PMLD LINK
sharing ideas and information

Arts and Culture

Winter 2015

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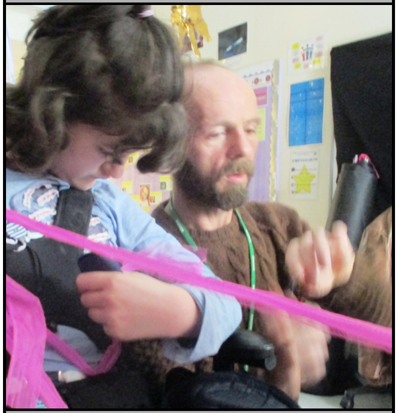
Winter 2015 contents

07 Theatre Venues



10 Sensory Art Project

16 Common Pulse

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

www.pmldlink.org.uk

Vol. 27 No. 3 Issue 82

GUEST EDITORIAL

Arts and Culture

The theme of this issue of PMLD LINK is Arts and Culture and it includes several thought-provoking pieces. The Arts form an important part of our cultural expression and several articles focus on what needs to be done and what is being done to make them accessible to people with PMLD. The first two articles are about making theatre inclusive and appropriate and consider the rights of people with PMLD to be given genuine drama experiences. There follow pieces which set out the case for inclusive experiences in art and music. Yet all artists constantly have to battle with providers and grant-makers to demonstrate the immense benefits and value of their work which, at first blush, is relatively very expensive and most unlikely to bring in any financial profit.

Whilst art, music and theatre form an important part of cultural expression, in this journal in the recent past we have published contributions on other topics. For instance, an important part of our cultural heritage is our great literature and storytelling traditions and several articles in recent years have demonstrated innovative ways of ensuring access. Movement and dance and other activities have also received coverage. Nor must we forget our popular culture – and in the news section of this issue you will find a report on an out-of-the-ordinary Sci-Fi convention..

We are often challenged when thinking of ways to involve people with PMLD in cultural activities which, at first sight, seem out of their reach because of their complex intellectual and other disabilities. Yet these pieces help to illustrate how people have found creative and innovative ways of giving them time and opportunity to participate meaningfully and genuinely achieve in different spheres. People with PMLD can, and should, and should experience pleasure and fulfilment as do others in their community. This is only what we should expect from a truly inclusive society.

As ever, there is also a range of news items and resources made available by various people and the journal has yet again shown that there is much that is stimulating and vibrant happening out there. Included here are articles that, seemingly, have nothing to do with culture but they are all in the various ways related to communication which is probably the ultimate cultural form of expression.

Finally, we have just lost yet another key figure in the world of working with and supporting people with profound and multiple learning disabilities. In October, Loretto Lambe, a fantastic member our Editorial Team, died after a long illness, bravely borne. Ironically, Loretto was due to be the editor of this issue and, indeed, edited some of the articles. Loretto was a champion of the rights of people with PMLD to be valued and was forever campaigning to chip away at the barriers to a truly inclusive society. She was also a leading light in stimulating the development of artistic and cultural activities for people with PMLD and surely would have approved of this issue and its content. The issue begins with an appreciation of her work and her legacy.

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An Appreciation of Loretto Lambe

The PMLD LINK Editorial Team

Our colleague Loretto Lambe died on Saturday, 17th October 2015 after a long battle with metastatic cancer. Loretto was a key member of the PMLD LINK editorial team from the journal's infancy and was also the founder and inspirational leader of the Scottish charity PAMIS. She will be long remembered for all of her work on behalf of people with profound and multiples learning disabilities and their families, carers and supporters. Her husband, Professor James Hogg, paid tribute to her in an obituary rightly saying that his "amazing wife" was an inspiration to so many others (The Evening Telegraph, 21 Oct 2015).

Loretto was born in Sligo in Ireland and trained as a pharmacist. She came to England in 1975 and joined MENCAP working closely with (Lord) Brian Rix. From 1985 she was coordinator for the MENCAP Profound Retardation and Multiple Handicap Section (formerly the PRMH Project) based at Piper Hill School in Manchester. This produced much useful research including a national survey of the needs of parents and carers of children and adults with profound and multiple impairments. A programme of workshops was established to address the priority needs for which parents and carers requested support and advice. The materials from these workshops was made available to anyone involved in service provision for people with profound and multiple impairments; for instance, the organisation of appropriate leisure activities for children and adults. Ann Fergusson, a PMLD LINK editor, recalls meeting Loretto in the 1980s when she was leading the project in Manchester and meeting some families who were involved or using the respite activities she had set up. Ann says that Loretto really was a lone pioneer in truly valuing and 'walking the talk' of authentic partnership working with families - even compared to practice today. Ann says that she took the excellent training and resource materials on to her next job and, in fact, has just recently loaned the early communication set to a colleague!

It was around this time that Loretto joined the PMLD LINK editorial team and both wrote for the journal and secured contributions from her colleagues and many contacts. She helped secure a grant from the MENCAP City Foundation which provided financial stability for the newsletter and ensured that it did not disappear. She contributed in no small way to the evolution of the newsletter into a credible journal and creating a greater balance of coverage, moving beyond school-specific concerns with the curriculum to include coverage of health and social care and inclusion issues for both adults and children.

In 1992 she moved to Dundee where she has lived ever since. She formed PAMIS (Profound and Multiple Impairment Service), the only organisation in Scotland working with people with profound and multiple learning disabilities (for more details visit: http://www.pamis.org.uk). Professor Hogg says: "She was dedicated and for the first couple of years she took no salary herself." The first years have been described as difficult but a breakthrough came when PAMIS was awarded a grant from the Scottish Executive to develop a family support service for three areas in Scotland. From its inception with Loretto as the only staff member, PAMIS has grown and is going from strength to strength due to her vision and leadership. PAMIS now has a staff team of about 20 and provides support to family carers through its Family Support Service, with directors in Tayside, Grampian, South Lanarkshire, Fife and Greater Glasgow and Clyde. The charity also provides support to family carers through the difficult and often stressful period of transition from children to adult services through its Futures Project; an Information and Library Service based at the head office in Dundee; specialist advice and information on all areas concerning complex disabilities; and projects to promote accessible leisure activities. As a founder member of the Scottish Consortium for Learning Disability, PAMIS helped shape the quality and future of policy and services in Scotland. Alice Bradley, a former editor of PMLD LINK, reminds us that Loretto had a strong commitment to partnership with other organisations including the Scottish government. Loretto provides a description of PAMIS in its early days when it had just a small core of staff in the Spring 1998 issue of PMLD LINK and this makes plain her vision for future work of the charity. Loretto retired in November last year as Chief Executive of PAMIS but remained committed to supporting the charity.

Professor Hogg says that Loretto was very pleased that the charity also became a research unit within the University of Dundee. PAMIS has close links with the School of Education, Social Work and Community Education at Dundee University, especially the White Top Research Unit which Professor Hogg planned and directed from 1991-1997. In Loretto’s obituary, Professor Tim Kelly, Dean of the School of Education and Social Work at the University of Dundee, says that Loretto was a tireless advocate for people with learning disabilities. He added: “Her forceful energy will live on in PAMIS and the School of Education and Social work and the wider university remain committed to supporting PAMIS to promote a more inclusive society.”

Loretto has tirelessly campaigned for the needs of people with profound and multiple learning disabilities and their families. She dedicated much of her life to fighting for a more inclusive society, as witnessed by her campaign for Changing Places toilets (there are now 120 in Scotland) and co-chaired the Changing Places Consortium. Alice Bradley recalls that Loretto was involved with the British Institute for Learning Disabilities (BILD) for many years, as an author, adviser to other writers, and contributor to different events. Loretto had an international reputation, particularly through the IASSID (International Association for the Scientific Study of Intellectual and Developmental Disabilities), where she was a member of the special interest group on persons with profound intellectual and developmental disabilities.

Loretto and her colleagues have regularly contributed to the PMLD LINK journal. For example in the Spring 2011 issue, there is an article written by Hannah Young and Loretto on Multi-Sensory Storytelling as an aid to assisting people with profound intellectual disabilities to cope with sensitive issues. Other articles which Loretto has authored or co-authored for the PMLD LINK journal cover topics such as understanding the emotional and mental wellbeing of people with profound and multiple learning disabilities (with Maureen Phillip in Winter 2005), supporting families (Spring 2008), and invasive health care procedures (with James Hogg and Brenda Garrard in Winter 2013). We also know from other publications that Loretto had interests in other artistic and cultural areas; for instance, using the sensory garden for developing a leisure activity and enhancing personal development and social interaction (Lambe, 1995).

Loretto was an enthusiastic supporter of PMLD LINK and right up to the last had been involved in editing this current issue of the journal and in the future development of the charity. Other members of the PMLD LINK team have vivid memories of her. Jeanne Carlin remembers her great story telling ability and humour, including some wonderful stories about her work from the early days when she was linked to Mencap and in particular (Lord) Brian Rix right up to the present. Beverley Dawkins recalls that not long after the launch of the Changing Places campaign in 2006, Loretto asked her to go to go to the Loo of the Year awards event with her - a glitzy event over Christmas lunch. They ate their starters over a cleaning product promotional film on how many thousands of germs are swished around public toilets by cleaners’ mops and their puddings while Les Dennis, the comedian, treated the audience to more toilet jokes than a person should have to hear in a lifetime, never mind one lunch. Having survived all this and the fact that one man on their table was dressed as a toilet duck, Loretto informed Beverley that this was all nothing compared to a trip to the 'World Toilet Summit'. Beverley notes that they were in agreement that one can know things about toilets that are best not to know but once one does they are very hard to forget!

Although saddened by her death, the PMLD LINK team have fond memories of working with her and value her support greatly. She made an outstanding contribution to everyone’s knowledge about people with profound and multiple learning disabilities and how best to meet their needs and make our society more inclusive.

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PMLD LINK
sharing ideas and information
Vol. 27 No. 3 Issue 82

Theatre for audiences with profound and multiple disabilities: is a section of society being culturally short-changed?

Ellie Griffiths

In the safe and cosy bubble of Oily Cart (a theatre company who make interactive theatre for young people with learning difficulties: www.oilycart.org.uk), it's easy to indulge the affirming notion that disabled children all over the world are consistently being treated to thoughtful and stimulating, multi-sensory theatre pieces developed specifically for them.

The parents and carers that come to Oily Cart's shows regularly observe the most amazing reactions from their children, often ones they have never seen before, as one parent articulated:

> "Finley's disability often means that he is always being asked to conform or work hard to fit into a social norm that is not suited to him and so he struggles. But as soon as we walked into the (theatre) space, Finley's differences were embraced and even celebrated. I felt like we were in a bubble of Finley's world and it was just magical. It was a stark contrast to the harsh world outside. I found the whole experience very emotional to watch and the Oily Cart Company have reminded me how wonderful my son is and we should be encouraging people to accept his differences rather than make him 'fit in."
> (Parent of audience member who came to see Oily Cart show The Bounce at JW3 venue (a Jewish arts centre in London), June 2015).

As a Theatre Artist I have created and performed in numerous theatre productions, many of which are interactive and take theatre into different contexts. I have never witnessed such unguarded joy, anarchy, intimacy and as many deeply moving responses from the audience as in this work.

There are other UK companies like Oily Cart who specialise in creating theatre made primarily for people with profound and multiple learning disabilities (PMLD) – but, to my knowledge, only three: an organisation called Bamboozle (www.bamboozletheatre.co.uk), who work mainly with puppetry, one in Northern Ireland called Replay (www.replaytheatrecompany.org) and a relatively new company based in Norwich called Frozen Light (http://frozenlighttheatre.com). All of these companies specialise in creating theatre for children, (although Frozen Light have adapted their current show The Forest for teenagers and adults.). An adult with PMLD currently has almost no access to work that is appropriate for them and it soon becomes clear that audiences with PMLD are by-and-large ignored by the theatre industry.

Internationally, I have heard tell of some 'good stuff' happening in America, as regards other groups of disabled people. The Lincoln Center in New York, (mentored by Tim and Amanda from Oily Cart), recently produced a huge multi-sensory theatre performance for people with autism ages five and above, with theatre company Trusty Sidekick. And in Chicago there is the Red Kite Project (also mentored by Oily Cart). Yet the more I research this field (to inform my own theatre-making), the more I find that these – apparently rather isolated – companies are the exceptions to the rule.

In April I went to the Berlin-based children's theatre festival Augenblik Mal, kindly supported in part by the Scottish children's theatre organisation Imaginate. There, I saw many wonderful shows created for young audiences. The festival spanned a full week and included some highly established, pioneering performances, workshops, discussions and forums. Yet there was NOT ONE theatre piece or talk explicitly for or about audiences with PMLD. There was not even a single 'relaxed' performance (A version of the show which has made an effort to be accessible for disabled people and provide a non-judgemental atmosphere so the young people and their parents/carers can enjoy the show without worrying about disturbing another audience member). I came home feeling inspired, but bewildered.

Article 31 of the UN Convention on the Rights of the Child states that:

> "Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity."

Yet if a whole section of society – in this case children with PMLD – is being excluded from theatre produced for young audiences, can we really say that all children's rights are being respected? I brought this up in a Q+A session with one of the Directors of a well-known and highly regarded European children's theatre company, asking him whether his organisation catered to these audiences. "But of course they can come," was his response. It's worth pointing out that this Director had just delivered an incredibly inspiring and passionate talk about the process of making visceral, sensory, experiential theatre work. Yet it was also perhaps because of this that his answer to my question felt strikingly naïve.

For a parent or carer to bring a child with profound and multiple learning disabilities to a performance, they may have to go through days of careful preparation and planning, risking extreme physical reactions such as seizures, and explosions of challenging behaviour due to the child's routine being broken. Even if the child responds well to the new, usually highly unsuitable environment, the parent or carer cannot guarantee supportive reactions and patience from other audience members. A child with profound and multiple learning disabilities may shout, make noises, move around during a performance, need to be repositioned or indeed make it clear within the first minute of a show, or even on the way to their space in the theatre, that they will not be able to tolerate staying to see the performance. In a society where people with disabilities are so rarely visible in public situations, most people are simply not conditioned to understand how to react or receive this without fear and misunderstanding. There have been several, well documented cases of children and adults being asked to leave a theatre because they are 'disturbing the audience', meaning not only do they miss out on a show they have paid (often very high prices) to see, but also have to deal with the huge shame and embarrassment of being 'removed' in a highly public arena. Most parents and carers are so resigned to this attitude, and a lack of provision of appropriate work, that they simply do not check the theatre brochures or websites or engage with the venues.

The Director's answer therefore seemed to highlight a lack of awareness – which I think is unfortunately quite common – of just how much time, thought, research and creativity needs to be invested in order to make a show both accessible and truly engaging for individuals with profound and multiple learning disabilities. It also occurred to me that his company might be missing out on the audience who could potentially provide the most fascinating responses to their work, and for whom their performances could have the most impact.

However, there was one talk at the festival that gave me hope. It was about a website called the International Inclusive Arts Network that defines itself as a 'global community' of Artists and companies making inclusive theatre performances. It also features an events page and a blog. Yet while the blog is sporadically updated, there does not seem to be an active community using the site and there is currently one event listed…I hate to say it but it does appear to be a big online White Elephant.

To gain insight into how festivals such as Augenblik Mal are curated, I spoke to Tony Reekie, the Festival Director for Imaginate, who has over 25 years experience in the field. He told me:

> "I have never worked with themes in mind when curating a festival, or have any particular slant beyond putting together a varied programme which covers age ranges, genres, moods. And they all should be 'good' or 'very good'. Whatever that means."

Asked whether he knew of any festivals or theatre companies, which gave audiences with disabilities, equal consideration, he said:

> Europe has none that spring to mind. I've always been struck by the lack of wheelchairs in audiences in Europe and the ongoing implications of what that means. They are getting art but it doesn't seem to crossover with the world we inhabit. Beyond the catch-all 'relaxed' performance…"

Could this be a clear indicator that across Europe at large we are still guilty of demanding people with disabilities conform to our world and complex minefield of social rules and rituals, rather than creating a space where, "differences were embraced and even celebrated"

I asked Tony why this worrying precedent might exist:

> "It's difficult for any area to develop when there are so few reference points for others to look at, emulate and go off in different directions from. And cost is a factor, and the danger is that such work is seen, and funded, as health before arts projects…"

I think Tony makes a really good point here, one that takes into account the practical challenges facing children's theatre companies or artists who want to specialise in this work today. This is an issue that requires further discussion in depth.

While all of the above may seem quite negative, I do think there are some positive signs on the horizon. The Arts Council England recently announced a large-scale investment in a project called Ramps on the Moon, which will provide funding to seven different performance venues in England, enabling them to produce accessible and inclusive theatre work. In addition to this, theatres such as The Festival Theatre in Edinburgh, the Lowry in Manchester, and notably the New Wolsey in Ipswich, have made real commitments to making their programmes more diverse, and to fund work that is specifically targeted towards audiences with PMLD. I have also noticed this year's Take Off Festival in Durham includes at least two shows which have specific PMLD versions available, and several which offer 'relaxed performances'. This is all really encouraging and perhaps suggests that UK practitioners in particular can be at the forefront of this vital progress.

As Tony Reekie notes:

> "It's where these islands can be a potential beacon for the world, as our starting point in terms of inclusiveness is further forward than most countries I can think of."

I therefore urge any Artist who is interested in this area of work to capitalise on these investments and take advantage of the support now being offered by venues and funding bodies. Let's make this a talking point at the relevant festivals, forums and theatre discussions, to bring it into focus both within the theatre community and the larger cultural context: shouldn't this audience have the right to encounter different types of art? And shouldn't we, as creative practitioners, embrace the opportunity to cater to different aesthetic sensibilities and tastes?

There is, after all, an infinite amount of diversity within this group. I find it mind-boggling that there aren't sound installations, sculpture exhibitions, interactive photographic projection performances or choral performances made especially for an audience who often has the ability to receive without cerebral, critical judgment and without self-consciousness; who experiences the performance or piece with highly attuned sensitivity and openness, being fully present in that moment. You'd think Artists would be fighting over such an audience.

As Maya Angelou said:

> "If you are always trying to be normal, you will never know how amazing you can be."

I would love to hear your thoughts on this.

Ellie's latest blog, 'Art and Access' (9.11.2015) is very relevant. To view this go to:
https://upfrontperformancenetwork.wordpress.com/2015/11/09/art-and-access-needs-versus-desires-for-audiences-with-pmld/

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NEXT ISSUE

Winter Vol. 28 No. 1 Issue 83

It's all in the detail

Do you have any stories to share?

If so, contact the editors:

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Working with Theatre Venues

Lucy Garland

Frozen Light makes multi-sensory theatre which tours to theatre venues across the UK. Currently we are in the middle of a 26 date tour of our latest show The Forest, which is taking us to theatres from Devon to Dundee. We are hugely enjoying this tour and have already met some incredible audiences.

As we have previously written a lot about our work in PMLD LINK, in this article, I want to concentrate on why we put our work into theatres and how we work with the venues to ensure they are accessible and hopefully leave a legacy of access in their buildings.

So why do we work in theatres and not take our work into schools or day centres? Well the answer is twofold. Firstly we are theatre makers and want to make the highest possible quality theatre we can for our audience. We want to utilise everything a theatre building has to offer, lights, sound, technicians, front of house staff etc. Secondly and most importantly we want people with PMLD to have the opportunity to access theatre appropriate to their needs in theatre venues. Personally, we love going to the theatre and making a big trip out of our day at the theatre, and we think that people with PMLD should also have the opportunity to access this experience. Often we are approached by schools and colleges who want us to come and perform at their institution. We have been told a number of times by schools that it would be much easier for them if we would come into their schools. We understand that it can be incredibly difficult for schools to organise trips out especially for their students with PMLD, but we believe it is important for people with PMLD to be able to access opportunities in their local community. We also want to ensure that people with PMLD are more visible in their local communities, and feel that this can’t happen if people stay in school/day centres all the time. We believe that, if people with PMLD are more visible, then society will start offering provisions for them - like changing places toilets, accessible theatre and other engaging activities appropriate for their needs.

By putting our work into theatre venues we have set ourselves many challenges and we have had to work our way around these by learning by experience. As a small theatre company, selling work to venues is a huge challenge- no matter what type of work you make or who your audiences are. When you add in the fact that the work is only for an audience of 6 people with PMLD and the venue is guaranteed to make a financial loss - then you make the job near on impossible. This is the position we are in.

We spend a lot of time defending our actions to venues. Why is the work only for 6 people with PMLD? It is crucial to us that the work we make meets and reaches the needs of our audience. It needs to be multi-sensory, it needs to be performed at close proximity, it needs to have one to one moments and it needs to be adaptable to the needs of the individual audience member. All of this points to the fact that audiences have to be kept small. Any more people and the quality of experience for the individual is greatly reduced. To anyone that has experienced working with people with PMLD this makes sense. To theatre programmers who are unlikely to have met someone with PMLD and have forever decreasing budgets, this is a really tough sell. Once people have seen our work they completely understand the importance of it, but before that point we have to work very hard to justify why a venue should lose money by programming the work.

For us though, making this work has to be about more than just money. Access is often expensive, but that doesn't mean that we should not make every effort we can to make this world as accessible as possible for everyone including those people with PMLD - and this includes the arts. On this tour we have been programmed by 26 venues. For us this means 26 theatres that understand the need to programme work for audiences with PMLD, 26 venues that understand that this is a bigger question than money and 26 venues that we are working with to open doors and offer theatre experiences to people with PMLD, many of whom have never been to the theatre before. This for us is really exciting. Our last tour was to 18 venues, most of which we are going back to plus more. We hope on the next tour we will be able to reach even more venues and audiences.

Alongside the show we offer each venue marketing and box office training. This not only helps them sell and market our show but leaves them with more knowledge about people with PMLD and the best ways to ensure their venue is welcoming for these audiences in the future. We find that a lot of the staff in venues we visit have never met anyone with PMLD or sometimes any kind of learning disability. For us we want to ensure that we give them the knowledge and information to allow them to feel comfortable when talking about and to people with PMLD. It can be challenging to market our shows; we find that traditional marketing channels often don't work. It is unlikely that someone who cares for someone with PMLD is going to pick up a theatre brochure and expect to find something for the person they care for. Marketing teams have to take a really direct approach - we encourage them to pick up the phone and contact their local PMLD communities. It can be really difficult for venues to convince these communities that our work is for them. I think this is often due to previous negative experiences to accessing community activities. One of the most common feedback we receive is being thanked for making our audience with PMLD feel safe. It's an interesting thing to

hear as when we are in the creative process we are not often thinking about safety. What I think it highlights is how often a carer of person with PMLD may have felt unsafe when previously going to the theatre. When we work with box office and marketing teams we look at making audiences feeling welcome and accepted.

On this tour so far we have found that the venues we are going back to for a second time have previous audiences coming back. There is a hunger from the PMLD community for accessible theatre and selling the show the second time round is much easier because audiences will now pick up the theatre brochure and keep an eye on the website as they know that their local theatre venue programmes work for the person they support. This is absolutely what we are trying to achieve. We want venues to keep programming work for our audiences so that they can access the theatre. We also hope that more companies will start making multi-sensory work for audiences with PMLD and then our audiences will have a theatre experience that is designed specifically for their needs more than once a year.

These are just a few of our thoughts on why and how we work with venues to ensure they programme work for audiences with PMLD. Our strategies are ever evolving and we want to pass on our best practice to theatre staff and venues. We really hope that by touring to so many venues we are spreading the word about multi-sensory theatre for audiences with PMLD.

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We Welcome any Contributions to PMLD Link

We are very flexible in our requirements for contributions to the PMLD LINK journal.

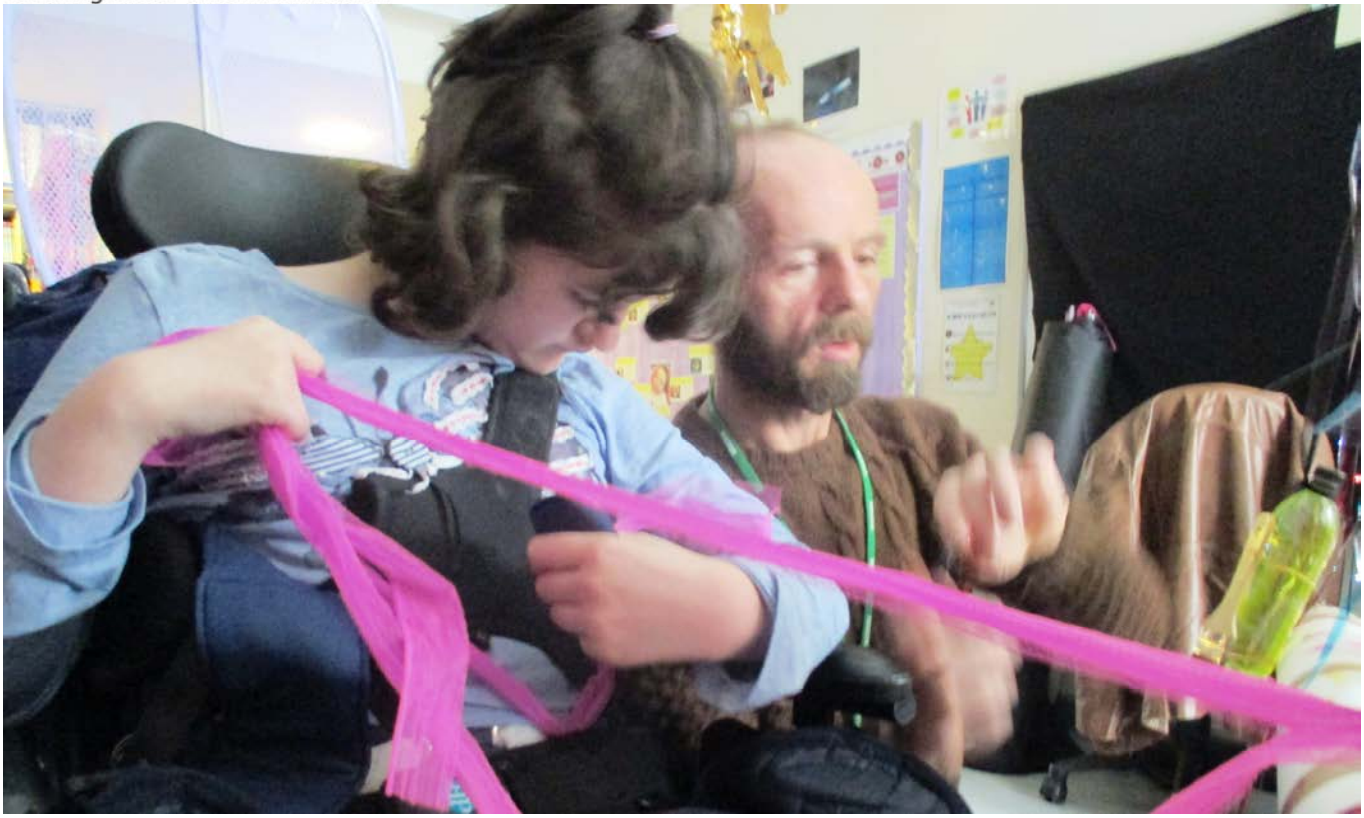
Articles are usually between 1 and 4 pages of A4 single-spaced, regular font size. This usually equates to between 350-1500 words. However we are happy to accept shorter or longer pieces. Ideally, we want you to have the opportunity to discuss what you want, rather than tie you to a fixed number of words.

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

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

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

Email: pmldlink@gmail.com



The Structured Sensory Art Project

Joanna Grace

I wrote for PMLD LINK Vol 26 No 3 (Issue 79) about the incredible journey of The Sensory Project. I am back to tell you about a new part of that journey: The Structured Sensory Art Project. This began in a room full of artists at Cardiff School of Art and Design. I was there to tell them about the wonders of sensory stories. I had just finished telling them about all the hidden benefits of narrative in our lives and how important it is that individuals with PMLD get the opportunity to access these benefits too when I stopped and looked around the room at graphic designers, fine artists, ceramicists, sculptors, and more. What, I wondered, did they get out of engaging with art? I broke off from my presentation to ask. The answers that they gave were the start of the Structured Sensory Art Project.

Not one artist mentioned an end product as the reason for their engagement: they did not paint to produce a painting, sculpt to produce a sculpture. The answers were personal but themes emerged: they engaged in art in order to better understand themselves, to better understand the world, and to benefit their mental health. These things were all things I wanted for people with PMLD. I began to wonder if, as with narrative, there was a sensory way to achieve them.

In the Summer 2015 edition of The SLD Experience (Issue 72) I wrote about the research rationale behind the structure of the sessions talking about the importance of expression for mental health; structuring sensory experiences for engagement, valuing staff and staff engagement; responsive environment, and also about the role mindfulness and silence played in our sessions. For those who are interested in the references to the research skimmed over here these can be downloaded from http://jo.element42.org/the-structured-sensory-art-project. In the present article I want to spend more time with the artists, and give you a sense of what they experienced.

The aims of the Structured Sensory Art Project were to:

1. Provide individuals with PMLD with the opportunity to independently create works of art.
2. Leave a legacy of engagement behind in the settings where it works, giving those supporting individuals

with PMLD the opportunity to look through fresh eyes. (Mencap, BILD and The Renton Foundation (2010/11) page 10 and Carpenter et al (2011)).

3. Create awareness of the abilities of individuals with PMLD and of the individuals themselves, with the hope that increased awareness will benefit campaigns such as Changing Places. (www.changingplaces.org.uk)

The pilot project ran in Curnow School with 8 artists who have PMLD and was supported by staff from the school as well as a volunteer team from The Sensory Project led by myself. We ran a four session pilot. I hope that in future, settings hosting the project will be able to run at least 8 sessions so that the artists can get the most out of the experience. We were getting more responses and more interaction from the artists as the sessions continued. It would have been fantastic to see what would have happened next.

Did we achieve those aims?

The exhibition, 'Uninhibited', formed out of the artworks produced by the artists who took part in the project, is touring the UK until the end of 2015. Tour dates and locations can be found on http://jo.element42.org. The title of the exhibition, 'Uninhibited', was chosen to reflect two things: the uninhibited self-expression achieved by the artists taking part in the project, and that creativity is not inhibited by disability.

I did not want people to view the art works in a kindly sympathetic manner, appreciating them because they were done by people with disabilities. I wanted them to appreciate the rawness of what they are seeing, the extraordinariness of uninhibited creation. Artist James Eddy endorsed the exhibition saying: "The difference between direct representational drawing and free expressive creation is simple. The first is limited by what the eye and mind can see, the second is open to what the soul can feel."

Expression in the form of sound or movement was also valued. Ali Golding of Movement Works, who was a wonderful source of advice and guidance throughout the setting up of the project, said "Movement is one of the most fundamental forms of expression. Through movement we explore and through movement we experience and understand – all of our movement experiences matter." Perhaps future iterations of the project will be able to display the full range of the artists' expression.

My favourite piece of feedback for ambition two was a member of staff in the school who told me: "until we tried this he was only interested if he was using the eye gaze; we've been using your technique and he's been doing everything all week."

The technique in question is nothing magical. Like everything at the Sensory Project it is low cost and simple to do: we used small bull dog clips and thread to connect the artist to their brushes so that they could paint with any movements and were not restricted to their hands. Informally between the Sensory Project team we came to call this the 'reverse marionette'. The artist looks like a marionette, in that they are attached to strings, but they are not being controlled - they are in control! I have stayed in contact with the school and know that they are still using techniques like this that they discovered during the project.

Many people contributed to the creation of the Structured Sensory Art Project. Jill Goodwin at Tingly Productions was a fantastic source of knowledge and insight and challenging questions. If you attempt a project like this, so many people will nod and smile and say "how nice," whereas Jill was very keen that it be meaningful and not tokenistic. Our discussions were wonderfully challenging and kept me on the straight and narrow. Jill and I discussed how art for people with PMLD can often be a process of having things done to them, rather than getting the chance to do. I do not wish to say that, for example, hand printing with an individual with PMLD is not a valuable activity since it may well hold wonderful social and tactile experiences – but is it art? Does it achieve those things the artists in Cardiff spoke of? To be art I wanted the creation to be as independent as possible. Jill made me aware of the wonderful Project Art who do this sort of thing all the time; co-founder Kate Adams' words about her son stayed in my mind throughout the whole project and I waited to see whether the art produced would all look the same with baited breath:

"We all express ourselves differently, but the images made by my son Paul, who has severe intellectual disabilities, and the other children in his class at his special school, were always all the same. I was disturbed by this at the time and put it down to the teachers and assistants physically helping the children to hold brushes and tools, and their well-intentioned desire to help the children produce images that looked like art. The children were distinct and individual in their ability to create art, but this was not communicated in the images they produced."

(Adams, 2013)

You can see the art work produced by the artists on http://jo.element42.org although this is no substitute for seeing it in the flesh. So if you can make it to one of the galleries hosting the exhibition do come along! I have not got room to share every artist's story, however much I would like to. Here are Chloe and Gabriel's creation stories.

Gabriel

On his first visit to the studio Gabriel responded with distress over the change to his classroom. In subsequent visits he displayed increasing curiosity and confidence, staying in the studio for longer periods of time. On his final visit to the studio Gabriel interacted with a pendulum brush made especially for him. We chose a brush made of a suspended feather duster based on what we had seen Gabriel show interest in during his earlier visits to the studio. Gabriel's painting was created through his interaction with the whole studio experience; the actual marks were caused by Gabriel being wheeled towards his brush. You could argue that the marks were, therefore made by Gabriel's facilitator, but that misses the reason behind the movement. The motive for the movement was Gabriel's responses, his facilitator followed Gabriel's joy. You can see in the photos that at the start of the session Gabriel does not appear connected to the environment. In later photos we see him making a connection with his facilitator, this shared connection feeds into the creation of his painting, which having been there as it was painted I feel truly represents the giggles giggled as it was created. Gabriel showed awareness, and enjoyment, of the marks as they were made.

Chloe

Chloe loved taking part in the warm up section of the session, but on the first two sessions did not interact with her brushes when it got to the independent creation part of proceedings. One of the Sensory Project volunteers had been advised not to touch Chloe as she was tactile defensive.

On the third session encouraged by advice from Ann Fergusson we decided to try a more tactile approach. We began by firmly squeezing Chloe's shoulder and then following this movement all the way down her arms, to let her know that it was going to be her arms that she was using. When our touch reached her hands we lifted them, touching the back of her hands only, and positioned them on her brushes which as you can see from the photo of her rig had a variety of sensory properties. We were delighted that this worked. Chloe was pleased to find her brushes and painted confidently.

On her final session we gave Chloe the opportunity to collaborate with another artist and together they created a huge piece on a rig of pendulum brushes that we set up so that collaborations would be possible. Much of this escaped camera. I wanted to be a part of things and not be distracted by recording, so the photos we have are in no way comprehensive.

The photos showed Chloe's obvious enjoyment of the warm up section of the sessions, her disinterest in her pendulums initially, the paired rig she used, Chloe working with facilitator Greg to swing the big rig pendulum, and Chloe mingling with her work at the end of a session. I also have on my hard drive a wonderful but incredibly short clip of Chloe and Greg dancing with their heads to the music we created.

Contact Details

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A complete list of references for the project can be found as a download at the bottom of http://jo.element42.org/the-structured-sensory-art-project

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James Eddy (www.james-eddy.com)
Ali Golding of Movement Works (http://www.movementworks.org/)
Jill Goodwin at Tingly Productions (http://tinglyproductions.org/tingly_productions/Home.html)

Vol. 27 No. 3 Issue 82

Intensive Interaction Through Music

Sarah Hodge

I stumbled upon musical interaction during a rainy day over the summer of 2014. I was desperate to find a new approach to communicate with my group of pupils with PMLD. I read the work of Prevezer et al (2012) and was inspired to attempt this approach with my pupils. The initial reading I carried out focused on work with pupils with autism spectrum condition (ASC), however with further probing, I have drawn on the work from a range of sources (please see references).

Musical interaction is based upon the principles of Intensive Interaction (Imray and Hinchcliff, 2014). Intensive Interaction is a well-known approach used to interact with pre-verbal individuals (e.g. Caldwell, 2005; British Institute of Learning Disabilities, 2004; Nind, 1996). Musical interaction is: 'based on the principles of Intensive Interaction and music therapy with its exponents arguing that it allows and encourages valid musical experiences; allows and encourages personal interactions; is a motivational communicative tool; is suitable for all learners (PMLD, SLD or ASC) who are at the earlier stages of communicative development and does not require musical ability on the part of the teacher' (Imray and Hinchcliff, 2014:95).

As a non-music specialist, the last line of this quote gave me the confidence to attempt this approach with my pupils!

From my reading, musical interaction encompasses a range of activities including the use of instruments, sensory props, games, songs and rhymes, anticipation games and work with a musician. This short paper only focuses on a small aspect; therefore I have presented this as Intensive Interaction through music rather than as musical interaction.

Aims

The aims of my music sessions are to encourage and promote:

- social interaction through a playful and social activity
- the development of communication skills (Prevezer et al, 2012)
- active exploration of the environment
- focus upon and response to a stimuli
- self-awareness (Prevezer et al, 2012)
- the opportunity for pupils to guide and control an interaction
- Pupils' confidence through pupil-initiated activities (Goodwin and Edwards, 2009)
- and finally, to interact 'with the child by entering in to their world by joining and mirroring' (Nind and Hewitt, 2001, cited in Goodwin and Edwards, 2009:3)

Intensive interaction through music in my lessons

My most sensory learners are those pupils working within P levels 1-3 who require multisensory techniques to promote their learning with a particular emphasis on using visual and tactile cues rather than auditory cues. We begin each session with the pupils exploring the object of reference for music. For our sessions this is a CD; this is consistently presented throughout the school to encourage pupils to anticipate and know that they are about to take part in a music session. We then observe the pupils; what movements are they naturally doing? This could be blinking, breathing, moving their head from side to side or movements of their hands/fingers or feet. Caldwell (2005:4) notes that people with PMLD 'are locked into a world of their own…[and] may be listening to feedback as unnoticeable as their own breathing rhythm, or the sounds of sucking their saliva'. It is this action, of the pupil communicating to themselves (Caldwell, 2005), which we want to reach and use as a starting point for interactions.

Once a movement has been identified, I then select the most appropriate instrument to match that movement and play it each time the movement is observed. Over the period of a few months we have seen these learners respond to the sounds and movements created by the instruments. The responses from these pupils have included smiling, laughing, reaching out towards the instrument and changing the tempo of their movements. Pupils have also begun to show an understanding of contingency responding. To see these responses have made these sessions magical!

Mohammed spends large amounts of his day moving his head up and down. He is a learner who occasionally *explores objects in his environment. Each time he moved his head, a tambourine was shaken. Over the course of two terms, Mohammed progressed to watching the tambourine as he moved his head. Towards the end of the third term he reached out to the instrument, giving eye contact to the adult and a smile!*

Ben enjoys clapping his hands throughout the school day. As he clapped his hands, a supporting adult tapped the drum. Initially Ben continued clapping, glancing occasionally at the drum. As this progressed over the year, he changed the speed at which he clapped. He also increased the frequency with which he glanced at the drum. By the end of the year, he reached out and held the adult's arm as she tapped the drum, giving her brief eye contact.

Some pupils have the ability to reach, grasp, and move instruments. During music sessions these pupils are offered two different instruments and encouraged to choose/indicate a preference. Pupils are then given their choice to explore. I had matching pairs of each instrument and would use the corresponding instrument to copy their movements. Initially pupils did not notice me opposite them, mirroring their movements, however over time pupils have recognised my presence and movements with positive results:

Charlie chose the hand bells from a choice of two. He instantly explored the bells by shaking them and moving them from side to side. After half a term, he noticed the adult was copying his actions and responded by laughing! After two terms, he changed the position of his instrument, from one hand to his other and placed it above his head and by his knees. He then began to look between his own instrument and the adults. Over the course of the year he increased the length of time he gave eye contact. He recently started to immediately look to my instrument and waited for me to be ready before he began exploring!

I have observed pupils communicate 'more' and 'no more' more readily during these activities. I have also witnessed lovely social interactions during this activity with pupils responding with increased eye contact and vocalisations, pupils reaching out to 'swap' instruments, smiles and laughter. One pupil, Anaya, displayed turn taking skills:

Anaya held a beater and tapped the drum. The supporting adult sat opposite her and tapped it at the same time. During the interaction, the adult became distracted by the environment and did not tap the drum in time. Anaya stopped tapping and looked to the adult and waited. The adult tapped the drum, then Anaya tapped, thus a turn taking game was established!

As the sessions have progressed, we have become familiar to which sounds pupils prefer and use these during our interactions with them. Typical responses from my pupils include stilling, eye contact, listening and pausing, turn taking, focusing upon a specific stimuli, active exploration of instruments, vocalisations, facial expressions and anticipation. Increased confidence and self-awareness have also been observed over the course of the year.

Concluding thoughts

The ultimate aim of my music sessions is to engage pupils in an interaction. Successful interactions are playful and show an increase in pupil confidence and self-awareness over overtime. Whilst I am still in the infancy of fully implementing musical interaction, I am greatly encouraged by the observations of my pupils so far.

In the world of our pupils with PMLD where much is 'done' to them, intensive interaction through music is an avenue in which pupils have the opportunity to exert control over their environment, thus empowering pupils. For these sessions to be effective we must value all forms of communication, be highly sensitive to pupils, ensure the interaction is led by the pupil, be patient, work at the pace of the pupil, and be highly attentive.

I have now worked across my school's 'PMLD department', with pupils aged 3 to 19 years. Teachers have been surprised by pupils' responses and these simple activities are now becoming established during music and communication sessions in our school. We currently do not have access to a music therapist; however it is my aim to form contacts with experts in this field to further enhance and develop my understanding and practice.

As Hans Christian Andersen once said:
"Where words fail, music speaks."

NOTE - names have been changed to maintain anonymity.

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Finding Our Common Pulse

Rachel Swindells, Ros Hawley, Mark Fisher and Juliet Goldbart

Common Pulse was a year-long music project for disabled children and young people, run at the Seashell Trust, Stockport, in collaboration with Manchester Metropolitan University (MMU). Funded by Youth Music, the aim was to make better use of Seashell Trust's Javanese gamelan, developing it as a resource for students, staff, families but also the wider community. To achieve this, the project involved multiple strands, including family and holiday projects, staff training sessions, and an evaluation led by MMU. At the heart of the scheme was a series of weekly gamelan workshops for students with complex learning disabilities drawn from across Seashell Trust's in-house school: Royal School Manchester.

Gamelan: what and why?

Gamelan is an ancient form of music ensemble made up of ornately carved percussion instruments (gongs, metallophones and drums) originating from the Indonesian islands of Java and Bali. Aside from its exciting range of instruments, what sets gamelan apart from other musics is the communal and egalitarian approach to music-making which defines the tradition. Collective musical expression is valued over individual skill, with the gamelan best thought of as a single instrument with many players. Due to the accessibility of the instruments, it has become increasingly common to find gamelan used in inclusive education and arts outreach programmes outside of Indonesia. While the Seashell Gamelan was purchased in the early 1990s, originally for use with students with hearing impairments, previous research has highlighted the potential applications of gamelan with wide-ranging populations including: adults with learning difficulties (McDonald et al., 1999), and physical disabilities (Sanger and Kippen, 1987), children with autism (Bakan, 2008) and in an SEN school setting (Loth, 2014). Few projects until now, however, have focused on using gamelan with individuals with more profound and multiple disabilities.

Student gamelan workshops

The primary objective of the weekly gamelan workshops was to enhance students' wellbeing, while developing social and musical skills. Twelve students aged between 5 and 15 took part, each assigned to one of two 45-mins sessions which ran throughout the academic year. Some students were recruited because they are known to enjoy music; others were put forward because they find busy environments difficult and it was felt participating might be therapeutic in this regard. Sessions were led by two specialist musicians and a gamelan practitioner in collaboration with members of Seashell Trust's education and therapy staff. Individual students came to the sessions with at least one support worker, with attending staff considered integral to the project team.

From the outset, the key challenge was to devise a way of engaging participants with diverse preferences and needs in what is a collective group activity: gamelan only makes sense when played as a united ensemble. This was tackled in several ways. Notably, delivery was grounded in a holistic, community arts approach which sees high quality music-making as intrinsically motivating and worthwhile. An ambition was to immerse those taking part in an aesthetically pleasing soundworld and one way this was achieved was through the recruitment of additional musician-volunteers. Importantly, having extra players on hand to keep the music going freed up the lead musicians to work more closely with those students requiring additional support. Cultivating respect for the music made in sessions was also achieved through, for example, decorating the gamelan room, training staff about gamelan within Indonesian culture, minimising off-topic chat and valuing listening.

To ensure maximum accessibility, students were encouraged to participate in the sessions in their own way – for example, by playing (with or without physical support), singing/vocalising, dancing, listening, observing, or, for those who needed more structure, following visual symbols. Likewise, a pragmatic approach was taken to attendance: students and staff were invited to drop in and out of sessions as appropriate to individual needs (as would audience members at a traditional Indonesian performance!). For some students 45-mins was too long a slot, while others needed at least 15-mins to attune to what was going on before being able to participate more actively.

Over time, a structure emerged whereby traditional repertoire was interspersed with opportunities for freer, student-led music-making and interaction: e.g. through 'conducting' group improvisations or turn-taking based musical conversations. Staff commented on how the gamelan pieces provided a framework (e.g. opening and closing songs) and enjoyable musical focus, but also a relaxing backdrop to nurture social interactions with students. Equally important, however, was the space left between pieces, which enabled students to shape session format and content. While most participants could not verbalise what they liked or did not like, they could and did show the musicians, whose creative responses sought to mirror students' sounds, gestures and/or vocalisations. One teacher commented that what was most beneficial was the "focus on listening to students rather than trying to teach them". Listening to students and attempting to understand their subjective experiences of music, as an embodied and multi-sensory phenomenon, was also highlighted as key by one of the specialist musicians.

"As musicians we learn to listen to pupils... we have to step into their world of sound – their time, their pace, their sense of music – so that we can understand and say, 'I can hear you' in our music making together. Music with these children is about touch, feel, sensation and frequency. It is about trust, confidence and feeling comfortable. It is about expression, but in order to be heard, we need to make it known that we are ready to listen" (Musician)

Next steps

Although the project has finished, the weekly gamelan sessions are continuing, led by two musician-volunteers who have recently been employed to ensure the project's legacy. The project evaluation is also ongoing. Preliminary findings indicate the gamelan sessions had numerous positive outcomes for students beyond the immediate enjoyment of participation. Reported short-term benefits ranged from anxiety reduction and improved tolerance of a busy environment, through to enhanced motivation to interact with others, improved self-confidence and the identification of latent musical abilities. The project team considers this to have been a successful pilot project and is now looking to develop a larger-scale research initiative to take this work forward.

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For further information about the Seashell Trust go to:
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The Sensorium

Steve Hollingsworth, Alison Stirling and Gordon Dutton

Steve Hollingsworth writes:

I've worked as an artist for Artlink, Edinburgh for the past 15 years, a charitable organisation that aims to bring experiences of art to those who are marginalised (http://www.artlinkedinburgh.co.uk).

An experimental strand of Artlink's work is a project called Ideas Team, this is where new ideas and artworks are developed around specific individuals with severe disability (http://ideasteam.org). The key to this work is how to empower people with profound and multiple learning disabilities to enter a sensorial world by their own choice rather than have that choice controlled by others. The first step is to surround a person with disability with an artist, care-workers, a psychologist, parents - like a type of ethics team who have at the centre a desire to create a unique artwork for the person in question to change perceptions, open up new perceptible worlds and to create agency for people who have the world imposed on them.

I was tasked with making a bespoke artwork for an individual with profound disabilities called Ben. Ben has complex needs and his carers help Ben in his day-to-day life. My interest was in going beyond his immediate needs and to engage Ben in wider sensory experiences that he could be in control of and gain enjoyment and stimulation from. Initially this entailed getting to know Ben - his personality and his preferences and also what he could perceive. Through working with Dr. Gordon Dutton, who is a paediatric ophthalmologist, I discovered Ben could only see elements in the upper part of his visual field. Having this knowledge enabled me to make sure Ben was able to see and hear the experiences I gave him. Over a period of 2 years I continually experimented with different types of sound and music and forms of light, slowly discovering what he enjoyed and responded to. I found that Ben loved high pitched sounds and, using this knowledge, I started to think about journeys and I wanted Ben to be able to 'travel' through sound and light. I gathered sounds that the planets make through their magnetic fields and accumulated images from the Hubble space telescope in order to allow Ben to go on a sensory celestial voyage in line with his unique perceptual abilities.

Working with Dr. Lauren Hayes of Edinburgh University we developed a computer-based system that is controlled by a joystick. Ben can use the joystick to discover sounds and move through a projected image giving the illusion of movement together with a colour changing LED system. His voice and the sounds he makes are also amplified and processed providing him with another reference of his presence in the unfolding combinations of light and sound he controls.

Ben has never controlled any sensory aspect of his life before. For him to be able, and inclined, to control his own stimulus and continually learn to do more is a huge step forward in having control in his life.

Alison Stirling writes:

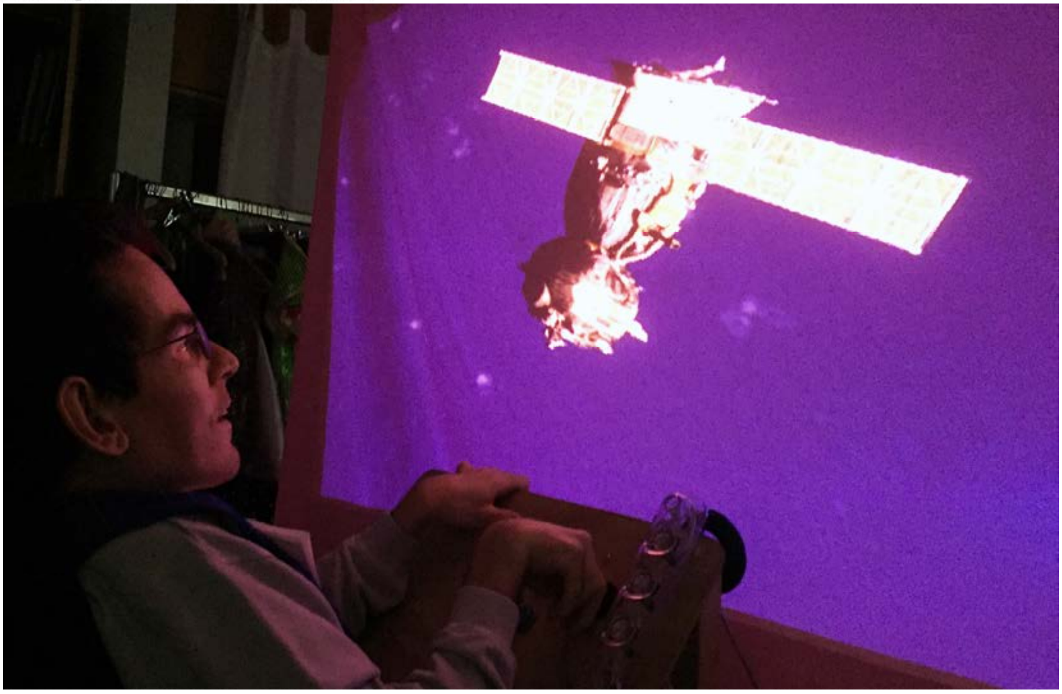
Steve Hollingsworth is an artist and a Ph.D. candidate at The Royal Conservatoire of Scotland. He explores the tensions between Sound, Light and Time, and is influenced by the profoundly different subjectivities he encounters in his work with Artlink.

The Sensorium currently exists in a prototype form: a functional sketch of an ambitious idea, regularly used and continually informed by two disabled individuals presently. Steve will further develop the Sensorium over the next two years, creating an artwork that can be used by many different people with profound learning disabilities.

The completed Sensorium will allow an individual to travel through the senses of sound, light, and potentially; vestibular and olfactory space: an amalgamation of slow-time thinking informed through acute observation in workshops with groups and individuals. Employing a wide range of ideas from Philosophy, Aesthetics and Vision Science, it will uniquely engage all people on whatever part of the perceptual and intellectual scale they happen to be and allow access to new perceptions driven by the choices and interactions of the user.

Gordon Dutton writes:

As a clinician who has spent many years working with children and adults with impaired vision, often associated with developmental and learning disorders, my view is that it is important to bring about a sense of pleasure and fulfilment through the medium of artistic



expression for all those who typically have limitations in access to both their surroundings and society.

The work of Steve Hollingsworth brings a refreshing new perspective to this ambition. Instead of being hidebound by the negative medical dogma of disease, disorder and disability, the approach he takes is to accept that everyone is ‘normal’ and to work towards ensuring that artistic presentation is accessible and interesting to all.

We each tend to assume that the world out in front of us is there for us to see with our eyes. However, the processes of seeing, recognising, visually understanding and moving through the environment through visual guidance, are now known to be entirely brought about by and within the brain. This is a complex process served by multiple brain areas and structures, wherein the process of vision is integrated with input from all the other senses, and our prior memories and knowledge. This internalised virtual, meaningful, constantly refreshing, multimodal, brain based representation of the external world accords us our internal reality, which we immediately endow upon what we perceive, by projecting it onto our environment, so that we can appreciate it and move through it without incident. Although this printed document is compelling out in front of you the, reader, its representation is in your mind, and it is this representation that you are currently processing.

So what happens if this representation of the outside world is impaired by damage to the brain? The outcome is an alternative form of internal representation in the mind, which is ‘normal’ for the affected person, who is unaware of what others are perceiving, yet may not see or may misinterpret what is presented, because it has not been rendered accessible. There is therefore a compelling need to develop a form of art, which, by designing and producing multiple salient elements that fall within the perceptual limitations of those with multiple disabilities so that they too can enjoy it in their own unique ways, and share this experience with those around them.

Steve Hollingworth’s creations take into account that the multiply disabled, uniquely appreciate what they perceive in the light of their own prior experiences and understanding and can, like everyone else, be entertained by, and appreciate key elements of multimodal artwork, in sound, light, colour, form and movement when elements of each modality are matched in their presentation, to fall within the limitations (or thresholds) for perception, attention and appreciation of the disabled observer.

From a social perspective Steve’s approach philosophically accords entirely with the conceptual frameworks which underpin disability legislation, as it extends the principles of the rights of the disabled to have access to the environment beyond the practical physical perspective, into the sensory and experiential domains of art, whereby they too can share in the experiences and pleasures of artistic expression.

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Gordon N Dutton is a Paediatric Ophthalmologist and Emeritus Professor of Visual Science at Glasgow Caledonian University

To view a video related to the developments discussed in the article go to: https://vimeo.com/142789529

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A Multidisciplinary Approach to On-Body Signing

Andy Thomson

Communication is intrinsic to our relationship with art and culture. We interact with art, culture and each other in a reciprocal manner and, as professionals, we support individuals with PMLD to interact and engage with the world around them.

In the borough of Dudley, West Midlands, several professionals working with children and young people with PMLD have teamed up to standardise the use of on-body signing (a tactile form of signing which the individual can feel to learn more about their world) across schools and beyond. The group comprises speech and language therapists, teachers of the visually impaired, intervenors for the visually impaired, teachers of the deaf, members of our Autism Outreach Service, staff members from special schools and a university lecturer in special educational needs (SEN). Despite the wide range of busy professionals, we manage to coordinate a meeting each school term to consider the implementation of communication strategies across various settings. Each group member brings their own professional knowledge and experience, but all joined because of their commitment to supporting the communication needs of children and adults with PMLD, particularly those with concomitant visual and/or hearing disabilities. Since the group's inception some six years ago, members have changed, but the ethos remains the same.

The group was borne out of a shared opinion that it was important to standardise the use of on-body signing and Objects of Reference (objects used to represent people, places and activities) in special schools. This consistency would, hopefully, make transitions an easier process for some of our most complex learners. In the Dudley borough, we now encourage use of a consistent set of on-body signs with the children (and, as of recently, with adults) who are not able to access Makaton signs. These on-body signs are taught to school staff, parents and carers – anyone who works with the individual in question. Anecdotal evidence suggests that use of these signs is empowering for the people working with these learners as they feel better equipped to support understanding of instructions, routines and transitions.

In Dudley, Makaton is used as the signing system to support people with SEN (www.makaton.org). With a working knowledge of Canaan Barrie signs (a sign system involving touching the learner's hands or body; see Seith, 2010), it was decided to adapt Makaton signs to support learners with PMLD and multisensory impairment. To provide the learner with information about what is going to happen, the person working with the learner completes a sign they can feel (and, therefore, do not have to look at or see). As the signs take place on the learner's body, particular care was taken not to be intrusive as the core list of signs grew to about twenty. As with the use of Objects of Reference (which the group has also worked to standardise across settings), these signs were used to provide the individual with information about what is going to happen or what is expected of them. Important messages were agreed upon – 'ready, finished, more, again, eat, drink, home', etc. Implementation of these signs was incorporated into individualised education plans and speech – language therapy targets. The people working with the individual are taught the signs and progress is reviewed.

In addition to a review of progress of those children and young people already experiencing these signs, work has now begun on a case study involving children who started school in September 2014, who had not previously been exposed to on-body signing. Information will be gathered from the teams around these children as regards the developing understanding of instructions and routines, which we hope will support our colleagues working with preschool children in Dudley. Since working with a speech and language therapist working with adults with learning disabilities, day centres and residential care settings have also expressed interest in our work. Developing such long term goals was always our intention and we are really enthused by the prospect of supporting learners before and after they access the school settings in which we work.

Being a member of this group has been a really useful part of continuing professional development – use and development of the on-body signs is constantly reviewed and particular cases are discussed (with respect paid to confidentiality). The group now has a representative working with adults with learning disabilities and is just starting to work closely with colleagues in preschool settings. Each of us regards the multidisciplinary nature of the group and the team working this engenders to be a real asset. The commitment of the members is apparent to all – we are aware that it is an important process in a changing educational landscape that we continue to strive to support understanding and access to the curriculum. This commitment is strengthened as we reflect on the origins of the group – initiated by Pat Denham, teacher of the visually impaired, who passed away suddenly in June, 2012. She is missed by all who knew her and the continuing work on on-body signing in Dudley is dedicated to her.

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PMLD LINK is a 'not for profit' charity

PMLD LINK was established to make a difference to the lives of children and adults with profound and multiple learning disabilities (PMLD). People with PMLD have profound intellectual and multiple disabilities, very severe communication problems, often extreme physical and/or sensory disabilities, and complex health needs. Their needs are frequently overlooked by more general support organisations for people with learning disabilities. PMLD LINK maintains a clear focus on this small and often hard to reach group. Since 2007 PMLD LINK has been a registered charity and its affairs are managed by volunteer trustees who have in-depth knowledge and are relatives of people with PMLD and/or are professionals with backgrounds in relevant health, education or social care services.

PMLD LINK is a 'not for profit' charity and its trustees and editorial board are all volunteers who give their services for free. All profits from the sale of the journal and all donations are used to maintain the production and posting of the journal, the development of the website and the management of Facebook and Twitter for networking and information sharing.

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

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Pause, Play, Rewind

Jules McKim

Pause

‘Stop briefly’, ‘hesitate’, ‘break’, and ‘wait’ are all synonyms of the word ‘pause’, which is used here to denote a certain behaviour, or perhaps a reduction of behaviour, during an interaction with someone. Pausing is central to the practice of Intensive Interaction. Intensive Interaction is “an approach to facilitate two-way communication with people with severe or profound learning disabilities and/or autism, who are still at an early stage of communication development.” (Department of Health (2009, p.38). The development, theory and practice of Intensive Interaction is described extensively in books and papers (Nind and Hewett 2001; Nind. and Hewett, 2005; Hewett, 2012; Hewett, Firth, Barber and Harrison, 2012; and Firth and Barber, 2011). Here I offer a framework to keep in mind key elements of practice while using the approach with people with PMLD.

Pausing itself is a useful habit to develop in all interactions: it allows action to be taken rather than a reaction to happen (Covey, 1989). Our reactions to events can sometimes feel like they have come from somewhere else! How often do we feel we have over-reacted or reacted in a way that on reflection we realise wasn’t helpful?

Pausing allows us to hold back, to observe, to process, to make our next step conscious and deliberate. I believe it is a habit we can develop. The ability to be still and allow things to unfold, can, with practice, be rather effortless. It is a form of not-doing; but the urge to do something is what takes time to undo. Mindfulness practice is a useful skill to develop in this respect. Kabat-Zinn (2011) defines mindfulness as paying attention on purpose to the present moment, non-judgmentally. With practice it will facilitate the process of pausing, tuning in to the person we are with and noticing subtle changes in their activity and mood.

Pausing is useful before we even start to interact. A pause in our routines and normal ways of supporting someone. A pause to observe and really look at the person. What are they doing when they are on their own and no-one is asking them to do anything? What do they do of their own volition? What are their hands doing? What are their eyes doing? What sensory input do they seem drawn to? This type of in-depth observation can be enlightening for many staff, especially those who have been working with the same individuals for a long period of time. Mindfulness assists us in responding to the person in the here and now rather than being preoccupied with thoughts of how they were previously or how we would like them to be. Having a beginner's mind can help us to ensure we have no assumptions about the person we are planning to interact with and truly see them once again, as they are, in this moment. This is the closest we can get to true person-centred thinking and behaving.

Pausing allows the person we are interacting with space and time to process, to integrate, to assimilate what has gone before. It also allows them to take a turn. Turn-taking sequences within an interaction with someone with a communicative impairment can only be possible if we pause and allow them to set the pace.

I joke in my work that I have Duct tape in my bag and will use it on chatterboxes who find it hard to be quiet. Joking aside, these habits can be hard to change. Those of us working with people with PMLD have often some history of entertaining, talking to, and enthusiastically encouraging people. It can therefore feel counter-productive to pause and wait.

Perhaps too, many of the people we are engaging with have learned to be passive. If they have had a life of being entertained, of being pushed and pulled from one experience to another, recipients of input rather than agents of output, they may not know yet how to fill a pause. With time and repetition and careful and respectful pausing their confidence will grow to fill the available air time.

But really it isn't a pause. We are pausing without input. So, we will be quiet, not prompt, not repeat the question, not wave the tambourine in the person's face. But we will still be engaged, tuned-in, waiting to respond to the person when they do something with a finely-tuned sense of timing: just the right response at just the right time (Schaffer 1977).

Research into caregiver-infant interactions concludes that there is a lot of not much happening, lots of waiting, lots of holding back by the caregiver (Brazelton, Koslowski and Main, 1974). Pausing here is necessary to provide contingent responding and also to leave spaces for the learner to respond, i.e. to facilitate the process of turn-taking. As infant-caregiver interactions are the natural model of communication learning, we can usefully adopt these behavioural observations to support the development of communication skills for people with PMLD.

Play

So, now, with the right intentions and in the right frame of mind we can start an interaction. Push play! The natural, informal pedagogy of everyday life for all of us is rooted in play and develops our awareness of self, environment and other and how to be social and relate to others (Tharp and Gallimore, 1988). An attitude of playfulness is necessary because it provides enjoyment for both parties and therefore there is in-built motivation to repeat the experience. Through play we learn about cause and effect, we experiment, we develop social skills, we learn about sharing, we learn about helping and showing as well as leading, we learn how to negotiate and resolve conflict.

Play is fun, voluntary, participative, creative and absolutely essential for the development of social and communication skills. When talking of play here, we don't mean people playing on their own with sensory objects. We mean paired play – a more skilled communicator playing with someone with communication difficulties. A person exploring the other's potential in a mutually enjoyable way. A skilled practitioner assisting the performance of their partner by scaffolding their skills and abilities and creating a balance between what their partner knows and what their partner finds engaging and more challenging. Turn-taking opportunities within this interaction should be acted upon and used to build reciprocity and new skills. Repetition within the person's repertoire should be facilitated and enjoyed to consolidate learning and build confidence and trust. The concept of the Zone of Proximal Development (ZPD) (Vygotsky, 1978) is a useful theoretical framework here that underscores the crucial importance of assisting performance. In brief, the ZPD is that area of learning and development that can only be accessed by support from another. Within support work, this stance informs Active Support – providing just the right amount of support to assist someone without de-skilling them, scaffolding their abilities to ensure failure-free experiences at the peak of their competence. Within communication exchanges it is the same: providing just the right amount of input, of responses to encourage, empower and engage without taking over and dominating.

I find it useful to reflect on being a parent here and remember Lego sessions with my children on rainy weekend afternoons. There were two ends of a spectrum: at one end was me taking over and building my own thing and trying to get my children to join in with me, or at least admit that my structure had more value than theirs; at the other end was me lying on the floor and watching what they were doing, commenting on it, passing the pieces at just the right time for them to develop the flow of their creative ideas. I think I spent time at both ends, and at all the points in between. The more satisfying interactions were those where I watched, allowed, supported and commented. During these interactions I could see my children's confidence and self-esteem grow before my eyes. The more overtly instructional were those where I dominated but I believe less was really learned within these interactions. I feel as a parent we need to do both and yet we generally tend to do too much directing. I suspect personality types and gender affect the position of our default style on this spectrum. I believe cultural beliefs and personal history affect this position too and also our flexibility to move away from it to inhabit other positions. I think it is worth keeping these interactional styles in mind when supporting people with PMLD, especially when using Intensive Interaction. A supportive, scaffolding style of interaction is more empowering, more respectful and allows a person-centred and person-led interaction to unfold.

Play implies both partners are enjoying the activity, for its own sake. We will potentially both develop new skills, certainly both develop a sense of the other as a person and co-create a deeper relationship. Perhaps at work when using Intensive Interaction it is helpful to think of our own ZPD in terms of our developing practice. A partner who gives us some responses at just the right time to encourage us will increase our confidence and trust in the approach and our own ability. Certainly this is a useful concept in staff development – ensuring new practitioners have the chance to work with someone who is relatively easy to interact with and gives unmistakeable positive responses.

It is worth considering during playful interactions if we have outcomes or targets in mind. Inevitably we will tend to have some outcome we would like to see. However, for the interaction to be truly on the person's terms we need to put outcomes to one side. Ensuring we are process-focussed will enable the person to move towards their own outcomes, their own goals within the context of exploring together a goal-less, mutually enjoyable interaction with each other.

Rewind

Rewinding is useful in two ways. Firstly, in the simple sense of going back to the beginning, doing it all again later: in 5 minutes, a few hours, later in the evening, tomorrow, the next day, etc. And to keep these interactions going. "Repetition is the engine room of forward progress." (Nind and Hewett, 2005, p.133). Repeating what worked before may well encourage the person to participate again. We should be reassured if repertoires are repeated for they provide familiarity, predictability, comfort and confidence and trust in the process.

And also, rewinding in the sense of reviewing and reflecting. To maximise the efficacy of Intensive Interaction critical reflection is essential (Hewett and Nind, 1998). To do this most effectively we need to consciously do this. Reflection will throw up useful insights into both our own practice and the skills, abilities and interests of the person we are interacting with. Self-reflection and analysis of one's own performance will develop skills and abilities, confidence and trust in the process. This is best done in a collaborative environment with colleagues or other family members. Give praise and ask for praise. We will usually know what we did less skilfully and our own areas for improvement. If giving more corrective instructions be gentle with the words used, make suggestions and ask open reflective questions. If receiving feedback take it all on board but avoid stressing over what was hard to hear.

The best form of record-keeping is videoing. A structure for a staff meeting is also found in pausing, playing and rewinding. A pause to first discuss the session including all involved or observing. Play the video and work alone making notes on the interaction, noticing actions and reactions of both parties. Finally, a feedback discussion followed by rewinding and watching again.

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Well-being

Ange Anderson

Since Aristotle in his Nicomachean ethics (350BC) used the term eudemonia, which today we refer to as well-being, academics continue to debate its definition often using objective measures that include social and economic conditions such as income, educational resources and health status whilst others have used subjective indicators including life satisfaction, anxiety and emotional well-being. Two of the most basic human needs are health and education and if we look at the UN Convention on the Rights of a Child we see that the right to be educated and the right to be healthy are two of the key principles. Education and health are underlying basic and intermediate needs.

Morrison, Gutman and Vorhaus's study (2012) demonstrates the importance of well-being for children and adolescents throughout their primary and secondary school education. Better emotional well-being is a key factor and studies indicate that activity and attention problems are associated with lower educational outcomes for children with PMLD.

It is obvious that early intervention strategies are needed to identify and support children in their emotional well-being when they have difficulty learning. Children who exhibit signs of troublesome behaviour may even be prevented from taking a downward spiral of disengagement. Therapeutic intervention can enable effective learning which in turn supports positive health and well-being, and good levels of health and well-being support effective learning.

Across the U.K governments are mindful of the capability approach of equality and they all strive to try to balance things out and promote well-being in schools to ensure pupils realise their potential and schools are inspected on how they manage pupils' well –being. In May of last year the National Assembly for Wales (2014) brought out an act to reform social services law; to make provision about improving the well-being outcomes for people who need care and support and carers who need support. This has implications if my dream, that special schools should be used to provide that extended well-being provision for adults with learning disabilities, is to be realised.

The act specifies that in relation to a child, "well-being" also includes physical, intellectual, emotional, social and behavioural development. It is a school's duty to create a nurturing and stimulating learning environment and to promote and enhance health and well-being. It is essential that staff recognise when and what kind of support is needed to ensure the mental, emotional and social needs of pupils are met. Dr Anthony Seldon, founder of Action for Happiness and Head of Wellington College, claims that the education system now 'focuses too heavily on academic learning and attainment and not enough on education for life.' (Seldon 2013)

It can be difficult to measure well-being accurately. Measuring objective well-being usually consists of collecting data. If we try to measure subjective well-being we come across the problem that feelings, like happiness, anger or enjoyment, are actually difficult to measure. In a special school where pupils have difficulty communicating all that we can do is study the behaviour of a person to gauge their well-being.

Pupils in a special school often have health difficulties as well as learning difficulties and sometimes they have emotional difficulties. Before they can actually access an education they have to feel able to access it. Special schools throughout the U.K provide various therapies to aid pupils' access to education and improve their well-being. Some of these therapies are the more traditional kind such as speech therapy and physiotherapy but other special schools offer qualified reflexologists, music therapists and vibro-acoustic therapists as we do. The way we treat our most vulnerable members of society informs them about their perceived value and place in society.

Do these therapies have any impact on the pupils' educational progress and their health? Do these therapies have an impact on their well-being? In the data driven society that we have become evidence is needed to show whether any therapeutic intervention has any impact.

Ysgol Pen Coch is constantly researching the effectiveness of its therapeutic intervention. The school uses Routes for Learning and B Squared assessment software to assess pupil's progress in the curriculum. The school provides a number of therapies- physiotherapy, speech and language therapy, visual therapy, hydrotherapy, reflexology, therapeutic music, Tacpac, Sherborne therapy, Rebound therapy and vibroacoustic therapy.

Therapies are discussed at Annual reviews and there is a moderation panel of staff who moderate the use of therapies in the school and meet regularly. The panel consists of heads of both departments and a lead therapist. The therapy targets are taken from Routes for Learning (RfL) or B Squared curriculum targets, Individual behaviour targets (IBPs) and individual education plans (IEPs). A target has to be met three times before it can be assessed as being achieved. The class teacher is informed by the therapist once the teacher set target has been achieved and a new target has to be set by the teacher if the teacher wishes for that particular therapy to continue. The attainment of the target is added to B Squared. At the end of each school year the B Squared GAP analysis software uses the data recorded by teachers throughout the year and produces reports and graphs and allows progress tracking week by week, month by month or year by year.

To measure the impact that the therapy has had on the pupil the therapist gives the class teacher an evaluation sheet to complete at the end of each therapy session. The most recent set of questionnaires on the use of therapies went out in November 2014 to all parents/carers and staff who were asked to comment through a different questionnaire. Pupils' views were also sought. Evidence for this is available in the therapies book the school has produced (Anderson et al, 2015).

Neuroscientists claim that what people say about how they feel corresponds closely to actual levels of activity in different areas of the brain and that therefore you can measure subjective well-being or happiness simply by asking people or their carers how the person feels (Waldron, 2010). That is what we have done. All of this information is analysed and a report produced (see p.106 of Anderson et al, 2015).

There is a need for a systematic study across special schools to focus on how they promote access to the curriculum for children with profound and multiple learning difficulties and children with severe learning difficulties and how this can improve their well-being. There is also a need to provide data analysis to show how effective this is.

What happens when our pupils become adults? How is their well-being catered for? When the government says people should have access to lifelong learning opportunities are they including adults with learning disabilities? Surely they must be or else they could be accused of discrimination. Therefore adults with PMLD have a right to access the facilities available in special schools today.

A gentleman with PMLD, who is in his fifties, attends our hydrotherapy pool once a week after school with a group of adults also with learning disabilities and their carers. His mother, who is in her eighties, comes along every week to watch him enjoying the experience. Not only is his sense of well-being improved, which is obvious to all onlookers as he enters the water and visibly relaxes but surely you would agree that his mother's sense of well-being has also improved..

I believe it is the duty of county councils to work closely with special schools to ensure adults with learning disabilities have the opportunity to access lifelong learning opportunities which in turn improves their well-being.

Visit https://twitter.com/ImpactTherapies to see photos of adults and pupils experiencing some well-being opportunities and our website at: ysgolpencoch.org to see the range of therapies currently on offer to our pupils.

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B Squared: http://www.bsquared.co.uk/AssessmentFiles/Introduction.aspx

Supportive Therapy Day in CMG ‘Keeping it real’ – meaningful, creative everyday interactions

Michael Fullerton

Engaging people with profound and multiple disabilities, purposefully, requires social support teams to be innovative, creative and able to develop and maintain a positive rapport. Simply being kind and caring, whilst being essential, is not sufficient to ensure people are engaged and have meaningful opportunities each day.

Within CMG (Care Management Group) we support around 100 people with profound and multiple learning disabilities in supported living, residential and day services in England and South Wales. To compliment support teams we have an internal Clinical Support Team to ensure the holistic needs of people with profound and multiple disabilities are met. We are proud of the support we offer to meet and promote the healthcare needs of people, particularly in relation to postural management and complex health issues such as respiratory difficulties, epilepsy etc. A greater challenge is ensuring the social needs of people are met, with people meaningfully occupied. The Clinical Support Team, and in particular Katie Reid (Healthcare Facilitator) and Erren Wheatland (Clinical Nurse Trainer), facilitate a PMLD Forum for support staff and managers to share and disseminate good practice. To inspire support staff and also to provide a fantastic day out for people with multiple disabilities the PMLD Forum have been holding a ‘Supportive Therapy Day’ each summer for four years now.

The Supportive Therapy Day is one of a number of initiatives to inspire people and guide support staff in developing a deeper understanding of the value of the opportunities presented. We must appreciate that not everyone is naturally creative or easily grasps initiatives such as Sensory Stories, in order to enhance understanding, communication, social interaction and general wellbeing. Planning for the Day starts months in advance, with input from the PMLD Forum to ensure the opportunities on the day will meet the interests of the people attending. Great care is taken to ensure there will be scope for everyone to ‘taste’ everything they want to on the day.

The range of opportunities available on the day include Sensory Stories, Bag Books, Reflexology, Hydrotherapy, Art Classes, Music and Drama Sessions (including the ever popular limbo dancing), using Assistive Technology to communicate and maintain control over your environment, Pet Therapy. The day ends with a sensory disco and the infamous ‘Pimp my Chair’ (inspired by the TV programme ‘Pimp my Ride’). ‘Pimp my Chair’ is a fiercely fought competition to see who can have the most creatively dressed wheelchair. People we support, with their families and supporters, spend weeks in advance hatching plans to develop the most creative chair and the results are amazing. Various superheroes have been represented, as well as the Spice Girls, Captain Jack Sparrow, Medieval Knights and various modes of transport.

The event this year also included a ‘Bird of Prey’ demonstration in which everyone, as they wanted, could get up close and personal with a range of wild and beautiful birds.

The aim is not simply that people will have a great day out. What is integral to the day is providing people with multiple disabilities with opportunities they may not have experienced before, or not with the same level of purpose. Support staff can gain heightened awareness of the value of each opportunity and learn more about what is appealing, or unappealing, to the person they support. We can and do provide training to staff in how to compile sensory stories etc, but providing real life situations to practice these skills and promote creativity can really make the difference in understanding how to apply initiatives in everyday life. This is what the Supportive Therapy Day is all about, encouraging people to engage in practical activities which enhance wellbeing every day.

The most apparent and heartening observation on Supportive Therapy Days is the rapport developed between support staff and the people being supported. Truly lovely interactions are witnessed and it is the style of activity that promotes and strengthens that. The activities are planning very much with interaction between people in mind, and that these are enjoyable – critically we all need joy in our lives.

Nabil Saraf, Superheroes!

A challenge also, in everyday life, is supporting and encouraging people with profound and multiple learning disabilities to interact meaningfully with each other. As most interactions are with support givers or family, it is important to create opportunities for people to engage with and enjoy time with their peers. The Supportive Therapy Day includes a lot of group activities, again to demonstrate to staff how to promote sharing, turn taking, communication and a sense of connection with peers.

People tend to leave the Day buzzing with excitement. Carl Johnson – who lives at The Ridgeway supported living service in Essex said - "I loved dressing up and had a really good day".

L-R Erren Wheatland, Carl Johnson, Katie Reid with Trevor Madden at rear

Katie Reid (Healthcare Facilitator) said "The people we support always love taking part in the Day. They really respond well to the different activities on offer and benefit enormously from meeting other people from CMG services around the country and getting the chance to try a wide range of different opportunities".

A risk is that support staff will go back to work and carry on as normal, treating this Day as a nice treat but not using new learning or inspiration in their day to day lives. This is where the PMLD Forum, Managers and Clinical Support Team are challenged to keep inspiring, reminding, encouraging and role modelling. Rare opportunities are nice, but not enough. Inspirational leadership cannot be sporadic, and can't simply say the job is done. Support teams require ongoing motivation and encouragement and, while the Supportive Therapy Day goes a long way, it's certainly only one part of a jigsaw to ensure people have enjoyable opportunities in their lives.

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Creating Small Sensory Learning Spaces

Clive Smith

Since the beginning of time infants have been placed in small spaces to rest - mangers, baskets, cribs, cots and bassinets (I have just found out what that is, look it up if you want to know!!) Why? Because in small spaces, infants are cocooned and naturally feel secure. Parents intuitively recognise that they are more comfortable and display fewer signs of anxiety. The newborn infant has yet to develop many of his or her sensory skills - vision, hearing and touch is very limited to the infant's immediate body area. The baskets, cribs and bassinets provide an extremely secure space where all sensory inputs come from one direction, in front, and the majority of that sensory experience comes from the infants' carers who provide and promote a sense of security. These spaces provide the first two elements identified by Abraham Maslow (https://en.wikipedia.org/wiki/Abraham_Maslow) in his famous work that outlines a hierarchy of needs: physiological needs, shelter and warmth and safety, security and, most importantly, freedom from fear.

As the infant develops they start to improve their sensory skills, most importantly their proprioceptive skills, learning about themselves, beginning to handle and explore objects in the world around them. Remember those old proper prams? The child lay there with a hood up and some rattles strung across the front. This meant the toys were always there in reach with no other distractions to look at. Infants learnt by constantly repeating the same actions over and over. For many of our students, particularly those with physical and complex needs, they are still at such an early stage of development. The impact of their poorly developed sensory skills in areas, such as vision or hearing and proprioception, holds them back from further development. Combine this delay in development with poor movement skills due to weak muscle tone and the ability to relocate to allow simple handling, and exploring becomes a real challenge. This is a serious issue because handling is an important stage in developing an understanding of objects and the world in which we live. It develops such notions of object permanence - an absolute prerequisite of developing preference, making choices and having an impact upon your life.

Lilli Nielsen, a Danish psychologist, famed for her work with multi-sensory impaired children, utilised her understanding of all this when she developed her 'Little Room' structure as part of her 'Active Learning' principles. The 'Little Room' is a purpose designed box that allows freedom and security to explore objects in an environment that is safe and consistent. We can employ similar principles providing a similar degree of security and permanence in our sensory work in many ways by using improvised stands and screens. Umbrellas work wonderfully for this and allow the work to continue outside the sensory room. For larger areas, pop up tents or shelters work really well.

We all know that working with the individuals that we do, catching the moment is essential. Individuals with complex medical needs may be alert for a very short period. Individuals on the autistic spectrum have a brief period where there are no anxieties, no sensory overload. Or maybe we just want to provide more sensory experiences in our teaching. Whatever it is, it is still a pretty good guess that these moments don't fit in with when the sensory room or sensory studio is timetabled in your favour! Or maybe you are reading this for your child at home and don't have a sensory room. Good news! There are many ways to create an improvised sensory environment - without a brolly in sight!

Sheets are just one fantastic way to create a back drop, draped over stands to create a sensory space; just laid on the floor they provide an instant contrast for lighter objects. Fibre optics on a black sheet will show up even in a brightly lit room. We can't always black out our classrooms or living spaces. A black sheet over a table will even help with normal curriculum or life skill sessions. It makes the individuals focus totally upon the materials that they should be using. Use coloured sheets to create a theme for sensory storytelling - blue sheets for water based stories, such as 'The Rainbow Fish'. Back project appropriate digital images to enhance the story telling. Fibre optics draped over the blue sheet creates a shimmering waterfall or river. Green sheets provide a back drop to jungle or forest tales - add some bird sounds, leaves rustling (using sound files on your iPad) to enhance the mood or to help the individuals' imagination along. A fan placed behind the sheet adds movement and atmosphere to the scene by blowing the sheets/

leaves and other props! Of course, white sheets become multi coloured with appropriate back projection, but think about not just using rotary or pico projectors! There are now available, for around £40, 12v LED lighting strips with remote controls enabling you to select any colour. Placed behind a white sheet they are safe and allow the story teller to select from white to green to red to blue at the press of a button. Check out your nearest curtain fabric shop who will probably have a range of cotton fabrics in all colours and, most importantly for school or centre use, they can provided as certified flame retardant materials. Last bit of kit, have a box or bin to keep your sheets and artefacts in so you can catch that moment. Enjoy your sheets!!

Contact Details

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Top websites for this issue

http://www.soundabout.org.uk - Soundabout is a national charity that supports school staff to learn how to make music interactively with their pupils with severe and complex disabilities.

http://www.usinabus.org.uk - Us In A Bus is a charity working with people with profound learning disabilities in their own homes using Intensive Interaction techniques. It also helps those caring for or supporting clients explore the use Intensive Interaction.

http://www.oilycart.org.uk - Oily Cart is a theatre company who make interactive theatre for young people with learning difficulties.

http://www.bamboozletheatre.co.uk - Bamboozle work together with special schools to help staff deliver the curriculum by multi-sensory performance tours and staff training workshops.

http://www.replaytheatrecompany.org – The Replay Theatre Company is based in Northern Ireland and does work for children and young people, including those with PMLD, for school groups, for families, and for festivals.

http://frozenlighttheatre.com - Frozen light is a theatre company based in Norwich which specialises in offering accessible multisensory performances in theatres to people with PMLD.

http://www.feeltheforceday.com - The Feel The Force Day is a convention that enables people with disabilities to have access to fun experiences of favourite films and TV programmes.

http://www.openstorytellers.org.uk - Open Story Tellers, among other things, offer Sensory Book Clubs that make stories more accessible for all by combining sights, sounds, smells, textures with the text to bring the books to life and training for teams running public spaces in how best to support people with additional needs and how to make sure their business is accessible to everyone.

http://www.voiceability.org - VoiceAbility is a charity that works across England with people who are vulnerable or marginalised to raise their voices and have their rights respected. The majority of the charity’s services are related to providing advocacy support to people who need it.

http://www.hft.org.uk - The HF Trust (Hft) is a Bristol based charity which aims to provide services for people with learning disabilities and their families through England that might enable them to live the lives they choose.

www.pmldnetwork.org for anyone who doesn’t know the network hosts a really good forum

FUTURE FOCUS

It's all in the detail

Five years ago Jim Mansell's (2010) report revealed the many shortcomings in provision for people with PMLD in his national review; Mencap/Lambeth Mencap (2010) offered similar findings from a local authority perspective. But have things moved on? It seems that this group of individuals and their families continue to be overlooked by services generally and as a consequence are often marginalised. A recent review of studies around personalisation for those with learning disabilities generally discovered that certain groups, particularly those with complex needs [including those described as having PMLD] were less likely to have experience of personalised services or its benefits (Harflett at al, 2015). By the very nature of this disabling profile, this population is least able to voice their concerns to these inequities. We need to speak up and act to address these issues by demonstrating what 'good' practice or 'good' services look like for people with PMLD.

'Getting it right' for people with PMLD is no simple task. It requires time and determination to meet their very unique strengths, interests and needs in the most responsive and meaningful ways. It takes time to really get to know the person, to discover the important things that really make the difference to 'getting it right' and to determine what works best. But this requires that people with PMLD are 'visible' in the first instance - to services, providers, communities and local facilities – and even within specialist services! Are they receiving equal opportunities? It is essential that this group of people are clearly on the radar and a constant item on agendas. It is not acceptable to expect people with PMLD to have to 'fit in' to activities or services that are not designed with them at the centre and this is true even of more general provision for people with learning disabilities. There is a need to change awareness of the needs of people with PMLD and for this to become 'entry point' for disability and access. If we can really get things right for this population, then we can most likely make access for everyone else with a disabling condition plain sailing! So this challenge needs our determination to raise our sights and strive to ensure that the best fit is the right fit!

In our next Spring issue of PMLD Link we want to learn from you about what 'good' looks like for individuals with PMLD. We hope you will share your insights and experiences of what has led to personalised support and positive outcomes. We are interested in what works well for individuals and for groups – how opportunities are created, how they are tailored to meet their very individual interests, strengths and needs, what makes them appropriate and successful compared to other services or activities that do not necessarily suit an individual and their needs. Even if we have not achieved that success yet, we can learn from our journey of discovery about what works well, what needs to change and how, to ensure things are truly person-centred.

We need to consider the big picture of what is essential to 'getting things right' for people with PMLD. We know there are many important factors that may include for example – finding appropriate and meaningful opportunities locally; the high costs of activities for this low incidence group,where there are no economies of scale; an appropriately skilled workforce – who themselves may feel isolated when working 1:1 in the community; fully accessible venues and places to meet; and the right planning and support make social connections that are sustained [Mills, 2015). Please share your stories in overcoming such challenges.

Have you got experiences of places that were fully accessible to someone with profound and multiple learning disabilities? Have you used community or public facilities that made day to day life effortless and as 'ordinary' as our own? Do you know of any services, who offer truly person-centred activities and opportunities to authentically include and engage people with PMLD? Have you discovered any places, hubs, clubs or groups who enable people to come together and develop friendships and social networks that may lead to a sense of community or belonging? We want to be inspired by the good practice that we know is out there. It may be patchy and very hard to find but if we share our stories we can learn from both the journey and the eventual successes we know are possible. By holding fast to our high expectations and aspirations for people with PMLD we can raise the bar, we can demonstrate what 'good' looks like and we can encourage even more people to rise to the challenge of a genuinely more inclusive world. Changing Places facilities are a great example of what 'good' looks like! If we could rely on these amenities in public buildings, in every town and transport hub the opportunities for people with PMLD could expand with very little effort.

Jim Mansell's report (2010) encouraged us to 'raise our sights' when considering people with PMLD and this needs to be our 'bottom line'. For too long services have generally held low expectations for this group of people – IF they even consider them at all? We could be challenging by suggesting that too often the concept of including people with learning disabilities is largely based on those who are able to have a voice to meaningfully participate in their local communities with the minimum of reasonable adjustments. Too often providers will consider that simply slowing things down or diluting the content will 'be enough' to mean people with PMLD can join in – when more often it means people with PMLD may more likely be 'parked' there with little meaning or engagement. Equal opportunities does not mean treating people in the same way but by responding to their difference and diversity; Ellie Griffiths (2015) reminds us of this when thinking about meaningful access [to the arts and culture]: 'What is generally overlooked is that people with PMLD have very different processing times and a wholly different way of relating to the world' – we need to respond sensitively to the subtleties of this view. We would like to suggest there is another perspective! Jim Mansell's legacy was to encourage us into 'Raising our Sights'. It is essential to hold high expectations and aspirations and as a consequence, raise the bar of just what IS possible. The ripples from our tiny drops in the ocean can collectively generate a swell ~ and hopefully a sea change! Together let's start a positive Tsunami of success for improved lives for people with PMLD. By 'getting it right' for people with PMLD we can literally improve the longevity and quality of their lives. Let's start with the next issue of PMLD LINK!

If so, contact the editors:

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REPORT BACK

Uninhibited!

Glyn Winchester

When I got a visit last spring from the amazing Joanna Grace asking for my advice on a project she was working on, I was honoured and immediately so excited about the prospect of being involved. I got to know Joanna through the Baby Sensory sessions I was running at Falmouth Art Gallery. She and her son were some of my first participants and Joanna generously gave me great ideas and resources for the sessions.

'Uninhibited' introduced me to the world of PMLD. Joanna described her ideas for the Structured Sensory Art Project, which offered a class of students the freedom of artistic expression. They would be given the opportunity to use new materials and work in a positive studio environment. I knew she was the person who would help these young artists soar.

Our lime painted 'Limelight Wall" is a rolling week long showcase for local Cornish artists who may not have the opportunity to feature in our major exhibitions. Walking into the gallery and seeing the 'Uninhibited' artworks framed and hung on the Limelight Wall, well, made my heart sing! I knew that there had been technical contraptions which enabled the young artists to produce this body of work. Viewing the works, professionally framed and hung, I could see and feel how much more than the mechanics was involved in their creation. Each brushstroke was an exquisite mark.

The feedback in the gallery from visitors was very positive. "Delightful," "Beautiful," "Inspiring," "I'd buy this work," were snippets people wrote in the comments book. It was a bonus for the gallery that some of the artists and their families came in to see the celebration of their work.

Falmouth Art Gallery had the honour of being the first venue to host this innovative project. We've been so happy that the exhibition is on a nationwide tour and continues to garner such acclaim. We look forward to launching future exhibitions!

Glyn Winchester is the Access and Interpretation Manager at Falmouth Art Gallery

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Today is Different

Russell Anderson

Today I saw a show (at the Old Fire Station, Oxford) made for teenagers and adults with profound and multiple learning disabilities. This is something of a first for me and I went in wondering how much of a useful write-up I would be able to contribute, given that I know little of what makes for meaningful and engaging work with PMLD audiences. As it turned out, I didn't have to know. I could see.

The Forest uses a simple narrative framework to immerse its audience in a succession of sensory experiences. Every sense was given a range of stimuli: from confetti paper raining down on us, to sound, music and song, to scented logs to smell and feel, to rain sprayed over us, wind blowing in our faces, even a couple of moments of taste… and the list goes on. That's not to say, though, that the show is simply a succession of sensory moments tacked together at the last minute with a story. What really struck me about the piece was how integrated everything was: the story acted as a driving force behind each new experience, which then (in part) functioned to place the audience within the story. So, for example, when the characters got cold and wet, we got cold and wet. It helps to maintain a flow and cohesion which really makes this a piece of coherent theatre, and not a series of 'set pieces', as it were.

Of course, I was not the primary audience for this piece, and what was fantastic to see was how well the company worked with their PMLD audience. The wonderful thing to watch was how the actors were genuinely happy to have the opportunity to work with them, to engage with them in very honest terms, and to share with them. There were many moments where they came to each audience member one by one, to offer an experience which was treated with a meaningful, gentle, but playful focus. It might be a moment of song, it might be offering food, it might be a scented lotion rubbed on the hands, but whatever it was, it always became a reciprocal exchange: not just something offered from company to audience, but often something offered in return from audience and accepted by company (and quite often with genuine laughter). There was a moment when the man next to me held out his hand, and the performer singing to him simply took it, and kept hold until she had to move on – offering him thanks as she did. I'm trying hard not to come off as patronising here, but it was a very powerful thing to see such simple moments of exchange clearly meaning a great deal, both to the audience and the performers.

But then, maybe I shouldn't worry about it being patronising, because I loved it too. I've been to a few sensory experiences, and I have to say that this one ranks quite high on the list. Not only did I feel like I had a wide range of sensory stimulation, but the combination of how well it integrated to the story, the playfulness, and the welcoming nature of the exchange between performers and all audience members made it a hugely engaging and satisfying experience. And some of the moments are just beautiful: in particular, a sequence using torches and small screens to create shadows – first for the audience, and then with them – was lovely. By the end of the show there was an incredible warmth in the room: everyone, from performers, to the PMLD audience, to their carers, and the odd observer like me, seemed to radiate a pleasure and a satisfaction that I don't feel nearly enough at the end of a theatre event. It's led me to wish there was more of this kind of work: I intellectually knew it was important before, but now I've felt it. We need more.

Contact Details

Russell Anderson is a theatre maker and PhD student at Oxford Brookes University, researching interactive narratives in the theatre. He runs Oxford-based Re:Conception Theatre Company. This piece previously appeared in his blog, Playing At Plays (08.10.15). E-mail: 13106792@brookes.ac.uk; or visit either https://playingatplays.wordpress.com/ or www.reconceptiontheatre.com

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All enquiries about subscriptions should be made to: Rob Ashdown at 15 Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7PH / e- mail: rob.ashdown@ntlworld.com

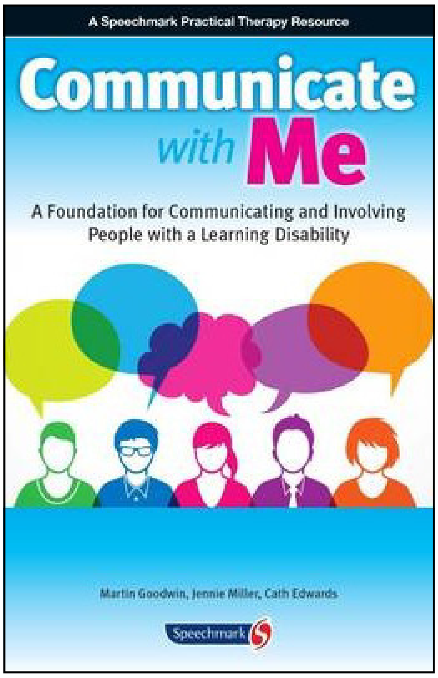
REVIEWS

Title: Communicate with Me – A Resource to Enable Effective Communication and Involvement of People with a Learning Disability

Authors: Martin Goodwin, Jennie Miller and Cath Edwards

Publisher: Speechmark

Price: £34.99



At the time of writing, we have not received a copy of the book to provide an objective review. The publishers say that Communicate with Me is a resource for anyone involved in supporting children or adults with a learning disability – including residential or community support workers, play workers, advocates and teachers who work directly with people, and also service managers who can facilitate change within service structures and promote good practice in their teams.

The authors'aim is to make this resource a practical and thought-provoking guide to communication methods and work practice approaches that can be successfully used to support more effective communication with people with a learning disability. It may be read from cover to cover or dipped into for reference and inspiration. It provides:

- Guidance in communicating and involving people with learning disabilities
- Practical examples, case studies, examples of good practice and information to support implementation
- Online access to supporting materials

In addition, Communicate with Me offers a quality assurance framework to support services and practitioners to improve standards surrounding communication and involvement.

Communicate with Me is available from Speechmark (www.speechmark.net/shop/communicate-me) and Amazon For more details go to the website: www.communicatewithme.com.

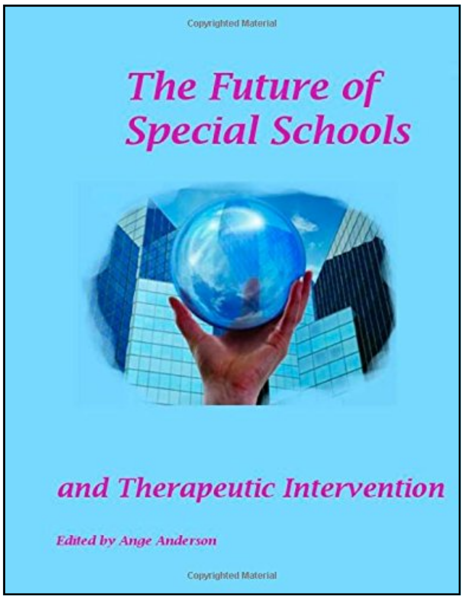
Title: The Future of Special schools and Therapeutic intervention

Authors: Ange Anderson and others

Publisher: Amazon

Price: £15

Link: http://www.amazon.co.uk/dp/1506193803



Ange Anderson is headteacher of a large primary specialist school in North Wales. She has edited this book which contains contributions from herself and many therapists and other professionals involved in the school. This book looks towards the future regarding the education and well-being of students with disabilities and other special needs. It offers practical information about a wide range of beneficial therapies for educators working with pupils with moderate, severe and profound and multiple learning disabilities. The book includes useful materials that may be photocopied. All profits from the book will go towards the future education of pupils attending Ysgol Pen Coch Specialist School in Flint.

IN THE NEWS

A Big Thank You to Chris Fuller

Chris Fuller has recently retired from the Editorial Team of the PMLD LINK journal. Chris brought to the team a depth of business experience coupled with knowledge about people with profound and multiple learning disabilities that will be much missed. As well as acting as an editor for the journal, Chris assisted the other editors greatly with her eagle eye for errors and possible improvements in setting out pages prior to printing. In recent years, Chris has used her business acumen to improve the development planning for PMLD LINK and applications to grant-making bodies to keep the charity not just afloat but moving forward.

Chris started teaching as a mainstream primary school teacher. By chance, while taking time out of teaching to bring up her own children, she was asked by a friend if she could stand in for few weeks as an assistant at a special school in London for children with severe to profound learning difficulties. Chris so enjoyed the work that she stayed at the school for 11 years.

Chris is perhaps best known for the development of Bag Books. She wrote and told stories targeted at pupils with the most profound learning difficulties. She found out through experimentation what many of us take for granted as good practice these days. If her pupils were helped to hold and feel objects and materials related to the story, their attention was more easily captured and held. Also, they respond to lively story telling and the injection of emotional charge into the teller’s voice. With sufficient repetition of the stories, she found that her pupils would begin to anticipate what was coming next and so, like any child, were able to enjoy a tale well-told.

In 1989 Chris was approached to write a guide to making and telling multi-sensory stories. This was published but Chris found that disappointingly few teachers actually had the time and/or the skills to make up the stories. So in 1993 Chris founded Bag Books as a charity that would make the stories and sell them at heavily discounted prices. Originally, the materials and stories were supplied in heavy duty calico bags hence the name. Over the years, in addition to book production, Bag Books became involved in running storytelling sessions and training people in multi-sensory storytelling. Today Bag Books produces multi-sensory books which are age appropriate for everyone, from youngsters to older adults. Chris has written about the development of Bag Books from its very small beginnings in this very journal (Spring 2013, Vol. 25 (1) Issue 74).

Bag Books has been an inspiration for many. For instance: Chris worked closely with PAMIS which has developed through its 'The Real Lives: Real Stories Project' over 50 personalised multi-sensory stories adapted from the Bag Books (http://www.pamis.org.uk/_page.php?id=48); and Nina Martinez of the Bexley Library Service benefitted from training in multi-sensory storytelling from Chris to develop her own practice with both children and adults (http://ninamartinez.co.uk/).

Chris retired from Bag Books in 2008 and freely devoted much of her time and energy to PMLD LINK. She has helped PMLD LINK to grow in ways that serve much better the needs of children and adults with profound and multiple learning disabilities and their families and supporters. We will miss her greatly but wish her well.

Campaign to Improve the Provision of Wheelchairs and Wheelchair Services

The Wheelchair Alliance was formed in January 2015 and is currently under the leadership of the British Paralympic athlete and cross-bench peer, Baroness Tanni Grey-Thompson. The Alliance is campaigning for a better deal for wheelchair users and aims to transform the quality and effectiveness of services across England.

The Alliance claims that there are around 1.2 million wheelchair users in the UK, roughly two per cent of the UK population. Wheelchairs have the potential to enable many people to live happier, fuller lives and yet the wheelchair services provided by the NHS often fall short of meeting the needs of users despite best efforts from clinicians and wheelchair services.

The Alliance aims to strengthen connections between key partners in order to bring about positive, lasting changes and shape NHS wheelchair services into a system that works better for its users. To this end, the Alliance has initiated a Right Chair, Right Time, Right Now campaign and the development of a Wheelchair Charter. The Right Chair, Right Time, Right Now campaign aims to raise awareness of issues in wheelchair services and highlight best practice, targeting those with the power to deliver change to make rapid improvements. The campaign also calls upon service users to fuel the demand for change by highlighting areas of improvement or by sharing their experiences. The Wheelchair Charter outlines ten principles for how wheelchair services should be commissioned and delivered.

To pledge your support and/or find out more about the campaign and charter, go to:
http://www.rightwheelchair.org.uk/

If you care for someone who uses a wheelchair or work with children or adults who are wheelchair users, the website provides resources and a list of some of the available support networks.

The charter is clearly something that every wheelchair user would want the Government to adopt but without the campaigning efforts of people it is feared that NHS England and the Care Commissioning Groups will not get behind it and there will be no change.

Celebrating the Legacy of Veronica Sherborne

Veronica Sherborne (1922 – 1990) was a pioneer in the development of movement work with children and adults including those with PMLD. As well as being a fantastic practitioner and teacher of adults who themselves went on to be practitioners, she wrote articles for journals, contributed to several books and her own book Developmental Movement for Children was published in 1990 (a second edition was published by Worth Publishing in 2001 (ISBN 1903269-04-0)). Sherborne developmental movement activities enable learners to be as active as they can. It uses the movement of the bodies of adult helpers or other learners to develop support, using free-flow activities, such as rocking, rolling, sliding, spinning, swinging, to build a rapport between the partners, to improve communication, relationships with others, self-confidence, self-knowledge and to meet social and emotional needs.

The Sherborne Association UK was founded shortly after Veronica’s death to continue and promote her work. It is a non-profit-making registered charity and part of an international organisation that is dedicated to maximising the abilities of all people with and without disabilities through the medium of movement. There are more details about Veronica, about Sherborne Developmental Movement and about available books, films and other resources on its website (http://www.sherbornemovementuk.org).

As you can imagine 2016 marks quite a significant landmark in the continuation of Veronica's work. You may be, in some way, connected to Veronica in the early days, or just appreciate the value of Sherborne Developmental Movement. Whatever the case, you will be interested in knowing about a special weekend that is being planned – June 24th to June 26th 2016.

The programme will include - 'Veronica the person, as a mother (with a contribution from her daughter Sarah), Veronica the teacher, Veronica the film maker, and the history and setting up of the Sherborne Association (how it all began). The latter part of the weekend will focus on the present work, and how it will move on in the future, both nationally and internationally, - and of course there will be a Movement session.

The weekend is being held at the University of Winchester about a mile from the centre of the city which is a great place to visit of itself. The approximate cost of the weekend which includes accommodation and all meals for 2 nights will be £170. The final costing and the booking form for the weekend will be on the website from 1st February 2016. But make a note in your diary now!

NICE: Challenging Behaviour Quality Standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. They draw on existing guidance, which provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

This quality standard covers the care of children, young people and adults with a learning disability and behaviour that challenges. Services for children, young people and adults with a learning disability and behaviour that challenges were described in Mencap's 2013 Out of Sight report as fragmented and at times ineffective and unresponsive to family needs, sometimes to the point of being abusive.

For children and young people, services are generally provided within education (through their school and the educational psychology service), as well as through paediatric services and generic child and adolescent mental health services (CAMHS). Families report that they have to deal with a number of disconnected services and that many are unable to help. Moreover, very few early intervention services specific to behaviour that challenges are routinely available for children with a learning disability.

For adults, care is often managed through a community learning disabilities team (CLDT), which includes a range of professionals. In many areas, social workers are integrated into the CLDT. For adults with a learning disability and behaviour that challenges, day services, or the residential/supported living service, may try to support them initially. Depending on the nature of the behaviour that challenges, there may be a referral to the CLDT and the adult's family or carers may also have access to the CLDT through the local GP or other agencies. However, carers often receive insufficient support from professionals who do not have the required expertise and do not provide help early enough.

The failure of services, and families not being able to cope, are likely to lead to overmedication for people with a learning disability, disengagement by professionals, and eventually 'out-of-area' placements. This quality standard is focused on ensuring that assessment leads to personalised care planning and access to meaningful activities. The statements aim to ensure that the approaches used by staff to support people with a learning disability follow the least restrictive practice and promote privacy and dignity.

Mencap and other organisations have been campaigning to make sure the government, NHS England and local authorities enable people with a learning disability and behaviour that challenges to return home from institutions like Winterbourne View. The Government had promised this would happen by June 2014. But Mencap claims that there was a total failure to meet this target and that figures show that there are still over 3,000 people with a learning disability stuck in units.

Mencap describes the latest plan (January 2015) from NHS England and its partners was very disappointing. It notes that a report from the National Audit Office (NAO) looked at the failure to date to make progress happen. When NHS England and the Department of Health were questioned by MPs on the Public Accounts Committee about the findings of the NAO report, NHS England announced that there would be a closure programme developed over the next 6 months.

The NICE challenging behaviour quality standard has been published on the NICE website (http://www.nice.org.uk/guidance/qs101).

Dysphagia research

How many people with intellectual disabilities experience dysphagia? Do you have information on this? Can you help? IHaL is planning to undertake a systematic review of published research on dysphagia in people with intellectual disabilities. They are looking at how many people with intellectual disabilities experience dysphagia, the health implications of dysphagia, and how dysphagia can be managed. They will search electronic databases to identify published research from 1990 onwards. If you are aware of any research that is ‘in press’ or already published that you think is relevant, they would be very grateful if you could contact them.

You can send information to Janet Robertson at:
j.m.robertson@lancaster.ac.uk

IHaL (The Improving Health and Lives) Learning Disabilities Observatory is part of Public Health England. It has a brief to keep a watch on the health of people with learning disabilities and the health care they receive. The website provides a lot of information; visit: http://www.improvinghealthandlives.org.uk/

An Accessible Sci-Fi Convention

There is a short clip from local BBC news on this accessible Sci-Fi Convention which is well worth watching:
https://www.facebook.com/bbclookeast/videos/960600064020873/

In brief, a friendship between a carer called JJ and a deaf blind man called Jimmy, inspired a Star Wars convention aimed at people with disabilities. The resultant Feel The Force Day is described as a truly unconventional convention. The organisers were concerned that film and TV conventions are just not able to enable full access to the subject they promote, so they decided to do something about it. Not only did they want to ensure good access but they also wanted to bring that to people in a fun way. The first event attracted over 400 people and was the first of its kind, in the World. The organisers aim to build their audience, with more attractions and a bigger venues.

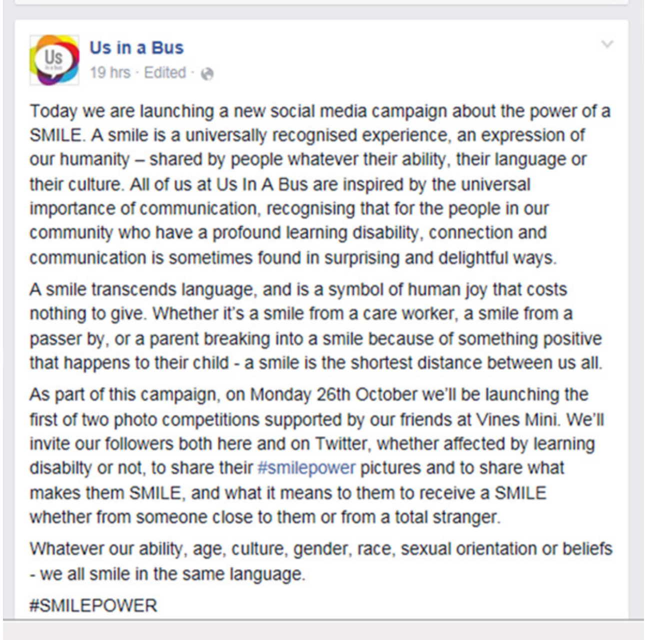
The events make costumes available to be touched, also props, vehicles, TV and film related smell jars… plus a few new and original ideas at each event. They encourage a fun and friendly atmosphere for all, whatever their disability, come along – carers, support workers and communication assistants will always have free entry.

Inevitably some of the characters may come from films which are rated above a 12A certification by the British Board of Film Certification (BBFC). After researching the BBFC's guidelines on film certification, the organisers have established a policy relating to various categories to establish which characters may be included within the event without causing anxiety or upset or offence.

The 2016 Feel the Force Days are in Peterborough (1st October) and Plymouth (23rd July). For more details visit: http://www.feeltheforceday.com

Us in a Bus #SMILEPOWER Social Media Campaign

Renee Carter writes that Us in a Bus has launched a #SMILEPOWER campaign on Facebook and Twitter. The aim of this is to increase the numbers of people engaging with the Us in a Bus charity on social media and therefore bettering interest in the charity's work. Renee worked with Emma Smith (a Communications Consultant) on developing the Social Media and she created the content to engage people. You may have seen an increase in posts sharing content from other sources and posts using #SMILEPOWER as a theme. Below is the introductory post on Facebook:



Today we are launching a new social media campaign about the power of a SMILE. A smile is a universally recognised experience, an expression of our humanity – shared by people whatever their ability, their language or their culture. All of us at Us In A Bus are inspired by the universal importance of communication, recognising that for the people in our community who have a profound learning disability, connection and communication is sometimes found in surprising and delightful ways.

A smile transcends language, and is a symbol of human joy that costs nothing to give. Whether it's a smile from a care worker, a smile from a passer by, or a parent breaking into a smile because of something positive that happens to their child - a smile is the shortest distance between us all.

As part of this campaign, on Monday 26th October we'll be launching the first of two photo competitions supported by our friends at Vines Mini. We'll invite our followers both here and on Twitter, whether affected by learning disabilty or not, to share their #smilepower pictures and to share what makes them SMILE, and what it means to them to receive a SMILE whether from someone close to them or from a total stranger.

Whatever our ability, age, culture, gender, race, sexual orientation or beliefs - we all smile in the same language.

#SMILEPOWER

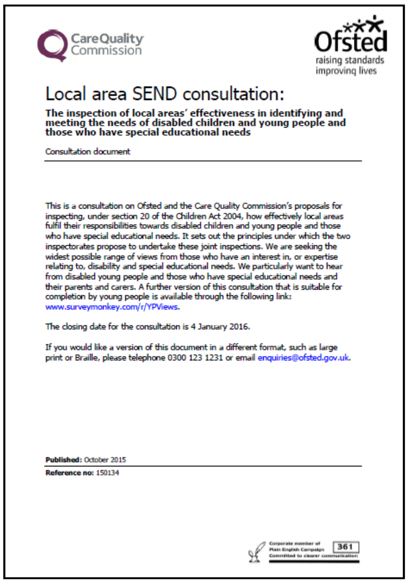
Below an image that Emma used to illustrate the campaign and capture the imaginations:

You can see from the introductory post above that a photo sharing competition has been used as a way to get people engaged. People were asked to share photos of what makes them smile. The competitions each lasted a fortnight and should provide an opportunity to test out what results are got from social media so as to see what the charity might do in the future.

Renee Canter is Business Development Manager of Us in a Bus. E-mail: reneecanter@usinabus.org.uk
Emma-Louise Smith is a social media manager. E-mail: smithemmalou@gmail.com

Consultation on Local Area SEND Inspections

There is currently a consultation on the Ofsted and the Care Quality Commission's proposals for inspecting how effectively local areas fulfil their responsibilities towards children and young people who are disabled and/or have special educational needs (SEND). The consultation document sets out the principles under which the inspectorates propose to undertake these joint inspections.



Care Quality Commission

Ofsted
raising standards
improving lives

Local area SEND consultation:

The inspection of local areas' effectiveness in identifying and meeting the needs of disabled children and young people and those who have special educational needs

Consultation document

This is a consultation on Ofsted and the Care Quality Commission's proposals for inspecting, under section 20 of the Children Act 2004, how effectively local areas fulfil their responsibilities towards disabled children and young people and those who have special educational needs. It sets out the principles under which the two inspectorates propose to undertake these joint inspections. We are seeking the widest possible range of views from those who have an interest in, or expertise relating to, disability and special educational needs. We particularly want to hear from disabled young people and those who have special educational needs and their parents and carers. A further version of this consultation that is suitable for completion by young people is available through the following link: www.surveymonkey.com/r/YPViews.

The closing date for the consultation is 4 January 2016.

If you would like a version of this document in a different format, such as large print or Braille, please telephone 0300 123 1231 or email enquiries@ofsted.gov.uk.

Published: October 2015

Reference no: 150134

Corporate member of Plain English Campaign Committed to clearer communication 361

It is important that these agencies receive the widest possible range of views from those who have an interest in, or expertise relating to pupils with SEND. They say that they particularly want to hear from disabled young people and those who have special educational needs and their parents and carers.

The closing date for this consultation is 4 January 2016 so there is not much time left in which to respond. The consultation document may be found at https://www.gov.uk/government/consultations/local-area-send-consultation. You may respond online; by email to Schools.PolicyTeam@ofsted.gov.uk; or write to the Schools Policy Team, Ofsted, Aviation House, 125 Kingsway, London, WC2B 6SE.

Community Care has helpfully posted on its website an outline from Charlie Henry, Ofsted lead on special educational needs, explaining what the processes for inspecting SEND provision will be (http://www.communitycare.co.uk/2015/10/22/ofsted-cqc-will-inspect-special-educational-needs-provision/?cmpid=NLC|SCSC|SCDDB-2015-1022)

From May 2016, Ofsted and the Care Quality Commission will jointly inspect local areas to see how they are fulfilling their responsibilities to children and young people with SEND who require local public services. These are the services they receive from their nurseries, schools and colleges and from the specialist therapists and other professionals in educational, health and social care services. These inspections are about how the whole local area meets their needs. The inspectors will not just want to see that services are being delivered well. They will want to see evidence that children and young people are progressing.

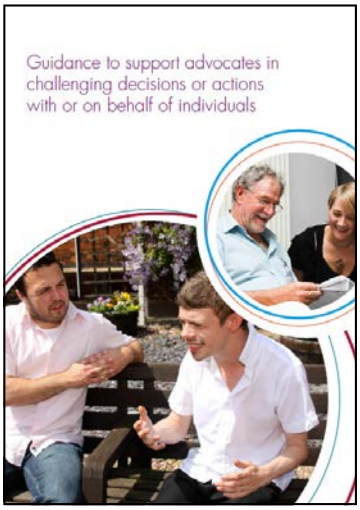
Under these proposals the local area Director of Children's Services and the Chief Executive of the local clinical commissioning group will be notified two working days before the inspection starts. The inspection team will meet the key managers and leaders from the area's education, health and social care services. They will also visit early years settings, schools and further education providers but will not be inspecting these providers since these are covered by other inspections. They will explore how the whole local area fulfils its responsibilities and how commissioners and providers collaborate to ensure that children and young people with SEND have their needs identified and met. They will assess how well schools and colleges are fulfilling the responsibilities of the new education and health care plans but they will also look at those who receive additional support but whose needs are not severe enough to require one of these plans. They will talk to children and young people with special educational needs, and to their parents too.

The report will take the form of an outcome letter which will highlight key strengths and recommendations. It will be addressed to the whole local area. Any further action by Ofsted and Care Quality Commission will depend on the findings of the inspection. Actions may range from requests for more detailed information on the steps that are to be taken to address the findings, to arranging further meetings or discussions with local area representatives and/or further inspection.

Charlie Henry comments that the likelihood is there will be some sobering truths to be told in the next few years. The question is whether this new way of inspection will help to bring about the changes required whereby all children and young people with SEND really do get the services they need to fulfil their potential and to be as independent as they can.

RESOURCES

Guidance to Support Advocates in Challenging Decisions or Actions with or on behalf of Individuals



Guidance to support advocates in challenging decisions or actions with or on behalf of individuals

VoiceAbility is a charity that works across England with people who are vulnerable or marginalised to raise their voices and have their rights respected. The majority of the charity's services are related to providing advocacy support to people who need it.

VoiceAbility has launched Guidance on Challenging Decisions. The focus is on situations where people face life-changing decisions which are unacceptable and on supporting the person to challenge those decisions. VoiceAbility worked closely with Empowerment Matters, Irwin Mitchell LLP, Dr Lucy Series and Steven Richards from Edge Consultancy and Training to produce the guidance, with substantial advice and input from advocates at VoiceAbility.

The guidance provides comprehensive information about informal and formal routes to challenge and provides reference materials, case examples and details about relevant legislation and statutory guidance. The guide is intended to help advocates to develop a 'tool-kit' of different approaches in order to get the best possible outcome for people depending on their views and situation. Advocates could be practitioners across the health and social care sectors as well as friends and family members who often have to take on the crucial role of supporting people to raise their own concerns, or challenge decisions on their behalf, where necessary. You can download the guidance in full from the VoiceAbility website. Go to: http://www.voiceability.org/what_we_do/resources

HFt's 'Guide for Family Carers: The Change from DLA to PIP'

The HF Trust (Hft) is a Bristol based charity which aims to provide services for people with learning disabilities and their families through England that might support them to live the lives they choose. The Hft operates a free Family Carer Support Service that is for family carers.

In recognition of the fact that many changes are being made to welfare benefits over the next few years, which are already beginning to have an impact, the Hft has produced a handy guide for family carers providing information about how the introduction of Personal Independence Payment (PIP) to replace Disability Living Allowance(DLA) might affect them.

Whilst the information in the guide is correct at time of writing (May 2015), benefits may change and Hft have undertaken to update the guide as the Government announces further changes.

You can download the guide and other useful resources at: http://www.hft.org.uk/Supporting-people/Family-carers/Resources/Guide-to-benefits/

To request a free printed copy, send a self-addressed A4 envelope with £1.24 (first class) or £1.17 (second class) worth of stamps to: Benefits Guide, Family Carer Support Service, Hft, 5/6 Brook Office Park, Folly Brook Road, Emersons Green, Bristol, BS16 7FL

Easy Read Guides to Health Conditions

The Foundation for People with Learning Disabilities has worked with easyhealth.org.uk to produce a range of Easy Read guides on key medical conditions and concepts. Topics include common conditions such as epilepsy, diabetes, obesity, earwax and tooth decay as well as information about breast screening, contraceptive injections and incontinence in women.

It is hoped that these materials will make it easier for doctors and nurses to help their patients with learning disabilities (or indeed anyone who struggles with written information) to understand some common health problems. Obviously, people with very severe or profound learning disabilities will not be able to read these leaflets but family members and other caregivers will still find them useful and they do contain clear picture materials which many people with severe learning disabilities may understand with support. The leaflets were translated from the original clinical summaries on the PRODIGY website and were subjected to the same rigorous clinical quality checks as all the other information published by PRODIGY (http://prodigy.clarity.co.uk).

For further information and to view the guides please see http://www.learningdisabilities.org.uk/our-work/health-well-being/easy-read-guides-health-conditions/ or http://bit.ly/1JAzLH0

SeeAbility Campaign


SeeAbility
Children in Focus campaign
An equal right to sight
Why eye care for children with learning disabilities needs reform

SeeAbility's Children in Focus Campaign wants specialist sight tests available in every special school in England. SeeAbility's team has been delivering specialist sight tests to pupils in a cluster of London based special schools since October 2013. It was found that children with learning disabilities are 28 times more likely to have a serious sight problem than other children, but are often not accessing the eye care they need. SeeAbility found nearly 4 in 10 pupils had no history of sight tests or eye care. Also it found that three quarters of children with disabilities who had been under the care of hospital eye clinics, and were now discharged, had no history of follow up sight tests in the community. There are over 100,000 children in special schools in England and, if these findings are replicated nationwide, it means thousands of children with disabilities are missing out on the eye care they need. If eye problems are undetected children's sight will be at risk.

It is argued that a special schools programme could reduce the risk of many vulnerable children being lost to the system. Unsurprisingly, as the children are in a familiar environment, they are more relaxed, and the system can be flexibly scheduled to fit in different tests or different children if a child isn't well enough to attend.

The findings are in a new report 'An Equal Right to Sight' from SeeAbility. This reflects on what has been found from two years of work providing sight tests to children with complex needs in their special schools. This can be found online at: https://www.seeability.org/uploads/files/Children_in_Focus_campaign/Equal_right_to_sight.pdf.

This report presents an equalities case for reform of sight tests. For an older report presenting the actual research in the first year, go to: https://www.seeability.org/uploads/files/Children_in_Focus_campaign/Full_annual_report.pdf

The charity's website also presents information on vision and eye care for children with learning disabilities including advice for parents, health professionals and teachers.

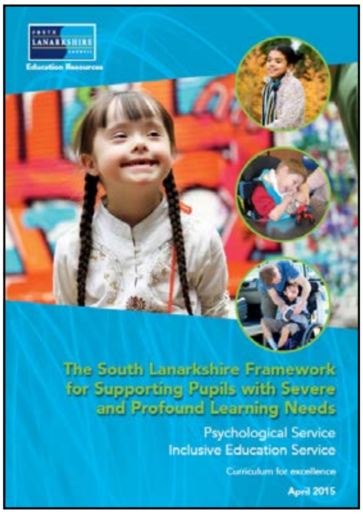
Jenny's Diary

University of the West of Scotland (UWS) has officially launched a new resource to provide a tool for families and practitioners to help people with a learning disability understand their diagnosis of dementia. The resource, 'Jenny's Diary', is a booklet and a set of postcards aimed at supporting conversations about dementia with people who have an intellectual disability. Clearly, this is not a resource to be used with people with PMLD but it was felt appropriate to provide information in PMLD LINK nonetheless.

This free resource was funded by a dissemination grant from Alzheimer's Society and developed in close partnership with Hansel, a leading social care provider based in the west of Scotland. An international advisory panel of people with a learning disability, families, academics and practitioners provided invaluable input.

The resource utilised actors, who are customers and staff at Hansel, to tell the fictional story of 'Jenny', who has a learning disability and is diagnosed with dementia. Jenny's Diary takes a three-step approach, initially opening up with dialogue about why Jenny may be experiencing changes, and how she can be supported to live as well as possible with dementia; secondly suggesting how to have a conversation with Jenny about her diagnosis of dementia; and lastly guidance on how to talk about dementia with Jenny's partner, George.

A New Curriculum Framework for Special Schools in South Lanarkshire



In April 2015 South Lanarkshire published a 'Framework for Supporting Children and Young People with Severe and Profound Learning Needs' put together by its Psychology Service and Inclusion Education Service. This is a practical document to aid schools in taking forward the curriculum for this group of learners and ensures that emphasis is placed on pupils' active engagement and on the identification of relevant and individualised learning 'outcomes.' The information and resources within the Framework aim to build capacity amongst school staff and inform teaching and assessment approaches which are based on an understanding of the development of this group of learners. It is plainly targeted at people who are new to this field of education and lack necessary knowledge and skills.

The document covers: definitions of severe and profound learning needs; key areas of the Scottish Curriculum for Excellence, including literacy, numeracy, health and wellbeing and the cross curricular themes of communication, cognition, self-help and independence, and physical skills; assessment, target setting and monitoring with an emphasis on formative assessment through observation and structured assessment and on teaching being driven not just by individual targets but also by the learner's 'interests, motivators and their active engagement or enjoyment of an activity'; a substantial section on appropriate teaching and learning approach explaining some key approaches in easily understood language and the importance of motivators, engaging and interesting activities and responsive environments; and, finally, health and wellbeing and addressing challenging behaviours sympathetically and positively. There is a selective list of references for further reading, a helpful page of useful links to online materials, and appendices on carrying out observations, paths to progress, indicators of engagement, a sequence for introducing objects of reference and other visual information materials, carrying out an assessment of challenging behaviour, possible banks of targets within communication and language, social interaction and communication, literacy, cognition, mathematics, self care and independence skills, physical skills, and various photocopiable resources such as observation sheets, ABC charts, and behaviour logs. There are also sample ASPs, nursery assessments and behaviour plans.

This could be a very useful document to support induction training and other elementary in-service training in schools and not just in Scotland. The document is free to download at: http://www.southlanarkshire.gov.uk/downloads/file/9818/framework_for_supporting_pupils_with_severe_and_profound_learning_needs

Pain in children with severe intellectual disability

Cerebra is a charity that aims to improve the lives of children with neurological conditions, through research, information and direct, on-going support.

The charity has produced a guide called 'Pain in children with severe intellectual disability: A Guide for Parents' This guide is intended to help the parents of children with severe intellectual and/or communication difficulties understand how pain may affect their child. It explains possible causes of pain in children with intellectual disability, presenting information about how pain may be shown by children who cannot tell us they are in pain and discussing the effects of untreated pain. A Resources section includes links to other briefings and tools that parents can access and the References section provides the details of the research which informs the guide.

This guide is part of a series of guides published by Cerebra that aim to give parents of children with disabilities and/or special educational needs information on how to get the help and support they need. This series of guides can be found on the Cerebra website: http://w3.cerebra.org.uk

A New Website for PMLD LINK

PMLD LINK has developed its new website and this is shortly going live. The old website will be discontinued but the new website has the same URL as the old one (http://www.pmldlink.org.uk).

The website has been developed by the Blayney Partnership with support from members of the PMLD LINK team. Financial support for the development has been provided by the University of Northampton. It has been designed to be accessible via PC, laptop, tablet or mobile phone.

There is more information on the website about the PMLD LINK charity and its aims. Many people do not realise that PMLD LINK is a ‘not for profit’ charity and its trustees and editorial board are all volunteers. The PMLD LINK journal is described and includes an invitation for contributions. PMLD LINK thrives on voluntary contributions to the journal and the website includes guidance on how you may get involved.

PMLD LINK has a Twitter account and a Facebook page which are used to keep followers up to date with news and developments. PMLD LINK welcomes sharing of views, news and information through these media and there are links to both on the website.

There is a full description of the subscription options available and the different rates. Payments can be made easily via PayPal. It is still possible for subscribers to set up standing orders with their bank or make BACS transfers or pay by cheque if they prefer these modes of payment. Details about Gift Aid are included.

There is a resources page but currently this is still under development. The PMLD LINK team is preparing resources to be uploaded in early 2016.

Paying subscribers have access to the members’ page of the PMLD LINK website which allows them to access downloadable versions of back issues from the last three years. Subscribers will receive an e-mail advising them of their Username which has to be their e-mail address and a new Password. Existing subscribers will have an account which we have populated with the information we already have about them. Subscribers may amend the information or add more details. Their account will also show quite clearly when their subscription is due to be renewed. Please be assured that this data is kept securely and in compliance with legal requirements.

People who are not subscribers can access the website and its resources, including older back issues of the journal from our archive.

Please take the opportunity to explore the new website. We hope that you will like it and see its exciting potential. During the next few months there will probably be a need to make other tweaks to improve the website and add more information. If you wish to make any comments on possible improvements, the PMLD LINK Team would be pleased to hear from you.

Inevitably, there may be some glitches with starting a new website. If you have any queries or any difficulties accessing any part of the website, please do not hesitate to contact PMLD LINK (at subscriptions@pmldlink.org.uk or enquiries@pmldlink.org.uk).

Also, we would welcome any good photos of children or adults with PMLD and their carers or supporters to further enliven the website. If you have any to offer, please let us know and we will contact you to explore the possibilities.

When the new website goes live, there will be three new contact e-mail addresses to get in touch with PMLD LINK:

subscriptions@pmldlink.org.uk - for any enquiries related to taking out a subscription or about renewing a subscription or other subscription related matters

editors@pmldlink.org.uk – for any correspondence related to the current issue or the forthcoming issues that require a response from the editors

enquiries@pmldlink.org.uk – for any other matters relating to the PMLD LINK charity or its services including the journal, the website and social media.

After a transitional phase, the existing e-mail addresses for PMLD LINK will cease to be used.

Currently PMLD LINK is preparing resources to be uploaded to the new website including many back issues that we have in our archives, subject to receiving suitable permissions where necessary.

Can you help us? We no longer have a copy of one issue – Issue 23. This came out in Winter 1995 and had the general theme of Promoting Independence. Do you still have a copy tucked away somewhere? If so, can we borrow it to scan it and include it in our archive? If you do have a copy, please contact us. Thank you. Email: pmldlink@gmail.com

PMLD LINK
sharing ideas and information

Vol. 27 No. 3 Issue 82

PMLD Network Forum
A Digest of Discussions
August to December 2015

Bella Travis

The PMLD Network forum is an open email discussion group which focuses on issues relating to PMLD. Here is a summary of the resources, news and reports that have been discussed on the forum over the last few months:

New study of health and care for people with learning disabilities
IHaL is starting a new study of health and care for people with learning disabilities. This will find out how many people with learning disabilities have a wide range of important common health conditions and how many have had important health checks, flu jabs and cancer screening. For a few particularly important conditions including epilepsy and diabetes it will look at how successfully they are being treated. IHAL will compare the experience of people who have learning disabilities with that of people who do not. More details here: www.ihal.org.uk/projects/primarycaredata

Readmission to hospital for people with learning disabilities
Pauline Heslop considers a study which looked at readmissions for people with learning disabilities and those without to see how they compared and how far such readmissions may have been preventable. See the Learning Disabilities Elf website: http://bit.ly/1LWC6zv

New factsheets from the Foundation for People with Learning Disabilities
FPLD factsheet: Handy tips on planning a flight for people with limited mobility
www.learningdisabilities.org.uk/content/assets/pdf/resources/flying-factsheet.pdf

FPLD factsheet: Leisure opportunities for children and adults with complex health needs and/or limited mobility
www.learningdisabilities.org.uk/content/assets/pdf/resources/flying-factsheet.pdf

Nearly 200,000 carers could boost their future State Pension simply by signing up for Carer's Credit.
Minister for Pensions, Baroness Altmann, is calling on all carers to check they are getting what they are entitled to. Read the Department for Work and Pensions' press release and find out more here: http://bit.ly/1JexRib

New online community
Members of the Choice Forum who live or work in Oxfordshire are invited to join a new online community for people who are supporting people with learning disabilities in Oxfordshire. It has been developed by a group of family carers and professionals working in the field. It can be found at: www.ldox.org

Campaign about better wheelchairs
The Wheelchair Leadership Alliance was formed in January 2015 under the leadership of one of the UK's best know Paralympic athletes, Baroness Tanni Grey-Thompson. This Alliance is campaigning for a better deal for wheelchair users and aims to transform the quality and effectiveness of services across England. To pledge your support and find out more about the campaign, go to: www.rightwheelchair.org.uk/

Factors which impact on the social networks of people with profound intellectual disabilities
A blog on the Learning Disabilities Elf looks at a study that seeks to discover the factors, which can most positively impact on the development and maintenance of the informal social networks of people with profound intellectual and multiple disabilities: http://bit.ly/1MrpoJu

Information request around management of constipation Discussion
The Improving Health and Lives (IHaL) team are preparing their next 'reasonable adjustments' report and the focus is constipation. The aim of the IHaL report, is to share information, knowledge and best practice throughout the country which will support people in improving services and care. The team would like to include as many good case studies as possible in this report. They would also like to signpost people to resources they can access free of charge. Please can you send your stories, examples of your work and resources to anna.marriott@ndti.org.uk

To take part in discussions please join the PMLD Network Forum at https://our.choiceforum.org/c/pmldnetwork
Visit the PMLD Network website at
www.pmldnetwork.org

Some Recent Articles on Arts and Culture in PMLD LINK

Spring 2009, Vol 21 (1) Issue 62 – The Joy of the Arts

Nicola Grove	*Telling and sharing stories*	p2
Chris Fuller	*On the road with stories: Story Go Round UK*	p8
Susan McLaren	*The use of the arts in different settings with people with profound and multiple learning difficulties*	p21

Summer 2010, Vol 22 (2) Issue 66 – Sensory Experiences

Naomi Rosenberg	*Move it groove it beat it feel it hear it sing it shake it rock it be in it*	p4
Adam Ockelford, et al.	*Sounds Of Intent: exploring how children and young people engage with music*	p7
Tim Webb	*Oily Cart – multisensory theatre*	p15
Sue Simmonds	*Soundabout Sparklers*	p27

Winter 2010, Vol 22(3) Issue 67 - Lifelong Learning

Penny Lacey and Penny Smith	*Inclusive libraries in practice*	p15
Nina Martinez	*Lifelong learning with Bexley Library Service*	p19

Spring 2011, Vol 23(1) Issue 68 – Speaking Up – Being Heard

Hannah Young and Loretto Lambe	*Multi-sensory storytelling: for people with profound and multiple learning disabilities*	p29

Summer 2011, Vol 23(2) Issue 69 – Sharing Perspectives

Laura Blake	*Interactive Sensory Stories: providing a means, a reason and an opportunity to communicate with children with profound and multiple learning disabilities*	p7

Spring 2012, Vol. 24 (1) Issue 71 – Life is for Living

Penny Lacey	*What people do in the day*	p7
Robbie Campbell	*Musicking with Joy of Sound*	p18

Summer 2012, Vol. 24 (2) Issue 72 – Family and Friends

Nicola Grove et al.	*Using storytelling to develop friendship and participation*	p17

Spring 2013, Vol. 25 (1) Issue 74 – Celebrating 25 Years of PMLD Link

Lucy Garland and Amber Onat Gregory	*Theatre for Young People with Profound and Multiple Learning Disabilities*	p16
Chris Fuller	*Small Beginnings: Bag Books*	p20

SHORT COURSES & CONFERENCES

Providers Details

Concept Training
15 Beach Street,
Morecambe,
Lancastshire LA4 6BT
Tel. 01524 832 828
E-mail: info@concept-training.co.uk
Website: www.concept-training.co.uk/

EQUALS
PO Box 107, North Sheilds,
Tyne & Wear, NE30 2YG
Tel. 0191 272 8600
Email: admin@equals.co.uk
Website: www.equals.co.uk

Hirstwood Training
Tel. 01524 42 63 95
Email: richardhirstwood@gmail.com
Website: www.multi-sensory-room.co.uk

Flo Longhorn training
Email: fplcourses@aol.com
Website: www.flolonghorn.com

January 2016

Title:	Advances in Down's Syndrome and Dementia
Date:	21st January
Location:	London
Provider:	Royal Society of Medicine
Contact:	intellectual.disability@rsm.ac.uk Tel: +44 (0) 7290 3942

Title:	Land of lights by the Oily Cart Company
Date:	15th December - 3rd January: artsdepot, London
Location:	
Contact:	Box office 0208 369 5454 Or see http://www.oilycart.org.uk/

Title:	Land of lights by the Oily Cart Company
Date:	12th - 23rd January
Location:	Clwyd Theatre Cymru, Mold
Contact:	Box office 01352 701521 Or see http://www.oilycart.org.uk/

Title:	14-25 Year Old Special Students: Creative Approaches to Supporting Very Special Students in Education & Beyond
Date:	27th January
Location:	London
Provider	Melinda Hutchinson & Flo Longhorn
Contact:	FPLcourses@aol.com

Title:	Creativity Rules, Okay!
Date:	29th January
Location:	London
Provider	Andrea Muir, Sarah Hall & Flo Longhorn
Contact:	FPLcourses@aol.com

February

Title:	Land of lights by the Oily Cart Company
Date:	9th - 13th February: Gulbenkian, Canterbury
Location:	
Contact:	Box office 01227 769075 Or see http://www.oilycart.org.uk/

Title:	Planning a Sensory Curriculum for Very Special People - Back to Basics
Date:	1st February
Location:	London
Provider:	Joanna Grace & Flo Longhorn
Contact:	FPLcourses@aol.com

Title:	Sensory Integration in the Classroom – An Introduction
Date:	8th February
Location:	Leeds
Provider:	Becky Lyddon & Flo Longhorn
Contact:	FPLcourses@aol.com
Title:	Helping parents of disabled children with sleep: 2-day workshop
Date:	Feb 9-10th
Location:	Birmingham
Provider:	Interconnections
Contact:	peter.limbrick@teamaroundthechild.com
Title:	Sensory Stories for Children & Teens with Special Educational Needs
Date:	9th Feb
Location:	Leicester
Provider:	Joanna Grace
Contact:	FPLcourses@aol.com
Title:	Planning a Sensory Curriculum for Very Special People - Back to Basics
Date:	10th Feb
Location:	Leicester
Provider:	Joanna Grace & Flo Longhorn
Contact:	FPLcourses@aol.com
Title:	Planning a Sensory Curriculum for Very Special People - Back to Basics
Date:	24 February 2016
Location:	Birmingham
Provider:	Flo Longhorn and Joanna Grace
Contact:	FPLcourses@aol.com
Title:	Sensory Stories for Children & Teens with Special Educational Needs
Date:	25 February 2016
Location:	Birmingham
Provider:	Joanna Grace
Contact:	FPLcourses@aol.com

Title:	14-25 Year Old Special Students: Creative Approaches to Supporting Very Special Students in Education & Beyond
Date:	26 February 2016
Location:	Birmingham
Provider:	Melinda Hutchinson & Flo Longhorn
Contact:	FPLcourses@aol.com
March	
Title:	Every Moment Matters: Interacting with the World through ICT
Date:	10 March 2016
Location:	Manchester
Provider:	Ian Bean FPLcourses@aol.com
Contact:	FPLcourses@aol.com
April	
Title:	Intensive Interaction Leadership course
Date:	1st April to 1st July
Location:	Malvern, Worcs
Provider:	Intensive Interaction
Contact:	http://www.intensiveinteraction.co.uk/courses-events/
Title:	Sensory Integration in the Classroom – An Introduction
Date:	28 April 2016
Location:	Birmingham
Provider:	Becky Lyddon & Flo Longhorn
Contact:	FPLcourses@aol.com
Title:	Every Moment Matters: Interacting with the World **through ICT**
Date:	29 April 2016
Location:	Birmingham
Provider:	Ian Bean
Contact:	FPLcourses@aol.com

May

Title: Planning a Sensory Curriculum for Very Special People - Back to Basics
Date: 5th May 2016
Location: Manchester
Provider: Joanna Grace & Flo Longhorn
Contact: FPLcourses@aol.com

Title: Sensory Stories for Children & Teens with Special Educational Needs
Date: 6th May 2016
Location: Manchester
Provider: Joanna Grace
Contact: FPLcourses@aol.com

Title: Sensory Integration in the Classroom - An Introduction
Date: 9th May 2016
Location: Manchester
Provider: Becky Lyddon & Flo Longhorn
Contact: FPLcourses@aol.com

Title: 14-25 Year Old Special Students: Creative Approaches to Supporting Very Special Students in Education & Beyond
Date: 10th May 2016
Location: Manchester
Provider: Melinda Hutchinson & Flo Longhorn
Contact: FPLcourses@aol.com

Title: Making Sense of Literacy for Special Learners
Date: 12 May 2016
Location: Birmingham
Provider: Les Staves
Contact: FPLcourses@aol.com

Title: Reaching the Parts of Special Maths a Formal Curriculum Cannot Touch
Date: May 13th 2016
Location: Birmingham
Provider: Les Staves
Contact: FPLcourses@aol.com

Title: Creativity Rules, Okay!
Date: 18 May 2016
Location: Birmingham
Provider: Andrea Muir, Sarah Hall & Flo Longhorn
Contact: FPLcourses@aol.com

Title: Phenotypes – recent advances in clinical practice
Date: 24th May 2016
Location: London
Provider: Royal Society of Medicine
Contact: intellectual.disability@rsm.ac.uk

Tel: +44 (0) 7290 3942

Title: Making Sense of Literacy for Special Learners
Date: 25 May 2016
Location: Nottingham
Provider: Les Staves
Contact: FPLcourses@aol.com

Title: Reaching the Parts of Special Maths: a Formal Curriculum Cannot Touch
Date: 26 May 2016
Location: Nottingham
Provider: Les Staves
Contact: FPLcourses@aol.com

LONGER COURSES (with Accreditation)

MA Education
Pupils with Severe and Profound and Multiple Learning Difficulties (P1: Contexts & Understanding P2: Curriculum & Teaching)
The course provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with severe and profound and multiple learning difficulties.
For further Details: The University of Northampton. Tel: 08003582232 Email: study@northampton.ac.uk

MA Education Physical Disabilities (P1: Contexts & Interventions P2: Curriculum Issues)
The first module (P1) provides opportunities for those with QTS and professional qualifications and experience in services for children, to engage in structured critical reflection, exploration of key substantive issues and overarching policy determinants in respect of children and young people with physical disabilities. The second module (P2) provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of physical disabilities. It engages students in debates concerning the relevance and practical efficacy of recent guidance and legislation in physical disability-related issues, and offers an in-depth series of curriculum-focused activity which is intended to enhance both the understanding and the practice of those working with children and young people with physical disabilities.
For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

MA Education Understanding Multi-Sensory Impairment
This module addresses the requirements of the National Special Educational Needs Standards (Extension 2.i – 2iv.). It is directly related to Pupils with Multi Sensory Impairment (MSI) The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with multi sensory impairment. It provides professional development for teachers and other professional colleagues working in an area of low incidence need and addresses priorities established by Local Authorities, individual teachers and others working with children and young people who experience MSI.
For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

Certificate in Higher Education (CHESL): Supporting Learners with SLD/PMLD
This course aimed at Teaching Assistants will look in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. These learners may also have other additional or associated disabilities, such as physical or sensory impairments. The course will examine topics of both a theoretical and practical nature to provide students with a greater understanding about this group of learners, together with a broad range of strategies and approaches that can be applied to practice. The sessions will include lectures, workshop activities, discussion and some visiting speakers.
For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

BPhil, PGDip and MEd Inclusion and SEN
Year 1 Learning Difficulties and Disabilities (Severe, Profound and Complex)
Year 2 Autism (Children) or Autism (Adults)
Distance Education
This two/ three year course contains 6 modules and students study the required number from this list for their chosen award plus a dissertation.

1. Understanding Learning Difficulties and Disabilities
2. Interventions for People with Learning Difficulties and Disabilities
3. Learning Difficulties and Disabilities: Communication and Behaviour
4. Special Educational Needs of Children with Autism *or* Autism (Adults) Understanding and Working with the Continuum of Need
5. Curriculum and Treatment for Children with Autism *or* Autism (Adults) Intervention, Care and Education
6. PGDip includes a practical project based on your work

MEd includes a research methods module and a dissertation
For further details: The University of Birmingham, email: isen@contacts.bham.ac.uk

BSc in Professional Practice
BSc in Professional Practice - includes forensic, mental health/learning disability, challenging behaviour, older person with LD and epilepsy modules. Students will be provided with an educational experience, tailored to their particular requirements, so as to gain professional experience. This will enable them to work collaboratively and flexibly within health and social care systems.
For further details: University of Chester Tel: 01244 511000 Email: enquiries@chester.ac.uk

MSc in Advanced Practice
The School of Health & Social Care, University of Chester, MSc in Advanced Practice (Learning Disabilities) - includes generic modules in research and inter-professional working plus 3 LD specialist modules (socio- political themes in LD; developmental perspectives on LD; profound & complex needs). This course is suitable for health and social care professionals who would like to develop higher levels of professional knowledge and expertise in their sphere of practice.
For further details: University of Chester Tel: 01244 511 000 Email: enquiries@chester.ac.uk

Postgraduate Courses in Profound and Complex Learning Disability
The course is studied by distance learning plus attendance at an Autumn Study School at the University of Manchester. The course accent is on moving towards increasing choice; developing community presence and participation; and increasing respect for individuals with complex needs. This approach underpins all aspects of course delivery. The course has three aims:
· To support the professional development of people working with children and adults with complex disabilities.
· To empower course participants to advocate for people with profound and complex learning disabilities.
· To enable course participants to develop knowledge and understanding of key issues in the field.
For further details: The University of Manchester, Lesley Jenkins Phone: 0161 275 33337 Email: pld.distance@manchester.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.
Severe, Profound and Multiple Learning Difficulties
Blended Learning (a combination of online and occasional weekend study on campus)
The Severe, Profound and Multiple Learning Difficulties blended learning programme has been developed for a range of professionals/practitioners who work with children and adults with learning difficulties in educational settings across the severe and profound range (SLD/ PMLD). The programme covers issues for staff who work in any education and learning services and has particular emphasis on working together to meet needs. The programme aims to help participants to study systematically, critically and in-depth, aspects of educating children and adults with severe, profound and multiple learning difficulties. Participants are encouraged to research and reflect on their own practice, carrying out small-scale research leading to developments and innovation.
For further details: University of Birmingham, email: severeprofoundandmultiplelearningdifficulties@contacts.bham.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.
Multisensory Impairment (Deafblindness) - *Distance Learning*
This programme enables teachers and others working in education related fields to work more effectively with learners who are deafblind (multisensory impaired). Some students are teachers working with children or adults, but others are from social services, medical, or residential work. A one-year programme can lead to the awards of Advanced Certificate or Postgraduate Certificate.
· A two-year programme can lead to the award of BPhil, or Postgraduate Diploma.
· A two-year programme with a dissertation can lead to the award of an MEd.
Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments.
For further details: University of Birmingham Dr Liz Hodges on 0121-414 4873 or email: e.m.hodges@bham.ac.uk

Adults with learning disabilities who have significant and complex needs

The School of Psychology at the University of St Andrews offers a Post Graduate Certificate by open/distance learning: "Adults with learning disabilities who have significant and complex needs". This consists of four distance learning modules, chosen from six, and is available to staff with a professional qualification or a first degree.

- Challenging behaviour
- Mental health
- Offenders with learning disabilities
- Older people with learning disabilities
- Profound and multiple disabilities
- Vulnerability, victimisation and abuse

The programme leads to further qualifications at Diploma and Masters level.
For further details: University of St. Andrews http://psy.st-andrews.ac.uk/people/personal/mc1/ Dr Martin Campbell email: mc1@st-andrews.ac.uk

SEN Foundation Degree at Whitefield Schools and Centre in partnership with Kingston University

The SEN Foundation Degree is a higher education qualification which combines academic study with work-based learning. It provides a training pathway for those who would like to remain in work whilst studying for a higher education award. The degree is specifically designed for professionals working with children and young people in educational settings who have additional learning needs. You will have an appropriate Level 3 qualification and at least two years' post-qualifying experience and must be working at least 16 hours per week in an educational setting with children from birth to nineteen years. Course start date: September 2014
For further details: Whitefield Schools and Centre, Louise Langsworthy l.langsworthy@whitefield.waltham.sch.uk

Postgraduate Studies at Whitefield Schools and Centre in partnership with Kingston University

The Postgraduate Certificate, Diploma and Masters programmes are delivered at Whitefield Schools and Centre in partnership with Kingston University, London. The Certificate course runs for one year and the Diploma runs for two years. Both years carry 60 ''M'' level credits, allowing access to the third year Masters Degree that takes the form of an educational action research project.
The *Diploma and Certificate* courses are practitioner based and there is a requirement that students are working, either as a paid member of staff, or in a voluntary capacity for at least two days a week with children or young people with special educational needs.
The *Masters programme* is also practitioner based but there is no requirement for work to be but students can be accepted straight on to this programme (subject to an official transfer request and University approval) if they already have the appropriate number of credits at ''M'' level.
Whitefield can also offer the mandatory qualification for teachers of pupils with Multi-Sensory Impairment (MSI). Teachers undertaking this course complete two years of study as above, addressing the mandatory standards for this course, followed by a four week assessed teaching placement working with MSI pupils in a recognised centre of excellence.
Course start date: September 2014
For further details: Whitefield Schools and Centre, Louise Langsworthy l.langsworthy@whitefield.waltham.sch.uk

PMLD LINK
sharing ideas and information

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Vol. 27 No. 3 Issue 82

PMLD LINK
sharing ideas and information

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

- short papers
- news of individuals, families or other groups
- information sharing
- requests from readers for information

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	Disability 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.
Jill Davies	Research Programme Manager for the Foundation for People with Learning Disabilities. Jill recently completed a Dept. of Health project on Meeting the needs of children with complex health needs. She facilitates the UK Health and Learning Disability Network.
Beverley Dawkins	OBE Chief Executive of Generate
Ann Fergusson	Researcher and tutor for severe learning difficulties and PMLD courses at The University of Northampton. Trustee of National Family Carers Network. Ann also has a family member with a learning disability
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
Wendy Newby	Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
Jill Pawlyn	Jillian Pawlyn has a background in Learning/ Intellectual Disabilities Nursing and is an enthusiast and advocate of Technology Enhanced Learning. During her years as a registered nurse Jillian has developed a specialist interest in the health needs of people with a learning/ intellectual disability in particular those individuals who have Profound Intellectual and/or Multiple Disabilities (PIMD/ PMLD). She is a member of both the national and local PMLD Networks
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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