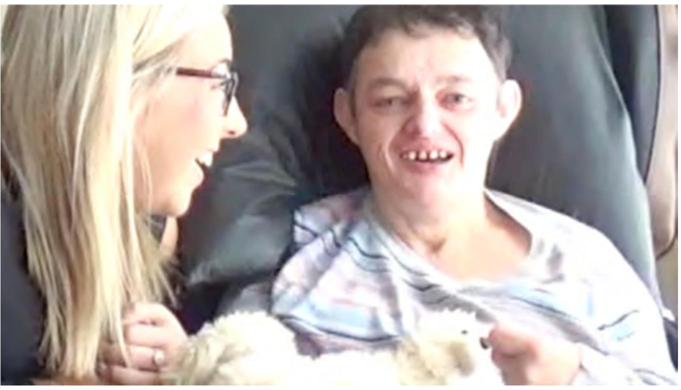
Rose was sat in her beanbag in her sensory room; she loves cuddly toys and was holding her monkey. Rose had her eyes shut and did not want to communicate with me. Looking back, I now realise that I was too much for her, my positioning was wrong and even though I was tuned in I responded to everything that she did. I should have been selective with my responses which relates back to Firth and Barber's (2011) idea that there is no need to imitate everything, that I should have reflected back a response very familiar and in this case, terminated the interaction as Rose clearly shows that she does not want to interact with me. I was too close, too in her face and, from looking back at video footage, my expressions and my available look were also too animated. This was the first time that we interacted in this way and I think Rose found it very strange. This interaction did not last long because I could tell that Rose had finished it, this is an important rule, and the only rule of II that: *'When the other person, the learner, has had enough, the activity should stop. If the person is not in the mood or the right frame of mind, probably do not start'* (Hewett, 2018: p.31).

April 2018- Shopping Centre

This photo shows that II is not a session that you have to plan, or 'do' in a 1:1 environment. Here, Rose and I are at our local shopping centre. We had been to the Disney Store and Rose had chosen the cat cuddly toy. We were on our way to the car park when Rose decided to throw the cat on the floor! This became a game very quickly and I used the principles of II. Due to this being the first time this kind of situation had ever happened, where Rose initiated a game, I got a bit over excited and, if this were to happen again, I would slow my responses down. However, this is the moment when Rose bloomed into the social butterfly that she now is because we were in the middle of the exit doors and we created our own little bubble, she did not care about anyone else and nor did I. It was a very special moment where Rose wanted to have a conversation with me in public!

June 2018- In the Garden

As part of the coordinator requirements, I had to mentor somebody in the practice of II. I chose to mentor my Mother, called Christine, and again, her journey started the same as mine, where Rose closed her eyes! However, due to Christine fine tuning her technique of II, Rose now interacts with her and initiates a conversation. Christine allows Rose to lead and pause. There is no rush to their conversation, it is unhurried and Christine is tuned in throughout and Rose knows this. Rose has developed the ability to turn take and enjoys taking in the social world around her.



October 2018: A Visit to Rose's Home - A WOW MOMENT

This screenshot is taken from an interaction that we had on 10th October, 10 months after beginning to use Intensive Interaction. This moment was spontaneous and I was lucky enough to have my camcorder with me to capture this conversation on video. This supports the view that II is not meant to happen in a pre-planned time slot, that interaction happens naturally and it just becomes part of how you interact naturally. As you can see, both communication partners are sharing so much joy and having fun together. This is the purpose of II and is what Hewett calls: *'mutual enjoyment'* (Hewett, 2018: p.28).

Rose used her voice and we had a conversation through laughter! It was truly amazing.

February 2019- A visit to Rose's Home
Again, I was so lucky to have my camcorder on me during this visit to Rose's home. During our II journey, Rose has created a repertoire of games that she initiates to play with me. She enjoys tapping her feet on her wheelchair and I respond by squeezing her feet and saying the word 'squeeze'. She has learned that she has the power to initiate communication and she is so clever that she teases me! Her mobility has become developed through using II; she moves her legs up, uses her right hand which she never used to and she nods her head. As a family member, this journey that is documented by video is priceless because she has been through difficult times during her life. I have taken some video evidence to a range of professionals, including a psychiatrist and he could not believe how much Rose initiates communication and even commented on her posture when she attended the meeting; how alert she was. This evidence has helped Rose to NOT have anti-psychotic medication so this is just amazing and supports how much II has made a difference to Rose's life and also how important it is to document the II journey on video.

Final Thoughts

Rose has made progress in her FOC, however the reason for this is because of my technique as an II practitioner and anybody can learn how to do this. As a practitioner, I am more relaxed, I do not do too much, I am totally tuned in with all of my senses, I have good positioning and I have an available look. Moreover, I am selective with my responses and respond in different ways, through touch for example and the main thing is that Rose initiates everything and I respond. We have repetitive sequences that Rose leads and I can tell by her facial expressions that she understands the turn taking and the fact that she is in control and has the power to talk to me and knows that I will listen.

Finally, communication is an essential human need and is recognised as a basic human right; *'Without it (communication), no individual or community can exist, or prosper'.* (Thurman, 2009: p.5).

Therefore, as Hewett (2018) discusses, II needs to be disseminated so that we can continue to support people who have severe, profound and multiple learning disabilities who have previously been socially isolated. Personally, the difference that II has made to Rose and my family is incredible and I want this for every family. As a researcher and teacher I am passionate to continue this dissemination. Rose has transformed from being socially isolated into a socially butterfly. Thank you Intensive Interaction for teaching me how I can develop such a meaningful and special relationship with my family member. Every person who is socially isolated deserves to be a social butterfly and through using II this profound transformation is possible and as Rose proves, age and disability is no barrier to communication!

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The Importance of congruent communication

Anne Laney

Our work at Us in a Bus is all about connection and communication – we facilitate opportunities for people with complex needs to explore sociability and self-expression. By far the most important and useful approach in making this happen is Intensive Interaction and we've been lucky enough to have been using and evolving this work since 1990. Some time ago our team established that if clear communication and open connection are what we offer, we first have to experience this for ourselves: as colleagues and with everyone we come in to contact with, not just the people who use our services. This has grown into an essential part of our Code of Conduct and Ethics.

Congruence: There needs to be congruence between what is expected of people who use our service and what we expect of ourselves. A lot is expected of people – they are observed, reviewed, reported about, encouraged to stretch their comfort zones, expected to learn, given feedback etc. We should not expect less from, and of, ourselves.

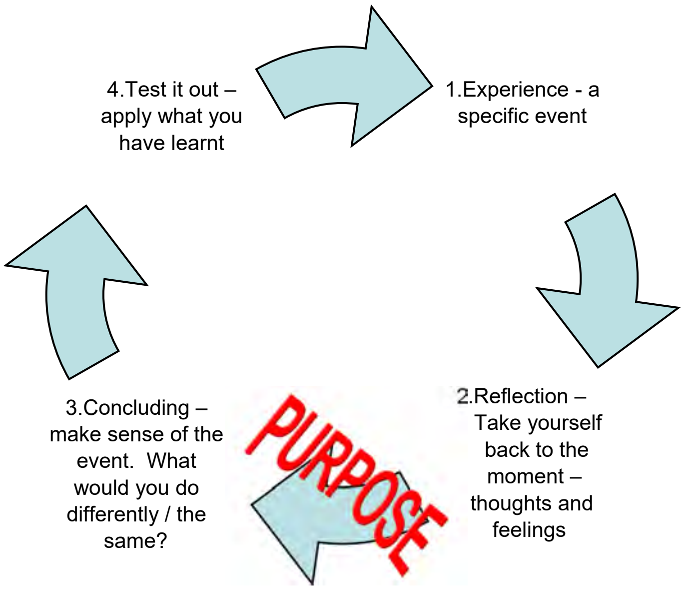
We aim to ensure that congruence underpins everything we do, ensuring that respect for those we work with is at the very core of our work. Our trouble-shooting, quality control processes and communication with each other must include the same level of scrutiny and honesty that is often expected of our Interaction Partners, for it to be a fair representation of the ideals we hold. Translating this principle into everyday practice is sometimes easy – and sometimes not.

We use Intensive Interaction every day: encouraging people to develop their fundamental communication abilities and their basic sociability, and playfully exploring activities together in a way that feels familiar and natural. A lot of thought, observation and reflection supports this and things don't always go to plan.
Over the years we have worked hard to effectively support our team to work through these moments and form strategies to solve problems. One of these ways is by holding regular 'Unpicking Meetings', which I'll describe here.

The American Educational theorist David Kolb constructed his Cycle of Experiential Learning in 1984 and it has been widely adapted to fit many different settings. It's presented in many versions and all break down the process of learning by "doing" into categories.

Our version, adapted from Kolb by Janet Gurney, our Director of Training, adds into the cycle what we as Intensive Interaction practitioners must hold in our head at all times: the concept of "PURPOSE". Why are we interacting as we do? What are our hopes for the person we're with? What do we hope to achieve?

So our version looks like this:



So, how do we use this to direct our trouble-shooting, "unpicking" meetings?

A few minutes discussion with our regular working partner usually results in examples of moments from sessions that have raised questions for us. As a team, we decide which of these we want to analyse in more detail. There are often themes that run through everyone's experiences. For example, how to work with sleepy people or how to best facilitate group interactions when one person is more energetic than the others. We work our way around Kolb's cycle, noting in detail the facts of what happened, what we thought about it and how we felt.

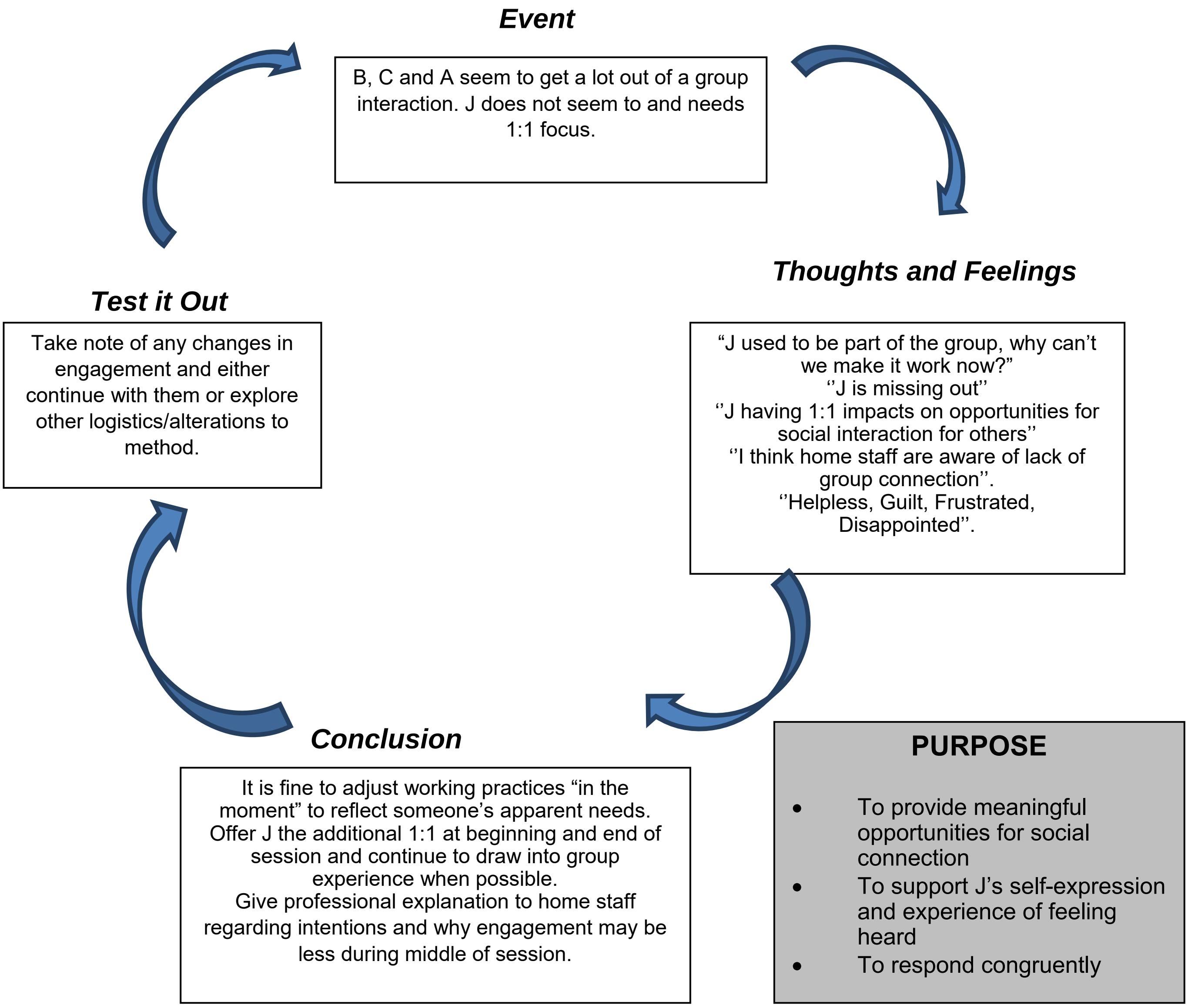
Sometimes there are expressions of discontent, dismay, insecurity, frustration, impatience and any number of other emotions. Practitioners share the thought that perhaps some support staff think they're rubbish, that they are rubbish, the person they're working with just doesn't want them there. Practitioners feel disheartened, sad, or upset that they can't connect as they would like.

So much doubt I hear you say! Well yes, often the nature of these meetings is to work through situations we are finding hard to navigate, so the subject matter will often be the less joyful moments of our work. They are however incredibly useful both as a guard against complacency, and to offer re-motivation and invigoration at times when we feel "stuck in a rut" or that things are not "happening". There are also exceptionally joyful experiences when moments of wonder have occurred within an interaction and are being celebrated.

After discussing the facts, thoughts and feelings and before we move on to what we may, or may not do differently, we focus on our purpose for the time we spend with this person or persons. Our organisational constant is to promote opportunities for people to explore their sociability, so this is without fail one of our main purposes. To ensure people feel valued, building esteem and confidence, supporting people to feel heard, promoting feelings of "good to be with" all, inevitably, are mentioned.

With that in our minds, we move on to considering what we might change, and this is the point at which we often realise that we are, despite our thoughts and feelings, meeting our purposes. The method sometimes needs tweaking, and Us in a Bus practitioners are pretty imaginative and creative people, so always have ideas about how to do this.

The figure below illustrates an example, drawn from a recent unpicking meeting



Event

B, C and A seem to get a lot out of a group interaction. J does not seem to and needs 1:1 focus.

Thoughts and Feelings

"J used to be part of the group, why can't we make it work now?"
''J is missing out''
''J having 1:1 impacts on opportunities for social interaction for others''
''I think home staff are aware of lack of group connection''.
''Helpless, Guilt, Frustrated, Disappointed''.

Conclusion

It is fine to adjust working practices "in the moment" to reflect someone's apparent needs.
Offer J the additional 1:1 at beginning and end of session and continue to draw into group experience when possible.
Give professional explanation to home staff regarding intentions and why engagement may be less during middle of session.

Test it Out

Take note of any changes in engagement and either continue with them or explore other logistics/alterations to method.

PURPOSE

- To provide meaningful opportunities for social connection
- To support J's self-expression and experience of feeling heard
- To respond congruently

It is incredibly easy for us to turn perhaps small sections of unsatisfying practice into huge chunks of disastrous work, in our heads. This method of deconstructing situations and getting to the most important elements of an interaction, together with the support of a team whose input reflects the value base they share, encourages continuous positive progression in practice. It also, just as importantly, supports us to identify and deal with any “cross-purposes” that might have found their way into our practice. We might be challenged to consider that we are too focused on “impressing” someone, such as other professionals, our working partner or support staff. We may discover we are trying too hard to “teach” or “make someone do something”. Feedback may indicate we are not always “being real”, as our Code of Ethics demands. The gold standard is of course being able to (and remembering to) do all this in our heads as we work, genuinely self-reflecting and making changes as necessary.

Of course, the experiential learning cycle is just as useful when used to examine interactions that are working really well – it helps us to notice exactly why it is positive. Once we have identified what it is we are doing that makes it ‘work’, we are more likely to be able to plan next steps and avoid complacency. We can also apply what is ‘working’ to other situations.

Sharing our practice concerns in this way within the team, and having the openness of culture to both ask for and offer support, is extremely valuable and illustrates a level of professionalism to which we aspire. Demonstrating the commitment to communicate with our colleagues in this way, and promoting congruence with those we provide a service for, is a sure-fire way to ensure they remain at the centre of our practice.

To read more about how we encourage each other to develop our practice and raise our standards, spend 99p and have a look at Chapter 8 of Dr Mark Barber and Graham Firth’s new E-book: Delivering Intensive Interaction Across Settings: Practice, Community and Leadership, Editors BARBER AND FIRTH, Amazon Kindle Edition, 2019.

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All contributions to our journal PMLD Link are welcomed. Share your ideas about future topics for the journal or make suggestions of authors we might approach. If you want to write for us yourself, it’s easier to get your experiences and thoughts into print than you might think. We also welcome shorter items about new resources, books, websites, events, courses or news in general.

PMLD Link readers include family members, carers and professionals working across child and adult services for people with PMLD. To see typical contributions, look at some recent back issues. You can download a free copy of PMLD Link from www.pmldlink.org.uk or sign up as a ‘Guest’ to view back issues of our journal.

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For more information contact Rob Ashdown (rob.ashdown@ntlworld.com).

PMLD LINK
sharing ideas and information

Increasing communication and connection between students with profound and multiple learning disabilities and their mainstream peers

Jenny Buckland

On September 4th 2014 the doors opened on our new special school. Built on the same site as a mainstream primary school, this was the start of an exciting journey towards integration, acceptance and friendships. Our motto being 'Two schools one community'. I work within the special school as the teacher for the students with profound and multiple learning disabilities, a job I have done for 11 years and one I absolutely love.

With a joint entrance and joint staff room we looked forward to relationships developing between the two schools. We wanted to make sure that these relationships were genuine, not forced or tokenistic so we planned activities that would facilitate the natural evolution of relationships between the staff and students of the mainstream and the special school.

Our first joint activity was a shared Christmas art project which has continued each year since. This project has developed from the children working quite separately or the mainstream children 'doing it' for the special school children. The mainstream pupils now work happily alongside our pupils, assisting where needed, but more importantly encouraging them to do things independently, giving choices and interacting with each other during the session. The natural and comfortable interactions between the children have been commented upon by the art specialists who come in from outside the school to facilitate these sessions.

With a shared lunch hall, each class has a designated table, but the mainstream pupils are allowed to choose to sit with the special school pupils if they wish. Initially just a few pupils from the mainstream school chose to sit with our pupils, but over the years the number of children who choose to mix has increased. Some of the special school pupils need a little more privacy to eat their dinner or need a less distracting environment which we are able to provide in our teaching kitchen. These children are often joined by friends from the mainstream school; after they have finished their own lunch, popping by simply to say hello.

The no pressure environment provided by mingling in the lunch hall has enabled pupils from the mainstream school to ask frank questions about their special school peers which we willingly answer. One such conversation with a girl from year one led to us beginning to invite pupils from the mainstream class to come and join us in my classroom. Every Friday a few children from the mainstream setting spent lunchtime with us, initially playing alongside my pupils in the soft play area and in the sensory room. It progressed to them taking part in parachute games to sensory stories where they were in control of the props. Over the years they have learnt how the children communicate as well as understanding why the children behave in certain ways and how they can help them to interact. One of the mainstream girls identifies one of the girls in my class as her best friend, a very high accolade indeed when you are 6 years old.

During the last week of our third year as a shared site, I was approached by a 4-year-old boy from the Reception class asking if he could ‘come and play.’ I said to see me in September. The first day back he was there at lunchtime. I had a change of classroom and mix of children which made it easier for me to have children spend time with us at lunchtimes. We decided that four days a week, children could come and play.

There are great benefits on both sides. Our pupils have shown tremendous developments in their communication and interaction skills. One child in my class spent a lot of the previous year napping during the day. Since moving classrooms and having regular sessions with her mainstream peers her attention and engagement has greatly improved. She becomes alert as soon as she hears the other children playing near to her.

During the Summer the gate to our class balcony was left open during play sessions. The reception and year one children had free flow joining us to push our children on the swing or swing together, share in water play and exploring our sensory boxes, sharing the objects with their friends from both schools. The photos from these times show faces alight with joy on all sides.

Over the past year pupils from the mainstream school have joined us for different activities. A term of music, weekly dance sessions and art activities. All of these activities enable them to see what our children can do. They do not do things for the children, they support them! The class team give them pointers e.g. ’support their elbow’ and are always on hand to ensure everyone is safe. The mainstream children have got to know what the special school children can do and how to support them to do more. The children are starting to sign and acknowledge our pupils’ communication even taking part in intensive interaction and mirroring. The most successful integration has come from the children themselves.

The response from the pupils’ parents has been extremely positive on all sides and the mainstream children’s parents often remark on how much their children talk about the special school children at home, extending their awareness and understanding of our children to their wider families. One parent summed this up:

> “I think the integration is great. The children learn about inclusion and they lose the fear of the unknown. It teaches them many ways to communicate and how to adapt their games to suit all abilities. My daughter has developed patience,

> kindness and learnt the joy of bringing fun to others – thank you"

What is really great is that these children are meeting our pupils out in the community and running up to speak to them and introduce themselves to their families. They will grow up with an understanding and acceptance of our learners and hopefully of anyone who is different from them.

Here is what some of the parents of the special school pupils said recently:

> "In the summer we were queuing for an attraction with my son and the girl in-front turned, looked at us and then said hello to my son by name. It made my day, to know that my son is accepted by the children."

> "I never expected my daughter to have real mainstream friends but their relationship is two-way, they swopped Christmas presents this year and we've met her family."

> "My son is an only child and his cousins are grown up so school is the only time he really spends with children that do not have difficulties. Their play and tasks and actions are so natural and they do not have to put as much thought into performing tasks. He can watch the children and have help to do activities and see how children react to things".

The last three years have been a wonderful journey towards improving communication and connection between the two school communities. I now have a time table on my classroom door which the mainstream children can use to sign up to visit us. Even with the timetable I still often have a queue of children by my door wanting to join us. This term they are able to choose which activity they want to join us for and we rotate this so our children can experience different activities with different friends each week.

The journey hasn't stopped yet; I look forward to the events to come as we continue to be 'Two Schools One Community'.

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Is a Peer an effective communication partner?

Cherycce Connelly

Providing opportunities for learners to create bonds and friendships with their peers, I feel, is as equally important as creating bonds with ourselves, as practitioners. After all, it is likely that many of our individuals will progress throughout their school careers with the same peer group perhaps even attending outside agency and community provisions together. Yet sadly it appears, certainly throughout literature, that peer friendships and interactions between individuals with PMLD may not be considered as valuable as their relationships and encounters with adults.

I am a learning and care assistant in a specialist school in Scotland, supporting a group of learners with PMLD, aged between 5 and 11. In my classroom, learners are encouraged to be aware of their peers, to hold hands when in close proximity, to experience turn-taking and to 'shout-out' and vocalise with their friends. As a University of Birmingham student on the Severe, Profound and Multiple Learning Difficulties course, I wanted to explore peer interaction further and I began questioning if there would be differences in how individuals interact together with no adult intervention, would these interactions be longer or shorter, and how does learner engagement differ between adult interactions and peer interactions? This led me to my research aim; is a peer an effective communication partner?

Peer Interaction

Despite advancing popularity in PMLD literature, particularly in communication and education, I am surprised to find peer interaction such an under-researched area. However, available research shows that individuals do not the lack the ability, nor the desire, to interact with their peers. Ware (1994, cited in Lacey and Ouvry, 1998) concluded that when experiencing peer interactions, individuals engaged in exploratory behaviours such as touching and vocalising together. In a study which sought to investigate playfulness among children with PMLD, Watson (2014) found that peer interactions among participants were responsible for 22 occurrences of arousal and excitement.

Evident from the literature was that individuals instead lacked both the opportunity to experience peer interaction and understanding from practitioners. Simmons and Watson (2014) suggest equipment causes physical limitations preventing an individual's access to his/her peers. They also acknowledge the teaching methods of education staff, for example one-to-one target focused working, as a reason why individuals do not seek interactions with their peers, but rather interactions from adults. Ouvry (1998) advocates that the complex means of communication adopted by those with PMLD, combined with the difficulties they experience in articulating emotions and desires may allow practitioners to incorrectly interpret their attempts to seek peer interactions, or they may not recognize these desires exist at all.

Communication Partner

Hewett et al. (2011) describe a communication partner as being reactive upon an individual's communicative actions, altering their own behaviours to become a valuable contributor who enhances the social activity. Although widely researched, and a highly-regarded tool in the education of learners with PMLD, I feel the literature concerning communication partners to be quite narrow with many sources only considering adults for this position. Whilst I agree that communication partners are an important instrument in allowing an individual to progress through meaningful social and communicative milestones, I would argue that a peer-communication partner may have equal success at engaging an individual at the very earliest of development, encouraging the beginnings of social and communicative skills. Ware (2003) expresses that it is "crucial" (p.79) that practitioners observe interactions between individuals, with Coupe O'Kane and Goldbart (2016) agreeing that individuals should experience diverse communication partners, situations and environments.

Understandably, a peer communication partner would not engage in reflective activity as described above. However, peer interactions can mirror an Intensive Interaction experience, following many similar principles; valuable one-to-one time, shared enjoyment and tasklessness. Hewett et al. (2011) describe an interaction as an event where an individual can experience a social world, allowing them to become of aware of the faces, voices, emotions of others and share their personal space. A peer-communication partner can provide opportunity for such experiences. After observing that her learners appeared not to take notice of each other in group sessions, Stothhard (1998) found small successes when she encouraged individuals to respond and interact together in pairs, however she did not elaborate on this further. Firth and Rapley (1990) suggest that individuals can build a relationship exchanging in non-verbal behaviours and elements of choice, intimacy, joint attention and persistence may all be present.

Also expressed within Intensive Interaction literature is the importance of sharing control during interactions, with Ware (2003) indicating that peer-communication partners allow interactions to be equal. However, it is well understood that individual's require time to process and respond (Lacey and Ouvry, 1998; Ware, 2003), and Ouvry (1998) warns when they do react it may no longer be recognized as a response. Therefore, interactions between peers may not always be equal, if one party has a stronger reaction time, they may begin to dominate the conversation with their own self-absorbing behaviours.

Method

Hosting interactive sessions with a learner was the most obvious method to conduct this study. However, ensuring that I collected the most pertinent results required some thought as there was many aspects of peer interaction which are of interest, and in need of research. I decided to focus on collecting data which answered the following questions:

- How does learner engagement differ between peer-peer interactions, compared to interactions with adults?
- Are there differences in how long an interaction between peers lasts, compared to learner-adult interactions?

To answer this question, I turned my attention to Mia; a learner who dis-engages from the world around her but enjoys experiencing Intensive Interaction. I took part in 3 interactive sessions with Mia before introducing Annie, a peer with similar likes, interests and skills, for 3 interactive sessions whilst I closely observed. I then compared observations between both partners. Each session took place on a resonance board with consistent play stimuli to encourage feelings of playfulness. When collecting data, I focused on Mia's engagement, using the Engagement Profile and Scale (Carpenter et al., 2015) within each session and the length of time which she sustained engagement.

I chose Mia as my focus child due to her low-levels of engagement and participation during classroom activities as, if nothing else, it offered an opportunity for us to spend quality time with an element of tasklessness. Coupling Annie with Mia to be her communication partner was not a difficult decision; they share similar communicative skills promoting equal partnership during the interaction. I also wanted Mia to be paired with a peer who had the ability to sit-up, reach and explore independently to limit adult intervention during their sessions.

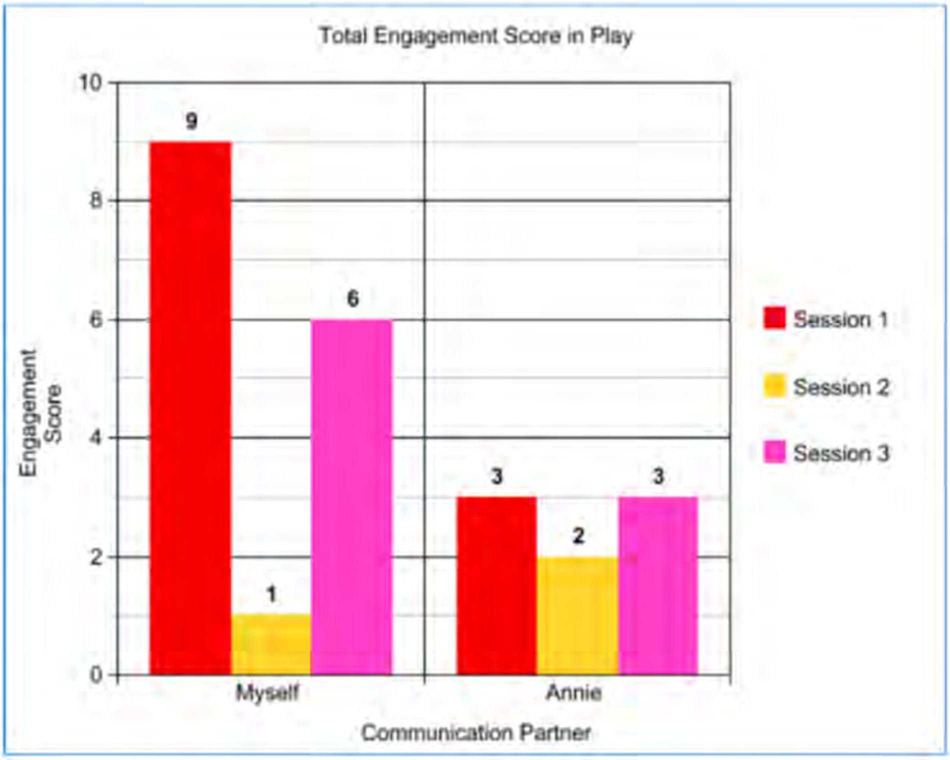
I wanted the interactive sessions to welcome various emotions, behaviours and outcomes so I set-up an area of the classroom with a resonance board and consistent play objects; feather-boas, beads and Christmas baubles. There was an element of curiosity to establish whether Mia would demonstrate a higher interest for play objects when in the presence of a peer, as perhaps their actions with it would be more natural and effortless which Mia can relate to. Adults often act driven by a hope to achieve an outcome, e.g. tickling and encouraging the individual to request more and anticipate. I also felt a communication partner is not just a person whom the individual has linguistic exchanges with, but also someone who enhances learning. For these reasons, I included observations where engagement/interest in play objects was evident.

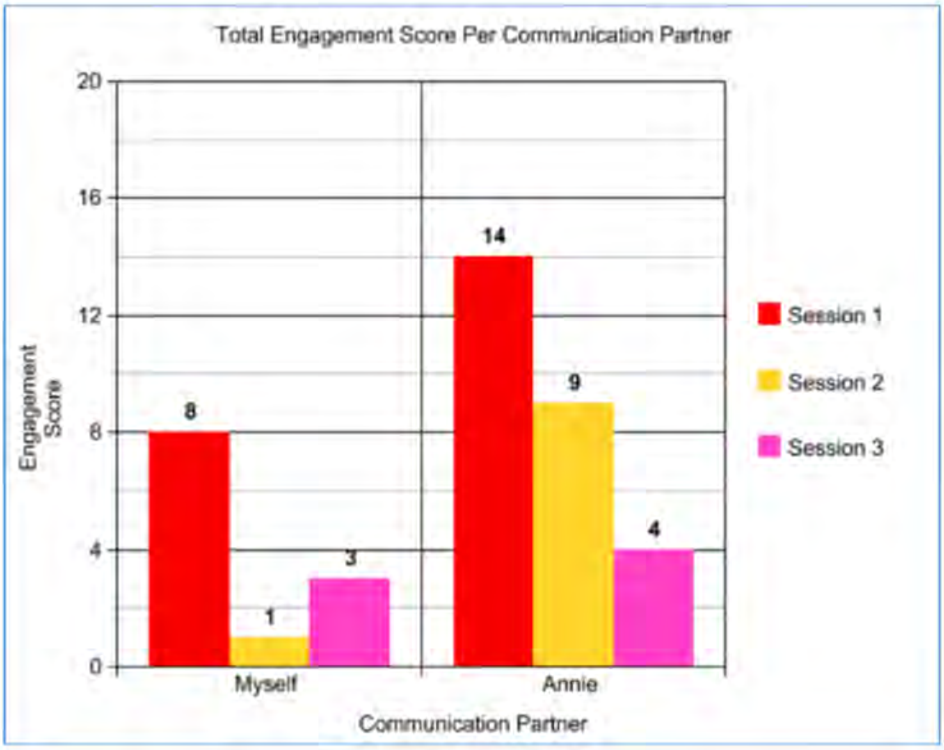
Results: How does learner engagement differ between peer-peer interactions, compared to interactions with adults?

The graphs below summarise Mia's observed engagement during each interactive session with both communication partners.

Figures 1 & 2. Mia's Observed Engagement with Play Objects & Communication Partner are on the next page.

The results show unarguably more success in Mia's engagement during interactive exchanges with Annie. This success which Annie found as Mia's communication partner could be due to the intrinsic nature of their interactions; both girls were able to communicate in a language natural and meaningful to them. It was clear in the observations that Mia was particularly responsive to Annie's touch, perhaps this was because Annie had a more spontaneous touch, exploring parts of the body which don't often experience nurturing or playful contact; shoulders, backs of the arms, head etc. During their first session together Mia displayed persistent behaviours, which have only been seen briefly in the past, when attempting to attract Annie's attention by rolling in close to her and vocalising with varying tones. Annie became engrossed in exploring the feather boas but responded to Mia's persistence by vocalising and turning her body to Mia. These findings are similar to those of Ware (1994).





Figures 1 & 2. Mia's Observed Engagement with Play Objects & Communication Partner

Results; Are there differences in how long an interaction between peers lasts, compared to learner-adult interactions?

The line graph below shows the recorded length of time each session lasted. I felt it was important to allow each interaction to come to a natural end and therefore sessions were terminated by Mia. However, in session 2 with Annie interactions between both girls came to an end but they were both content with occupying a shared space. Session 2 with myself is recorded at '0' because although Mia showed some slight awareness of my presence, she did not seem willing to participate in an interaction and therefore rejected this session.

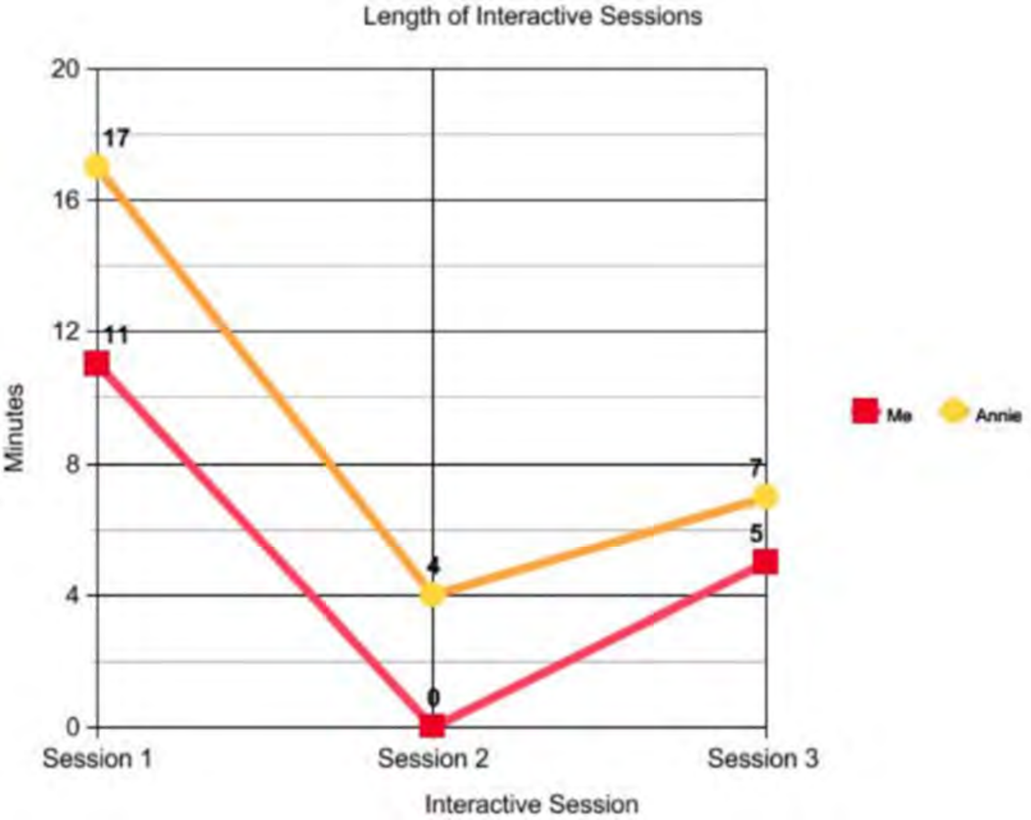


Figure 3. Length of Time per Interactive Session

The sessions which saw Annie as the communication partner appear to have been the longest. I felt this is also due to the more intrinsic atmosphere, as explained above.

During our interactions, Mia initiated an interest mostly in play objects rather than myself, which required her to expel more energy during our interactions, as the game-like routines we engaged in required her to maintain awareness, visually track and share a joint attention. In contrast, during interactions with Annie other senses such as touch and aural, were dominant and although both girls were aware of each other eye contact was fleeting, this allowed for a more relaxed atmosphere throughout their interactions. Secondly, once Mia found herself in a comfortable position she was contented lying close to Annie and her movements became less frequent. However, with myself Mia moved her body closer, but her limbs continued lift up and fall back onto the board.

So, is a peer an effective communication partner?

Given the complexity of everything this question involves, this study alone could not provide an accurate answer. Such a question requires broader enquiries; more studies which include individuals with various communicative abilities and also specific studies which investigate differences in how peers with PMLD communicate. Then an informed answer can be provided. Comparing myself and Annie as communication partners was only a beginning step into this interesting, yet neglected, field of research. However, I feel this study shows that both adult and peer communications partners have their benefits, and for Mia a peer-communication partner has proved effective.

I feel the advice of Ouvry (1998) may be an appropriate finishing point as it may encourage us as practitioners to place more value in peer interactions. Providing opportunities for peer interaction will simultaneously provide individuals with opportunities to create friendships, as the practitioner it is our responsibility to respect and support this social need. An individual's relationships may only consist of immediate family, and practitioners who are paid to be involved. And if research has taught us anything, it's that anything is possible among this unique group of individuals.

Contact Details

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If you have any queries about subscriptions or accessing the website, please do not hesitate to contact Rob Ashdown, PMLD Link Treasurer (email: rob.ashdown@ntlworld.com).

The Village School and Charterhouse PMLD Expressive Arts Project

Emily Grassi, Cynthia Adobea-Aidoo, Jenny Cooper,
Luke Crookes and Marc Woodhead

Between September 2017 and July 2018 the Village School in Brent and Charterhouse Museum in Central London collaborated on a year-long expressive arts project. The project made available multi-sensory experiences and allowed students to experience expressive arts activities within a new environment. Leaders of the project talk about it and what the students gained.

Cynthia Adobea-Aidoo, Charterhouse learning programme manager

The project was planned to give children with SEND (special educational needs and disabilities) and complex needs the opportunity to access high quality and enriching museum experiences centred on British history. The project sought to include multi-sensory experiences of an ancient building, access to specialist knowledge and expertise, and an innovative way of exploring the expressive arts curriculum within a new environment. Working with artist-educator Marc Woodhead and music and cross-arts educator Luke Crookes, the project used art to contribute to pupil progress and achievement across the arts domains using Arts Award Discover as the focus and assessment tool. The whole class of children with PMLD successfully received an Arts Award Discover at project's end.

The Charterhouse is a former Carthusian monastery in London, located between Barbican and Smithfield Market. Since the dissolution of the monasteries in the 16th century the site has served as a private mansion, a boys' school and an almshouse, which it remains to this day. In January 2016 we opened our doors to the public with a new museum, learning centre, public square and café. As part of our learning offer we offer a free SEND programme sponsored by the Worshipful Company of Haberdashers. The programme aims to bring our medieval and Tudor history to life through tailored on and off-site sensory experience that make use of art, music, costume and replica objects.

In September 2016 I connected with Jenny Cooper from The Village School, a SEND school in Brent. Jenny proposed a year-long project modelled on a similar project she had worked on with the National Gallery. Personally, I was keen to take part in the project to gain expertise working with a SEND school to develop future SEND programmes, create a project model that could be followed with other groups and develop resource boxes. In addition, I was keen to demonstrate how heritage buildings can be accessible to vulnerable groups with a range of complex needs.

The project comprised a planning meeting, followed by an initial visit to the Village School to see how sessions were structured as well as an opportunity to meet pupils. The project was then delivered between October 2017 and June 2018 and comprised three in-school music and art sessions and two class visits to the Charterhouse, including a final celebration event.

Emily Grassi, Charterhouse learning volunteer

A framework for the collaboration between PMLD audiences and museum heritage sites.

Prior to my involvement in this project I had no experience working with people with PMLD. At the time of Jenny's first visit to the Charterhouse I was interning there as an MA student (MA Museum and Galleries in Education, UCL Institute of Education) and fascinated by her vision of how multi-sensory experiences could be developed for students inside this historic building. As such, I ended up focusing my MA dissertation on this topic.

The first question I was interested in answering was: what are museums and heritage sites – particularly in London – currently offering PMLD audiences? To my surprise, I couldn't find many resources or specialised publications mentioning museums and historic buildings. Thus, an important part of my inquiry consisted of interviewing professionals working with this audience around London (including the British Museum, National Gallery, Museum of London, Geffrye Museum, Westminster Abbey and Historic Royal Palaces). These interviews provided a framework within which to develop the Charterhouse project and to analyse the relationship between PMLD audiences and cultural institutions in general. For the purpose of this article I will summarise the outcome of my research centred on two key questions below:

What can cultural institutions offer visitors with PMLD?

Museums and heritage sites can provide facilitated multi-sensory sessions tailored to the needs of their learners using objects, space, movement, sound and smell to communicate a variety of stories. Such sessions can be delivered as a one-off or become longer projects and inspire a year-long series of classroom lessons. Together with learning, engagement and fun, one of the most important services that these institutions can offer is inclusivity and visibility within popular public spaces, alongside the opportunity to use public resources that should be accessible every member of the community.

What are the challenges of this collaboration?

It is undeniable that this type of collaboration presents challenges for visitors with PMLD and their carers when it comes to health and safety, accessibility and availability of services such as adult changing facilities. There is not an easy and one size fits all answer to these needs. It might be helpful to know that often museums and heritage sites can use or apply for ad hoc funding that can finance, for example, transport, specialised resources and expert facilitators. Readers may ask themselves whether they can be certain that visiting a museum or heritage site will provide a positive experience to their students and I will leave my co-authors to answer this question more extensively. However, I would like to end by saying that clear communication is crucial to ensure that all needs can be welcomed appropriately. When adhered to, my experience is that the results can be exceptionally rewarding and positive for all.

Jenny Cooper, assistant head at The Village School

Our experience at The Charterhouse - On behalf of Class 9 at the Village School

What an amazing year we had! None of us had been inside a very old building before; our school is very new! The Charterhouse project took us on a journey through a medieval monastery, to a Tudor dance, a jousting tournament and a little contemplation in the chapel.

This project included all of us in dance, music, art, dressing up, seeing, smelling, feeling and lots of fun. We processed through the cloisters dressed in made-to-measure monks' robes and we recorded our own plainsong-style chants with our voices which were played back to us during the procession. We learnt a Tudor dance and performed it in the Great Hall, dressed up in rich and poor people's Tudor dress- we looked funny in the mirrors! We made banners and pennants in Art which decorated our wheelchairs and we made a grand entrance into the hall before the fun, fast jousting began! We met some of the brothers. They came and talked to us outside in the courtyard while we were having lunch and made us feel welcome at their home. One of them played the organ for us in the chapel which was exciting because we had been listening to recorded organ music in school, but it wasn't as good as the real thing.
We made so many friends in this project- Cynthia and Emily visited us at school to teach us the history through smells, seeing, touching and movement. Later, Luke came in with his bassoon and made up songs about us using the sounds we had composed ourselves. He got to know all our personalities and these fed into the songs! We loved the bassoon and it sounded even better when he played it to us in the cloister at the Charterhouse itself. Marc helped us make pennants and a banner symbolizing each one of us and these were the starting point for our entry to the Tudor Hall and the jousting game. Every week in school we listened to The Charterhouse project music and did the art and practiced things like the procession and the dance. One day we processed all around our big school like monks and the staff that were with us chanted all the way round. Everyone we passed on the corridors and in reception looked at us and wondered what we were doing. EVERYBODY noticed we were doing this project- we became famous in our school!

At the end of our project, we saw a film of the whole year that was made. This film covered everything we needed to get an Arts Award Discover and we are all going to get our certificates presented this term. We are very proud of our awards and we absolutely loved our time with The Charterhouse. This is a project everyone should do!

WHAT WE LEARNT:

- How an old building feels, looks and smells and how much fun it can be

WHAT OUR TEACHERS LEARNT:

- How to make an old building accessible to us so that our complex needs and disabilities do not prevent us having that experience

Marc Woodhead, visual artist educator, and Luke Crookes, musician and cross-arts workshop leader

To imagine the perception of a pupil with PMLD moving through the different historical rooms of the Charterhouse for the first time, seemed such a privilege to me. What would they see? What would they feel? What would they experience? What would it mean to them? All these questions were at the forefront of my mind when planning and facilitating the project for PMLD pupils and staff from The Village School.

To comprehend an encounter between a PMLD student and the wondrous spaces at Charterhouse is to imagine another view of the building, a different perspective of the world, the event itself becomes full of potential and mystery. And to begin to interpret the responses of the students requires working closely with the experts, the wonderful staff at The Village School like Dierdre and Jenny.

I felt incredibly lucky to be able to collaborate with Luke Crookes on this project as my primary expertise is interpreting the visual world, a love of painting, of history and ideas. Luke responds to the pupils live in the space, playing bassoon, also recording and sampling the voices and noises of the students, creating layers of music and soundscapes, that evoke and reflect both, the student's personalities, and their responses to the spaces of the museum.

Luke and I became fascinated by the different layers of history at Charterhouse. We were amazed by the atmosphere of each room and the surfaces of the walls - the stones, bricks, wooden panels and columns, the wallpaper, tapestries, light, stained glass and icons, and how all these elements change the feeling and temperature of each room.

We focused on two historic rooms in Charterhouse, the Norfolk Cloister and Great Chamber. As the children and staff arrived at the Charterhouse we sang Tudor style name songs before processing into the building to the sound of Tudor style bassoon playing.

In the Norfolk Cloister, we evoked the sombre and enchanting mood of the Carthusian monastery. We dressed each student in white Carthusian hooded robes and held palm leaves created at the School whilst Luke played drones and we chanted vocal sounds. We sang each of the children's names and enjoyed a bassoon improvisation reflecting each child's mood. Luke echoed the students' vocal sounds into the space by sampling their voices along with the sound of monastic bells as we processed through the cloister. It was magical.

In the Great Chamber we decorated Tudor pennant flags using hand over hand printing of cut out heraldic shapes. We used a large flag Dierdre's students painted in school to welcome each student in to this grand space whilst singing a personalised fanfare of each child's special qualities. Staff interacted with the children through percussion playing to Tudor music and bassoon improvisation as we sang "We're all going to the Charterhouse, to the Charterhouse we will go". The children performed a Tudor dance and we finished with a joyful Tudor joust holding pennant flags and charging across the chamber to music and cheers.

A truly collaborative project. To witness the students of The Village School encountering and responding to Charterhouse was such a gift, because, to imagine the perception of their experience offered a completely different perspective, an alternative view of heritage buildings and of reality.

Online information

Arts Awards - www.artsaward.org.uk
The Village School - www.tvs.brent.sch.uk
Charterhouse - www.thecharterhouse.org

There is a link to the project video - http://www.tvs.brent.sch.uk/website/charterhouse_project/370081

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IN THE NEXT ISSUE

Summer Vol. 31 No. 2 Issue 93

Values and Ethics

Do you have any stories to share?

If so, contact the Guest Editors:

Martin Goodwin, Rachel Parry Hughes and Rob Ashdown
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Copy date
10th June 2019

More information on page 49

PMLD LINK
sharing ideas and information

Profile bags promoting inclusive conversations and stories

Louise Molineux

Communication plays a central role throughout our Staffordshire County Wide Complex Needs Service for adults. Inclusive communication is integral, as we aim to provide and develop person centred approaches to service provision.

As well as one page profiles, communication passports, intensive and responsive interaction and activities which promote sensory engagement there is always a strong focus on developing new and creative ways to support communication.

In 2018, Cannock Complex Needs Service developed Profile Bags for each citizen; the bags proved to be a portable, dynamic effective person centred communication tool. Citizens were able to literally pull their stories and conversations out of their profile bags, as we pull ours from our metaphorical story bags.

Their personal stories were developed by involving families and link workers. Favourite daily routines, holiday stories and weekend activities were revealed. It was then our task to bring them to life. The bags came together quickly, with link workers creating the sensory stories and story massages, co working with the families and gathering the required and favoured sensory experiences and personal items.

The actual bags were made from striped fabric found in a cupboard. Each citizen's name was embroidered and then sewn on to the bags. Alternatively, the bags could be personalised. Favourite colours or sensory attachments and badges could be incorporated on to the bag.

Contents of a Profile Bag

In brief a profile bag contains the following personalised and inclusive conversations.

- A unique personalised story massage about the person.
- A personalised sensory story about them, including the required sensory experiences.
- A puppet likeness of the person (optional)
- Favourite sensory items and experiences, CD's, aromas, scarves and so on.

On the 13th of April 2018 we hosted the Profile Bag Launch at Cannock Complex Needs Service. Carers and families were invited to attend and the contents of the bags were viewed for the first time. It was great to see the smiles and hear the laughter as favourite sensory experiences were explored, stories shared and the puppets used instinctively to engage with their children or siblings. There were so many special and inclusive moments, with our citizens clearly at the heart of the interactions and conversations.

The feedback from carers was positive and one parent asked if their son could take the bag to a caravan club to share with his friends. The gentleman and his parents have been part of the club for years and they meet up most weekends. It's very sociable, they access different caravan sites and enjoy social events when there, discos, karaoke and so on. When he took his profile bag to one of their meetings, their friends sat with him and looked through the bag with him, interacting with him and having fun with the contents together.

During the following two coffee mornings we noticed that carers had picked up the profile bags and were looking through them with their sons and daughters, this reflected the value and accessibility of the bags both practically and emotionally.

Recently, a gentleman took his profile bag in to a review meeting; it was used to great effect. The gentleman was able to share his story about how he enjoys going out in Dad's campervan to buy a newspaper. He then showed us his laminated Coca Cola logo and Top Gear magazine. For once, we were all listening to the gentleman as he communicated to us about the things that are of importance to him. The parents appeared delighted. From our perspective it was an enlightening experience to observe how the profile bag changed the dynamic of a review by enabling a nonverbal gentleman to not only contribute but to lead the conversation.

As a 1:1 activity the profile bags really work. Our citizens respond positively (and why wouldn't they?) as their favourite items, experiences and stories offer that quality inclusive time. Overall, we have noted increased levels of recognition, anticipation, response and engagement when sharing their stories with them.

One gentleman is able to advocate what he wants by pointing; he now regularly requests his profile bag. To support with this the bags are positioned so that they are in view and accessible, giving him the opportunity to take control and decide for himself as to when he would like to look through and share the contents of his bag.

A further use relates to how they enable our citizens to connect with their peer group. Social gain can be facilitated when sharing their stories with each other. Opportunities to access inclusive social activities are important as they promote a sense of belonging and self-esteem. The puppets come in to their own during this activity as they become a visual indicator in terms of whose story is being told.

In conclusion, as a communication tool we have experienced how versatile and valuable these person-centred profile bags are, supporting meaningful and inclusive time spent one on one, or in reviews and meetings and as a social activity sharing their stories with others.

As the bags are portable there is scope for them to be used in settings outside of the Day Service, including home, or whilst in respite care. This is something to be explored further. The bags are dynamic and will be updated and added to over time, just as our own stories and experiences change and develop so will theirs.

Contact Details

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Useful Websites

https://www.storymassage.co.uk .
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See you online

Eye gaze

Lucy Williams

Communication with each other is something many of us take for granted. People with disabilities can face many barriers to effective communication and those with PMLD even more so.

My son, Thomas, was diagnosed with severe brain conditions (Polymicrogyria and Microcephaly) soon after his birth in 2011. We were told to expect he was "highly likely to have significant problems". I'm not sure when I really knew I'd never hear him speak, but time went on, and we didn't get the start of the babbling we'd experienced with our daughter, and he was significantly delayed in all aspects so we came to accept he was profoundly disabled.

Thomas also has limited motor skills and nothing like fine motor skills, so signing or pointing aren't options either. At 6 months of age he was also diagnosed with Cerebral (or Cortical) Visual Impairment (known as CVI). That means that his brain cannot adequately process what his eyes see. We were told he was practically blind and would always be so. He was given a certificate of sight impairment.

For years then Thomas' communication has been pretty much limited to crying, laughing (which he does a lot of) and smiling (which he does even more of). He vocalises in other ways and we, as his parents, and close family and carers are also familiar with them and which are happy and unhappy sounds. Thomas has never been able to indicate even the simplest of choices. He's just had things done to him.

In November 2014, when Thomas was 3 and a half, I visited the Kidz Up North exhibition. When I had a glance around the Smartbox stand I didn't see there'd be anything suitable for Thomas. They provide assistive technology and I saw things like tablets, where the user would touch the screen to indicate choices, absolutely way above Thomas' capability, so I was going to move on. However, someone talked to me and I told them about Thomas. I was surprised, and slightly sceptical when they told me they had equipment that may be suitable for him given his level of understanding and his visual impairment. I agreed to a trial of their eye gaze equipment. It was worth a try, I reasoned.

Not only did Smartbox determine that it was worth pursuing a trial, but also the relevant NHS departments came on board. The Speech and Language Therapist got the Assistive Technology Department involved and they loaned Thomas other equipment such as head switches. I often wonder if they'd have become involved had it not been for the Smartbox involvement and eye gaze assessment. Thomas had a loan of the eye gaze equipment for 2 weeks in 2016, when he was 5, then a further 2 weeks a few months later when a new camera became available. What he achieved amazed me. Yes, to anyone else it was minor, but for Thomas it was huge. He seemed to grasp the cause and effect and he was able to focus and activate things on the screen. One of the most advanced activities he did was to fire custard pies at individual faces on the screen. A circle with a face in it would appear and when he looked at it a custard pie would splat on it. A new face would then appear elsewhere, and so on. Never in my wildest dreams did I imagine Thomas would be capable of that but he had a few goes where he went from one face to the other with little delay, showing his understanding and ability.

Sadly, the NHS ultimately decided they wouldn't purchase Thomas his own eye gaze equipment. They decided he couldn't use it to effectively communicate so they wouldn't fund it. I was disappointed but not surprised given the financial constraints the NHS is under. The Speech and Language Therapist recommend use of an E-Tran frame to see if Thomas could develop and show an understanding of eye pointing as a means of communication. Thomas' school had seen the benefits of the eye gaze for him and other children so they purchased the equipment so for the last two years Thomas has been working with the E-Tran frame and a little with eye gaze. He has developed well, although I find the E-Tran frame frustrating, as I'm not certain I'm interpreting correctly whether Thomas is looking at the picture or not, and I don't want him frustrated that I don't respond how the staff at school do.

I had been aware from the outset that The Sequal Trust funded assistive technology for people and may purchase Thomas eye gaze equipment but I didn't apply until earlier this year. To my shame I delayed Thomas getting this equipment. I didn't like to take charitable funds for Thomas to maybe not use the equipment enough or for him to never develop from custard pies. I felt guilty applying but I was finally convinced to try.

Again, I should have had more faith in Thomas. He has had the equipment for three weeks and has already made enormous strides. We had training less than two weeks ago and the trainer downloaded different programmes and set them up for Thomas. Thomas can now indicate if he wants more or to stop and he's been doing so. He can also choose between two of his favourite activities: "Bubbles" or "Tickles". For "Bubbles" I trigger the bubble gun for about 10 seconds then for "Tickles" I tickle his head with the head massager. He soon got the idea from our first attempt. The first day he wanted bubbles first but then he was quite certain he wanted his head massaged over and over again. After a while I tried asking if he wanted more or to stop and he chose more. I couldn't bear to stop so his bath and bedtime got later and later. Finally, I had to sadly take the choice to stop from him. He's gone from strength to strength though and sometimes he is choosing to stop!

When we were first trialling eye gaze equipment in 2016 I read about a boy who got this equipment at 16 years of age (http://www.bbc.co.uk/news/disability-35705489). His family didn't know what he could understand and he had very limited communication. Now he uses eye gaze technology to communicate in sentences. We'll never know if Thomas is capable of communicating to that level, but we're now that step closer. Who knows what he can do!

Contact Details

Lucy Williams is parent of Thomas.

https://ridingonastar201295083.wordpress.com/

Raising the Bar III - Call for Papers

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Using assistive technologies within authentic learning experiences

Leigh Wharton

I work at an outstanding school with many examples of sector-leading practice. The school prides itself on providing very high-quality provision and standards for pupil (and staff) wellbeing. The philosophy is that pupils need to feel safe, secure and in good health before they can attend to high-quality learning. As a result, we work closely with a range of multidisciplinary teams to ensure that the holistic needs of each child are well met.

The curriculum is specifically designed to meet the individual needs of every pupil. We focus heavily on Communication, Digital Competency, Numeracy, Wellbeing, and Thinking Skills. The sole aim is to help children enjoy school and acquire key skills that they will need to become active citizens in today's 21st-century society, regardless of any disability. Our strategic aims are ambitious and are rooted in providing the very best for our pupils. These aims are:

1. Promoting the highest quality individualised teaching and learning.
2. Investing in staff - aiming to put world class people in front of our learners.
3. Unconditional support for parents/families - seeking 24hr curriculum.
4. Celebrating difference within the local, regional, national and international community.
5. Enhancing the physical environment - promoting equality of access.

Within my school, we are proud advocates of the ‘Communication Bill of Rights’ produced by the National Joint Committee for the Communication Needs of Persons with Severe Disabilities (Brady et al., 2016). We ensure that the Bill of Rights is at the heart of our school particularly when our pupils access the local community. We are particularly passionate about rights 11 and 12:

> “11. The right to have access to functioning AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
> 12. The right to access environmental contexts, interactions, and opportunities that promote participation as full communication partners with other people, including peers”

Within my class, Dosbarth Seren Fach (a class for pupils with PMLD), we have focused heavily on using assistive technologies within authentic learning experiences, both in school and out in our community. Rather than being passive participants in their lives we have ensured that, by accessing a range of assistive technologies, the pupil's voices are always heard. This gives the pupils rich and rewarding learning experiences in real-world situations. Examples of this can include: purchasing age appropriate magazines in the local supermarket with BIGmack switches; buying fruit and vegetables with a switch from a local market to take back to school and make into a meal to send home for their families to taste; and pupils having a lead role narrating a primary Christmas concert using eyegaze technology and switches.

Just imagine not being able to access the world around you. Imagine being passive participants in the world and not being able to have your voice heard. Thankfully, there is no danger of that in our school. Through creative use of high tech and low tech assistive technologies, we are overwhelmed by what our pupils achieve. We are inspired by them and driven to open up more experiences.

Obviously, something like this does not come overnight. It takes several months and years of working on switch skills, switch placement, eye gaze skills, eyegaze placement, E-Tran board skills, and finding out what positive reinforcement each child needs. I have been through several packs of stickers, chocolate buttons,

magazines, and countless Olly Murs YouTube videos!

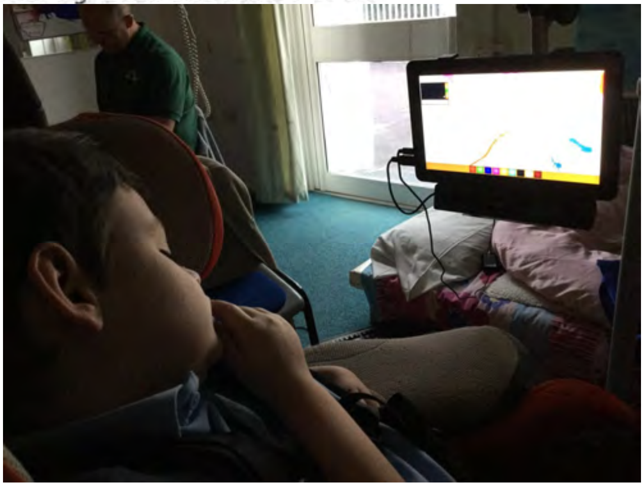
As Mansell (2010, p.19) states "Such technological aids offer the prospect of enabling people to communicate with others and to control aspects of their environment such as where they are." However, I believe it has the potential to do so much more. Indeed, I have seen it with my own eyes. I have seen the power of technology in helping pupils to express their sense of humour, their character, their emotions, their compassion, their fun, their pain and their frustrations with certain lessons/ situations. I've seen the power that technology brings which helps pupils develop friendships and relationships and allows them to control all aspects of their environment. After all…it is their environment!

To achieve fantastic results, you need to take some calculated and safe risks. The kind of risks I am referring to are those that might not work. We've spent hours planning plenty of activities that have not had the desired outcomes. To overcome this, it is vital to have innovative and creative members of staff to take what is learned in the classroom into the wider community. They need to be on board with all aspects of communication. I am very lucky to work with an amazing group of staff who understand communication is a basic human right for the pupils. They are the ones that are able to take what is learnt on a one-to-one basis with me out into the wider communities and to integrate pupils with PMLD into greater roles within the school. They are the ones that champion the pupils, challenge them to communicate in different environments and raise expectations of what pupils can do.

I have found the pupils' confidence has skyrocketed over a short period of time when using assistive technologies within the classroom setting and more recently when out and about in the local environment. Our pupils are now active participants in all aspects of school life. It's helped the pupils to focus on what they can do independently. By using switches and eye gaze, it has raised awareness that not all communication is verbal. It has also helped to destigmatise some of the myths and preconceptions of pupils who have PMLD. The aim of any communication work undertaken is to enable pupils' who have PMLD to shape their own learning, access the curriculum, raise their attainment and interact with others by means of assistive technologies.

Over the last 18 months of working with assistive technology users, I have had several personal highlights within my class:

- A pupil using eye gaze technology to tell staff that her mother was running the Cardiff half marathon. We used a basic yes/no on screen and asked questions regarding what she did at the weekend. As you can imagine we were all in complete shock and pretty stunned. Her mother was asked if it was correct and it was.
- Using switches to choose and purchase items at the local shops. The pupils had great fun although some of the trashy magazines are not quite my taste.
- All the pupils within my class had a starring role in the Primary Christmas concert. Pupils used a mix of switches and eye gaze to narrate the whole of the



concert. One parent commented that it was a very proud and emotional moment seeing her daughter open up the concert. This is one moment in both my career and life which I will never forget. I loved seeing how equal our pupils were on that stage. I loved seeing how the other pupils in the school respected them greatly and it was a fabulous, inclusive experience for all.

- The formation of a professional learning community with other professionals within the South Wales area who have a vested interest in assistive technologies. This has been a good forum to share best practices and develop high quality activities in the face of austerity.

Ultimately taking the principles out of the classroom and into the real world can be a really rewarding and a positive experience for everyone involved. Within my school, there are exciting times ahead for our assistive technology users. We are planning for the successes and championing positive risks. The work that we are doing with assistive technology within the PMLD classes is ongoing to support the ever-changing needs and expectations of our pupils so that they will be able to communicate with anyone that they may encounter in their lives.

In conclusion, we need to challenge the presumed expectations of where and how to use assistive technology. We need to have a high expectation of our pupils and for them to be able to access the world around them using assistive technologies and ultimately raise the bar. We believe passionately in our school's aims and aspirations and we always seek to celebrate ability and not define disability!

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Ysgol Ty Coch website: www.ysgoltycoch.co.uk

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Student voice when supporting adult learners with PMLD

Rachel Gale

Student voice is a term which refers to the way in which students are encouraged to give their opinions on things that are happening in and around the college. It can be in relation to things that they would like to change, or possibly opposing a proposed change. It is also a way in which learners are able to direct their own learning, and to influence and to change their own environment.

Student voice is very empowering for young learners, and has been known to increase levels of engagement, and improve commitment to learning (Mitra, Serrierre and Stoicovy, 2012; Quinn and Owen, 2016).

There are a variety of ways in which learners can be invited to share their views within a college setting, however, in whatever way practitioners decide to approach student voice, Robertson and Taylor (2007) warn against the danger of the term 'voice' implying that the student body only has one voice. The suggestion is that some places may only be listening to the more articulate students, or to those who agree with what the staff want to hear, so they advise educators to think carefully about how students are listened to. In addition to this, many writers in this field (Kubiak, 2017; Mitra, Serrierre and Stoicovy, 2012; Quinn and Owen, 2016; Robinson and Taylor, 2007) are warning about the dangers of tokenism in student voice, and advising that students' opinions are sought in a way that leads to changes which are significant to them, and enhances their learning environment. It is therefore not always easy to make student voice opportunities meaningful for every student within a school or college.

Because students who have PMLD learn in a different way to some of their peers, and as the degree to which these learners can intentionally share their voices is hugely variable (Lawson et al., 2015), good practice regarding student voice might look different with regards to these learners. For students who are communicating at a pre-intentional level in our college, we are heavily reliant upon our experienced staff team to ensure that their voices are heard. As it is widely known in the PMLD community that every tiny behaviour exhibited by these young people can be communication, we have frequent 'student voice' meetings with the staff who are supporting these learners. We have opportunities to discuss the behaviours that a specific individual presents when we believe that they like something, and therefore wish to continue it within their curriculum, and also the behaviours that we believe the individual exhibits when they do not like an activity or experience. The meetings are important because they enable us to get a broad picture of that young person, and how they show their likes and dislikes. It also opens up opportunities for staff to discuss how we can use this information to influence the student's learning process. Within these meetings we are also able to discuss behaviours that the young person may present, that we may have interpreted differently as staff, or behaviours that are so subtle, they may have been missed by some people on the team. Although for some learners we may never be certain that we are interpreting their responses with 100% accuracy, by having these discussions we believe that we are able to be as accurate as we can. It is worth noting here that we follow the advice of Goodwin, Miller and Edwards (2015), who advise that practitioners should not assume that when someone initially pushes something away or does not engage with an activity that they do not want to participate; it could be that they need more time or opportunities to get used to the new stimulus or activity.

Within our college, we support a wide variety of students who have complex needs, and the responses they give are not always easy to interpret. For example, for some students, a smile might not necessarily indicate that they are enjoying something, it could be an indicator of anxiety, and it is important to find a way to distinguish the difference. For these students we are using a much more lengthy process to determine how they are expressing themselves. As atypical communicators, when communicating with someone, it is natural to tend to look mostly to their face for their responses. When supporting pre-intentional communicators, communication partners also try to take in their body language to look for clues for how they are feeling about what is happening. However, when supporting these learners, it is only possible to take in so much information at a time, and one can only realistically focus on one or two small areas of their body – especially when physically supporting that learner with an activity that also requires focus. It is very easy to miss small clues or indicators from these young people about how they are feeling. So we are using videos of these more complex learners in a variety of situations, watching them more than once and recording every response given by every part of the body. This gives us a much broader idea of how the individuals are using their bodies to respond and a clearer idea of which behaviours to look out for when supporting them.

As a college, we are finding that through these methods we are gaining clearer views of how our students communicate, and are therefore able to use this information to establish learner preferences, and adapt the curriculum and teaching approaches to support individual needs. Through these practices, we believe we have found a way to enhance how we listen to the voice of our PMLD learners.

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Play My Way!
Enabling child-centred playful opportunities

Martin Goodwin

The barriers and challenges to enabling child-centred play with children* with PMLD are significant. Without adequate support, play opportunities risk becoming activities that replicate the child's common experience of having limited or possibly no control over their experiences. In consideration that such children experience unresponsive services or hardly any service provision at all, or indeed services that prioritise meeting important medical and care needs rather than the needs and rights of being a child, those with PMLD could easily be described as being play deprived. Consequently, from a social model perspective, children with PMLD are rendered 'dis-abled', through being denied vital experiences of childhood.

Imray and Orr describe a range of difficulties that may challenge the child with PMLD, such as problems with generalisation of schemas, difficulties of working memory, limited spontaneity, and understanding abstract representations and limited experiences of narrative (Imray and Orr, 2015). These difficulties are compounded by communication difficulties and profound cognitive challenges that may mean that intentional communication is at an emergent or pre-intentional stage. Thus, being able to direct or negotiate the play experiences of these children is contingent on workers who can meaningfully elicit their responses and/or patterns of behaviour.

Enabling child-centred play with children with PMLD requires much diligence, active reflection, and sensitive interactions that show value for the child. The play relationship may be therapeutic and developmental in nature, and in practice (due to the extent of the child's impairment and the nature of social restrictions) it aims to be sensitive to the child's needs.

Within specialist and inclusive play provision play opportunities are often sporadically implemented against a play taxonomy (Hughes, 2002), in checklist format. Whilst providing a valuable framework for neuro-typically developing peers, in the case of children with PMLD it is important to promote awareness of playful 'behaviours which are precursors to, or the building blocks of, play' (Goodwin and Edwards, 2009: p.3). Consequently, I encouraged child-centred and child-led experiences that were intended to enable increasingly open-ended, intrinsically motivated play.

Examples of experiences and interactions that allow for a child-centred and child-led approach might include:

- Participation, supported or otherwise, in structured games
- Exploration of materials which may or may not lead to something else, e.g. choosing fabrics for den building, investigating play-dough, messy play, etc.
- Considering options and making choices and communicating those choices in their own style, e.g. eye pointing, reaching, vocalisation, etc.
- Interacting with the child by entering into their world through joining and mirroring (Nind and Hewett, 2001)
- Differentiation of approach to enable participation of youngsters and play to be meaningful and at a developmentally appropriate level
- Gross and/or fine motor movements or stillness in response to stimuli
- Enjoyment of group activities, e.g. singing, lycra, bowling, simple dice with music games
- Experiencing and responding to a performance, e.g. a dramatic sensory story
- Spontaneous shared experiences with an adult, e.g. peek-a-boo, other simple games and shared stimuli
- Encounters with peers, e.g. when lying on the floor, discovering the other person, perhaps making eye contact or vocalising

(Goodwin and Edwards, 2009: p.3).

Whilst a re-envisaged taxonomy of play may help play workers to understand what play may look like for children with PMLD, it does not help a play worker to consider and reflect upon, how a child might like to play, or how to respond to the child in a contingent way.

Children with PMLD will need a solid foundation of elementary experiences from which they can begin to understand themselves, others and the world around them. However, experiences that they are exposed to should always centre on the child, by sensitively encouraging and building on responses in an organic and not overly prescribed way. Play routines should offer the maximum amount of flexibility so that children with PMLD through increasingly shared communication and sensitive interaction can shape their own play experiences. Play workers need to sensitively reflect on their interactions and observations of the child, and structure play experiences that foster engagement.

Play My Way

The Play My Way creative play opportunities map was developed in 2009, as a tool to support the development of child-centred experiences through utilising a listening and responding approach (Goodwin and Edwards: 2009; Goodwin, 2013). The Play My Way map is based on concepts of person-centred thinking and planning. The approach has been used to support play workers and other practitioners who play, to observe, reflect and plan, and it offers a simple framework that focuses on supporting child-centred playful experiences.

Of late, motivation has been intensively argued as a key factor in supporting children's engagement (Carpenter, 2011), and engagement profiling has supported increasingly active participation of children with PMLD within education environments. The Play My Way map additionally recognises that motivation is an essential ingredient towards engaging children, and it attempts to provide a simple format to capture their engagement, so that play can become increasingly responsive.

The Play My Way approach has mainly been utilised with children with PMLD who are demonstrating that they are at a sensory motor level, where properties of objects are explored by the person using their bodies to explore stimuli such as ‘touching’ or ‘mouthing’. It has also been utilised with children who demonstrate that they are at a relational play level, where properties of objects are explored by the person, such as how objects can be used together or what you can do with objects by ‘building, grouping them or associating them’ in various ways (Sherrat and Peter, 2002: p.46). The Play My Way map has also supported practitioners who are following principles of intensive interaction, by enabling them to reflect on how to centre their interactions to the needs and perceived wishes of the child and action plan the next steps.

The tool uses four simple questions that can be revisited, amended and added to as observations and interpretations of the child with PMLD change. I would now like to discuss the use of the tool by describing how it is best used, and by offering a practical example that shows how it supported practitioners to develop child-centred play experiences for a child with PMLD called Eoin (not his real name).

Using the tool

Stage 1: What does the person appear to enjoy?
Within this box, workers listed general reflections on what the person seemed to enjoy. These reflections were based on observations and interactions, and from additional information gained by asking parents and others. Observations should aim to be as descriptive as possible. Workers can comment and record activities, materials, sounds or any other stimulus and behaviours that the person seems to enjoy by showing a response. Each example of what the person appears to enjoy can be utilised as a potential avenue for further exploration, and can be captured as part of what we see the person do. Alternatively, provocations that you provide the child with can be used to see how he/she responds.

Stage 2: What do we see the person do?
Within each box the workers put one observation. Workers should detail only what they see and should avoid any interpretation at this stage, for example: ‘Eoin repeatedly shakes the rattle by grasping it and bringing it backwards and forwards’.

Stage 3: How does the person respond?
Within this box the workers made comments on how the child responds to stimulus or to people. This is best done by observing the child during interactions. Again, workers should detail only what they see, avoiding any interpretation at this stage. The range of responses that workers collect will help them to ensure that interactions or opportunities you have designed are what they feel the child enjoys.

Stage 4: What opportunities/experiences could we provide?
Within each box (in line with the columns in stage 1) the workers put ideas about opportunities that they could provide. These should follow stage 1: ‘what we see the person do’ and stage 2: ‘what the person enjoys’. To enable the most intrinsically motivating play, it is best to develop ideas from stage 2: ‘what we see the person do’. If they are finding this to be limiting the range of opportunities available to the person, they could additionally develop opportunities by utilising information gathered at stage 1: ‘what does the person appear to enjoy?’ or indeed a mixture from both stages. Within this section, workers should try and think as creatively as they can to develop ideas that enable the children to play their way. From this planning, workers should look at how they can maximise opportunities to develop play on an individual basis: with a worker, by using motivating stimulus as appropriate; or with other

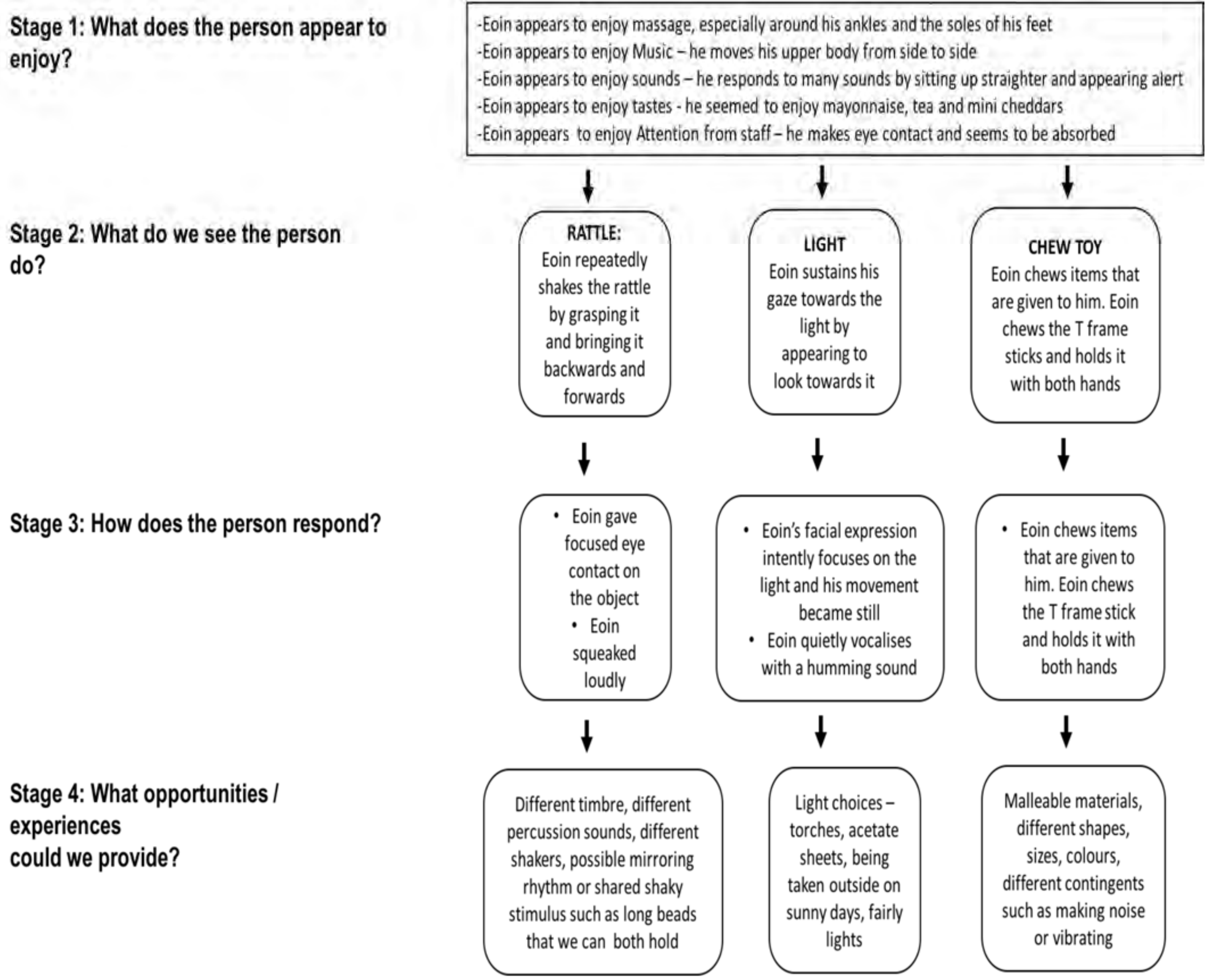

Fig 1: Play My Way Example of Eoin

children, by pairing or in groups. After this stage, the model can then be revisited in a circular fashion by missing out stage 1 or adding to 'what does the person appear to enjoy?' by revisiting other ways in which a person might engage.

Reflections on using the tool

The development of child-led/interactive approaches that develop shared control is not an easy task. It is easy to overlook subtle behaviours that may impute a desire to play and further challenging to respond to those signals through interpretation. Also, child-centred play relies on sensitive observation and the consideration of multiple interpretations undertaken by staff who know the person well, who are equipped with sufficient knowledge, and who are able to respond to potential signals – so that the dynamic of play (McConkey, 2006) can be fostered. Children with PMLD require contingently responsive interactions that use motivating stimulus based on an understanding of what we think that person is interested in, based on 'what the person appears to enjoy', 'what we see the person do when they explore a stimulus or interact' and 'how we see the person respond'.

Beginning to explore the 'Play My Way' questions may support play workers to provide increasingly child-centred opportunities/experiences. Workers may find that they can intuitively decide on potential experiences to offer the person; however, the framework may be useful for people with less experience, or for those who want to reflect on or evidence the child-centred opportunities that they facilitate. The framework is not a guide on how to play with the child. Nevertheless, it may inform or be used with documents such as play passports (see www.debbywatson.co.uk). Some children with PMLD, particularly those with very small behavioural repertoires or displaying a high frequency of stereotypical behaviour, present particular challenges in relation to how we can engage them. Reflection using the Play My Way framework may further our understanding of such a person. In an increasingly time-pressured and funding-limited environment, a tool which promotes a systematic process of exploration that is relatively easy and straightforward to undertake may prove valuable.

Due to the limited exposure that staff had to PMLD children, and the lack of appropriate play training, the Play My Way process needed active facilitation from a skilled facilitator. The facilitator needed to closely support the process of observation, reflection and generation of potential ideas. The discussions held were immeasurably valuable in shaping positive practice. The use of play journey books, where children's play was documented and evidenced, alongside a process of listening and responding (Goodwin, 2013), proved effective in aiding reflection and re-observation. After time, play workers focused on reflecting on action in relation to the four key questions, and their play practice became increasingly child-centred.

The Play My Way tool has been helpful to services and individuals who aim to make play increasingly child-led and child-centred. The effectiveness of the tool is greatly improved with the support of active facilitators, a commitment to provision of training, and an ongoing process of listening and responding (Goodwin, 2013). It is recognised that 'the best opportunities to play are shaped by people – the "software" of play' (Beunderman, 2010: p.xix). If we are truly committed to valuing the experience of childhood and supporting children with PMLD to access quality play, then let's give staff the support to do so!

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Note

* The term children has been used in this article in view of brevity, but equally includes young people and adults with PMLD who may also access playful or interactive opportunities.

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Do pupils following the National Curriculum lose valuable communication opportunities?

Samantha Battersby

As a teacher of pupils with PMLD I became increasingly concerned that, by following a broad National Curriculum (2014) timetable, pupils were increasingly missing out on the fundamentals, especially communication. I therefore decided to conduct a study to explore the communication opportunities available to a pupil with PMLD, in a complex special needs primary school following the National Curriculum.

The study

The research recorded one child's access to 'communication tools' throughout a school week, the tool (or activity) used, and the frequency of use. In classifying communications, I followed a communication intervention categorising approach, based on those used by our Speech and Language Therapists; intensive interactions, objects of reference, audio cues, switch-based interventions (BIGmacks) and choice-making using objects. All tools would be well known by all parties and within the school's practice. When I noticed the child make vocalisations toward an adult and this wasn't acknowledged or given very brief attention, I recorded the incident as an observation of no communication. I discussed the observations informally with the staff members to gain a better insight as to why this was not being developed.

Findings

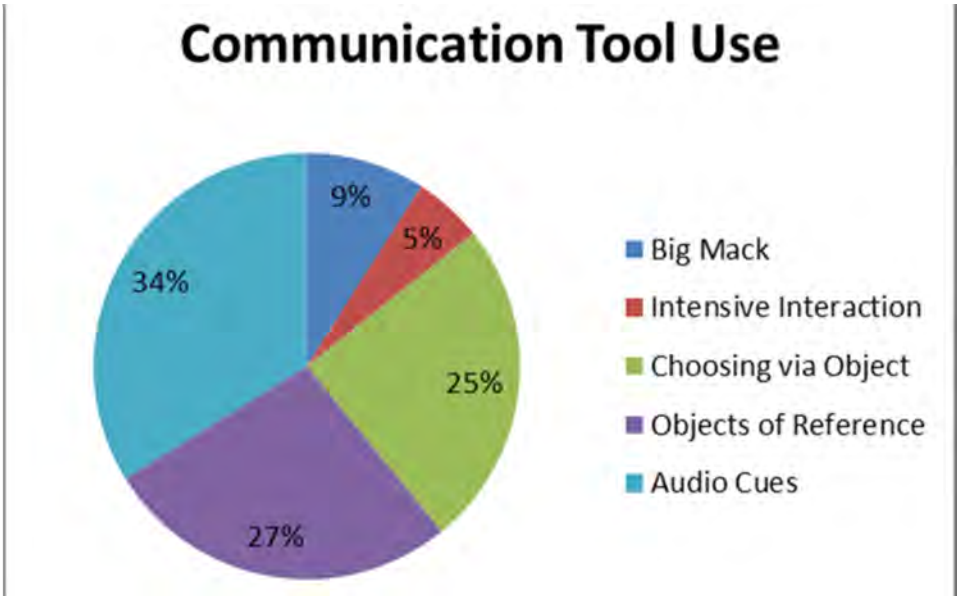
Perhaps the most significant result was how frequently opportunities for communication were missed. Communication tool access was at 58% of the opportunities during the week, using all the differing tools that I used as a measure, with the results indicating that more could be done to improve the pupil's communication for a significant part of the week.

When use of cues connected to the time table are discounted, such as audio cues which are not child-led, the results were even more significant, only occurring for 36% of opportunities during the school week. The chart below shows the type of communication tools or approaches the pupil was able to access.

The most common tools used were audio cues (34%) followed by objects of reference (27%). Whilst these are important, as some of my pupils seem to recognise these cues, these are not child-led communication tools.

The next most frequently used tool was choosing by object (25%), which is more often child-led. However, it could be argued that whilst a pupil is able to choose by gesture or eye pointing which option they would like, they still have to choose one of two objects preselected by the adult, which may not be what they desire.

Next came BIGmack use (9%). Many pupils in the school have shared BIGmacks and consequently these tend to be used for specific times, such as repeated refrains in



big book sessions. They were used in specific lessons, rather than pupils having continuous use so they can select when to use them. The results seem to indicate that use of this tool is led by staff considering when would be a good lesson or time to use it.

Lastly at 5% is intensive interaction. There were only six incidents throughout the week. There were eight incidents where the pupil vocalised toward an adult but this was not acted upon (and therefore not recorded). Intensive interaction is probably the most child-led of all the communication tools yet it is the least occurring for the pupil.

There were ten recordings of missed opportunities. In one the staff member said she hadn't realised that it was an opportunity to respond and further (encourage or continue) the interaction. In two the staff members were concerned the ensuing noise might be a problem for other pupils. The concern regarding noise and not recognising the opportunities the pupil's vocalisations give us, perhaps links to staff not understanding fully the benefits intensive interaction gives the pupils and the limited staff training that has occurred on this topic in school. In seven staff didn't follow the opportunity as they thought it would distract from the learning outcome of the lesson. The pupil's vocalisations were not missed in English lessons but it was observed in a Science lesson that when the pupil was independently pressing a switch they vocalised in a pattern, but the staff member did not respond and instead gave them a verbal prompt connected to switching. The pupil ignored the prompt and again vocalised, and when this yet again was ignored they withdrew their hand from the switch and the staff member had to use hand over hand prompting for them to press the switch. What is particularly interesting is that the pupil had already been pressing the switch, so at the time of vocalisation they had already achieved the learning outcome. Yet the staff member felt that it was important to continue with the learning outcome, as this was a Science lesson and she felt we must work on science skills. As well as missing the communication opening, the pupil appeared to become agitated and opted out of the activity suggesting that by ignoring them we are affecting their ability to consolidate the learning outcome anyway.

I expected there to be barriers created by following a National Curriculum based timetable, but I was surprised by the level of obstacles it created. Only three lessons out of twenty had communication opportunities throughout the lesson; two of these lessons were the weekly Speaking and Listening lessons and the last was Reading. Both the Speaking and Listening lessons were also the only lessons where intensive interaction, BIGmacks and choosing via objects were all present. This demonstrates that in these lessons not only were multiple opportunities given, but a broader opportunity to communicate by differing means. It is curious that by following a curriculum that should allow for depth, according to Ashdown, Carpenter and Bovair (1991), it is actually limiting the type of communication opportunities on offer, which is a concern of Lawson et al. (2015) who highlight that the desire for breadth will only limit opportunities.

Whilst daily English lessons occur, only two of the lessons are based on communication and that is reflected in the communication opportunities on offer with Reading and Writing being the focus of the remaining lessons. Within the Speaking and Listening lessons, intensive interaction was used, but not for the majority of the session (up to 50%) despite this being the pupil's preferred communication tool. As intensive interaction is not reflected in their current targets, this was seen as additional to the learning outcome and consolidating a previous target.

School targets are set for a term with an expectation these will be met by the end of the term. This does not allow for developing the targets over time as proposed by Hewett (2012) which means that, although the staff should be following the pupil's lead in intensive interaction, they already have an end goal in mind at the beginning of the session. This takes away the pupil's control and could make them less motivated as the interaction could take a different path to what interests them. Imray and Hinchcliffe (2014) discuss motivation as a key factor in the process of developing communication suggesting the barrier this lack of control could create. This also generates a desire for a linear expectation of development so whilst the target maybe about their response in a particular lesson it lacks opportunities for the pupil to transfer those skills or to develop them over a longer period of time. Imray and Hinchcliffe (2014) discuss the barriers short term targets create, especially as pupils with PMLD develop over a long period of time and they may not do so in a direct fashion.

The observations in this study highlighted the difficulties created by trying to follow a set timetable with specific subject learning outcomes. The majority of times the research showed missed communication opportunities because staff felt they needed to remain committed to the subject lesson learning outcome rather than any emerging communication. In discussions with the staff a lack of understanding about the importance of communication over other areas also proved to be a stumbling block. Very little training has been given on communication in school and this coupled with a timetable that gives no added weight or importance to communication has perhaps set a premise that all subjects have equal validity This research might support the view of Jones, Pring and Grove (2002) of the importance of staff training and that of Goldbart, Chadwick and Buell (2014) that staff values are a contributory factor in the success of communication strategies.

But does the literature support my concerns? When discussing the National Curriculum Imray and Hinchcliffe (2014) argue that the evidence suggests that pupils with PMLD do not make enough advancement using the National Curriculum. They go on to discuss how communication needs time to develop in a holistic environment, not a compartmentalised one, highlighting the need for multiple daily opportunities alongside specific timetabled lessons. This might suggest that our broad timetable, with equality (equal time given) across the subject areas, creates barriers to pupils' access and success. When considering suitable curriculums Colley (2013) advocates that to ensure personalisation a curriculum must not be strictly adhered to. So if it prevents individuality does it have to be broad? Lawson et al. (2015) discuss this concept of adaptation, balancing the National Curriculum with pupil needs. One school they cite as an example splits the learning into different levels so the pupils with PMLD have a curriculum weighted differently, specifically allowing more time for communication. It is interesting they chose communication to be the most weighted, but as Hewett (2012) asserts communication, is a complex system and understanding it should be the most important aspect of the curriculum.

It could be argued that some of the difficulties that arose due to the timetable following the National Curriculum are due to its implementation rather than the curriculum itself. As a school the timetable is equally divided with the same weight being given for Speaking, one hour per week, as, for instance, Religious Education, by following an unadjusted form of the curriculum. If the school had chosen to implement the subjects differently like the examples given by Lawson et al. (2015) perhaps this would have enabled for more opportunities for the pupil to use their communication skills. However, how much can the pupil truly benefit from a curriculum that teaches them History, but lacks consistent opportunities to develop their communication? Whilst a weighted curriculum might offer more opportunities than is currently provided, a more specific curriculum, as proposed by Colley (2013), might take those opportunities further. This would give greater flexibility for adaptations and a more individualised approach tailored to the pupil's specific needs, especially in the area of communication.

Recommendations and conclusions

Whilst this is a very small scale research project and therefore has limited applicability, it did produce some concerning results. My study highlighted great variations in communication depending on the lesson subject and the staff members' values regarding the overall purpose of the lesson fuelled by the schools use of the National Curriculum. Hewett's (2012) belief in the need for repetition and Imray and Hinchcliffe's (2014) assertion that communication opportunities should be frequent, considering it to be a key skill for pupils with PMLD, contrasted strongly with my findings. The arguments for and against using the National Curriculum demonstrate that even if we are to continue to use it, more could be done to adapt it as exemplified by Lawson et al. (2015). But my research findings lead me to consider this: by following such a curriculum, what weight are we giving to our pupils' learning, what are we saying is important? Not just to the pupils but also to the staff. And what are the repercussions of that?

Contact Details

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PMLD LINK
sharing ideas and information

Vol. 31 No. 1 Issue 92

'Moods, Sweats and Sex'
A sensory approach to teaching SRE

Helen Dunman

I have worked at the Chailey Heritage Foundation (CHF) for many years and have had whole school responsibility for PSHE & SRE (Personal Social and Health Education & Social Relationships Education) for some years. I also teach Drama to the older students and often bring these two areas together when teaching. I'm coming from the simple place that I want to do PSHE/SRE really well and help others feel confident to do it well, especially where some people may find it difficult or think it's taboo. In this article, I want to share some of the work I'm doing at the school and talk about what's working. All of our students have severe physical disabilities and are sensory learners to a greater or lesser degree, with a range of different learning needs.

The Mirror Project

A couple of years ago I wanted to explore and develop the whole area of 'Body Awareness' and it struck me that people who use wheelchairs may never see their whole body easily and certainly may not ever have seen their own genitals or be able to see how their body is changing and developing during puberty. Many pupils were very unsure of what genitals they had and although I know that for some people that might always be tricky, I felt there was more I could do. Nearly all of our students use incontinence pads and are changed on a bench in the hygiene areas. So I did a bit of research with a supportive colleague who went through the movements she would do whilst changing someone. When you're lying on your back even with your head propped, you can't see anything much. So it made sense to place large mirrors alongside the bench so that when a student is rolled they can really see themselves. This is a very simple idea but actually required a lot of work. Researching the mirrors, writing a rationale, getting funding and getting the staff trained and on board. It's so much more than young people just looking at themselves in a mirror. So staff are trained in giving really clear short explanations of what they are doing and why - using sensory cues if needs be and to use appropriate anatomically correct language, in a caring non-judgmental way. For example: "Ok, you've done a poo and some has gone inside your vagina, I need to clean you there with this wet wipe (sensory cue) and put on your cream (sensory cue) so you don't get sore."

Staff are encouraged to say when they are rolling a student to look in the mirror "You're a girl, with a vagina" and to gently point in the mirror. For some staff this was a challenge and I needed to be really clear about why we need to use clear anatomically correct language, with no confusing euphemisms.

As students reach puberty I ask staff to talk and show them the changes: "You're growing some hair around your penis – yay, you're a teenager ----- you're growing into a man!"

Impact

More students are able to correctly identify 'what they've got' (by pointing/indicating on an anatomically correct doll) and everyone across the school is able to really look at themselves and be more at the heart of a very intimate activity that they could feel quite distanced from. Students are reported to really look at themselves, some smile, there is definitely increased engagement. It's learning in context.

The Puberty Stories

One of the huge areas of SRE is of course all the many changes that happen during puberty. Puberty is happening it seems at an increasingly young age for our children, and we need to prepare our sensory learners for this in a way that suits them.

There are off-the-peg resources out there which I had used in the past but I increasingly felt that I needed to write my own, bespoke for our guys. I was also being asked by staff and parents for help, such as, "What do I actually say and do when teaching X about periods, sweat, moods, crushes?"

Stories are a great way in and so I started to write the catchily titled 'Puberty Stories' - in a simple bite sized way with sensory props, often using anatomically correct dolls. The idea was that staff could choose from a whole range, download a script and use it as the basis when working with students. These stories can be adapted for individuals and can last for as long as you want.

Staff report that they feel more confident in tackling SRE when they can use a story script. They know that they are using the right language and it is reassuring. There are more in development but current titles include:

- Pippa's Period,
- Poppy's/Pete's Private Time,
- Craig's Crush,
- Dave's Deodorant,
- Maddie's Good Touches,
- Tim's Bad Touch,
- Keeley's Kiss

One group for example spent nearly a whole term working on 'Dave's Deodorant' which involves recreating a sweaty tee shirt, lots of sensory work with every possible type of deodorant (sprays, wet crystals, roll-on etc.). The students tried each type and then went on a shopping trip to buy one for themselves that they had shown the most positive reaction to, on the most consistent basis.

In 'Pippa's Period', I use the doll and change her pad with fake blood in it, she has a hot water bottle which I share with the student as part of the story. I also share this story with people in the hygiene unit, to place the learning in context. Interestingly, going into the hygiene unit to share a story makes some of the students laugh and immediately has their interest, more so than if I do the story in a class. (We did a bespoke one for a young woman who, staff told me, was able to show a positive preference for types of food she wanted around the time of her period, and not so much at other times!) This has been extended so that girls might be shown their own pad with blood in it when they are being changes.

In 'Craig's Crush' I recreated some of the physical feelings you may have in your body when you fancy someone: hot with a heat pad, butterflies in the tummy with a vibrating snake, and so on.

Anatomically Correct Dolls

I love anatomically correct dolls and have always used them in my PSHE/SRE teaching. I really recommend that you use them too. They can be used in drama to do things that you couldn't do on a real person, they can be used to assess the young person's understanding, or simply to act as a stimulus to a student. I had a student who was at the stage where a story was too much, she didn't always show an obvious interest in items but she did show consistent interest in the naked female doll. She reached out and seemed to focus very intently on it as her TA held it and said the names of different body parts to her, as well as signing 'woman'. This was reinforced in the hygiene unit when she was changed and was encouraged to look in the mirrors. We had a lot of success with this student.

Teachers often contact me to ask where these dolls can be bought. So far I have always bought from America although www.bodysense.org.uk run by the Revd Jane Fraser have some very interesting things in their catalogue and are based in England. When I bought the last set of dolls I googled 'Anatomically correct dolls for education' and chose a website from that search (be careful doing that on a school computer!) Unfortunately they aren't cheap.

The Drama Circle

This is a technique that I use with some students to help them distinguish between pretending and reality, especially helpful if you are going on to teach something more sensitive. I have a 10-metre-long piece of lycra that can easily stretch around a group of staff and pupils who are sitting in a circle. It can either be put on the floor at people's feet or put on people's laps, so they can see it more easily and touch it. I demonstrate that 'inside the circle drama happens' by going inside the circle and becoming a dog or something easy to understand. Any students who want to can with help, then have a go at pretending, inside the circle, and the scene is set! This makes it much easier for me to teach subjects such as inappropriate touch or bullying, as it's clear to students that this is a drama situation. The dolls are very useful for this as they can be touched in a way that I couldn't do with a real person.

Trickier Topics

Ok let's talk about masturbation. I do a story called 'Poppy's Private Time' and 'Pete's Private Time', as part of the Puberty Stories. These explain what masturbation is, that it is OK and that it must be done privately.

Jo Grace often talks about using items creatively without blowing the budget and this is a case in point. I was given a latex penis 'stress ball' (don't ask!) and saw its potential as a useful and cheap teaching tool! I hollowed it out, made a small cut and placed it over the existing penis on the male doll. It is easier to demonstrate what happens to a penis when it is erect and I am also able to place a small syringe inside which I load with a dilute flour mixture to replicate semen. All this may sound a bit 'over the top', but I believe that for our sensory learners, we can't be coy: explicit sensory cues are very helpful for learning.

The message that the student is getting is that it's ok to explore his or her body. Students will have also previously done work around who else can and can't touch their bodies and why this is. Do remember not to try and do too much in one story - keep it bite sized.

Staff at CHF are trained to be non-judgmental if people are exploring their bodies when they are changed. Most of our young people would not necessarily be able to ask staff on the residences if they can have private time, even if they wanted to, due to lack of communication ability. So I have discussions with our care staff about making sure that young people have time alone after a bath when they can be naked on a bed or a fleece, nice fabric on the floor, or wherever's best. This could be for them to explore, masturbate or just enjoy being naked with a cool fan. It is also to make sure that they are given regular times in the day, a regular time, when they can masturbate. TA sense of routine as so often, can bring reassurance.

Communication

Chailey Heritage School staff with Chailey Clinical Services have been pioneering for decades now in making sure our young people have full access to communication. Down the years, especially when we had less complex students than we have now, we have 'surprised' professionals, and sometimes parents, with comprehensive swear-word pages/screens, for example. Having symbols or words for every aspect of PSHE/SRE is crucial, they can only communicate about sexual/ growing up stuff if they have the words or symbols to do so. So I'm constantly making sure that they have the words and symbols they need and also the Makaton signs for us as staff as appropriate.

Amazing PSHE/SRE moments

There have been many amazing and moving moments teaching SRE to our students. One particularly sticks in my mind. I was keen that a group of very sensory learners would have the chance just to look at their own bodies without all the medical apparatus and orthoses that they are usually enclosed in, and to look at themselves as the amazing young women that they were becoming. We took them shopping and they each were helped to buy bikini fabric and matching shorts, following their positive and negative responses. We made the classroom into a cool chill out area, using wicker screens, and lay them each on a mat covered in silk saris, with a mirror alongside them. It was truly moving to see them look at themselves as women, how they see women on TV or the internet, not purely as medicalized. Then we spent weeks following Flo Longhorn's amazing programme (Longhorn, 1997) on different body touches using different stimuli, whilst they were wearing these pretty clothes, and monitored their responses for a body sensory diary. In so many cases we could feel a raising sense of self-sesteem – not something you could measure or put numbers to (thank you Simon), but something definitely there.

Training – for a sexuality positive environment

For SRE teaching to work and have a positive effect, everybody around the young person has to sign up to it and a strong ethos must be embedded. It can't just be a discrete lesson, then back to previous practice, the fundamentals we teach need to be part of their lives at school. At Chailey Heritage we offer regular training sessions which explain to everyone why we're doing what we're doing and how best to develop our SRE teaching. We discuss how we can personalize learning so that individual students have a bespoke programme – which exactly fits the ethos and practice of our CHILD Curriculum (chf.org.uk/purposeful-learning). Ongoing support is given to staff to help them feel confident.

I also offer training to other schools and organisations where there are young people with learning and/or physical disabilities. This can be either my off-the-peg training, demonstrating the techniques we use, or training bespoke to the organization who wants us. Invariably, people are first shocked by the bluntness and graphic nature of my presentations, and then feel empowered, and see how getting this are of teaching right can make such a huge difference to the young people, and their families. They are always fun sessions and there's lots of discussion.

Parents' involvement

We run regular parent workshops, to support parents in their own confidence and as a forum for discussion of any issues and concerns in this sensitive and emotional area of their children's lives. This is very gratefully received and well attended. As with many things for our young people, it is extremely useful to have complementary practice at home and school (and the residences) around SRE issues, and these workshops help promote this.

Summary

I love teaching SRE and constantly try out new ideas to keep up with new challenges, new needs and new information. Every child and young person has a right to be put at the centre of everything that happens to them, and this is crucially important in intimate care and helping them to understand, as far as possible, all the changes that happen to them during puberty. Students need positive messages about their bodies and emerging sexuality and they need well trained staff who will appropriately advocate for them.

It's a tall order so staff need to be comfortable and confident in delivering SRE in a sensory way so that they can make a real difference to the quality of the lives of our special young people.

Individual pupils, of different cognitive abilities and experience, do of course, take away more, less or different understanding from my practice. I think it's important to note that the very sensory aspects of my work (the puberty stories for example) still do have a strong impact on our pupils who use verbal language. Conversely, talking and explaining around our pupils whose experience of the world, and meaning within it, is primarily sensory can also have a positive impact. Never dismiss what may be being understood!

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Editors note:

Chailey Heritage School is a special school for children and young people aged 2 to 19 with physical disabilities, and complex health needs. The pupils also have learning difficulties, some very profound through to those who are able to achieve entry level certificates by the time they leave. Therefore, some of the activities described may not be relevant to pupils with PMLD and may be more appropriate for pupils with severe/moderate learning difficulties.

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In the Next Issue

Values and Ethics

Do we care enough?

Since people with PMLD are subject to the impact of the ethics and values of those who support them, how we should care is not always clear cut and requires ongoing reflection.

The Summer 2019 issue of PMLD Link has the theme of 'Values and Ethics'. Values ethics are deeply situated and are complex. Complex issues and dilemmas arise through the day to day experiences of living a life with PMLD; not only because of the needs that arise due to having multiple impairments but also because societal barriers and attitudes interfere with the rights, freedoms and quality of life that we would expect. Communities do not always take the vulnerable position of people with PMLD seriously and care is not always taken to afford them their rights.

For the Summer 2019 issue we would like to invite contributions which speak to a wide range of ethical questions including, but not limited to, the following:

- Do we care enough?
- What dilemmas do you face as a parent, carer or professional supporting a person with PMLD?
- What complex decisions do you have to make on behalf of people with PMLD?
- Who do you think should speak for people with PMLD (if anyone)?
- Is it a good thing to identify people as having 'profound and multiple learning disabilities'?
- What can people with PMLD teach us about what matters?
- What is required for people with PMLD to become 'anchored within a community'?
- Independence v. interdependence, rights v. relationships - where should we focus our efforts?
- Do we want people with PMLD as our friends as well as our clients / pupils/ patients?
- What can different cultures and religions learn from each other about responding to profound disability?
- How well does the law serve us in promoting the wellbeing of people with PMLD?
- How do we create and sustain 'ethical organisations' to support people with PMLD (including schools, care providers, social services and health services)?

We look forward to receiving your contributions!

Martin Goodwin, Rachel Parry Hughes and Rob Ashdown

IN THE NEWS

FEEL Free Theatre Shows

FEEL Theatre specialises in creating shows and workshops for young people and children on the Autism Spectrum and with Profound and Multiple Learning Disabilities. They are taking their interactive show 'Sensory Circus' on tour around schools and community groups. They plan to tour England and South Wales this June.
3rd - 7th June: London (plus surrounding areas) and South East of England (now fully booked)
10th - 14th June: South West of England and South Wales
17th - 21st June: Midlands
24th - 28th June: North of England
To learn more about sensory circus, please visit: www.feeltheatre.co.uk/sensory-circus
If you would like more information or wish to book Sensory Circus for your school or community group, please email feeltheatre@gmail.com.

CASCAIDr

CASCAIDr is the Centre for Adults' Social Care – Advice, Information and Dispute Resolution. This charity operates online and uses self-employed caseworkers who are informal experts in the Care Act, and health, social care and human rights law in general.

It is providing Care Act Conundrums 2019/20 – a series of 12 webinars for the purposes of public and professional education about people's legal rights to care and support. These are for adult service users, families, carers, care providers and professionals. Cost - £15 per session. They are held at 12pm and 8pm, on the last Thursday of every month (not Boxing Day!)

25 Apr - Carers' rights and their role in delivering choice
30 May - The Care Planning rules
27 Jun - Reviews and Revisions Rules
25 Jul - The charging system
29 Aug - Direct Payments and Health Budgets
26 Sep - Supported Living pros and cons
31 Oct - Continuing ordinary residence / 'continuity' rules
28 Nov - 'Choice' rules
2 Jan - S117 / Continuing Health Care status and adult social care
30 Jan - complaints, legal remedies and compensation

For more details and to book a place go to: https://www.cascaidr.org.uk/webinars/

Extra Costs of Living

Life costs more for disabled people and their families. Scope has published a report called 'The Disability Price Tag' based on updated research for 2019 that reveals the extra costs faced by disabled people and families with disabled children. Key findings for families with disabled children include:

- On average families with disabled children face extra costs of £581 a month.
- For almost a quarter (24%) of families with disabled children, extra costs amount to over £1,000 a month.

The report, which contains urgent recommendations for Government action, can be accessed through Scope's website at: https://www.scope.org.uk/campaigns/extra-costs

NICE Quality Standard: People's experience using adult social care services

This quality standard covers the experience of adults using social care services. It applies to all settings where people use social care services, including people's own homes, residential care and community settings. Its aim is to help people understand what care they can expect and to improve their experience by supporting them to make decisions about their care.

The NICE quality standard covers four important aspects of establishing and receiving social care support: assessments, having control through personal budgets, continuity of care, and ensuring people who access services have their views and experiences heard by commissioners and providers. The standard was published in February and is available at: https://www.nice.org.uk/guidance/qs182

Kidz to Adultz Events in 2019

Kidz to Adultz' events are organised by Disabled Living. These free exhibitions are dedicated to children and young adults up to 25 years with disabilities and additional needs, their parents, carers and all the professionals who support and work with them. Details, free tickets and show guides are available on the website: https://www.kidzexhibitions.co.uk/

The exhibitions are a one stop shop for the most up to date advice and information on mobility, funding, seating, beds, communication, sensory, transition, education, housing, employment, accessible vehicles, transport, style, sports, leisure and more.

Free accredited seminars take place alongside the exhibitions with presentations covering a wide range of issues and interests to families, carers and various professionals. Entry is on a first come, first served basis. The Coventry event took place in March. Other scheduled events are:

- Thursday 16th May 2019 - Farnborough International Exhibition & Conference Centre
- Thursday 4th July 2019 - Thornbury Leisure Centre, Bristol
- Thursday 14th November 2019 - EventCity, Barton Dock Road, Manchester

Dates for an event in Scotland have yet to be confirmed.

Learning disability and autism training for health and care staff: A Government consultation

In February the Government launched a consultation to seek views about how to ensure staff working in health and social care have the right training to understand the needs of people with a learning disability and/or autism and the skills to provide the most effective care and support. The document contains various proposals.
The consultation actually is due to close on 12th April but you may still wish to access the available documents. https://www.gov.uk/government/consultations/learning-disability-and-autism-training-for-health-and-care-staff

Revising the Mental Capacity Act (2005) Code of Practice

This year sees the first revision of the Mental Capacity Act (2005) Code of Practice, with the call for evidence closing on March 7th 2019. The Mental Capacity Act covers England and Wales, and was designed to protect and empower people aged 16 and over, who may currently lack the mental capacity to make their own decisions about their care and treatment, or those who may have capacity but wish to make preparations for a time when they may lack capacity in the future.

The MCA came into force in 2007 and in light of changes in case law, and lessons learned, the government called for a revision in order to better reflect current needs. This review will address the code of practice, which provides guidance and illustrates how the Act operates, on a day to day basis. This legislation covers a wide range of decisions and circumstances, aiming to provide a flexible framework to ensure that individuals are placed at the very heart of the decision-making process, with any decisions made in the individual’s best interest, with the least restrictive impact.

Deprivation of Liberty Safeguards (DoLS)

The Deprivation of Liberty Safeguards (DoLS) are part of the Mental Capacity Act 2005. These safeguards aim to make sure that people in care homes and hospitals are looked after in a way that does not inappropriately restrict their freedom. The Law Commission 2017 report recommended that DoLS should be reformed, naming the new system the Liberty Protection Safeguards (LPS).

The Liberty Protection Safeguards will themselves be supported by a brand-new Code of Practice. This statutory document, will support implementation and provide examples of best practice to both carers and practitioners, and will complement and be an integral part of the revised part the MCA Code of Practice.
The Bill is currently progressing through parliament but widespread concerns have been raised by charities, providers and user groups about a significant number of issues. These include the new responsibilities on registered care home managers and the potential for conflict of interest for providers, the critical interplay with the Mental Health Act (currently not addressed by the Bill), and the actual definition of a deprivation of liberty. At the time of going to press, the government’s proposed ‘definition’ was rejected by the House of Lords, who backed an amendment to change the description.

To see what happens next with the MCA code of practice and the new Liberty Protection Safeguards visit
https://consult.justice.gov.uk/digital-communications/revising-the-mca-2005-code-of-practice/
https://services.parliament.uk/bills/2017-19/mentalcapacityamendment.html

New Subscription Rates from 1st April 2019

UK Individual £25.00

UK Organisation £35.00

EU/Overseas Individual £32.00

EU/Overseas Organisation £45.00

Thank you to all subscribers who responded to the PMLD Link survey about raising the subscription rate. People were overwhelmingly supportive and recognised the need for the annual subscription to increase by £5 in order to meet the costs of production and mailing.

Many respondents to the survey indicated that they still wanted to have a hard copy of the journal and we will continue to send all subscribers a printed copy of the journal as well as making available privileged access to the Member's Page of the website. This allows subscribers to access downloadable versions of back issues from the last three years.

More than half of the respondents to the survey indicated that they would be happy to access a downloadable pdf online and forgo the hard copy for a reduced subscription rate. PMLD Link will now investigate the possibility of offering an online subscription from 1st April 2020 for those who want this.

The journal remains the only UK journal focussed on the needs of children and adults with PMLD. Thank you for your support for it.

If you have any queries, please do not hesitate to contact Rob Ashdown (PMLD LINK Treasurer) via either info@pmldlink.org.uk or rob.ashdown@ntlword.com

UPCOMING INTENSIVE INTERACTION EVENTS

from the Intensive Interaction Institute

Intensive interaction Good Practice Course 3 tutored days
04.04.19, 05.06.19 & 18.09.19, QEII Jubilee School, London, W9.
08.04.19, 0807.19 & 09.09.19, Mount Pleasant Hotel, Great Malvern, Worcs.

Intensive Interaction for People with Autism 1 day
03.05.19, QEII Jubilee School, London, W9.

Intensive interaction for People with PMLD 1 day
09.05.19, Cambridge Hotel, Huddersfield, Yorks.
06.06.19, QEII Jubilee School, London, W9.

Intensive Interaction for People who Speak
10.05.19 Cambridge Hotel, Huddersfield, Yorks.
07.06.06 QEII Jubilee School, London, W9.

Intensive Interaction Coordinator Course 21 days
18.06.19, fist block, Mount Pleasant Hotel, Great Malvern, Worcs.

See full information and application forms: www.intensiveinteraction.org

Intensive Interaction Institute

RESOURCES

‘Exploring the Envelope of Intensive Interaction’ – by Dr Mark Barber and Karryn Bowen (Intensive Interaction Australia)

This resource features scenes shot in Australian special schools, showing young learners taking part in intensive interaction sessions, with observations and commentary by Mark Barber.

Freely available now on YouTube on the following link: https://www.youtube.com/watch?v=RvxlyiCErMg

Quest for learning

Quest for learning is a guidance and assessment resource to support teachers and classroom assistants of learners with profound & multiple learning difficulties (PMLD), providing ideas for and pathways to learning, from the Council for Council for the Curriculum, Examinations and Assessment.

Follow the ink below to the guidance booklet.

http://www.nicurriculum.org.uk/docs/inclusion_and_sen/pmld/quest_guidance_booklet.pdf

Thematic Units for Students with PMLD

http://www.nicurriculum.org.uk/curriculum_microsite/SEN_PMLD_thematic_units/index.asp

Guidance on Managing Constipation

Chronic constipation in childhood can result in acquired mega colon / rectum if inadequately treated leading to potential ongoing chronic problems into adulthood, including death.

Bladder and Bowel UK have published a paediatric pathway for treating children with difficulties opening bowels or with regular soiling.
https://www.bbuk.org.uk/wp-content/uploads/2019/02/Paediatric-pathway.pdf

Oral care and people with learning disabilities

This government guidance contains information about oral care and dental treatment for people with learning disabilities. It is intended to be of use to family carers and paid supporters that help someone with their daily oral care and in accessing dental services. It also aims to help staff in dental teams to provide services that are accessible to people with learning disabilities. There is information about how learning disability staff can support this.

There is a legal obligation for dental services to make reasonable adjustments to ensure that their patients with learning disabilities can use their service in the same way as other people.

https://www.gov.uk/government/publications/oral-care-and-people-with-learning-disabilities/oral-care-and-people-with-learning-disabilities

‘Understanding Suraj’: Ian Ingram NL Productions

This 45 minute film about has been generously gifted as a free learning and teaching resource by Ian Ingram at NL Productions – and is now available on YouTube.

Suraj is a young man from Bradford, and has profound and multiple learning disabilities. The film shows how Suraj has been supported by his care staff and specialist staff from the NHS, to build connections and relationships. Commentary from Suraj's family, his staff, and Graham Firth give insights into how using intensive interaction has helped people gain a deeper understanding of his communication, and how this has reduced or helped with episode of frustration and self-harm. https://www.youtube.com/watch?v=mIeuaOn_70c

How to support people with learning disabilities and/or autism to take part in their Annual Review: Together Matters

Together Matters has produced a guide for family carers , people and organisations supporting people with learning disabilities and/or autism to take part in their annual review with Adult Social Care. This guide was written by the Quality Check team at Together Matters. The team were visiting people at home, in both supported living and residential care, to find out about the quality of their support and to give ideas for improvements. The team realised that sometimes people who found it difficult to communicate in traditional ways or were uncomfortable in formal meetings, were missing out on the opportunity to contribute to their annual review. The guide was initially aimed at support staff, with practical ideas that could easily be followed or adapted for the person they were supporting. During the development of the guide the team realised that it could also be used by families to advocate for their relative to have more involvement. The guide suggests a reflection on how the review went so that learning can be noted and built on in the next year. In this way, review meetings should be organised and held in a way that works for the person whose review it is. It may be used to help people participate, particularly those who find meetings stressful, difficult or boring. It includes ideas to help people, who do not feel able to go to meetings, to contribute in other ways.

In many local authorities it seems that the time available for a review meeting has become more pressured and the main focus sometimes ends up being on finances. In order to keep a focus on all the important aspects of a person's life, the team went on to develop a template to help people prepare for their annual review. Although this is not specifically for people with profound disabilities it could be used by their families and/or paid support to keep a focus on lots of different aspects of life, including friendships and community involvement. Both of these resources are available to download free from www.togethermatters.org.uk .

Cebrebra template letters to get appropriate support

Cerebra has created a series of template letters to help families write to their local council or health body to ask for information or make a complaint. They have different letters for England, Wales and Scotland, available at: https://www.cerebra.org.uk/help-and-information/legal-help/precedent-letters/.

One of the biggest concerns reported to Cerebra relates to the fact that families may not be getting the support to which they are entitled when it comes to continence assessment and provision. There are template letters if (a) your child been refused a continence assessment at home; (b) your local continence service isn't providing enough pads/nappies to meet your child's needs; and (c) your child getting unsuitable continence products
There are also template letters covering other subjects.

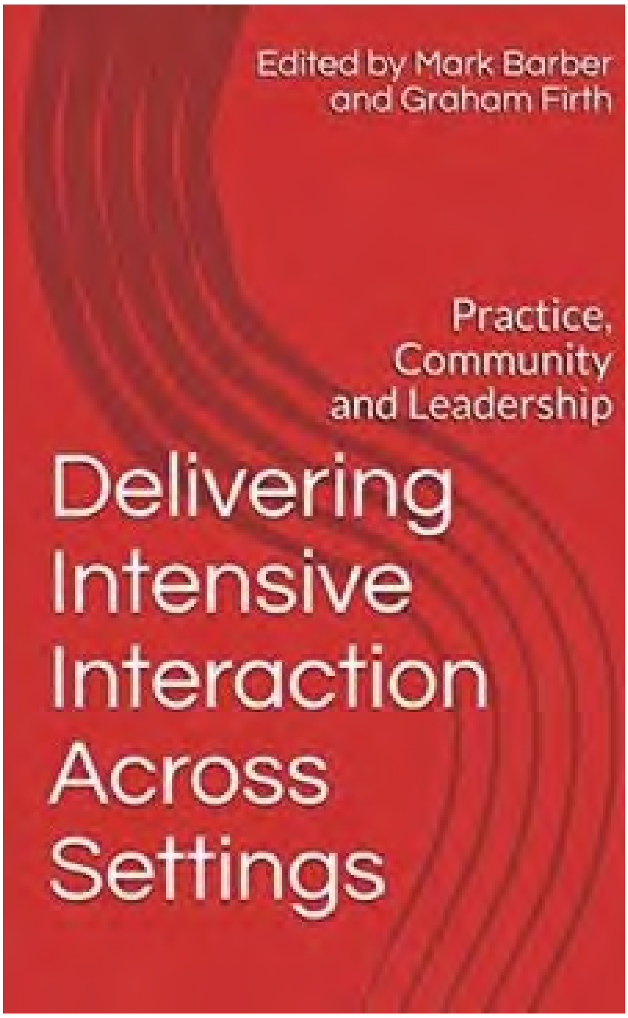
Sensory Symposium

Sensory theatre for and with audiences with complex needs
Monday the 3rd of June 9.30am-4:30pm
Festival Theatre Studio, Edinburgh: Potterow, Edinburgh EH8 9FT

Provided by Upfront Performance Network, Frozen Light, Capital Theatres and Independent Arts Projects. This Sensory Symposium aims to bring together people who share the ambition to raise the standard of cultural provision for audiences with complex needs. This will be an opportunity to gain inspiration and question 'what next?' for the sensory performance sector.

Register for free to attend the symposium via Eventbrite. (https://www.eventbrite.co.uk/e/sensory-symposium-sensory-theatre-for-with-audiences-with-complex-needs-registration-58626013986)

REVIEWS



Title: 'Delivering Intensive Interaction Across Settings: Practice, Community and Leadership'
Editors: Mark Barber and Graham Firth.
Date: 2019
Pages: 247
Publisher: Amazon Kindle e-Book
Price: £0.99 from Amazon.co.uk

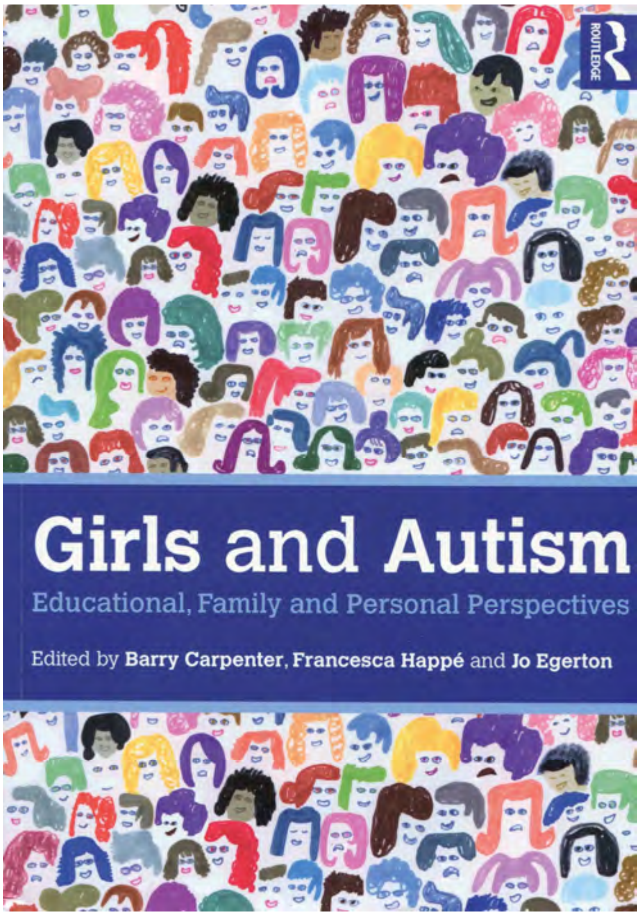
This a trend that it is hoped that other writers may pursue. Instead of producing an expensive textbook, the editors and their contributors have published this book as a Kindle e-book through Amazon at the minimum fee allowed.

This book contains 14 insightful chapters each detailing their experiences and reflections on using Intensive Interaction across a range of care and educational settings. The contributors are all at different points in developing quality Intensive Interaction in their settings - some initiatives have only been implemented in the past few years and some have two or three decades of history. This makes it possible to benefit from the insights of people working in schools or services where Intensive Interaction is now well-established as well as from people who are at relatively early stage of implementation, sometimes working without much support.

Readers from a range of services and organisations will benefit because the contributors, including a parent, come from a range of schools and services. Note that this is not a book about how to develop your own knowledge and skills in Intensive Interaction, although insights are offered throughout. Instead, it provides inspirational stories and solid guidance on how to ensure that Intensive Interaction becomes embedded in a setting in the most effective way possible. Especially important in this regard are the introduction by Mark Barber and Graham Firth, Graham's explanation of the key concept of an Intensive Interaction Community of Practice and the final chapter, also by Graham, on organisational and institutional issues and change management, including a revisit to the decades-old myth that a lone hero innovator can affect change unaided in complex social organisations. The other chapters by practitioners from the UK, Australia, New Zealand and Denmark, some of them past contributors to PMLD LINK, all offer useful guidance and interesting accounts of the highs and lows, the positives and the negatives of introducing Intensive Interaction into their settings.

What comes through all the chapters is the commitment and dedication of the authors and the crucial development of like-minded, skilled and enthusiastic communities of practice, which is achieved only through careful organisation, planning, professional development opportunities, reflective discussion and mutual support - and the unstinting support of leadership teams. The chapters are lengthy (about 15 to 20 pages of text on average) and each require careful consideration and noting of key messages, and revisiting, but they are well-written and readable.

There are some minor typos which can be forgiven but one problem (at least on an iPad) is the lack of an interactive contents list (there is a contents list but it has no links to the individual chapters). This means that is not a simple matter to shuttle to and fro between chapters, although a simple search for an author's name will usually help the reader to locate the start of the relevant chapter fairly quickly.



Title: Girls and Autism: Education, Family and Personal Perspectives
Edited by: Barry Carpenter, Francesca Happe and Jo Egerton
Publisher: Routledge
Cost: Paperback £29.99
Pages: 193 plus xx

Although published in March, this book was officially launched on World Autism Awareness Day on 2nd April. The book draws its contributors from people who come across as committed and passionate advocates for girls with autism, many of whom contribute to the National Autism and Girls Forum supported by the NAHT (https://www.naht.org.uk/about-us/our-councils-committees-and-forums/autism-and-girls-forum).

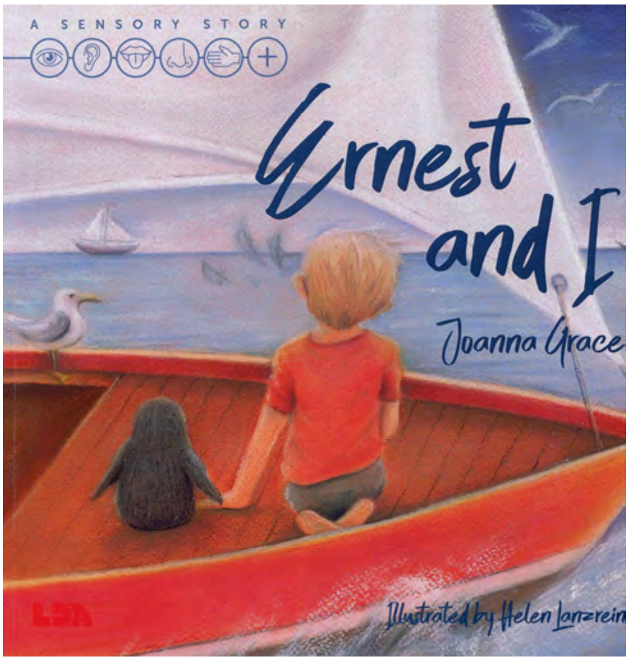
Let's be clear – the book is not about autistic girls with PMLD. The book is concerned with describing the ill-met needs of all girls with autism, and there is a minimum of twenty thousand in England, the majority of whom will be in mainstream schools. Until recently, it used to be thought that there was a much higher ratio of boys to girls with autism, about 4:1 or even higher as regards more able children and young people, but accumulating evidence suggests a gender ratio that is closer to 3:1 or even 2:1. As well documented by contributors, misdiagnoses or failures to diagnose occur because many girls do not fit the traditional profile associated with males with autism, especially if they are functioning in the average range intellectually. Also, despite their fears and anxieties, many girls with autism want to fit in with their peers and conform to expectations. However, their efforts at 'camouflaging' or 'masking' their problems can be mentally and physically exhausting and, while they may work for a while, eventually serious mental health problems result from their unmet needs and the chronic lack of support, particularly in mainstream schools. Almost all professionals in the education, health and care sectors are likely to encounter girls with autism at some point and they need information to understand them better. This is what this book sets out to provide and does exceptionally well. It covers a wide range of topics and the editors have secured very able contributors who are drawn not just from professionals but also from parents of girls with autism, and students and older women with autism themselves. Indeed, a particular strength of the book is the 'voice' that is given to girls and women who are autistic, both in the chapters written by autistic individuals and also throughout other chapters where may be found accounts or quotes from girls in schools and young women moving into the post-school world with all of its uncertainties. Despite the relative lack of research on the life experiences of girls with autism and successful ways of supporting them in school and throughout life, the contributors provide a wealth of detail and guidance plus signposting to sources of further information.

The book is divided into five sections:

1. An introduction, including a survey of what we know and do not know about girls and autism.
2. Girls and autism: the lived experience of girls and their families from early life, through the school years and into adulthood.
3. Girls, autism and education: with a focus on what schools need to do to improve their understanding of needs, their support arrangements, their teaching approaches and their curricula to avoid the exclusions from school that plague the lives of so many.
4. Autism, adolescence and social networks: this section provides some insights from developments in neuroscience but is mostly concerned with mental health, experiences of friendship and adolescence and sexuality, offering advice on potential difficulties and the support that can be given, both proactive and reactive.
5. Autistic girls: looking to the future. The chapters here cover the development into adulthood and the transitions to post-school education and employment; developing the skills of the workforce so that they can provide support and prepare girls for transitions; the changes society has to undergo to become inclusive and how to help girls with

autism to become more positive and understanding of society and roles. The final chapter serves as a 'call to action' and a reminder of the myths and truths expressed throughout the book.

This book is essentially very positive despite the unflinching descriptions of the complexities of life and school and the barriers that exist for girls with autism. It maintains a focus on what is possible and what is achievable even with the current reality for the majority of poorly coordinated support and insufficient services. It is a highly recommended read both for parents and for professionals working in or with schools, colleges, career services, as well as the health and social care sectors.



Title: Ernest and I
Author: Joanna Grace
Publisher: LDA (www.ldalearning.com)
Date: 2018
Price: £12.99
Pages: 32 including 12 full page colour illustrations by Helen Lanzrein

This delightful little book is one of two sensory stories by Joanna Grace, the other being 'Voyage to Arghan' (which was not sent for review by the publisher). 'Ernest and I' tells the story of a boy growing up at sea and his subsequent move to land. He is autistic. 'Voyage to Arghan' is an adventure into space following a girl with Down Syndrome who wins a competition to be the first child in space.

'Ernest and I' is intended to allow young children to experience comforting and challenging sensations in a safe place where they feel secure. In common with other sensory stories, it offers a narrative which places few linguistic demands and the brief sentence on each page is accompanied by a bright and colourful picture together with suggestions for making available sensory experiences that are both relevant to the text and enriching. Incidentally, Ernest is a cuddly toy – a knitted penguin in the pictures – but any toy of an interesting fabric and appearance would serve.

Joanna Grace provides guidance on how best to share a sensory story giving time for each page for children to take in the words, interpret the picture and feel the sensory experience. She emphasises the importance of keeping the experience of the book the same each time it is read with a child because children like the predictability of a familiar story and will take in more information each time they hear it. She lists the resources that have to be on hand when telling the story. These books are good for family members, including siblings, to share with the child, regardless of their level of ability. 'Ernest and I' can be shared by anyone with anyone and will provide interesting tastes, sights, sounds, smells, touches, movements, and, with many children with disabilities, could help them identify and express emotions. Try it, for fun!

Of course, children with PMLD have profound intellectual impairments and associated language and other problems. But it simply cannot be assumed that there will be no benefit at all for them from this multisensory story and others like it, as so often described in the pages of this journal. First and foremost, there will be the hopefully pleasurable time regularly spent by a child with a trusted person.

SHORT COURSES & CONFERENCES

April 2019

Title: Sensory Play Day
Date: 16th April
Location: Maidstone YMCA
Provider: SenSational
Contact: sensationalkent@yahoo.com 07534423627

Title: Develop Your Sensory Lexiconary
Date: 26th April
Location: Bath
Provider: The Sensory Projects.
Contact: sensorystory@gmail.com

Title: Communicating with Relatives and Carers
Date: 26th April
Location: Tamworth
Provider: Simple Stuff Works
Contact: trainingadmin@simplestuffworks.co.uk

Title: Person Centred Reviews and Meetings
Date: 8th and 26th April
Location: Tamworth
Provider: Simple Stuff Works
Contact: trainingadmin@simplestuffworks.co.uk

Title: Communicating with relatives and carers
Date: 30th April
Location: Tamworth
Provider: Simple Stuff Works
Contact: trainingadmin@simplestuffworks.co.uk

Title: Story Massage
Date: 30th April
Location: South London
Provider: Story Massage
Contact: (www.storymassage.co.uk)

May 2019

Title: Beginners' Makaton course – parents & carers
Date: 7th – 8th May
Location: Sheffield
Provider: Becky Lyddon
Contact: beckymakatontutor@gmail.com

Title: An Introduction to Intensive Interaction
Date: 8th May
Location: Redhill
Provider: Us in a Bus
Contact: Caroline - 01737 823310

Title: PBS International Conference: Implementing Positive Behaviour Support
Date: 8th - 10th May
Location: Birmingham Conference and Exhibition Centre.
Provider: BILD
Contact: http://www.bild.org.uk/our-services/events/bild-2019-pbs-international-conference/

Title: Intensive Interaction for People with PMLD
Date: 9th May
Location: Cambridge Hotel, Huddersfield
Provider: Intensive Interaction Institute
Contact: https://www.intensiveinteraction.org/training/courses/pmld/

Title: Engagement in a Sensory Curriculum
Date: 13th, 14th and 17th May
Location: Manchester, Glasgow, London
Provider: Hirstwood training
Contact: lois@hirstwood.com 01524 426395

Title: PMLD-Developing Creativity through Music and Movement
Date: 15th May
Location: Glasgow, Adelphi Centre
Provider: Concept Training
Contact: t: 01524 832 828
e: info@concept-training.co.uk

Title: Introduction to Intensive Interaction
Date: 17th May
Location: Niland Conference Centre, Bushey
Provider: Intensive Interaction Institute
Contact: https://www.intensiveinteraction.org/training/courses/pmld/

Title: Story Massage
Date: 20th May
Location: Fife, Scotland
Provider: Story Massage
Contact: (www.storymassage.co.uk)
info@storymassage.co.uk

Title: Story Massage
Date: 21st May
Location: Fife, Scotland
Provider: Story Massage
Contact: (www.storymassage.co.uk)
info@storymassage.co.uk

June 2019

Title:	Europe in Action.
Date:	5-7 June
Location:	Vilnius, Lithuania
Provider:	Inclusion Europe
Contact:	www.inclusion-europe.eu

Title:	Story Massage
Date:	4th June
Location:	Chichester, West Sussex
Provider:	Story Massage
Contact:	(www.storymassage.co.uk) info@storymassage.co.uk

Title:	Intensive Interaction for People with PMLD
Date:	6th June
Location:	QEII Jubilee School London
Provider:	Intensive Interaction Institute
Contact:	https://www.intensiveinteraction.org/training/courses/pmld/

Title:	Beginners' Makaton course – parents & carers
Date:	6th – 7th June
Location:	London
Provider:	Becky Lyddon
Contact:	beckymakatontutor@gmail.com

Title:	Story Massage
Date:	12th June
Location:	Portlaoise, Eire
Provider:	Story Massage
Contact:	(www.storymassage.co.uk) info@storymassage.co.uk

Title:	Story Massage
Date:	13th June
Location:	Belfast
Provider:	Story Massage
Contact:	(www.storymassage.co.uk) info@storymassage.co.uk

Title:	Strategies to support learners with SEMH
Dates:	17th, 18th and 21st June
Location:	Manchester, Nottingham, London
Provider:	Hirstwood training
Contact:	lois@hirstwood.com 01524 426395

Title:	Story Massage
Date:	26th June
Location:	Manchester
Provider:	Story Massage
Contact:	(www.storymassage.co.uk) info@storymassage.co.uk

Title:	Intensive Interaction for People with PMLD
Date:	26th June
Location:	Holiday Inn, Birmingham
Provider:	Intensive Interaction Institute
Contact:	https://www.intensiveinteraction.org/training/courses/pmld/

Title:	Follow Up Makaton course – parents & carers (must have completed the Beginners' Makaton course)
Date:	19th – 20th June
Location:	London
Provider:	Becky Lyddon
Contact:	beckymakatontutor@gmail.com

Title:	FEEL IT – an immersive introduction to Sensory Processing Difficulties and how to support children & adults
Date:	28th June
Location:	Birmingham
Provider:	Sensory Spectacle
Contact:	hello@sensoryspectacle.co.uk or www.sensoryspectacle.co.uk

July 2019

Title:	Next Steps with Intensive Interaction
Date:	4th July
Location:	Redhill
Provider:	Us in a Bus
Contact:	Caroline - 01737 823310

Title:	Curriculum at the Heart of Learning
Date:	5th July
Location:	NCVO, Regent's Wharf, London
Provider:	EQUALS
Contact:	www.equals.co.uk; or tel 0191 2721222. E-mail application form to paul@equalsoffice.co.uk

September 2019

Title:	An Introduction to Intensive Interaction
Date:	6th September
Location:	Redhill
Provider:	Us in a Bus
Contact:	Caroline - 01737 823310

PMLD LINK
sharing ideas and information

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Date: ……………………………………………

About Us

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

Rob Ashdown	Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
Jeanne Carlin	Retired Disability Consultant and a parent of a young woman with PMLD.
Helen Daly	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.
Ann Fergusson	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.
Michael Fullerton	Michael the Director of Quality and Clinical Care with CMG, a social care provider supporting adults with profound and multiple learning disabilities. Michael is a registered learning disability nurse and leads a health team focused on the quality of life of people with PMLD.
Martin Goodwin	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.
Joanna Grace	Joanna Grace is a sensory engagement and inclusion specialist. She is the founder of The Sensory Projects which are run on the principle that with the right knowledge and a little creativity inexpensive items can become effective sensory tools for inclusion. Joanna tweets for us on @PMLDlink follow for ideas and information.
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
Becky Loney	Becky has a background in running creative services for adults with PMLD, and now works as a professional advocate and involvement worker for an advocacy charity. She uses creative and arts-based approaches including music, sensory storytelling, and intensive interaction. Becky is also passionate about raising awareness and expectations, to build high quality support that is truly person-centred.
Wendy Newby	Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
Sue Thurman	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.
Bella Travis	Policy Lead, Mencap

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

PMLD LINK

sharing ideas and information

PMLD Link is a journal for everyone supporting people with profound and multiple learning disabilities.
Visit www.pmldlink.org.uk

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