

PMLD LINK

sharing ideas and information

Raising Our Sights: 10 years on

Winter 2020



Vol 32 No 3. Issue 97

ISSN 2042-5619

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GUEST EDITORIAL

Raising Our Sights: 10 years on

We wanted this to be a bumper Winter Issue of the journal to mark 10 years since Professor Jim Mansell's seminal Raising Our Sights report. Due to the generosity of contributors, we have not been disappointed.

This issue starts with some background about the Raising Our Sights report and a recap of some of the major activities and milestones over the last 10 years from our perspective. We have also included a great article that Professor Mansell wrote for the PMLD Link Journal setting out his findings and recommendations. We then share some of your thoughts and reflections about Raising Our Sights and progress since that time.

This issue includes articles on a range of topics, which share ideas and great practice to inform and inspire others. Many of the pieces include a focus on the Covid-19 pandemic and the creative ways in which people have adapted support and activities during this time.

The practice shared in your articles very much reflects some of the key elements of good support and services, which Professor Mansell identified in his report: Good services are individualised and person-centred; Good services treat the family as expert; and Good services focus on quality of staff relationships with the disabled person.

We know that often examples of good practice are down to determination and brilliant efforts from individuals and there is still a lot of work to do to remove the barriers to good support for people with PMLD. Please continue to share your good practice and ideas about how to remove the barriers.

On behalf of everyone in the PMLD Link team, we wish you all and your families and friends a happy and safe 2021.

Guest Editors: Rob Ashdown, Bella Travis, Maureen Phillip and Michael Fullerton

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ISSN 2042-5619

Raising Our Sights: Ten years On

The Guest Editors

In 2009, 'Valuing People Now' updated the Government's plans for all people with a learning disability, which had been set out in the 'Valuing People' White Paper in 2001. In 'Valuing People Now', it was acknowledged that people with profound and multiple learning disabilities had largely missed out on the positive changes brought in since 'Valuing People' in 2001. 'Valuing People Now' had a specific focus on including everyone, and as part of the delivery plan, the Department of Health commissioned Professor Jim Mansell of the Tizard Centre at the University of Kent to review support and services for adults with profound and multiple learning disabilities. Professor Mansell published his report 'Raising Our Sights' in 2010.

In 'Raising Our Sights' it was demonstrated that, despite clear government directives, there were many inequities experienced by people with PMLD and their families when it came to access to appropriate and responsive services, which most of us can take for granted. In many respects the major obstacles to implementing personalised services for this group of people were not a lack of money but low expectations and poor understanding of their needs and the needs of their families and supporters. Mansell's report set out important recommendations for national and local government and health and social services to address these inadequacies. The report is worth reading in full but Mansell produced a helpful summary of the issues and his recommendations that appeared in this journal reproduced here on pages 5 – 10. This does much to highlight both the good practice and the barriers that need to be overcome if adults with profound learning disabilities and their families are to benefit from personalised support and be able to participate as active and valued members of their community. Therefore, the editors felt that it was important to reprint it in this issue on the following pages.

The focus of 'Raising Our Sights' was on adults but also in 2010, Toby Salt reported to the DCSF (the department for education of that time) about the worrying position of a diminishing workforce of appropriately trained teachers to meet the needs of the growing number of learners with severe or profound and multiple learning difficulties in schools. The foreword to the report included this statement: '...this is a sector, and a group of learners, that have been out of the limelight for far too long. It needs significant focus, not least because it includes some of the most complex, most vulnerable and indeed expensive learners in our system' (Salt, 2010, p.2). In Scotland, Peter Doran chaired a review of services for children and young people with 'complex additional support needs' which movingly spoke of positive developments in services but also the frustrations of many parents and professionals. The resultant report made 21 recommendations for the Scottish Government.

So what has been achieved in the ten years since these reports were published? Regular readers of this journal over the past decade will be very familiar with anecdotes, research and official reports demonstrating that both children and adults with PMLD continue to receive poorer quality services when compared with others (with/without disabilities) and, generally, are still too often overlooked. However, by contrast, there have appeared in this journal and elsewhere stimulating accounts of cutting edge practice that has enabled people with PMLD to lead healthy, full and meaningful lives they want. All too often, these positive developments have only occurred because passionate individuals or small groups of well-informed people or some remarkable organisations have worked hard to make things happen despite lack of resources or funding or strategic support from governments or local authorities which too often fail to recognise the particular vulnerability of this group, the isolation of families and the professional development needs of the workforces in the health, education and social care sectors.

It is true that there have been some significant developments in the wider sectors of both special education and adult learning disabilities services but only a relatively small amount of time and investment has been spent in developing services and resources that truly meet the needs of people with PMLD. Perhaps rather more has been seen in the special education sector in terms of developing appropriate curriculums and assessment such the Welsh and Northern Ireland government revisions to Routes for Learning and Quest for Learning and associated teaching programmes and resources (Welsh Government, 2020; Council for the Curriculum, Examinations and Assessment, 2020). England saw the development of attempts to make available online training materials for teachers of learners with severe, profound and complex learning difficulties that had been funded by the government (Department for Education, 2012) and a continuing battle to develop appropriate assessment materials culminating in the introduction of the Engagement Model which will

become mandatory in 2021 (Standards and Testing Agency, 2020). But in all the countries of the UK significant developments in the education of children and young people with PMLD still mainly depend upon the initiatives of individual schools or some consortiums of schools or a few forward thinking people engaged in higher education research and consultancy work. A common theme is that there is still a continued need for government to focus on the strategic commissioning of national and local developments that have been recommended previously.

As regards services for adults, in 2013, Mencap and the PMLD Network published a series of 'Raising Our Sights How-to guides' that had been developed with funding from the Department of Health, to help local areas implement the 'Raising Our Sights' recommendations. These are still available and deserve to be more widely read than they seem to be. They are aimed at families and supporters of adults with PMLD (although they do contain much of relevance to children) as well as commissioners and providers of services. There are 10 How-to guides covering different topics and showing how to: recognise good services and support for people with PMLD; challenge and campaign where people with PMLD are not getting the right support; and ensure that necessary changes happen, with clear messages for commissioners and providers of services. There is an additional Guide targeted at commissioners of local services. Because the guides are so important, a briefing note is included in this issue of PMLD Link (see page 11).

In the absence of national frameworks, the examples reported in the PMLD Link journal and the 'Raising Our Sights How-to guides' make plain for commissioners and service providers, including schools, the high quality outcomes that can be achieved. They serve as inspiring models but it is far from clear that they have been noticed by many of those who have key roles and budgetary control in planning and commissioning services. A constructive development that PMLD Link has espoused may help to change the picture. A working group of motivated individuals with the support of some organisations has developed a series of standards that could be used as a catalyst to establishing consistently high quality provision and services across education, health and social care everywhere (Doukas et al., 2017). The fundamental purpose of the 'PMLD Standards' is to establish a set of indicative, national benchmarks clarifying what 'Good' provision looks like for children and adults with PMLD. These standards have been designed expressly to enable the commissioners of services and the services themselves to evaluate the quality of provision through regular and ongoing self-review. They explicitly describe what ideally should be evident across all education, health, and social care services.

There are two main components to the standards. The first set of standards aims to give guidance and support to organisations on how to provide high quality care to people with PMLD. Their emphasis is on what people at all levels and ranks of an organisation's structure should contribute to delivering such support. A second set of standards, focuses on the individual with PMLD and their specific needs and organisations are expected to self-assess against these standards to identify actions to improve the quality of the support they provide.

PMLD Link hopes that these standards will be adopted by commissioners and providers of services and has strived to bring them to the attention of government agencies including those which monitor, inspect and regulate education, health and social care services. Moreover, PMLD Link wants to ensure that families and other key stakeholders have awareness of these standards, so that there should be clarity, from the outset, of what level and type of standards may be expected for the persons with PMLD whom they represent and for whom they act as advocate.

To these ends, PMLD Link has promoted the PMLD Standards in this journal, through social media and through contributions to conferences but more spectacularly at 'Raising the Bar' conferences held in 2017, 2018 and 2019. The conferences were well received and people praised the speakers who described good practice. What was good about these conferences was that they placed family members alongside professionals. Liz Wilson, when asked for her feedback, commented:

"Wow, what a day! Families, once side-lined by 'the experts' took centre stage side by side with practitioners who share a determination to raise the bar so that a 'PMLD' label can no longer be confused with a 'no hope' label."

Wilson (2017, p.40)

Carrie-Ann Sutton also reported:

"Friday 25th October 2019 was my first time at Raising the Bar, and I found the prospect of attending alongside a large number of professionals such as Learning Disability Nurses, Teachers, Parents and other Practitioners quite daunting. Nonetheless, it soon became the highlight of my year! Raising the Bar gave me the opportunity to network with a range of inspiring people, who I felt an instant connection with, given that we shared a passion and ambition to improve the lives of children and adults with PMLD. This is what makes Raising the Bar so unique."

Sutton (2019, p.42)

In a reflective contribution about the 2019 conference, Elly Chapple noted:

“A theme that ran throughout the day was the message that people are not what we always assume, and often we aren’t listening or reflecting enough. It sounds simple, but listening to the parents that shared their stories, there was a commonality around the often lack of understanding of what their child could do, who they were and what we should expect.”

Chapple (2020, p.43)

So in the UK we have much to feel pleased about as well as feeling many frustrations about repeated failures to improve in key areas. When you have read the pieces in this issue of the journal we would welcome you sharing your views with us. We will summarise in the next issue any comments that we do receive. What do you think has been achieved in the past decade? What improvements are needed to have a positive and enduring impact? What actions must be taken to remove the barriers to improvement and what are realistic and achievable timescales? What do we expect from the leaders of national governments and local agencies?

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Raising Our Sights: Services for adults with profound intellectual and multiple disabilities

Jim Mansell

Raising Our Sights was a review authored by Professor Jim Mansell of services for adults with profound intellectual and multiple disabilities (referred to in PMLD Link as adults with profound and multiple learning disabilities) carried out as part of the implementation of *Valuing People Now* which was the Labour Government's three-year strategy for people with learning disabilities. *Raising Our Sights* looked at good practice and the barriers that stop people getting the support that they need.

People with profound intellectual and multiple disabilities are among the most disabled individuals in our community. Faced with such undeniable need, why is it that they and their families have such difficulty getting help? The evidence from families themselves is that prejudice, discrimination and low expectations underlie why families have such difficulty getting help. A common experience appears to be that families are told that they cannot have the services they need because their needs are too great – that the amount of money involved is 'better spent' meeting the needs of a larger number of people with less severe needs. As well as prejudice and discrimination, expectations of what it is possible to achieve are very low.

Raising Our Sights

Although people with profound intellectual and multiple disabilities are very disabled and do experience a much higher mortality rate than the rest of the population, it is evident that many live well into adult life, do recognise people around them, do respond to circumstances and do enjoy activities and relationships. Irrespective of the difficulties, and just like any other parents, most families love their disabled child and want the best for them. They want to protect them from harm, and to provide love and security for them. New models of providing services in a person-centred way should make us raise our sights. Examples of good practice show that, in general, the 'personalisation agenda' (Prime Minister's Strategy Unit 2005; Department of Health 2007) - the framework of person-centred planning and highly individualised services, increasingly funded through individual budgets - is providing what people need and want.

A second reason for revising our expectations is the coming revolution in information technology. Research suggests that people with profound intellectual and multiple disabilities can learn to use microswitches to indicate a preference or control an event (Lancioni, Reilly and Basili, 2001; Lancioni et al 2008). Such microswitches may need to be adapted so that they are

operated in different ways, depending on the physical impairments of the disabled person. Similarly, electric wheelchairs have been adapted to follow a track and their controls are replaced by motion sensors or other microswitches tailored to the disabled person's skills. This provides a means by which people with profound intellectual and multiple disabilities can move around their environment (Nilsson and Eklund 2006; Odor and Watson 1994). The intelligence built-in to the wheelchair makes it safe to use in spite of the person's disability.

Such technological aids offer the prospect of enabling people to communicate with others and to control aspects of their environment such as where they are. For people often dismissed as unable to communicate the possible impact on the attitudes of others, being able to control aspects of their environment is at least as important as the direct effect on the person's quality of life. These technological developments, are beginning to make an impact in schools and colleges and so some people with profound intellectual and multiple disabilities will have had experience of them. They appear, however, to be almost unknown in services for adults with profound intellectual and multiple disabilities.

Elements of good services

Good services are individualised and person-centred

All the examples of good practice involved designing and delivering arrangements tailored to the individual person's needs and preferences. Some families had achieved personalised arrangements before individual budgets were possible, through lobbying to shape services in the way they needed. Others were using individual budgets to achieve the same result. In both cases, good services also overcame organisational barriers (for example between health and social care) to deliver the services the individual needed in a coordinated way.

Good services treat the family as expert

In all the examples of good practice families had taken a leading role, often battling against the perceived

indifference of public services to get what they needed for their disabled family member. In most cases families had used self-directed services involving individual budgets to control and direct the main services they needed. Some families were playing a large part in recruiting and managing staff, whereas others were leaving most of this part to service providers. These families were also being treated as experts by other services they used. For example, in using hospital and other health services they described how professionals listened to their advice about how best to serve their disabled family member, making adjustments to appointment times and approaches to assessment and treatment as required. Recognition of the expertise and commitment of the family means that these services are not only person-centred, but they are also family-centred.

Good services focus on quality of staff relationships with the disabled person

Sufficient personal assistance is essential, both to provide safe care and support and also to enable the person to have as good a quality of life as possible. In describing the staff who provided support to their disabled family member, there was remarkable consistency in family views about what was important. The key attribute was that staff should have a warm, respectful and caring relationship with the person. This was viewed as much more important than the particular background or training that staff had, as a mother explained:

“Often – not always but sometimes – the best people have been people who have come with the right values and attitudes and with no experience whatsoever...That’s why it is so important that the person understands and has that ability to build a relationship, to see the person as a person. You can teach all the rest.”

Families did, however, put a lot of effort into ensuring that staff learned how to support the disabled person in the best way, using written policies and procedures, modelling by more experienced staff, supervised practice and attendance at training courses. Communication is fundamental to these skills. Staff need to be able to recognise and respond to the full range of communication, including eye-movements, facial expression and body language.

In addition, research suggests that there is scope for better support from personal assistants given more access to training, as one professional interviewed explained:

“I see too many people being wheeled round shopping centres for hours at a stretch, by poorly paid and insufficiently trained staff.”

There is great potential to provide a better quality of life for the person with profound intellectual and multiple disabilities, if staff are helped to build on the foundation of a good relationship with the person they support by using person-centred approaches.

Good services sustain the package of care

Families described the importance of reliability and continuity in the provision of basic supplies like incontinence pads, rubber gloves and medicines. They were clear that if these were to fail, they undermined the quality of life of their disabled family member. Having achieved the package of services they wanted, some families were confident that they would continue to be supported. Others were anxious that they had to repeatedly justify the package in the face of pressures to make financial savings or that restrictions might be imposed on how they could use their individual budget.

Good services are cost-effective

There appears to be no research on the cost-effectiveness of services specifically for adults with profound intellectual and multiple disabilities. The families using services identified in this report as providing good practice, reported that they were similar in cost to the alternatives they had considered or had experience of. The cost of care packages ranged from £62,952 to £179,000 a year. It is self-evident that services for adults with profound intellectual and multiple disabilities will be more expensive than those for people with less severe disabilities: the major element of costs is personal assistance and these people will need personal assistance most of the time if they are to have a good quality of life.

The cost-effectiveness of good services for adults with profound intellectual and multiple disabilities is therefore much more likely to be reflected in:

- higher quality of life
- lower costs on families (including non-monetary costs)
- lower needs in other areas (eg health)
- or in the future,

than in lower costs of the package of care. On this basis all the families, and the commissioners they were working with, thought that the arrangements they had in place were cost-effective.

Extending good practice

Government plans to continue to extend self-directed services will provide the opportunity for more families to experience the benefits. As this happens, a

- Continued leadership from government will be required to ensure that personalisation is not compromised.
- Families should be able to get help in securing and running self-directed services from user-led organisations or self-help groups of other families.
- Independent advocacy arrangements suitable to represent the interests of adults with profound intellectual and multiple disabilities should be funded.
- Government should continue to lead the development of more effective transition arrangements so that there is proper planning and timely provision of appropriate services as people move into adulthood.
- Up-to-date information about the number, needs and circumstances of people with profound intellectual and multiple disabilities in each area now and in future should be collected to enable effective planning of services.
- Sufficient numbers of personal assistants should be available, trained in person-centred approaches to communication and support that meet the needs of adults with profound intellectual and multiple disabilities, through training that involves families and adults with profound intellectual and multiple disabilities in its delivery.

Box 1 Extending Good practice

number of risks or potential problems can be identified which need to be dealt with and in the course of reviewing good practice, a number of more specific obstacles to improvement have become apparent. These obstacles particularly affect people with profound intellectual and multiple disabilities.

Alex shares a 3 bedroom bungalow in an ordinary residential street with Simon. The bungalow was the property of Alex's family and when it became available it was decided that it would become Alex's new home. Alex's father approached SENSE to ask them to find someone else to be a tenant in the property and so Simon (who has less severe disabilities) joined him. They had not known each other particularly well before living together as they went to different schools. The families knew of each other but had not had much previous contact.

Simon and Alex have one bedroom each and the third is used as an office/sleep over room for night staff. The bungalow has a small kitchen and this includes some adapted equipment, such as a drinks level indicator and a talking microwave. It has a garden which is paved with raised flower beds (good for both young men as they both have visual disabilities) and a garage. Additional hand rails were put on the steps in the garden.

Both families receive funding for the package of care as a direct payment. This pays for 1:1 staff support but includes only one sleeping member of staff at night. In addition Simon and Alex receive housing benefit, incapacity benefit and upper rate Disability Living Allowance which are used for rent and living costs. They

are both tenants and both pay monthly rent. Alex and Simon also attend a SENSE Resource Centre for 5 days per week which they attend with their support staff. The Learning and Skills Council fund 3 days per week and social services fund the other 2 days per week.

Conclusion

Adults with profound intellectual and multiple disabilities are a relatively small, easily identified group of people with undeniable needs for care and support. Despite these needs, they and their families have often not been provided with services to adequately meet them.

The 'personalisation agenda' expressed in government policy does appear to provide a better quality of life for adults with profound intellectual and multiple disabilities and their families. Continued progress in widening access to these kinds of services will enable more people to benefit from them.

No amount of investment is going to radically change the need for support for this group of people. Greater efficiency in other aspects of health and social care may free up resources which can be spent on them but they are not going to be the source of savings. Their services are relatively expensive because their needs are high. Greater cost-effectiveness will come from getting the most out of those resources, in terms of the quality of life experienced by them and their families, and through the reduction of harm and ill-health to them and their carers.

Most of the work required to tackle the obstacles identified does not require large amounts of extra resources. It requires reasonable adjustment to policies, procedures, rules and priorities to ensure that adults with profound intellectual and multiple disabilities get the support they need. In general, adults with profound intellectual and multiple disabilities require such substantial amounts of support from staff that person-centred services are not likely to be significantly more expensive than the old congregate models of care.

Where extra resources are required (as for example in the application of technology to empower and enable people) these will be difficult to find during the current world economic crisis. Hard times should, however, dictate the pace at which we can achieve our objectives, not the nature of the objectives themselves. In the words of the United Nations (2006) Convention our obligation is to work towards “achieving progressively the full realization” of the rights of this group of disabled people.

Author details

Jim Mansell was Professor of Learning Disability in the Tizard Centre at the University of Kent. Sadly, Professor Mansell died in 2012. Shortly before he died, he was awarded a CBE for his services to people with a learning disability. The work he did, focusing on people with PMLD and others with complex needs, helped ensure that some of the most marginalized people in society remain at the forefront of our thinking. For more details see the appreciation by Beverley Dawkins in *PMLD Link* (Spring issue 2012), 24, 1, 33.

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Housing	Revise arrangements for capital subsidy [...] to remove the disincentive to provide adequate housing for adults with profound intellectual and multiple disabilities; resolve the apparent contradiction between social care policy and housing policy [.....].
Access to community facilities	Amend Part M of the Building Regulations so that all newly built major public buildings provide a Changing Places toilet; identify and disseminate good practice in the provision of access for adults with profound intellectual and multiple disabilities to public swimming pools.
Health services	NHS bodies should pay particular attention to meeting the needs of adults with profound intellectual and multiple disabilities [.....]; they should ensure they provide health services to adults with profound intellectual and multiple disabilities in each area which focus on protection of body shape, dysphagia, epilepsy and investigation and resolution of pain and distress; the Board of each NHS Trust should consider a report specifically focused on the adequacy of health services for adults with profound intellectual and multiple disabilities and approve an action plan to ensure adequate treatment.
Wheelchairs	Reform the wheelchair service; provide powered wheelchairs where family members, paid staff or others need them in order to move the disabled person; people who have used powered wheelchairs (e.g. 'smart' wheelchairs) at home or at school during childhood should have the option of continuing to have them provided in adult life, where this sustains or enhances their quality of life; other people should be provided with powered wheelchairs, suitably adapted with 'smart' technology, where this sustains or enhances their quality of life.
Communication aids and assistive technology	Decide whether funding the provision and repair of communication aids for adults with profound intellectual and multiple disabilities is the responsibility of the National Health Service or of Local Authority social care services; review and disseminate the available research and practice; fund research and demonstration projects in each region; commission organisations which have expertise in this area, to advise families and agencies about new opportunities presented by these communication and control aids; to offer opportunities for people to try out different equipment; and to train staff.
Further education	State as policy the goal that everyone with profound intellectual and multiple disabilities should have access to further education, in order to help funding bodies develop appropriate objectives and plans; monitor the volume and quality of provision; create incentives for specialist colleges to partner with local non-specialist further education colleges to increase the quality and amount of local provision for adults with profound intellectual and multiple disabilities.
Employment and day activity	Ensure that adults with profound intellectual and multiple disabilities are able to take part in a wide range of meaningful activities – including employment, education and leisure activities; continue to provide places which can be used as a base from which adults with profound intellectual and multiple disabilities can take part in different activities during the day.
Short breaks	Provide a range of short break services in every area with staff with sufficient skills, expertise, equipment and facilities to meet the needs of families supporting adults with profound intellectual and multiple disabilities. No family supporting an adult with profound intellectual and multiple disabilities at home should be denied regular short breaks.

<p>Training</p>	<p>Offer subsidised or free places to families and personal assistants on any training courses relevant to the care of adults with profound intellectual and multiple disabilities. Individual budgets should include provision for training of personal assistants.</p>
<p>Clinical procedures</p>	<p>Adapt policies and procedures already used in children’s services for use in services for adults, involving representative bodies of the relevant professions and agencies; base these on the principles that (i) arrangements will be designed so that they sustain and enhance the quality of life of the disabled person by enabling clinical procedures to be carried out when and where needed, and (ii) arrangements will be coordinated and consistent between agencies, avoiding unilateral exclusions and consequent service gaps; focus on procedures identified by families as currently problematic, including all relevant care settings, such as hospitals, community services and people’s own homes. These policies should specify who is responsible for carrying out clinical procedures in different situations and should deal with issues of clinical governance, legal liability and insurance.</p>
<p>Funding</p>	<p>Health and social care services should always work in close partnership both in planning and commissioning services and in providing them. Local authorities should continue to play an active part as the lead agency for learning disability services in all service development and should continue to lead individual assessment and planning, even when continuing health care funding is provided. However funded, services for adults with profound intellectual and multiple disabilities should be developed in line with the government’s personalisation agenda. They should be designed around the individual and be person-centred, they should treat the family as expert, they should focus on the quality of staff relationships with the disabled person as the key to service quality and they should sustain the package of care.</p>

Box 2: Specific Obstacles to improvement

This is a lightly revised version of an article by Professor Jim Mansell, which appeared in PMLD Link (Winter Issue, 2011) Vol.22(No.3), pp 2-7



A Note on the Raising Our Sights: How-to guides

The Raising Our Sights How-to guides were developed with funding from the Department of Health to help local areas implement the recommendations in the Raising Our Sights report from Professor Mansell. They are aimed at families and supporters of people with PMLD as well as commissioners and providers of services. There are 10 How-to guides covering different topics and showing how to: recognise good services and support for people with PMLD; challenge and campaign where people with PMLD are not getting the right support; and ensure that necessary changes happen, with clear messages for commissioners and providers of services. There is an additional Guide targeted at commissioners of local services

In addition, there are six Raising Our Sights videos which accompany some of the guides and highlight the impact that the right support can have on the lives of people with PMLD and their families.

The How-to guides and videos can be accessed via the Mencap website. Go to: <https://www.mencap.org.uk/advice-and-support/profound-and-multiple-learning-disabilities-pmld/raising-our-sights-guides>.

Inevitably, with the passage of time some details about national strategies in the How-to guides need updating due to political developments and some links to websites with information and resources have been broken. Nevertheless, they contain much pertinent information and guidance and recommendations that still have relevance today.

Because they are so important, the How-to guides have all been uploaded to the resources area of the PMLD Link website. A brief description of each of the guides which picks out some of the key messages contained within them has also been uploaded to the 'legislation' domain of the resources area.

Raising Our Sights 10 years on – some comments

What is lacking is an update on what has happened and what has not. PMLD Link tried to find out opinions of authors of the guides and its followers on Facebook and Twitter. Short pieces about the guides were posted inviting comments. There has not been time to do a thorough review for this issue, but some of the responses received follow here:

'Would be so good if commissioners paid this (Raising Our Sights) the attention it deserves and took it up. Would be good to know of areas where they have.'

'We have come so far but not farthest yet. Senior management and teachers (working with pupils with PMLD) should come from the PMLD background and Training should be robust especially when it comes to learning support staff.'

'One: I would say that people with PMLD still have very low visibility within 'mainstream' society. If you aren't working/caring for someone with PMLD, it can be rare to come across. Two: Love that the number of #changingplaces continues to increase.'

'...this time last year (I) would have talked about cuts to advocacy services, a focus on crisis intervention and the fact that many people least able to speak up for themselves were and are still living in hospitals because of a lack of suitable community provision. Against this background finding 'creative ways to listen to people with PMLD' was probably little more than a pipe dream. As it (the Raising Our Sights Advocacy How-to guide) says: 'when budgets for all services (including advocacy) are being cut, it can be convenient to assume that family members can take on the advocacy role'. And so a lot of representational advocacy depended on families having the energy and confidence to speak out.

Fast forward one year and the issues are still the same but a number of reports, including that from the JCHR (parliamentary Joint Committee on Human Rights), highlight the impact of the government's coronavirus regulations on human rights. If advocates can't form close, long term relationships with people with PMLD and family members cannot visit them - who raises questions or speaks on their behalf?'

If you have any comments or queries about the Guides, PMLD Link would love to have them. Contact: info@pmlmlink.org.uk

The guides are also available on the resources area of the PMLD Link website.

Advocacy PDF

Clinical procedures PDF

Communication PDF

Health PDF

Personalisation PDF

Support for families PDF

Training the workforce PDF

What people do in the day PDF

Wheelchairs PDF

Commissioning PDF

Housing PDF

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

Subscriptions are for 12 months from the point of subscribing. You will receive 3 issues of the PMLD LINK journal. During this period you will have access to the members' page of the PMLD LINK website (www.pmlmlink.org.uk) which allows you to access downloadable versions of back issues from the last three years. Subscribers only can access these. Other older issues are in the public domain of the website.

In order to access the members' page on the PMLD LINK website, you need a Username which is your e-mail address and a Password. You will be sent a link to your personal website account and you can create/reset the password.

We have a limited number of copies of back issues remaining which are available at £5 per copy so may be able to provide you with copies of issues that you may have missed.

If you have any queries, please do not hesitate to contact Rob Ashdown (PMLD LINK Treasurer) via info@pmlmlink.org.uk

Siblings of disabled people – what has changed in a decade?

Clare Kassa

Sibs is the only UK charity dedicated to supporting the siblings of disabled people. The charity was established almost 20 years ago and we have shared the journey with thousands of siblings in that time. When the charity was established, the central focus was on supporting young siblings, and the main activity was training people to set up local sibling support groups. In those early days, we rarely had queries from adult siblings, and those who did come to us usually did so to offer their help! Today we are working with more adult siblings than ever before.

Adult siblings play a crucial role in the lives of their brothers and sisters. They provide support, care and advocacy at the same time as juggling support and care for their elderly parents, their own children and their work. They rarely receive acknowledgement of their role and their expertise, or support for their own needs.

During the last 3 years Sibbs has established a network of peer support groups – siblings have told us that these groups are a lifeline, a chance to meet other people who “get it” without having to explain themselves.

“I had never really had contact with anyone else who had a sibling with learning disabilities throughout my life. So meeting a group of people who experienced the same situations and emotional responses to those situations was really overwhelmingly liberating for me” – Member of a peer support group

Instagram launched ten years ago this month. The landscape of social media has changed enormously, helping more siblings to now be able to connect virtually - even if they can't physically travel to an adult sibling group, they can meet or read about other siblings online. Sibbs has 4 social media channels – we recognise how important it is for siblings to find us and know that they are not alone. Do give us a follow on Twitter, Facebook, LinkedIn or Instagram.

We have also produced guides and information specifically for siblings, who often seek our help at times of crisis, such as when a parent or carer can no longer provide care. We have seen the type of queries coming into the charity change significantly over the last 10 years. The help needed now is far more complex. The requests are often focused on navigating legal issues, with mental capacity or concerns about future planning among the most common. As important as providing information is, we also recognise the importance of listening to siblings and giving them the opportunity to

Sibbs

For brothers and sisters of disabled children and adults

share their experiences. We have been doing some important work with counsellors to help them understand the nature of those experiences, enabling siblings to find support from professionals sympathetic to their needs.

This summer we were proud to publish our eBook for adult siblings on self-care. Siblings are used to putting the needs of others before their own, meaning their own health and wellbeing is often side-lined. Already we have had a great response – over 500 copies of the book have been downloaded so far.

Covid-19 has been tough for adult siblings with 91% of respondents to our May social media polls telling us that coronavirus has made their situation more challenging. Some adult siblings have moved back into the family home to support the care of their brothers and sisters. Others are dealing with the stresses of managing care situations from afar. With funding from the Government's Coronavirus Community Support Fund we have been hosting a series of online information and support sessions for adult siblings. The topics have included shielding, coping with anxiety and stress, and mindfulness. We are hosting a further session on legal

issues in December and we have more online sessions planned in the spring, thanks to new funding from Learning Disability England.

But adult siblings are still an overlooked, often hidden, group of family carers. Indeed many adult siblings don't consider themselves carers at all. One adult sibling said, 'I feel reticent to use this label because I just see it as being a sister'. In fact we know very little about the demographic of adult siblings. We launched the first survey for adult siblings in the UK earlier this year in partnership with the University of Warwick. Results are expected later this year and we look forward to sharing our findings.

We still feel there is a long way to go before the important role siblings play is acknowledged by service providers – something we are working hard to change. So often siblings are not valued as they should be and not included in key discussions about their brother or sister's lives. The sibling relationship is the longest relationship across our lifespan. When we support siblings well, it also has an impact on the wellbeing of disabled brothers and sisters and the wider family.

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Further Information

'Self-care for siblings' has been written by Sibs for adult siblings in the UK who have grown up with a brother or sister who has a lifelong disability. You can submit a request for the book which will be sent by e-mail at: <https://www.sibs.org.uk/support-for-adult-siblings/ebook-for-adult-siblings/>

If you would like to find out more about Sibs' work please take a look at the website www.sibs.org.uk

Connect with us on social media



Remember to tag us on social media ~ @PMLDlink

Twitter: @PMLDlink

Facebook: PMLD Link

Facebook: Raising the bar - CoP for the PMLD care standards

Use the hashtags #pmlD and #pmlDchat to join conversations about making a positive difference to the lives of people with PMLD. See you online!



What people with PMLD in our community need from specialised services

Helene Abbiss

Since 1991, a range of people with multiple disabilities (called students), the majority of whom are people with PMLD, have used Parity for Disability's services to facilitate the daytime activity that they need. They access equipment and resources at our three day services, building sessional activities and community provision into their schedule. They manage the day in the ways that work for them. Staff undergo training to support communication and participation in activities, as well as administering medication, catering for acute medical care requirements and providing personal care.

Evidencing the difference that our three 'bases' make to the people who use them has been an ongoing challenge. Though we consult with students and conduct reviews, evaluation is difficult. The consequence has been a constant battle with local authorities over the daytime provision the students need and how much this should cost.

Then came lockdown. A horrendous experience for almost all carers and extremely difficult and distressing for most of the students. We developed an outreach service that offered interactive activities digitally, by phone and by post. There were distanced sessions in gardens and staff provided some assistance with physio within homes. We did as much as we could. However, in

the aftermath, the consultation we carried out drew a heartbreaking picture of the heavy toll that restricted access to services took on people with PMLD and their families.

"Overall the whole experience has been detrimental to my daughter's physical and mental health," one parent said.

"My daughter had absolutely no interaction with anyone other than us her parents for pretty much 12/14 weeks," we heard from another. "This is an awful situation for her to be in as she doesn't understand what is happening in the world like we do, and normally, she is a very outdoorsy, social young lady."

At the root of the suffering was absence of social interaction and companionship (outside of close family members), lack of space and equipment for physical movement, and limited resources for any meaningful activity.

Social Connection and Friendship

A recurring theme throughout the responses was the great level to which students missed social interaction, with testimonials specifically stating that students missed their friendships. Carers described the negative effects of no contact with people besides family:

“It seemed like nothing we could do would make her happy, she would have her head down all day with very little interaction.”

During an unrestricted day, with trained staff to support communication and encourage students to exercise control over their environment, the connection and bonding happens naturally. There is conversation or interaction throughout the course of the day, particularly when planning and taking part in activities either indoors or out in the community.

The isolation caused a downward spiral for one student. “She is less confident with people due to lack of contact with others.”

Because our services are set within communities, plenty of interaction and relationship-building takes place between students and the public. Students with more ways to communicate will sometimes interpret for students who are at earlier stages of communication. Our music therapy service, which provides funded places for students, has also facilitated successful social interaction through communication and emotional support and development.

Space for Movement and Mobility

Almost all respondents said students had less space at home for walking or standing work. No one could access hydrotherapy and most missed out on stretching exercises.

As a result, we learned that a large number of students experienced limbs seizing up, stiffness, muscle spasms, weight gain, pressure sores and discomfort when in a wheelchair.

Parity outreach staff were unable to offer a full physio programme as some equipment was not available at home. Pre-lockdown, in addition to making use of the large spaces and accessing local hydrotherapy, almost all students were using specialised ‘Motomed’ stationary bikes on a regular basis, at flexible times that fit into their day. Through trialling new developments in equipment as

they become available, we aim to meet students’ complex health needs. ‘Raising Our Sights’ notes this as a primary purpose of local bases for activity (Mansell, 2010).

Motomed came into use across all our services in the last 10 years. Another arrival is the multi-positional Acheeva therapy bed, from which students with health issues can keep participating when they might otherwise have to spend time alone in a hospital bed.

“At Parity, my son used the Motomed regularly, which helped him physically and emotionally,” a parent said. “During lockdown we didn’t have access to any specialist equipment.”

Alternatives were not adequate. As another parent explained, “My son didn’t want to go outside in the garden - for dog walks or daily exercise. There was no hydro, no physio other than the exercises we could do ourselves. Hence he put on weight - movement not affected so much. But he became withdrawn.”

Meaningful Activity and Informal Learning

During lockdown, all students still needed stimulation and a purpose to the things they did with their day. “My daughter became anxious, stopped eating and drinking due to stress and change in her routine. This has led to significant weight loss. Routine, interaction and having meaningful activities are very important to my daughter.”

Working to a flexible timetable, students build learning and development into their activities. They work on skills that are key to survival and mental and emotional health, as well as skills that promote their quality of life. Students take an active part in planning and decision making. They have access to flexible transport. Since 2010 we have developed outdoor weeks at local activity centres with the students. More Changing Places toilets have meant more destinations for learning and enjoyment, like Alice Holt Forest and Marwell Zoo.





Regular student discussion groups generate ideas and feedback. Students see what others are doing and try it for themselves.

In contrast, during lockdown, many students became withdrawn. "Trips out (mostly daily walks) didn't really seem to help, he spent the whole time with his head down and not even looking where we were going. My son seemed depressed and this was his way of expressing himself."

Through the students' informal learning, they experience the benefits of being able to do more and achieve more. "Our student's confidence had soared at Parity and we are hoping that the return to the day service will enable this to be rebuilt."

The learning doesn't stop with age. After a student, already in her thirties, trialed an eye-controlled device, Parity bought the device for all students to try. Over the following months this student developed her skills so that she was initiating conversation and expressing needs and wishes that she could not articulate before. She eventually obtained her own personal device and this appears to have helped her through a subsequent big change to her living arrangements. EyeGaze devices are now available across all our services, where more students are following a learning curve in their own time. As stated in Raising Our Sights How-to guide 9, "Services must acknowledge that people with PMLD can learn, but will need more time and can require a huge amount of repetition." (Mencap and PMLD Network, 2013, p.5)

In the same way, students are achieving more with a giant, interactive screen, or Visilift. There's now one at all services as well as a number of iPads. Students' digital skills and confidence are such that those at a Parity service can link up with those still at home, plus further members of the community that they would not otherwise interact with in the current situation.

"It was wholly apparent when my son went back to Parity that he was so very happy to be there again! His world is gradually beginning to open up again."

Before lockdown, students took opportunities to use their voice, presenting to a health and social care student society, meeting with representatives of the local hospital about installing a Changing Places toilet, visiting a new centre for health in Farnborough to discuss accessibility, testing a new taxi commissioned by the local council. We had been progressing work experience opportunities through a company partnership. For the time being, we can use our digital capabilities to keep those connections going.

Making Progress Through Better Evidence

One parent summed up the government's understanding of the situation. "We have found that during this lockdown period, us/people with severe learning disabilities have been forgotten about. There was a lot of talk from the media and government aimed at the elderly in care homes, nothing about those with PMLD living at home with parents..."

Areas that warrant more in-depth investigation include the increase of challenging behaviour during lockdown.

The barrier to progress is the lack of evidence proving the need, providing the clout to ensure packages of care really meet requirements. We aim to strengthen our evidence-gathering, showing decision makers the continuing high cost when those needs are not met.

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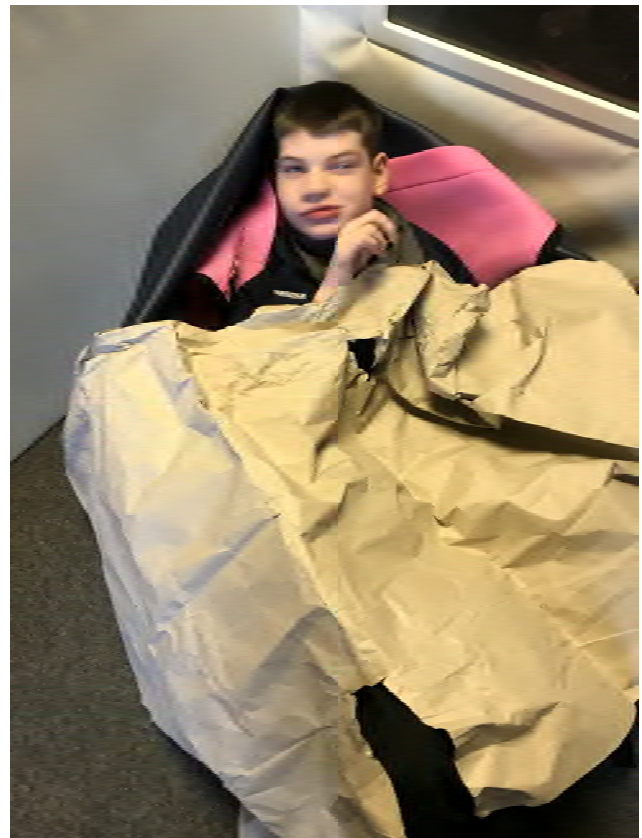
Riding the emotional corona-coaster and its effects on the touchscape of the classroom

Julia Barnes

Ravenscliffe High School is a generic secondary school in the north of England with over 200 pupils across 2 sites. For 28 years we have run on a secondary model where students are timetabled for different lessons with specialist teachers in ability-based and mixed ability groupings. It is a busy, complex system but students benefit from the balance of bespoke lessons and being part of an inclusive, supportive learning environment.

For me, the outstanding statement from the report *Raising Our Sights* is; 'Good services treat the family as the experts' (Mansell, 2010, p.9) and that's what we strove for as we planned the reopening of Ravenscliffe for our students with the most complex needs. Because of the vulnerability of this cohort of students and the impossibility of guaranteeing social distancing, our students with PMLD had yet to return to education in the classroom. However, the government had directed that legally every student had to be offered a fulltime place in September (GOV.UK, 2020).

Throughout lockdown I had been in weekly contact with most of our families of students with complex needs. I was aware of some of the difficulties that they had experienced. As always seems to be the case, the lockdown had affected exponentially those that are the most vulnerable. The local children's respite centre closed, personal assistants (PAs) were prohibited from providing support, and for some of our students who were shielding carers were too much of a risk owing to the number of households they work in. Additionally, medical procedures and appointments were cancelled; orthotics, wheelchair services and specialist resources such as hydrotherapy pools were unavailable. As Mansell identified, parents already faced an exceptionally challenging care responsibility – 60% spending more than ten hours a day on essential physical care and woken up on average three times a night (ibid, p.4). My families recounted the additional workload lockdown had created for them and their offspring. After only a few weeks, families could identify that their offspring were missing school and were frustrated by being solely with their family members 24/7. One family had identified recognisable symptoms of mental health difficulties in their son including withdrawal, loss of interest in food and lethargy which they blamed on his isolation from his community (PAMIS, 2011). This was compounded by his visual and cognitive impairments, which meant he was unable to participate in virtual contacts with extended family members and classmates through Zoom, etc.



In recognising families as the experts, when it came to planning the provision for their offspring to return to school in September, I was repeatedly made aware of the balance between wishing to keep their child safe but acknowledging their offspring's need to be in contact, often physical contact, with their peers and familiar staff members. It was repeatedly acknowledged that COVID-19 was not going to disappear and that social distancing was impossible if we were to educate and care for their loved one. I could not teach with staff and students maintaining 2 metres apart, isolated from one another and only experiencing requisite touches – those to clean, feed, position, etc. (Goold and Hummell, 1993). The questions most frequently asked by parents and carers concerned whether we would be able to take over the physiotherapy programmes and specialist positioning that families had strived to complete throughout

lockdown, alongside therapies such as rebound and hydrotherapy. Following these conversations plans were made, classrooms transformed, a new changing places room built and a comprehensive risk assessment written. Ten out of the twelve families chose for their offspring to return to school in September.

Diary for the first week

Focusing on the touch experiences of all, which is my research interest (Barnes and Hewett, 2015), I kept a diary of the first week back which I would like to share with you:

TUESDAY 8th SEPTEMBER, 2020 – Training Day

There was an atmosphere of nervous excitement about our re-opening as my staff team discussed the risk assessments, handwashing protocol, PPE use, etc. An experienced classroom assistant remarked; “What I’ll really miss is being able to give the kids a hug.” This is something that had been considered when writing individual students’ risk assessments with the leadership team. We had discussed the classroom activities and had agreed that as we needed to touch for intimate care, positioning, physio etc we would use massage and other beneficial touch. Hugging is also deemed to be beneficial touch to meet student’s need for emotional wellbeing. This was especially pertinent because over the previous six months these students had been out of education, at home with their families. With the lack of respite, PA hours, etc., at home students would have been hugged regularly throughout each and every day (The British Psychological Society, 2020). Therefore, as part of the Recovery Curriculum (Carpenter and Carpenter, 2020), if a student indicated they wished to be hugged, staff would provide this. Whilst this would involve the staff member wearing a mask, in most situations, it was unanimously agreed by the staff team.

WEDNESDAY 9th SEPTEMBER, 2020

Students were so excited to be back as demonstrated by smiles, waves, enthusiastic rocking and clapping. They did not seem at all fazed by the masks and visors staff were wearing for different activities and did not reach to remove them as we had anticipated. And there were hugs – for some students as soon as they got off the transport, they requested a hug by reaching out. Others demonstrated this need by holding onto our arms and clothes, reaching for familiar touches such as ‘scruffles’ (what we call reciprocal rubs on the head over hair, personal to that student and their favourite greeting with familiar people). For some students the moment came when they were being supported to stand – big all-encompassing hugs!

Emotionally these nurturing contacts felt somewhat overwhelming for me. Since March I had only hugged my husband, Dad and three cats and counted myself exceptionally lucky not to have been living on my own. I had visited family when restrictions lifted but not even hugged my aunts, sister or two-year-old niece. It created a happy classroom, staff feeling attuned to students and students being lively and communicative.

This human social interaction of nurturing touches was starkly contrasted against the lunch time experience. Eight students were sat at tables with a hot roast dinner in front of them each with a staff member sat alongside wearing a disposable apron, gloves and visor. I felt very uncomfortable wearing this level of PPE and when supporting my diner hand-over-hand to hold the spoon, very aware of how touching or wearing disposable gloves can convey psychological messages of ‘dirty’ as well as being uncomfortable for the student (Mirfin-Veitch et al., 2004). The scene resembled something out of a film – the sheer number of people wearing PPE in the everyday experience of eating a meal. It will take some getting used to and is very time consuming to put on, dispose of, store appropriately and keep clean.

THURSDAY 10th SEPTEMBER, 2020

As we were positioning students to share a sensory story we noticed two students were holding hands and making eye-contact, one seated in a tall wheelchair and the other a PPod seat. One of the students was offered a ball and held it and then immediately shared it with the student next to her. There was joint attention resulting in the development of a game with the first student tugging the ball just out of the other’s reach and laughing. The student with the ball had a younger sibling and I had observed them interacting together in Zoom sessions. The other lived with grandparents and had not had contact with children since school closed in March. It was so pleasing to see that students could interact – making the burden of the strict regime of handwashing, sanitising and disinfecting of resources worth every minute!

FRIDAY 11th SEPTEMBER, 2020

Third ‘get up’ and we were all tired, students were quieter and several students experienced seizures. Hugs were slower and calmer. The two students interacting with each other clearly wanted to be together and there were eye contacts, vocalisations, and shared strokes on each other’s arm. It did get a bit much for the student without siblings – indicated by a bit of hair pulling.

That afternoon was a calm, relaxed session watching a Zoom assembly, playing with toys or enjoying a massage. A student sitting in a PPod chair made persistent eye–

contacts with me across the room. She picked up her ankle-foot splint and presented it to the staff member closest whilst vocalising and moving it to her foot, indicating she wanted to stand. Staff supported her to do so and she walked towards me vocalising with her arms outstretched. I was sitting on a plinth next to another student supporting them in sitting on the edge. She just made deep eye contacts and hugged. The kind of 'I'm tired, I've had enough, hug'. Whilst I was able to detect that general feeling within her and the rest of the class, it was her way of communicating that directly to me.

In reflection

The first week back had been extremely full on and exhausting for us all. There had been many worries concerning the appropriateness of what we could offer our vulnerable students. There is no guidebook for the current situation and the advice from the government had to be interpreted, adapted and risked assessed for the needs of all in the classroom. It felt to me that, in line with the parental requests, we had balanced the need for robust infection control with touch for care, therapy and providing physical attunement to enable students a means of communicating their emotional and psychological needs (Calvey, 2018, p.39).

I could not have considered an alternative approach where touches were limited to those deemed 'essential' where students would potentially feel isolated when using their equipment, positioned 2 metres away from each other. This was highlighted by education professor Youdell (2020) in the webinar 'Living with the pandemic':

"[W]hat would happen to a generation of children if they were raised to understand that touch was fundamentally dangerous and unwanted?"

Whilst the pandemic may have changed the way we think about touch forever (Hammond, 2020), I hope that we are able to value and prioritise the importance of our personal touchscapes. For the most vulnerable that is a tricky balance between protection and emotional wellbeing. But, elaborating on Professor Youdell's point, all children need to know that touch is natural, necessary and part of what makes us human.

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Oily Cart's Uncancellable Programme: Doorstep Jamboree

Ellie Griffiths

Oily Cart have spent almost 40 years touring sensory theatre shows made especially for young people labelled as having Profound and Multiple Learning Disabilities. Their shows to date have all involved close up interaction with performers, passing around of sensory objects, and touch as central components. Here I would like to talk about how the company have adapted their work during the COVID 19 pandemic.

The Doorstep Jamboree was our first live performance since the pandemic began. At first, when we found we were no longer allowed into theatres and schools, or any of the places we normally perform our shows, we created a plan B, then a plan C, before realising we needed to reimagine the entire format of how we usually work. We called this our 'Uncancellable Programme.' Our priority was to make sure that audiences who have barriers to access were still being served during this time and did not become invisible. Even if you are shielding you still have the right to play, creativity and connection.

We made three versions of the 'Doorstep Jamboree' show, so each family could pick what suited them best. One happened over Zoom; another was a mini gig outside family homes, in their garden or on their doorstep. We sent these families packages of sensory props so there was a tactile element they could still enjoy close up. We dedicated a song in the gig to each young person and sent them a professional recording of this

afterwards, as part of the Jamboree album, so they have a lasting memory.

"For us to see Doorstep Jamboree, it had to come to us. We've been out four times since March. Shielding's paused but we haven't stopped because it's not worth it. We all have to be here at the end of this. We haven't had any support or respite. Since March, it's been 24/7 caring for both children, all day, every day."

(Doorstep Jamboree family)

There was also a bigger outdoor gig, with a six-piece band, that happened in playgrounds and outdoor spaces, so families could still have a communal experience in a safe way. I wanted these outdoor gigs to feel like a mini sensory Glastonbury – where everyone was invited to the party! Even in the toughest of times, there is always room for colour and music and celebration.



At first, I was apprehensive that without being able to use touch, and with social distancing, we would not be able to make the show feel special for our audiences, or create the same connections with the young people. These moments are always what make Oily Cart shows. We had to really rethink the set-up, finding ways to still make the show feel like an immersive 360-degree experience. We made colourful bird puppets to fly over the audience's heads, and guided the parents through a dance with their child using touch. I was impressed (and relieved!) how much these new versions still seemed to resonate with people. The audience's feedback overall has been overwhelming. During such a challenging time, it clearly meant an awful lot to people. It showed me that by investing all the same artistry, rigour and attention to detail that goes into a normal theatre show, into each family's experience, you can still make a really special experience that feels very intimate. Theatre so often can be seen as intimidating, or snobbish – it was refreshing to do something that felt really direct and said 'we'll come to you, because you are important', rather than the other way around.



For our musicians this tour was very special too. Each had not been able to share their music with live audiences for 6 months. It meant a lot to everyone to be able to work, to play and to connect during this time. As the first show started, in front of an audience of children at an inclusive early years centre, all the stress and worries of risk assessments and health and safety melted as I watched the children and parents react. All of us need some escapism, colour and music to get carried away with. It was really moving to witness.

"You shared the most important message in the most beautiful and fun way. Thank you for the goosebumps and smiles."

(Doorstep Jamboree Family)

The music in the show was co-created with young people labelled as having complex disabilities. Our Jamboree band has disabled and non-disabled musicians in it. This was crucial to represent and advocate for a community that are so often not listened to by people in power. If you haven't heard of her yet, check out Miss Jacqui, a spoken word artist and disabled activist who is one of our band. She brought lyrics into the show that really brought home our message to the amazing families we work with at this time.

Thank you to everyone who danced, jammed and made some noise with the Jamboree band. The gigs may be over, but we'll keep on singing: "You should be listened to. You matter. You should be seen. You are important." (#WeShallNotBeRemoved)

Doorstep Jamboree did:
31 performances for
129 young people and
135 parents and carers

Further Information

Miss Jacqui is a Poet and Songwriter. Find out more at: <https://www.missjacqui.co.uk/>

Oily Cart will be launching the Jamboree album, which features Balkan tunes you can party to at home, co-created with young people labelled as having complex disabilities, in early December – <https://oilycart.org.uk/shows/jamboree-the-album/>

Oily Cart's next project, 'Space to Be', will be touring in March. This show will all be done through packages and audio, sent directly to family's homes across the UK. To register your interest, please contact alison@oilycart.org.uk

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The importance of music education at the Children’s Trust School

Franz ‘Sonik’ Allard

‘A degree of musicality is to be found in every person regardless of one’s needs or abilities and on this basis, everyone has the capacity to engage and develop in music in different ways and according to one’s personal interest.’

(Wilde, Ockelford and Welch, 2016, p.19)

Context

The Children’s Trust School is a non-maintained special school based in Surrey. The school supports day and residential children and young people aged 2 -19 with a wide range of special needs including complex education, health, therapy and care relating to neurodisability and brain injury.

Since 2016, the school has been on a journey of transformation to ensure that the educational offer seeks to understand the ways in which the children access, engage and learn best. As an outcome, its first wholesale change was for the school to adopt the IMPACTS curriculum devised by Rosewood Free School in Southampton, being secure in the knowledge that the developmental and progressive curriculum model provided the basis for personalised, meaningful learning.

The school has since used the needs of the pupils to drive its offer and, following pupil needs analysis, agreed with the findings of a national survey of music in special schools in England which recognised the significance of music in special education and its equal, if not most important, place amongst other subjects in the curriculum (Welch et al., 2015)

Scott Harris, a Senior Specialist Teaching Assistant at the school who is studying PGCert in Sounds of Intent, describes the music offer prior to these curriculum developments: “Initially, aside from music therapy, music provision was in need of development. Focus on music education was peripheral. It wasn’t that music was deemed unimportant (in fact music was all around us), but used in the classroom principally as a communication tool in the form of sound cues”.

Fast-forwarding to February 2020, music is an integral part of meaningful teaching and learning, play and leisure during term time and the school's enrichment offer. The school has developed a dedicated 'music hub' led by a qualified teacher with a specialism in the Sounds of Intent framework of musical development and has committed to supporting the training of a second teacher. There is now a personalised approach to music delivered through timetabled group and individual sessions and Key Stages 4 and 5 also have access to our age-respectful and bespoke school band CedarSuperSound. The aims of providing everyone with access to music education as well as music therapy, promoting and developing musical development and interests, fostering achievements and sense of belonging through meaningful contributions and connections with others, are now embedded and highly valued through the school.

So... Why music?

'We are all musical, we just need the opportunity for our musicality to be developed and celebrated. Such is the prime purpose of music education.' (Welch, 2005, p.119)

Believing in an inclusive, broad and culturally rich curriculum means that music education is not only desirable but essential to all our young people. Ongoing research (Wilde et al., 2016) shows that music promotes cognitive development as well as physical and mental wellbeing, but also exists as an innate ability in children, including those with disabilities and sensory impairments. Assuming that all our young people share this inherent capacity to engage and participate in musical learning, making music is not just an enjoyable and motivating activity but becomes an essential skill to promote and develop. This highlights how crucial it is to tap in and nurture all abilities as early as possible by way of an effective and inclusive musical education.

What is 'musical inclusion'?

Our ethos is that environments need to empower with a shared acknowledgement that all our students can develop musical skills and use them to play, communicate with others, create and express themselves.

In broad terms, musical inclusion is to give an equal opportunity and access to music-making to everyone, regardless of circumstances or barriers to learning. It is facilitating music teaching and learning to all learners by providing access to music-making activities with the right support in place. It is maximising an individual learner's potential with bespoke support so they can enjoy, achieve and progress. In summary, musical inclusion really is identifying things one may do in their practice that are excluding and finding ways to empower their young people by removing these barriers.



The music offer at The Children's Trust School

'Each person is an active participant in the activities they engage in, their actions and responses determining what happens.' (Doukas et al., 2017, p.24)

Concretely, our aim is to allow our students to exercise agency over how they engage in musical activities and develop their music learning in the process. In line with Jellison's recommendation of what inclusive music classrooms should look like, our music sessions are provided in the safe, fun and positive environment that is our Cedar Music Hub, and designed to encourage young people to become 'musical decision makers' (Jellison, 2012). Opportunities are maximised for the students to initiate playful use of sound, rhythms and musical patterns and it is the expectation that staff involved will respond to all sounds with the view they are made deliberately, even if it is not always the case (Ware, 2003).

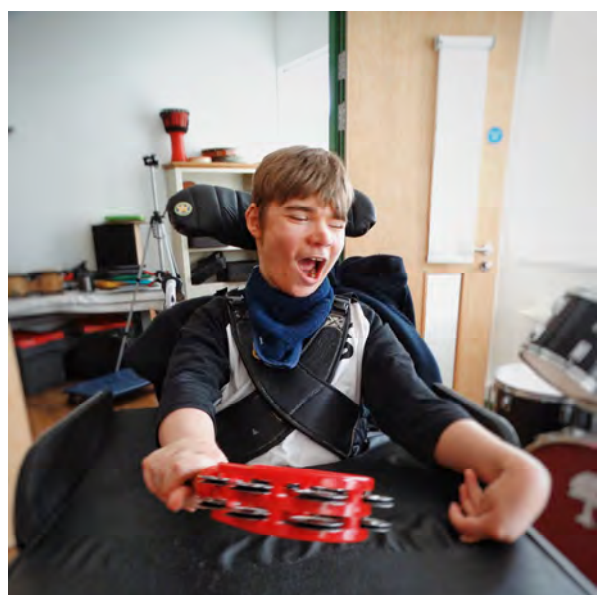
The musical interactions should encourage purely sound and noise making but also lead to activities that are socially recognisable as music and that will resonate with musical meaning for the young people. Similarly, it is important to allow pupils to interact musically with peers as well as educators in a positive and reciprocal way, thus emphasising that all musical contributions have value. Other key aspects of the musical interactions are the student led element and the motivation and ownership brought from the pleasure of playing.



Effectively gauging engagement, measuring progress and setting objectives

Music education at the school is underpinned by the Sounds of Intent musical development framework, which came about in response to perceived inadequacies of the P Scales Music descriptors and the absence of appropriate alternatives. The Sounds of Intent framework was designed to enable those with special needs to access music and assist music practitioners in their observations and the measuring and mapping of students' musical profiles.

The Sounds of Intent principles are used to inform and support musical development through three domains: Reactive, Proactive and Interactive. Effectively, young people are learning to listen and respond, create and control sounds and finally, interact and communicate with others through sounds, rhythms, songs and group performances. All our music sessions are tailored to suit



individual needs using a range of strategies and rooted in this unique, evidence-based framework.

Having used the Sounds of Intent framework rigorously and continuously for the past two years has confirmed its effectiveness as a tool to monitor and measure engagement and progress in the musical skills of young people working below National Curriculum Level One. Additionally, for a music teacher working with students with PMLD, being able to conclusively demonstrate that everyone is musical and can make progress is fundamental in helping to promote the value and necessity of a music education for all.

Enriching lives through music

'There is need to enable all young people to access high quality music making'. (Wilde et al., 2016)

Music is a powerful sensory experience for the young people we work with and when rendered accessible, it becomes an outlet for self-expression and opens to a world of creative opportunities. From this perspective, the launch of our school band CedarSuperSound was a natural progression as a meaningful avenue for enrichment and self-fulfilment. In its three years of existence, our accessible band has composed, rehearsed and recorded two original songs (currently available on all music streaming platforms), and is about to release their third number - a spectacular and salient take on David Bowie's "Heroes". The school has made available videos of the making of these songs on YouTube and these vividly show and explain how our students were immersed in the music making process right from the outset. Witnessing the young people's high levels of engagement, pure enjoyment and sense of achievement during their creative endeavour is a continuously inspirational experience!

Celebrating achievements

Among recurring highlights are the end of the year assemblies, when our students' successes are shared with families and the wider school community. These are always very special and often emotional moments for parents and staff as our young people are being rightly celebrated for all their achievements, musical and otherwise. The last Autumn Assembly of 2018 was a particularly notable milestone as twenty-three of our students were awarded certificates from Trinity College London in recognition of their musical abilities following the school's participation in a nine month pilot scheme with Sounds of Intent and Trinity College that aimed at promoting the musical achievements of children and young people with learning difficulties. This year, some of our Key Stage 5 students will be entered for an ASDAN accreditation for a Sound, Rhythm and Music module.



Collaborations and future plans

In December 2019, the school's partnership with Adam Ockelford and Sophie Gray from Sounds of Intent, launched a set of Music Cards encompassing 200 activities using sound and music and especially designed for children and young people with acquired brain injury and neurodisability. This innovative set of resources directly relates to Levels 1-3 of the Sounds of Intent framework and, once a young person's level of functioning is established, it simply is a matter of choosing a card at that level or just beyond it in order to nurture progress. It is important to highlight the fact that the activities on the card were expressly designed with families, carers and non-music specialist teachers in mind. In other words, the resource offers a range of musical activities that are suitably inclusive and accessible to all in or outside a school setting. If interested, the Music Cards sets are available to purchase for a nominal fee by contacting the school.

Another fruitful collaboration started in April 2019 with Resonant Tails, a project instigated by Yvon Bonenfant, researcher and Artistic director at Tract and Touch. Resonant Tails is a striking artwork and voice machine designed to entice vocalisations, encourage communication and create unique and immersive soundscapes in the process. In practice, the object captures the vocalisations and sounds of our students and then echoes them back with a range of playful and exciting effects available at the turn of a knob. To render the experience even more compelling, the sounds produced will, if desired, make the machine's orbs glow and vibrate. Since its inception, Resonant Tails has developed to be a real success in school as a fun, motivating and interactive activity that now, often becomes led by the students themselves and with minimal staff intervention.

Supporting young people through the Covid-19 crisis

This year the delivery of music sessions has been affected by the Covid-19 pandemic outbreak that dramatically unleashed itself on our shores. As the country entered lockdown, the Children's Trust School remained opened as staff strived to continue to deliver education and care as safely as possible and in a semblance of normality. Of course, these ongoing and unparalleled times are anything but normal and the negative impacts brought on by the restrictions and necessary safety measures have to be acknowledged. At the peak of the pandemic, our young people showed extraordinary resilience as structures and routines were radically altered; peer groups changed as classes morphed into house bubbles, educational outings and family visits at the weekend were suspended, and



familiar faces disappeared under masks hindering communication. Yet, during this incredibly challenging period, music-making activities were essential in maintaining the social and bonding environment necessary to nurture wellbeing and mental health.

Throughout the Spring and Summer terms, we endeavoured to deliver daily outdoor music sessions, encouraging all our students to continue to develop their musical aptitudes as well as offering them an outlet to release their emotions and creative aspirations through the inherent cathartic and healing powers of music. A wide range of virtual learning activities that can be accessed by families at home as well as learners staying on our residential school houses was made available on the Children's Trust School website. In September, the School implemented a 'reconnection and recovery' intervention program based on Barry Carpenter's recommendations (Carpenter and Carpenter, 2020) and our aim in the Music Department has been to fully support its delivery as music offers unique opportunities for social bonding, fostering social inclusion and cultural coherence as well as being recognised for its beneficial effects on physical health and wellbeing (Hallam, 2015).

Ongoing Journey

As this article highlights, the school has been on a transformative and exciting path that started four years ago and it remains as committed as ever to build on this momentum and to continue to advocate for young people with PMLD the right to access meaningful teaching and learning that includes the high quality music education they deserve.

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Further Information

The Children's Trust School - <https://www.thechildrenstrust.org.uk/school>

CedarSuperSound videos - <https://www.youtube.com/watch?v=WB-SuqyGgkQ>
and <https://www.youtube.com/watch?v=AssyAX7gSE0>

ImPACTS curriculum - <https://www.rosewoodfreeschool.org.uk/curriculum/impacts/>
and <https://www.thechildrenstrust.org.uk/school/about/impacts-curriculum>

Sounds of Intent – <https://soundsofintent.org/>

Tract and Touch – <https://www.tractandtouch.com/resonant-tails>

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Identifying autism spectrum condition in a person with profound and multiple learning disabilities

Gerard Wainwright

Heather (not her real name) is a gentle, thoughtful and expressive 36 year old woman who has lived in the service I manage for about 16 years. She has profound and multiple learning disabilities (PMLD), is non-linguistic and due to her profound learning disability has limited understanding. Heather can find it difficult to manage her environment; she easily becomes overstimulated and often needs support to spend time in a neutral setting where there is minimal sound, visual distractions or other stimuli. If not, she can become highly agitated making it difficult for her to relax or engage in most aspects of daily life. She benefits from a predictable daily routine, takes time to bond with her carers and can appear introverted and aloof at times. Like many people with PMLD it has often been assumed that her difficulty processing information is the result of her complex learning disability.

Heather was referred for an autism diagnosis via the local learning disability team early in 2020. Initially there was a reluctance to pursue this on their part and a requirement that further evidence be provided why an assessment was required and whether it would be of benefit. Assessing autism in someone with PMLD can be difficult as many diagnostic tests rely on a certain level of understanding and ability to answer verbal and written questions. In addition, the view is often taken that the impact of autism is less significant than that of the PMLD – in effect posing the question what difference would a diagnosis of an autistic spectrum condition (ASC) have? A possible example of the inequality many people with PMLD routinely face; it's unlikely we would require an adult who doesn't have a learning disability to evidence why a finding of autism may be important to them. There are many examples of people with a late diagnosis of ASC feeling a sense of relief and developing an increased insight and understanding of aspects of their behaviour and cognition they previously found troubling and confusing (Bulluss and Sesterka, 2020). Why would we deny this opportunity to a person with PMLD?

It's estimated around 40% of autistic people have a learning disability, compared to just 1% of people without autism. There are very few, if any, specific studies concerning ASC in adults with PMLD. This is clearly an area which requires further research. If a significant number of people are potentially excluded from a diagnosis, and others go through life unaware of their autism then the figures that are available are unlikely to be an accurate reflection of the true picture. We know that other neurodivergent conditions such as dyslexia, dyspraxia and ADHD are often associated with ASC, as well as specific neurodivergent conditions

associated with sensory processing and executive functioning (NHS, 2019). Perhaps there is an element of diagnostic over-shadowing in adults with PMLD who are assumed to present some of these conditions primarily as a result of their complex learning and physical disabilities?

Based on evidence of observing Heather it's clear she presents behaviours and reactions associated with a diagnosis of ASC. These appear to have a significant impact on her day to day life, ability to form relationships, her communication and her sensory processing. Her assessment was undertaken by the learning disability psychology team. It was made clear that a full diagnosis would probably not be possible, but a professional judgement could be given if there was evidence consistent with a diagnosis of ASC. The assessment took the form of discreet observation and asking staff who know Heather well detailed questions about her communication and behaviour.

The purpose of the referral was never about labelling Heather. Those who care for her accept her as the unique person she is and value her for her individuality and many wonderful qualities. The process was undertaken in order to support and provide evidence for best interest decisions which could potentially help improve certain aspects of her life - not only to understand her better but to enable a focussed approach to planning better support services for her. Specifically, when making reasonable adjustments as Heather can become distressed and upset by routine health appointments, particularly those involving hospital stays and finds regular changes to the medication prescribed by her neurologist highly distressing.

There is growing evidence that autistic people can react very differently to drug therapies than the general population. In Heather's case changes to her anti-epileptic medication often have a severe impact on her, leading to dramatic changes in her seizure presentation but also affecting her behaviour, resulting in periods of her appearing highly unsettled or alternatively withdrawn and closed off (Gravitz, 2017).

Another point to consider is that the experience and expression of pain are different in autistic people - an awareness of which would also have an influence on her care.

Another aspect that will be familiar to families and carers of people with PMLD is the fragmented nature of decisions and treatment provided by many of the wide number of professionals and specialists who are often involved in their lives. The highly focused approach of specific professionals can result in decisions based on a distinct aspect of the person's condition but not necessarily in the overall best interests of the person with PMLD. This can lead to a very disjointed approach with individual professionals rarely coming together to make a collaborative decision. In Heather's case she has input from a speech and language therapist regarding her ability to safely swallow, dieticians regarding her nutritional status, physiotherapists to support her postural care, occupational therapists to look at the best possible equipment for her, a neurologist to prescribe medication aimed at controlling the seizures caused by her epilepsy, psychiatry to prescribe medication to help support her mental health, her GP for her general health and many others.

Some of the aspects of Heather's behaviour and presentation which appeared consistent with ASC include but are not limited to -

- Significant difficulties around food. Including eating and the sights and smells associated with food. Historically this has always been the case, there are reports that food appeared to be linked to over-stimulation and seizure activity from childhood.
- She does not adapt well to changes in medication which can profoundly affect her behaviour. This has been and continues to be a significant issue in drug therapies to manage her seizure activity.
- Changes to routine can have a negative impact. A consistent approach is important in reducing anxiety which can often be overshadowed by over-stimulation including loud laughter and apparent difficulties modulating emotional responses. Once Heather becomes overstimulated it is difficult for her to relax, this can impact on her sleep pattern, health and well-being.
- Repetitive and self-stimulating behaviour - She will

often chew and bite her fingers when highly stimulated and presents other self-stimulating behaviours.

- Can appear withdrawn. Typically, she prefers to avoid eye-contact and appears to find side by side contact more comfortable and acceptable than face to face. She will sometimes initiate contact by placing her foot on the person's lap sat next to her.

Implications of the diagnosis of ASC

The report from the psychologist following the assessment concludes that Heather clearly indicates, over and above someone with the same presentation, that she meets the criteria for ASC. This will have a significant impact on managing her care and supporting best interest decisions under the Mental Capacity Act.

- Provide evidence that reasonable adjustments should always be considered. Recently Heather was required to have a relatively low risk day surgery, but the hospital insisted she stay in the previous night to keep her place on the surgical list. This was not in her best interests as it caused significant anxiety and distress. The professional judgement that she has ASC may now help evidence that this is the case and avoid the need for unnecessary procedure-based decisions.
- Provide evidence to support best interest decision about medication changes which may have a negative impact outweighing the therapeutic benefit. Heather does not appear to react in a neurotypical way to changes in her epilepsy medication. Small changes can lead to a significant impact on her behaviour and psychological and emotional wellbeing. Again, her ASC will be used to demonstrate to the neurology consultant that these changes may not be in her best interest and that a period of stability free of changes in her drug therapy is ultimately in her best interest.

The outcome of the professional judgement of ASC is a positive one for Heather. Already it has made a difference to her. In addition to the reasonable adjustments and caution in medication prescribing, her carers consider aspects of her ASC when supporting her and are better equipped with the knowledge, skills and understanding to meet her needs.

But the process of the assessment also raises several questions. Why aren't tests available for ASC which take account of people with PMLD? Why isn't autism considered important for people with PMLD? Why is it considered inevitable someone with PMLD will present in certain ways? A diagnosis of autism is no less important for someone with PMLD than it is for a person who doesn't have a learning disability. Why aren't people with

PMLD afforded the same considerations as other people. Surely this is a clear example of inequality and discrimination? At a time when neurodiversity is increasingly being celebrated in online and other communities, people with PMLD often appear invisible and are not part of the debate. Why is this?

Contact Details

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LDE webinar: Raising the Profile - PMLD Core & Essential Service Standards

Friday, 22 January 2021, 10.00 – 11.00

By Michael Fullerton of Achieve Together

There are still many barriers excluding people with 'PMLD'. What does inclusive best practice look like and how can we make it happen?

All providers of education, health and social care and support should be adapting and actively meeting the standards when supporting children and adults with profound and multiple learning disabilities. Likewise, the Standards are a tool to be used by families, commissioners and regulators when assessing what 'good' support looks like. As we step into 2021, Achieve Together will discuss how one adult social care provider has helped shape, and use the Standards to continually improve support, and ensure consistent benchmarking of the vision and approaches. Among other advances, this has led to people with profound and multiple learning disabilities being more involved in self and peer advocacy. Learn more about this journey, and the people involved.

This webinar is for Learning Disability England members only. Tickets are available from Eventbrite: <https://www.eventbrite.co.uk/e/webinar-raising-the-profile-pml-core-essential-service-standards-tickets-127174521417>



Hanging Out Program – Part 2, or should I say the first part?

Sheridan Foster

In the Summer 2020 issue of PMLD LINK (p.14), I introduced the Hanging Out Program (HOP). In this issue I want to share thoughts about what is often the first part of HOP, the greeting.

The greeting with a person with PMLD is a complex, yet foundational thing. Many people may be wondering why I am talking about greeting. “Hello”. Simple. But, unfortunately, too often greetings do not serve the purpose they were designed for – to use contemporary jargon, they are not fit for purpose.

Let me unpack. A greeting should be two people coming into awareness of each other. Person one shows person two that they are aware of them, and person two shows person one that they are aware of person one. To call upon psychological jargon, it is an ‘intersubjective beginning’ relying on ‘reciprocity’.

But too often, this is not what I see. Instead I see person one say “Hello” to person two from several metres away and then person one continues to the next action of their day. I see no signal in person two that they have either noticed the ‘greeting’ of person one, nor any signal of their greeting back.

So let’s think for a moment about what an authentic (while I often hate using that word because it automatically classifies other things as inauthentic) greeting might look like. What are the essential ingredients for an authentic greeting?

The most important ingredient of an authentic greeting is shared meaning. This means something that both person one and person two understands. If person two does not understand speech and person one only uses speech, then the requirement of shared meaning is not met. If person two has a severe vision impairment and person one uses a wave, then the requirement is not met. Person one might think they have done a greeting, but person two does not experience being greeted, and they do not greet back.

So a method of expression must be used that can be understood by both people. Person two must understand that they have been greeted. This might mean person one has to use touch, closer contact, or for some people, the person’s name alongside “Hello”.

The second ingredient is opportunity for person two to greet person one back. Sometimes this is called reciprocity. The step, one that is too often overlooked in greetings, may take a bit more thinking. For some

people, it might be simple; they may be able to say “Hello” back, or they might return a greeting by raising their eyes or hand in a wave.

For some people, person one may need to actually prepare a way that person two can greet back. When people offer their hand in a hand shake, person two can greet back by grasping the hand and shaking it. So much can be communicated in that simple handshake, from how person two feels at that moment and how they feel about the other person. A firm shake may express that the person two is anxious and needs some reassurance. A quick shake may indicate a mind elsewhere. A slow lingering handshake can indicate a comfort with the situation and person.

Some people will not be able to reach out their hand, they may require you to put your hand into theirs, squeeze their hand in greeting and then wait until they squeeze it in possible recognition. For some people, a foot to foot type handshake may be meaningful.

There may be some people who may be able to take turns in different sounds as a way of saying “I see and hear you, and you see and hear me”. An essential thing to know is that turns can not be taken if one person can not do what the other person is doing. So the greeting must be planned to enable person two to do something that they can already do.

Each person with PMLD may have a unique greeting – a unique way of understanding that they have been greeted, and a unique way of expressing their greeting back.

This is where each HOP should start. This is how each day should start. Moments must start with the awareness that someone is near me and hears me; anything less is inauthentic...

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“Not anymore!”

Sara Davis

A mom proudly shared a video of her wonderful home playground and water table, which reached a climax with her child very seriously at play with a shovel and ice. There is pride in her accomplishments when she asks him playfully, “Look at you! Are you having fun?” “Not anymore!” he says testily, packing up the toys and shoving them away. Of course not. It wasn’t about her, at least as far as he was concerned.

One of the principles of Active Learning, developed by Dr Lili Nielsen, is that play isn’t about praise or doing it right, and play is probably the most important way people learn, especially people at the earliest stages of development. The joy of solo play is that it is unselfconscious. We all know the feeling of being startled by the awareness of an audience. I am never so good a singer as when I’m in the shower and never so terrible as when someone outside, who I didn’t know was there, starts clapping! Interference and praise feel patronizing when you’re playing; that is, doing things you are enjoying doing for their own sake. Outside interference, even when it is reinforcing that you’re doing it right, makes play suddenly feel like work.

And yet, what’s wrong with a little check in? A little positive feedback that someone is doing this right? Dave Hingsburger (2020) rightly points out in his video “On Praise” that sometimes we get so wrapped up in praise being a technique of Applied Behavioural Analysis that we withhold it, at the expense of being kind, or even respectful. Building up the self-esteem of people with PMLD is important and we know they don’t get all the opportunities to show off that other people get. And we all know providing care or teaching when the person doesn’t feel liked or appreciated doesn’t accomplish much in terms of care or teaching.

Praise and feedback are important teaching techniques. “Good job!” helps when learning a skill you’re not equipped to learn on your own. Learning to look before crossing the street, learning to eat with a spoon, even toilet training typically happen long before a person is at the developmental stage to put them on their To Do list. I tried but could not get anywhere learning to play, or even just tune a guitar on my own: I didn’t even know what each string was supposed to sound like. Learning a language without a teacher modifying their speech for your ability and offering regular feedback is almost impossible, especially if a person is learning their first formal language. Free time to play with language, that is, babbling, vocalizing, singing, playing with their lips and breath, is necessary, but regular feedback and response to their communication is essential, too.



Since people need both free play and direct teaching, it’s important, then, to know the difference, and how the person might flow in between the two moment by moment, playing independently and then reaching out for interaction or help, playing and then hitting a roadblock and needing intervention. Without knowing the difference we’ll not only be the killjoy but we can destroy the child’s natural love of learning; or we could hurt their self-esteem and our relationship as they try something difficult and receive no help or recognition for their efforts.

Like the mom in the video, sometimes we feel a little guilty or left out seeing a person with PMLD playing on

their own, but we shouldn't as they are working hard at learning. It's fine if it's something they have been doing for a long time and for many years. So long as it still holds interest, they are still learning from it. They will stop or do it slowly with a bored expression when they are done with it. Then we can switch it out for something different.

It can take some time to help someone learn they can call out for help when they need it or switch to something new or some social time, and we can do that by being nearby and responding to their calls for attention and help, no matter how quiet they may be. Pushing the toy out of reach and communicating they want you to pick it up and return it is a social game we play where both communicate to each other—"please help" and "when you ask, I will help you."

My goal with my students with PMLD is that they can enjoy three types of activities: things they can do on their own (without feedback), things they are learning to do with help that may eventually become things they do on their own (with feedback), and social time, knowing that these three will blend into each other moment by moment.

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For online information about the work and ideas of Lili Nielsen, go to <https://liliworks.org/> and to <https://activelearningspace.org/>

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Many organisations that are subscribers (typically universities, schools, colleges, NHS services, charities and some other groups). We recognise that each organisation has paid for a higher subscription so that all members of their community (e.g. students, teaching assistants, nurses, therapists, family members of people with PMLD) to be able to access these recent issues. We want these organisations to be able to share recent issues within their community.

We ask that organisations make plain to community members that downloaded copies should not be shared online with others outside their community.

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Independence by proxy

Simon Yates and Julie Tilbury

All the young people at Chailey Heritage School, a non-maintained, special school for children and young people aged 3 to 19, have a physical disability, complex medical difficulties and a range of cognitive abilities. For those who have profound and multiple learning difficulties who cannot verbally explain what makes their life good or bad, we must find other ways to learn about this. Initially, this means observing and documenting what a positive and negative response looks like and from there we go on to document what elicits a positive or negative reaction.

Over the years, we make the closest observations of what a young person likes and does not like. What activities they enjoy, their musical tastes, foods, flavours of toothpaste, or milk feeds or scents for deodorant. Anything which is likely to impact them or for which they may have a personal taste.

This personal element is something which runs throughout the Chailey Heritage Individual Learner Driven (CHILD) curriculum, tailoring it to each and every child, designed with professionals and families around

each young person to support them to fulfil their potential. They are unable to be independent in one sense because of their physical and sensory needs but they can develop 'independence by proxy', i.e. they can have as much control as possible over their own lives through our interpretation of their responses over a long period of time. As we would learn about their medical, physical or communication needs, so we learn about the aspects that make them an individual, their preferences, likes and dislikes.

At Chailey Heritage, we feel an immense sense of responsibility to ensure that the young people in our care live the best lives possible. This is especially important for our pupils with profound and multiple learning difficulties and particularly when they transition to another setting. They may have been with us from our nursery provision or joined us later on in their schooling. Whichever it is, we strive to ensure a smooth transition and make certain that not only are they prepared for the change, but that the new setting is prepared for them.

It seems such a small thing for many of us, as it is hard to imagine what it would be like to consistently be fed something you do not like or constantly wear a scent you cannot stand. At a basic level it might underline the learned helplessness (Seligman, 1975) many young people with PMLD experience. Preferences can serve to motivate, support learning and underpin communication as the students learn that when they show they like something they have it again. Or when they show that they don't like something their response has been honoured and it isn't repeatedly presented. It's a perfect example of Jean Ware's 'responsive environment' (Ware, 2003) as we respond to preferences and make it clear we notice. As Joanna Grace on her website, and many others before and since, would remind us, the ability of these young people to communicate is not dependent on being able to learn certain skills but on us being able to listen and respond (Grace, n.d.).

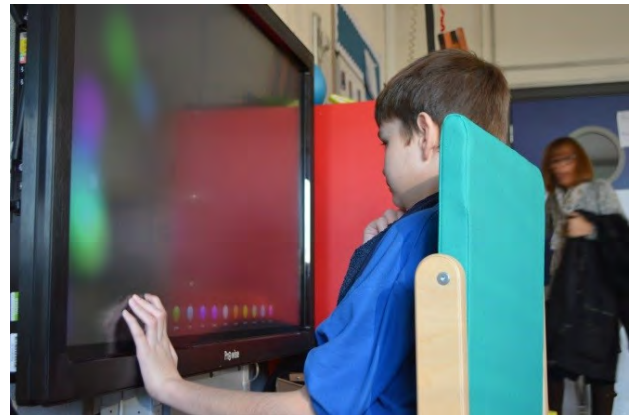
We have such detailed information from the young people, their families and from years of observation, and it is our responsibility to hand it on to the next organisation involved in their care. We make sure the receiving organisation has all of this documented in detail, and in transition we 'train' the receiving staff, how to 'be' with the young person, as far as we possibly can. And, if we can, we check up on them, checking out the set-up of the new place and answering any questions. A small thing to us, but a massive difference to the lives of young people with PMLD, independence by proxy is essential.

Nicholas

Nicholas is a very sociable, affectionate and expressive 18 year old who loves to be kept active. He can be shy if he is not sure of someone and if he is bored he will fall asleep. Nicholas shows he is bored by putting his hands over his face. He loves deep pressure massage on his arms and legs and has made progress having his head touched. He has an affinity with people and animals and shows a great empathy for the moods of others. He is very curious about the animals on the farm and will initiate touching an animal or person rather than an object, he particularly likes the guinea pigs, goats and chickens. Nicholas also has complex epilepsy, a learning difficulty and a movement disorder. As Nicholas is shy

with new people it will be especially important that he meets new staff in familiar surroundings. Any placement will need to take into account his love of animals and being physically active.

In addition to the medical, educational and social and emotional and physical information which is comprehensively documented in a set of personal profiles which make up the CHILD curriculum, more specific information is also gathered.



This includes the toothpaste flavours, scent and musical preferences plus any personal information which will support staff to make life more comfortable for Nicholas. All the information is documented and included in the profiles to accompany any young person to their transition destination, whether that is with Chailey Heritage Futures (provision for young young adults aged up to 25) or elsewhere.

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Further Information

CHILD Curriculum - <https://www.chf.org.uk/purposeful-learning.html>

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Many thanks for your support.

ABC, should you include me?

Gemma Culverhouse Chave

This piece offers reflections of my recent research project into whether phonics is ever an effective tool to be used in the PMLD classroom. With a government focus on the use of phonics for teaching reading to all, are settings buying into schemes in order to conform and please Ofsted, or are senior leadership teams making informed choices about the best methods for their individual pupils?

My tenth year of teaching has been one of the most challenging and revealing by far. After teaching in a mainstream primary school for three years, I was fortunate enough to make the move into teaching within SEN settings, which is where I have stayed. This academic year was my first working with pupils who were grouped as having PMLD. I have not stopped questioning and reflecting upon my own practice and that of others. This new and exciting opportunity coincided with the completion of my master's degree in psychology. Choosing a dissertation focus was immediately clear - the senior leadership team for the school I was working in, adopted 'Read Write Inc.', a literacy scheme for primary schools marketed by Oxford University Press. Claims that all children can learn phonics and that it is a useful teaching tool for all, led me to the title for this article and the focus for my research. Being new to the classroom for children with PMLD enabled me to look at systems and approaches through a clear lens, constantly asking questions and seeking to find accurate guidance.

I embarked on several months of research which involved talking to experienced and insightful practitioners. The main aim of the dissertation was to explore the effectiveness of phonics as a strategy for teaching reading when working with children who have PMLD. Phonics is currently considered the best practice for teaching reading within schools in the UK but there is little research into this aspect of educating pupils with PMLD. I also wanted to explore possible links between the use of phonics and Augmentative and Alternative Communication (AAC). It is important to acknowledge that AAC does have a place in supporting those pupils who are able to engage with it successfully; Berkowitz (2015) discusses how it can be used effectively to support areas of literacy when used appropriately.

A qualitative design was chosen. Participants volunteered their involvement; some by responding to a post within a support group for teachers of children with PMLD. Following their expression of interest, a consent form and questionnaire were sent out. One of the questions asked if they would be happy to be interviewed. Responses were used from ten participants across the UK

and two of these were selected to interview. Both written and spoken results were analysed using a 'thematic approach'. Analysis of the responses showed different opinions, experience and practice.

Seven out of ten participants stated that they have used phonics in some form within their settings and were able to describe some approaches and strategies. All participants acknowledged the value of phonics for some pupils (mainly not those with PMLD). One participant wrote about how she had used her phonics sessions to focus on using the pupil's senses to explore sounds in their environment, like birds singing or a door shutting. Another participant explained how she had adapted 'Letters and Sounds', Phase 1 phonics (DCSF, 2008) to suit the needs of her pupils, using environmental sounds or musical sounds and linking their sensory stories accordingly.

In a school where Read Write Inc. has been adopted, one senior leader discussed how one teacher adapts the scheme for her group of children with PMLD. He described sessions as being short and multi-sensory, where the pupils may have one sound as the focus for a half-term. During this time, they would explore objects beginning with that initial sound, be shown the letter and hear it repeatedly. Periodically the teacher would offer the choice of two sounds to the pupils, in an attempt to provide them with an opportunity to assess learning of the letter-sound correspondence. Despite this participant offering an example of a pupil who could point out the sound 'a' when offered a choice of two, a term is a long time. How valuable would this be? Also, there was no evidence of the pupil being able to retain this information over time.

Other participants stated that the use of phonics in the PMLD classroom is a waste of time. One participant stated: 'I would no more teach phonics to someone with PMLD than I would to a new-born baby – it is not relevant for them'.

The most important discussions that took place as part of this research, were those which involved the question of

whether pupils with ‘profound and multiple barriers to learning’ are often misdiagnosed as pupils with PMLD and vice versa. For instance, Jonathan Bryan was born with severe cerebral palsy which makes it difficult for him to communicate but a few years ago he started speaking with the help of a spelling board (BBC, 2018). Jonathan’s story was explored and discussed by some participants by way of encouraging phonics in the PMLD classroom.

This raised so many further questions. I was forced to consider my own understanding, the understanding of the participants and our education settings - Are we all in need of information and awareness-raising about terminology and how to ensure pupils are in the correct settings/ class groups in order to receive the appropriate teaching ? Would some individuals who are wrongly grouped as pupils with PMLD, benefit from phonics? Is it wrong or unfair to group together children who present as having PMLD? If we place pupils with PMLD in generic class groups, does this cause more incorrect and inappropriate outcomes?

The answer to my dissertation question was answered; put simply phonics is not an effective tool to use with those who have PMLD. Carrying out an interview with one participant, whose knowledge and understanding of PMLD is vast, led me to reflect on my research focus. I picked it apart. NHS Midlands and East (2012) states that those in our community with PMLD are amongst the most disabled; ‘they have a profound learning disability which means that their intelligence quotient is estimated to be under 20 and therefore have severely limited understanding’. Taking this information into account, made my dissertation title erroneous. Perhaps, it shifted my focus to where it should have always been. The main question for me now is this: How can we as practitioners be sure that pupils designated as having PMLD do not have less severe cognitive impairments that are masked by profound and multiple barriers to learning? How do we provide opportunity and have expectation, appropriately? Attempting to assess the cognitive ability of all individuals is a complex task. Addressing these questions in future research, would be beneficial in supporting practitioners who are making decisions in their classrooms. Whilst we do not want to ignore the possibility that some children may in fact be cognitively able to benefit from phonics, we also do not want to be repeatedly providing phonics for pupils who are unable to comprehend it. That is not only a waste of their time, but somewhat cruel.

Personally, I was fortunate enough to begin a journey, one involving a process of development and learning for myself and an altered way of thinking. The insights and words from participants along that journey were invaluable. There were some moments during this process where I paused and questioned the value of my

dissertation, wondering whether it was beneficial to ask these questions since it had become about far more than phonics by then. The practitioners who gave their time and words, reassured me. We are in a profession where individuals hold buckets full of experience and ideas. This is a profession where practitioners strive to do the best for pupils in their care, regardless of diagnosis, readily sharing with those still at the beginning of their own career journey. I feel fortunate to be a part of this profession.

Contact details

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What is Rebound Therapy?

Eddy Anderson and Paul Kaye

You've probably heard the phrase - and if you work in a special school it may well be offered to your students - but what on earth is 'Rebound Therapy'?

In one sense that is a slightly inaccurate question, for the true value of Rebound Therapy lies in the fact that part of what occurs is not physically 'on earth'. The essential value of the process is that 'earth' is left behind, for a brief moment. Consequently a new freedom is found in controlled movement away from gravity's straitjacket in a sort of relaxed 'poetry of motion' - available to all, irrespective of any disability.

The phrase 'Rebound Therapy' was coined by the founder, Eddy Anderson, in 1969 to describe the use of trampolines in providing alternative opportunities for movement, therapeutic exercise and recreation for people with a wide range of special needs. Participants range from people with mild to severe physical disabilities and from mild to profound and multiple learning disabilities, including those with dual sensory impairment and autism.

Rebound Therapy is used to facilitate movement and increases or decreases in muscle tone. It promotes

balance, sensory integration and relaxation whilst improving fitness and exercise tolerance. It also creates a great opportunity to improve communication skills.

The approach is already popular in special needs schools and is becoming increasingly popular in mainstream schools with special needs units. It is also used by some forward thinking professionals in health and adult services. This is partly because the trampoline is a piece of apparatus that virtually everyone can access, benefit from and enjoy, regardless of their abilities.

The worldwide body for Rebound Therapy is 'ReboundTherapy.org' (the working name for Rebound Therapy International Ltd.) who state that in addition to the benefits listed above, it is an ideal vehicle for cross-curricular teaching activity; with the potential for teaching such things as numeracy, colour recognition, positioning (left, right, backwards, forwards, clockwise and anticlockwise), communication, social awareness and consideration of others. They further state that the



unique properties of the trampoline offer ample opportunities for everybody to enhance movement patterns.

The work is intrinsically motivating and enjoyable and the returns are high in therapeutic terms, for the time and the effort involved. Benefit is enhanced considerably when the facilitator (operator) achieves the skill to create variable patterns of movement in harmony with the needs of the individual (user). The two people then share the surface of the trampoline, with the facilitator adjusting the effect of weight and speed in order to ensure smooth transitions between the phases of movement carried out.

The fact that the activity is so enjoyable can enable it to be used as a motivational aid to learn. Many teachers also report increased concentration and willingness to learn in the classroom following a Rebound session.

Below are just two of many reports we have received regarding the benefits of Rebound Therapy:

Example from a School

We use Rebound Therapy within our PMLD department which benefits students immensely in many areas. We have noticed considerable progress over short periods of time and often get a better response/level of engagement (particularly with our more complex students) on the trampoline than we get in the classroom. Not only does it promote their

communication, it obviously affords them a unique physical opportunity to come out of their wheelchairs and move their body in a way like no other.

Example from parents

Katie was born three months premature and as a result has Cerebral Palsy. This condition affects all four limbs and her trunk control. Katie is a full-time wheelchair user. As with all new therapies, we went to the session with a fairly open mind. We hoped that it would be a fun experience for Katie that it would help relax at least some of her tight muscles. Katie was excited by the thought that she would be trampolining.

Katie took to the trampoline immediately. With the support and encouragement she was given she felt very stable and confident. The session began with gentle bouncing that allowed her to relax from the outset. One exercise involved her bouncing while sitting on a 'peanut' therapy ball. This imitated horse riding which she found challenging but enjoyable. It was noticeable that as the exercise progressed her legs and feet relaxed down. This enabled her to push down on the trampoline with her legs and become more involved in the activity. The activity that surprised us the most was the stretch with a parachute. It was a simple exercise that clearly relaxed her whole trunk.

The session exceeded our expectations. The benefits were visible as her muscles gradually relaxed down as the session progressed. It was epitomised by her sitting with a straight back in a bean bag as she bounced on the trampoline. Katie has great difficulty in maintaining her balance when seated but she showed great control unaided. We also noted that even her usually-clenched hands opened and she showed splayed 'star' fingers. Katie said, "Do you know why I liked it? It was fun exercise." To Katie fun exercise is the best therapy.

The Rebound Therapy practitioner training course is approved by AfPE (The Association for Physical Education) in the UK and is an internationally recognised programme.

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For further information on arranging a training course, visit www.ReboundTherapy.org or email: info@reboundtherapy.org or telephone 01342 870543

Emotional and mental wellbeing – the launch of a new resource

Julie Calveley

At this time, perhaps more than ever before, the importance of proactively taking care of our mental wellbeing is widely recognised. The UK charity, Mind, says that “The Coronavirus pandemic is having a huge impact on our mental health” and have declared it to be ‘a mental health emergency’ (Mind, 2020).

During the latter years of the 20th century and the early millennium, approaches to mental health have mainly been in the form of medication and ‘talking therapies’, such as cognitive behavioural therapy and psychotherapy. The STOMP project (Stopping the over medication of people with a learning disability, autism or both) highlights that other ways of supporting mental health may be more effective and safer than medication, and that talking therapies generally require a level of cognition and verbal skills that makes them inaccessible for people who profound and multiple learning disabilities.

Developments in neuroscience have contributed to an understanding of the inextricable link between the mind and the body. They have shown the important role that experiences and practices such as mindfulness, being in nature, having quality interactions, massage, exercise, yoga, dance, art and music play in mental wellbeing.

The NHS (2020) ‘5 steps to mental wellbeing’ are based on a body of evidence that has accumulated over recent years showing the positive impact that a variety of non-medical and non-talking strategies can make to our mental health. There are numerous resources and ideas on the websites of the NHS and other organisations such as Mind (who also promote the importance of getting as much natural light as possible and keeping meaningfully occupied) on how people can put these 5 steps into practice:

- Connect with other people
- Be physically active
- Learn new skills
- Give to others
- Pay attention to the present moment (mindfulness)

Most of the advice on activities and strategies that are promoted are not immediately suitable for people with profound and multiple learning disabilities. However, arguably with suitable adjustment and sensitive facilitation, they can bring benefit to people with profound and multiple learning disabilities.

Taking care of the mental wellbeing of people with profound and multiple learning disabilities is particularly crucial for a number of reasons. It is known that people with learning disabilities are at higher risk of suffering mental health problems, in part due to their vulnerability and their care, medical and support needs, which may also make them more susceptible to experiencing loss, loneliness and trauma. For some, the changes and restrictions imposed as a result of the pandemic may exacerbate their stress and distress (The British Psychological Society, 2020). It has also been found that mental health problems, including depression and anxiety, are more prevalent for this group than for the rest of the population (Fergusson et al, 2008, O’Hara, 2020).

Therefore, at what for many is a particularly difficult and challenging time, it is essential that we attempt to answer the question ‘What do evidence-based emotionally nurturing experiences look like for people who do not use words to communicate?’ in order that people with profound and multiple learning disabilities and their carers are not ‘left out’ and that we do the best we can with the knowledge that we have.

NAC (Non-verbal Affective Care) is a non-profit, community interest company that has been created to contribute to the improvement of emotional and mental wellbeing for children and adults with severe and profound intellectual disabilities. NAC provides guidance, training and information on making evidence-based mental wellbeing experiences accessible for people with severe and profound intellectual disabilities. To achieve this, NAC has four overarching aims

1. To contribute to the improved emotional and mental wellbeing of people with severe and profound intellectual disabilities by providing caregivers access to practical guidance.
2. To increase awareness of the emotional and mental health needs of children and adults with severe and profound intellectual disabilities.
3. To seek clinical collaborations for the improvement of accessible mental health therapies and treatments.

4. To signpost other services and sources of guidance, training and information on the mental and emotional wellbeing care of people with severe and profound intellectual disabilities.

NAC works with a range of organisations and individuals to produce specially adapted guidance that is made freely accessible to all those involved in direct care, support and education, via the NAC website (www.nacwellbeing.org). The experiences are organised into categories that have emerged from the evidence and can be made suitable for people with profound and multiple learning disabilities, do not require specialist equipment, are inexpensive and are described clearly and in a step-by-step way:

- Arts and Creativity
- Interaction and Relationships
- Mindfulness
- Movement
- Music
- Nature
- Senses
- Touch

This guidance is not intended to replace the need for clinical assessment and intervention, and NAC operates and promotes the use of this guidance according to its underpinning values:

- Integrity - Taking care of the mental wellbeing of everyone is important and this includes people with severe and profound intellectual disabilities as well as their carers and ourselves.
- Person-centred - What works for one person may be different for another, and therefore any approach that is safe and evidence-based or underpinned by science and brings positive outcomes may be offered.
- Free at point of access - People with severe and profound intellectual disabilities should be able to benefit from the kinds of information, approaches and support that others can access free of charge.
- Collaboration and sharing - We value joint working and believe that people with severe and profound intellectual disabilities will benefit most when knowledge, expertise, ideas and resources are pooled and shared.

As a new venture, NAC is keen to make contact, collaborate with and receive feedback from people with profound and multiple learning disabilities, their families and anyone involved in their care, education and therapy. Please visit the website for more information and to start exploring and trying out the guidance.

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Further Information

The NAC website: <https://www.nacwellbeing.org/>

For information about the STOMP Project go to: <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>

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Launch of Posture Positive

Rachel Wright and Sarah Clayton

Posture Positive is an exciting new project funded by NHS England and lead by Simple Stuff Works and Born at the Right Time. It is seeking to imagine and develop excellence in postural care for people with learning disabilities. Although postural care isn't as sexy as sensory stories or eye gazing technology, good posture for people with learning disabilities is the foundation on which all other exciting, interesting and accessible activities are based. If Zac is in pain sitting, he won't be able to concentrate to learn. If Sophie cannot sit straight in her chair, she won't be able to use her head to activate augmentative communication. Without 24-hour postural care, John might develop restrictive arm movements, impacting his ability to mobilise using his electric wheelchair.

In order to improve services, it is vital to fully understand the experiences and impact current postural care provision is having upon everyone involved – especially families and individuals. A survey was therefore designed to capture the reality for individuals with postural care needs, their families and the professionals who support them. The response was remarkable and unfortunately challenging to read. Families have really suffered in the wake of coronavirus, feeling isolated and abandoned; resulting in deteriorating health for people with learning disabilities and their families.

One mother wrote it was, "heart breaking to see. I've felt like I'm watching a car crash and there's nothing I can do and no one cares." While another said it, "Makes us feel out of control and stressed that we are not doing the best for my child that may have long term implications." The feedback from professionals represented the difficulties they are facing with ever changing guidance, staff being furloughed and no longer being able to see the families they support.

The good news is, there is sun on the horizon. Both families and practitioners reported some great practice being undertaken across England and the Posture Positive project wants to bring together a collective voice of families and professionals who are committed and

determined to act, ensuring postural care improves for all.

On 23rd November 2020 Posture Positive was launched by sharing more detailed results of the survey and hearing from those making small, significant steps towards excellence in postural care in this ever-changing world. It is through uniting our voices and acting together that we can begin to dream, build and share what excellence looks like for people with learning disabilities who have postural care needs.



**POSTURE
POSITIVE**

Contact Details

Rachel Wright is founder of Born at the Right Time
Sarah Clayton is CEO of Simple Stuff Works

For more information follow on Facebook at Posture Positive Collective, go to www.posturepositive.co.uk or email contact@posturepositive.co.uk.

Coronavirus and people with learning disabilities: What are the some of the issues for family carers supporting people with profound and multiple learning disabilities?

Jill Bradshaw, Samantha Flynn and Chris Hatton

We are at the start of a UK-wide project looking at the impact of coronavirus on the lives of people with learning disabilities. We have two surveys which we will ask people with learning disabilities or family carers/paid supporters to complete three times over the next year. We know from our conversations with family carers and paid supporters of people with PMLD that they and their relatives/people they support can feel invisible. We want to make sure that the experiences of these groups of people are very much included and visible within our project. This article reflects some of our initial conversations with family carers about the impact of the coronavirus on the lives of people with PMLD and their family carers/paid supporters.

Worries about health

People with PMLD often experience additional health issues which place people at increased risk from coronavirus. Sometimes whole families are staying at home to protect their relative from the risk of coronavirus and have been doing so since March, and this group seem to have been forgotten about. Family carers are very concerned with the possibility that Do Not Attempt Resuscitation Orders might be put in place automatically as a result of the presence of a PMLD. Carers think that testing might be less likely to be made available for this group and are also worried about how a swab test might be carried out with a person with PMLD.

Complex communication challenges mean that it can be harder to identify health issues in people with PMLD and carers are mindful that many health issues are always attributed to the PMLD. Accessing support for health needs has been even more difficult in times of coronavirus. Whilst some health issues can be identified through a remote consultation, people with PMLD are less likely to be able to access support in this way; their methods of communicating pain, distress and discomfort are likely to be idiosyncratic and health needs may need to be identified through a physical examination.

Lack of contact

The virus has resulted in restrictions on physical contact and many carers report being unable to go and visit their relative if they are living in residential services. Although one of the ways we describe our 'new normal' is by referring to 'social' distancing, for most of us we are not so much 'social' distancing but rather 'physically' distancing ourselves from other people. Our

communication and interaction skills typically mean that we can still socially connect with others in that we can chat (even in full PPE) without being physically near to one another. We can even do so at great distances through technology such as Zoom. For someone with PMLD, even that relatively small act of physical distancing when we are in the same room as an individual can be hugely problematic and may also mean a loss of 'social' interaction. Communication and interaction with people with PMLD often means being physically present and close enough to be hands on and requires communication partners to join the person in their world. That is so much harder and sometimes impossible to do if even a short physical distance is imposed.

Most people have experienced changes in the activities that are available to them but for people with PMLD, family carers report that it had been much more difficult to meaningfully engage in e.g. alternative activities online.

Who is caring for carers?

For some, coronavirus has meant providing additional care and support for a relative. This might be because a relative has moved back home. It might be because a relative was living at home previously but had been supported by family carers and paid supporters. Restrictions have reduced the amount of paid support available.

Family carers report feeling physically and emotionally exhausted. Some families were only expecting to care for and support their relative at home for a relatively short

period and are expressing concerns about burnout. Some family carers are described as being beyond burnout and at crisis levels. There are similar concerns about paid supporters.

Families are worried that they might be viewed as having 'coped' with reduced levels of paid support and that this might reduce what support was offered in the future. Other families report a breakdown in the family and feeling that they had needed to opt for residential care as the only way that their relative would be able to access the 24 hour support needed.

What about advocacy?

Family carers typically provide a constant in people's lives and coronavirus has prevented many from visiting their relative. All of us have found reduced contact with other people difficult but at least we know why this is a necessity. These changes will have been incredibly difficult for people with PMLD to make sense of. Lack of presence in people's lives is an even bigger worry for families in terms of them not being able to continue to advocate for their relative in ways that they are able to do during typical times.

Family carers also report that the restrictions had resulted in some opportunities for their relative to form closer relationships with paid supporters. This is seen as positive but families are very aware that paid supporters are rarely around for the entirety of people's lives.

If you want to know more about the survey, or take part in it, please visit the project website for more details: www.covid19learningdisabilities.co.uk

Contact Details

This report was co-authored by Dr Jill Bradshaw, Dr Samantha Flynn, Professor Chris Hatton and the Coronavirus and people with learning disabilities survey team

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In the Next Issue Training and Development

The next issue of PMLD Link will focus on Training and Development. We want to know what has helped you to develop as a person, a parent, a carer or professional supporting people with PMLD. Have you benefitted from a particularly good training course or educational programme? Or perhaps a particular book or film opened your eyes to a new world? Maybe you've learnt the most from simply being with people with PMLD. This has certainly been transformative for many of us on the PMLD Editorial Team.

Standard 3 of the PMLD Core and Essential Service Standards (2017) focuses on Development. If you are developing or delivering innovative training for families of people with PMLD, or care staff or professionals working with them, please write about it for us! We would love to hear how you are meeting (or exceeding!) the PMLD Standards in this area. We imagine that the current pandemic time has created many new challenges for you. Tell us how you have adapted your training so you can deliver it digitally or changed your content to meet new needs arising from the coronavirus situation. Do you deliver training with people with PMLD as co-trainers or experts by experience? Tell us how you do this and share your stories of the impact of this training. Perhaps you work for an organisation which oversees training? We would love to hear how you take account of the needs of people with PMLD and their supporters.

Finally, and perhaps most importantly we are particularly interested in hearing all of our readers' thoughts on how training and development can help to ensure that people working with and for people with PMLD have the right values, so that they can truly help people with PMLD to flourish.

We are looking forward very much to receiving your contributions! Please remember that we are always happy to help with writing so if you have an idea, get in touch!

Deadline for submitting articles, news, etc. is 1st March 2021

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REPORT BACK

How can we promote 'togetherness', apart?



This is the journey of a community festival, tasked to promote visibility and true inclusion, in a world of physical segregation. In 2018 and into the past, Castle Hill School had strong tendrils reaching into the community and the community was reaching back. Care homes were enjoying sign and sing sessions with our students, primary groups from different schools joined on site for nature walks and sculpture building, a local ladies' group enjoyed meals served by our sixth form enterprise group, our students joined other schools to socialise at music events, sports events, and drama productions. Drum circles popped up, fayres tempted shoppers, we rolled up our sleeves for art projects, plays were written. We were out there. Visible. We wanted (and still want) to further engage the community, to encourage the individuals to embrace the 'complex needs' community as a contributing and integral piece of a collective. We decided to celebrate our true inclusion and our community with a festival, give these groups a

celebration to aim for! Showcase our connectivity! We launched CastleFest!

CastleFest2019 was jubilant! With a café, fairground games, performances scheduled across two stages, karaoke, an ice cream van, dancing, drama performances, an art gallery and parade, we invited our community to be joyful with us. To overhear GCSE Drama students talking about make-up with their Castle Hill peers, or see friends from a local day-centre dancing with our staff and students, to see primary children playing hoops together in the hall highlights how we all love to have fun, and we are all part of a whole.

CastleFest2020 was on track to be bigger. But we had to stay at home. We went digital. In just six weeks. The challenge was to engage our students in something on a screen - the artists' ingenuity engineered interactive, playful (sometimes instructive!) activities supported by music, dance, props and drama. School 'mail dropped' line-up posters, lists of props, short 'how to' guides to parents, and lots of hype to get people at home engaged. The school 'home learning' topic of 'celebrations' encouraged folks to make bunting, try cake recipes, face paint, and make costumes ahead of the festival. On the day, we asked for videos and photos of people celebrating in their homes - we were broadcast all over Huddersfield and were delighted to see people dancing along in their own settings! Hundreds of people tuned in.

The question is, how do we, for CastleFest2021, make a secure plan for a community arts festival which is accessible to people at home, our friends in the community, people at school, but also includes the mutually beneficial and reciprocal elements of the original concept? And 'secure' here means that any decisions made as a result of the changing nature of the global health crisis won't impact the day! At the moment, groups are working on projects and 'checking in' via video conferencing to share progress and chat. We are planning a mixed approach, with some carefully planned on-site festivities, and some digital. Remote connections are developing normality and strength, and the 'pen pal' model is reinvigorated! However, it is our hope, in these disconnected times, that the heart of CastleFest, the meaning of community togetherness and true inclusion, develops heft, and snowballs towards a vibrant and fierce celebration.

Rachel Stevenson, Castle Hill School, Huddersfield
For more details go to: www.castlehillschool.org.uk/castlefest2020/

With special thanks to Katrina Whale, Greg Firth, and Michael Isherwood, and to Sophia Berry, who bravely takes the mantle of coordinator for CastleFest2021!

Sensory Festivals

With physical sensory training events currently off-limits due to the Coronavirus pandemic, 'online' training resources have become the new way forward for many businesses, and Hirstwood Training is at the forefront in embracing this new trend.



'The Sensory Festival' originally came from an idea we had as Covid-19 was shutting down businesses and schools all over the country. The original concept came from a company offering an online Beer festival. They created a YouTube channel and sold tickets to view the private videos. Interesting!

We were further inspired by PMLD link, which is, without doubt, the best place for curated information for practitioners. It's easy to go onto YouTube or Pinterest and get some fabulous ideas but PMLD Link offers information which is written by people who really understand PMLD and have innovative and inspirational ideas. So that's why we created a video all about PMLD Link for our Resources Pavilion!

We knew that we wanted something interactive and professional for teachers, assistants and other teams working with PMLD and Autism. We are able to host online events and training courses via our website (<https://hirstwood.com>) aimed squarely at PMLD and other additional needs but aimed purely at special education.

We are very lucky to have a contact list that includes some of the country's top practitioners, and they were all willing to contribute. So, after a period of intensive preparation, 'The Sensory Festival' (11-12 July) was born. It brought together a community of parents and practitioners to collaborate, experiment, create and share exciting new ideas and ways of working with learners with complex needs, autism and SEND. Our panel discussion in July was comprised of Diane Rochford OBE, Professor Barry Carpenter CBE, OBE PhD, Carol Allen, and Richard Hirstwood with the amazing practitioners Julie Cowpe-Stephens and Helen Dillon. It

was a weekend of video presentations, online workshops and question and answer sessions with access to a chat room, which was open for the weekend of the festival and a place to comment, connect and chat.

We soon discovered the additional benefit of using a chat room – schools could communicate with each other and share best practice, worldwide! Many schools attended both sensory festivals from all over the globe, including New Zealand, Australia, Denmark, Israel, UK and Canada.

Following the success of the Sensory Festival in July, we held a second festival in October. 'The Sensory Festival 2' (10-11 October) created a wealth of sensory ideas and strategies around supporting engagement in learning and the emotional resilience of learners with complex needs, autism and SEND as we transitioned out of lockdown and back into the classroom. It created networking opportunities for practitioners to share, discuss, question, listen, debate, collaborate, and problem solve.

This time, the video presentations were located in themed 'Pavilions': Sensory, Autism, iPad, Music, Transition, Engagement, Resources, and even a Toilet Pavilion! Again, all the videos were closed captioned to make them as inclusive as possible.

The aim of the second festival was to rejuvenate sensory approaches to having fun, building and maintaining relationships and re-engaging pupils in their learning. Once again, the feedback from delegates has been wonderful.

At the second sensory festival, we were delighted to include presentations from talented practitioners worldwide: our first contributor from the USA, 'The King of Swings', Alex Lopiccio; from New Zealand, Maximiliano Pierret; and from Australia, Penelope Earp!

Listening to feedback from both festivals resulted in the birth of The Parent's Sensory Festival (5-8 December) aimed specifically for all parents of children with complex needs, autism and SEND.

We're now currently planning Sensory Festival 3 – which will take place in Spring 2021. Watch this space!

Richard Hirstwood
Founder and lead consultant for Hirstwood Training/
<https://hirstwood.com/>

IN THE NEWS



Meet Daisy

Rebecca Dickens, Daisy's Class Teacher at Springwood Primary School in Irlam, writes: Meet Daisy, a recent addition to our class at Springwood Primary School. Daisy was our entry for the local community scarecrow festival and we had lots of fun making her. It was a great opportunity for exploring straw with our hands and feet, smelling it, watching it fall down and for working on our motor development as we grasped, released, squashed and squeezed the straw. We felt it would be great for our local community to know a little more about our class and the amazing pupils in it and Daisy encapsulated this. We included something personal to each child in our class when creating Daisy, whether it be her love of chocolate cake and custard, her purple hearing aids or her personalised G-tube cover. Daisy has been a great way of raising awareness and promoting the importance of inclusion which in turn will aid in the challenge of removing barriers and creating a more enabling world.

Capacity Law and Rights Information

Get some legal clarification on the current situation for people with learning disabilities and their families. Birmingham Law School, Wolferstans Solicitors, Bringing Us Together, and others have collaborated to run a series of 6 CLARITY Sessions. These started in November 2020 but several will take place in January to March 2021. The aim of the CLARITY project is to improve access to justice for disabled people and family carers through enhancing understanding of mental capacity law and human rights.

CLARITY stands for Capacity Law and Rights Information to You and these zoom sessions are aimed specifically at people with learning disabilities and their families. It is planned that, after each CLARITY session, a report of what was talked about will be posted on the www.legalcapacity.org.uk blog.

For more information go to: <https://www.legalcapacity.org.uk/clarify-project/>. There is a link for registering via Eventbrite.

Deaths of people identified as having learning disabilities with COVID-19 in England in the Spring of 2020

This report examined data from the English Learning Disabilities Mortality Review (LeDeR) and NHS England's COVID-19 Patient Notification System (CPNS) which records deaths in hospital settings. It found 451 per 100,000 people registered as having a learning disability died with COVID-19 between 21 March and 5 June, a death rate 4.1 times higher than the general population after adjusting for other factors such as age and sex. But as not all deaths in people with learning difficulties are registered on these databases, researchers estimated the real rate may have been as high as 692 per 100,000, 6.3 times higher.

Deaths were also spread much more widely across the age spectrum among people with learning disabilities, with far greater mortality rates in younger adults, compared to the general population. The death rate for people aged 18 to 34 with learning disabilities was 30 times higher than the rate in the same age group without disabilities, researchers found.

Among people with learning disabilities, the rate of COVID-19 deaths for adults in residential care was higher than the rates of COVID-19 deaths of adults with learning disabilities generally. This difference is likely in part to reflect the greater age and disability in people in residential care. A third of those with learning disabilities who died were living in residential care.

With cases developing anew across the country, it is essential to learn the lessons from the first phases and develop rigorous infection control measures to support people with a learning disability, whether or not they live in a care home. The Government has asked SAGE to review the findings and give advice on what more can be done to keep people safe.

The report is available at:

www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19

Changing Places toilets

In October, the Department for Transport published a further list of service stations - on A roads and motorways - that have been successful in their bids for a share of government funding for Changing Places toilets. Find out more and see the 'second round funded areas' list at: www.gov.uk/government/news/disabled-people-to-benefit-from-better-journeys-thanks-to-service-station-funding

Family Voices

Learning Disability England in partnership with Together Matters wrote a short paper pulling together a huge variety of comments, thoughts and ideas from family carers whose relative is living at home with them or in the local community. Family Voices includes suggestions for moving on from the pandemic and makes a case for changes that need to take place in the way social care is delivered. Family carers will hopefully appreciate hearing about shared experiences whilst practitioners and commissioners will gain insight into the concerns of families and changes that could make a difference.

You can access the paper at: <https://www.learningdisabilityengland.org.uk/news/family-voices/>

1971 - 2021 : Celebrating 50 years of very special education

Flo Longhorn is setting up next year a celebratory website of historical good practise in the field of very special education (i.e. with a focus on children and young people with PMLD).

If you have any contributions such as comments/materials/photos or clips, Flo is happy to see if they will fit on the website. Contact her on florelonghorn@gmail.com

Jamboree : Celebrating unheard voices through rhythms of the Balkans

Composer and BBC Radio presenter Max Reinhardt has brought together an ensemble of Balkan musicians and young people with complex disabilities to create a suite of melodies to inspire dancing and connection called Jamboree the Album.

Each track featured on the album was created through improvisations between professional musicians and young musicians, many of whom do not communicate through verbal language.

The sensory nature of the tunes and soundscapes produce an inclusive, immersive musical experience developed for everyone of all ages to enjoy together. The band travelled across London to the doorsteps and streets of families with young people labelled as having complex disabilities who are still shielding because of Covid-19 during September and October 2020. The tour was also a protest and advocacy tool to make sure those shielding are not invisible.

Doorstep Jamboree is the first project in Oily Cart's 'Uncancellable Programme', developed in response to the pandemic crisis. Over the next 18 months, Oily Cart will take work online, into homes and onto the streets to ensure they are serving their community throughout this difficult time.

The album is available to buy through CD Baby and digital distributors from 2 December For more information and an explanatory video go to: <https://oilycart.org.uk/shows/jamboree-the-album/>

Carnival: An exploration of chaos and calm

Natalya Martin was awarded the Boundless Accelerator Bursary in May 2019. She has been working on 'Carnival' since May 2019 and it is continuing to be developed over the next 2 years.

Set on a fictional island surrounded by a body of water, Carnival is an interactive installation that will creatively explore how mental health and emotional wellbeing, specifically anxiety, affects the lives of teenagers and young adults with complex needs, through spoken word, sound looping and colourful multi-sensory experiences.

In 2021, Natlya will be collaboratively working with teenagers and young adults, and their families directly from their homes to develop this project; with plans in summer 2021 to work in collaboration with young adults aged 19 - 25, and the life skills centre they attend for further development. The installation aims to not only be an exploration of anxiety and mental wellbeing, but also a vibrant celebration of our lives and our differences.

If anyone is interested to know more or get involved with this project, including young people and their families, or practitioners, please do get in touch. Natalya would love to hear from you: natalya.sensory@gmail.com
To stay up to date with the project visit www.natalyasensory.co.uk/carnival

Project report: understanding the who, where and what of learning disability liaison nurses

This report was completed by Gwen Moulster Consultancy for Health Education England (HEE). HEE commissioned it to:

- Support understanding about the current Learning Disability liaison nurse workforce.
- Inform the national strategy work around recruitment and retention.
- Identify what is needed to strengthen the acute liaison nurse's contribution to reducing unnecessary deaths and improving treatment for people with learning disabilities' in NHS services.

A short review of the literature was conducted to explore best practice in relation to the key areas identified as likely to increase risks of premature death among people with learning disabilities. Best practice guidance and effective team working were also reviewed. The report contains the results of an online survey of liaison nurses' experiences; a review of job descriptions and person specifications; focus groups with self-advocates, families and nurses; and semi-structured interviews with individual nurses.

The report concludes that more learning disability liaison nurses are needed to help stop people with learning disabilities dying prematurely. It notes that learning disability liaison nurses are valued by self-advocates and their families but that many don't know about learning disability liaison nurses and don't know how to get their help. It was also found that most learning disability liaison nurses have not had any further training and they often have to learn on the job.

The report's recommendations to HEE include:

- Create a new plan for Learning Disability liaison nurses that will help them move forward in their career.
- Create a 'Learning Disability liaison nurse' framework that will support them to do their job well.
- Think about the title 'Learning Disability liaison nurse' and change this to fit with the actual role of the nurse. Look at financing a plan to help Liaison teams get better and stronger.

The report is available at <https://www.hee.nhs.uk/>

Report: Valuing voices: Protecting rights through the pandemic and beyond

This report was posted on the NDTi (National Development Team for Inclusion) website in October. It expresses concerns of advocacy services that disabled people and care home residents have seen their human rights breached, and access to independent advocacy and health and social care cut, during the coronavirus pandemic. The report also recommends a series of actions, especially targeted at local authorities, that could prevent a repeat of these problems, as the second wave of coronavirus sweeps over much of the UK.

The report is the result of a survey of nearly 450 advocates carried out in June. Advocacy organisations across the UK, including NDTi, worked in partnership to run the survey. It commends the messages contained in the paper 'Advocacy Covid-19 and Beyond' issued in September by ADASS (Association of Directors of Adult Social Services).

The report by NDTi can be found on social media by searching #ValuingVoices. It is available online at: <https://www.ndti.org.uk/resources/publications/valuing-voices-protecting-rights-through-the-pandemic-and-beyond>

The ADASS report, which includes links to a 'mythbuster' from ADASS, is also available online at: https://www.adass.org.uk/media/8173/advocacy-during-covid-and-beyond_final_20200817-002.pdf

RESOURCES, ACTIVITIES AND INFORMATION

The 'PMLD Community' continues to face challenges created by Covid -19. In the Summer 2020 issue, the editors offered some direction to websites and social media platforms that share inspirational ideas, and offer information and advice. This following listing offers updated links. It is by no means exhaustive but illustrates the wonderful work that is going on during this difficult year.

Webinars, Podcasts and Covid information:

Sibs: The coronavirus outbreak is especially challenging for the brothers and sisters of disabled children and adults. Sibs is the only UK charity dedicated to representing the needs of the estimated half a million young siblings and 1.7 million adult siblings in the UK. For information about the impact of Covid-19 on siblings and advice for adult siblings and parents of younger siblings go to: <https://www.sibs.org.uk/coronavirus/>

Surviving through story: This group have offered a series of live and recorded training webinars, a growing body of real life 'stories from lockdown', valuable resources and practical advice on story- sharing. Facebook: Surviving through story; website: www.survivingthroughstory.com

Simple Stuff Works: A series of informative webinars offer clear and practical advice on postural care, for those caring for people at home. Go to: https://www.youtube.com/watch?v=ZV2_fUZNMkMo&list=PLx7Dyp1wZw_v90WLWexpbBGrp8SLhk_Ag

Other resources are available on the Simple Stuff Works website: <https://www.simplestuffworks.com/resources/>

Learning Disability England: The Coronavirus Hub is a source of information, webinars, resources and platforms for connecting people. <https://www.learningdisabilityengland.org.uk/what-we-do/keeping-informed-and-in-touch-during-coronavirus/>

Frozen Light: Podcasts and Sensory Resource Kits. A growing library of podcasts, created to stay in touch with

the PMLD community during the time of corona virus. Sensory Resource Kits of previous theatre performances to use at home, as an alternative offer to their live multisensory shows. <http://frozenlighttheatre.com/>

Bringing us Together offer legal clarification on the current situation for people with learning disabilities and their families through a series of webinars They are running 6 Zoom sessions for a project called Clarity - Capacity Law and Rights Information to You <https://bringingustogether.org.uk/>

Activity sessions, ideas and resources

Flo's Apps For Very Special People: Flo Longhorn has produced the fourth edition of 'Flo's apps for very special people.' This gives details of lots of tablet apps, including apps for Christmas. Her earlier lists of apps for May, June and September are still available. Flo reports that Edition 5 will be out in the New Year. If interested to access these lists, send Flo an email at : flopml@gmail.com Flo has very generously put all her multisensory education books on a website to download for free. Visit the link below to access them: <https://sites.google.com/view/flolonghornsensorybooksfreedow/home>

On the website Flo says: "I am happy for you to have my books and use them in your work or play with very special children and adults. Just remember that most were written many years ago when there was hardly any information or research around. What education there was, had to be led by a very inappropriate, subject based UK national curriculum. Some of the terminology/subject labels may be old fashioned but the philosophy and sensory dominance still remains constant as always...."

Story Massage Programme's Free Follow-Along

Message Stories: The combination of story with positive touch is fun, relaxing and fully inclusive for all children and adults with PMLD. And the whole family can join in too – so everyone enjoys the benefits. The Story Massage Programme provides regular free Live sessions and follow-along videos which are proving really popular in homes and schools. Mary Atkinson, co-founder of the programme, showcases a whole variety of topical sensory stories including those written by Gill White from PAMIS, Pete Wells from Sensory Stories Podcast and the team at Surviving Through Story. You can check out the free videos on their You Tube Channel and Vimeo Channel. And do look out for upcoming Facebook, You Tube and Instagram Lives too! If you would like to train in the programme there is a flexible online course. All the links are on the website: <https://www.storymassage.co.uk> or email info@storymassage.co.uk

Resonant Tails is an artwork, a console, a voice-machine, designed for young artists with PMLD. It is a touch

interface. It captures the voices of the people who use it, and it echoes them back in sound light, and vibration. People using it can hear themselves, and then become ever more playful with their sounds. A vocal art project has been completed with several special schools and a video describing the project, a sound library, and learning from the project are all available by following the buttons from: www.tractandtouch.com/resonant-tails/

Sensory Spectacle: Online DIY sensory activities available via Facebook: Sensory Spectacle. Their website and YouTube channel have an abundance of resources, videos and information. <https://www.sensoryspectacle.co.uk/>

Jensory Ideas: Engaging, interactive, sensory activities suitable for learners of every age. Jen Steptoe presented sessions throughout lockdown. Jensory offers a weekly video, with a monthly theme. These cover sensory and musical activities plus ideas for sensory boxes and valuable information on how to use specialist approaches and strategies to support the additional needs of people with PMLD. Facebook and Instagram: Jensory Ideas; YouTube channel: Jensory

Pamis: The Virtual Activity Programme developed by PAMIS has been designed to support the physical and emotional well-being of families at this difficult time. There is a series of 11 videos and accompanying booklets to offer support with sensory regulation. There are also guides and videos, full of ideas for creating multi-sensory stories, drama, arts and crafts, music, sports, dance and postural care. Go to: www.pamis.org.uk

Making SENse Creative: Caroline Hill provides various stimulating, sensory activities to encourage and support creative communication for adults with a range of disabilities. <https://www.facebook.com/sensorycreativeMakingSENse/>

Bag Books: Live and interactive sensory stories! Nina Martinez uses the wonderful Bag Books props to lead you through a host of interactive stories old and new, Access via Facebook and YouTube. Some free stories and DIY ideas on their website www.bagbooks.org

Collars & Cuffs Co: Collar & Cuffs Co is a sensory musical theatre company. Their Sensory Adventures in Lockdownland presents different projects undertaken in responding to the Covid-19 pandemic, including sensory stories plus Story Massages, accompanied by original songs and sound effects. Use is made of the very simplest of materials and equipment to ensure accessibility. Go to www.collarandcuffs.org/

Oily Cart: This long-established theatre company offer a range of resources from short films about how the company makes its shows, to sensory activities for home or at school. <https://oilycart.org.uk/resources/>

Soundabout: Soundabout is a charity that uses music and sound to unlock the potential of people with complex learning difficulties. Their Facebook page and YouTube channel offer a variety of activities each week. Hello Songs provide a singalong to start the day. Learn a new song each week - for people of all ages with PMLD and their families. Little Soundabout offers music-making sessions for children with PMLD in the early years (0-5.) Soundabout Live provides interactive music-making sessions people of all ages with PMLD and their families. Soundabout Life is relevant for young adults with PMLD (18-26.) For details about times with links to Facebook and YouTube go to: <https://www.soundabout.org.uk/autumn-winter-schedule/>

Big Top Musical Adventures CIC: This musical team offer a range of Interactive and engaging sessions. A selection of their sessions are available online at: <https://www.bigtopmusic.co.uk/inventory>

The Sensory Projects: In the Covid-19 resources area on this website Jo Grace provides links to a range of resources aimed at people with additional educational needs. She has vetted the resources to ensure all are free. The Sensory Projects also offers training options and free and purchasable resources. Go to: <http://www.thesensoryprojects.co.uk/covid19-resources>

Pete Wells Sensory Stories: This website provides links to Pete's special sensory stories for free and associated resources, his special stories podcast, tips for classroom practise and more! <https://sensorystoriespodcast.com/>

SENSE is the charity supporting everyone who is deafblind and people living and working with them. A series of Sense services are now also available online, to tackle loneliness and isolation, through the Sense Connect programme. <https://www.sense.org.uk/get-support/online-support/> SENSE has developed a series of toolkits for art, minigames and dance. <https://www.sense.org.uk/get-support/arts-sport-and-wellbeing> It also offers toolkits for play. <https://www.sense.org.uk/get-support/support-for-children/play-toolkits/>

National Development Team for Inclusion (NDTi): The NDTi has posted a range of resources to support the implementation of health checks for people with learning disabilities. The guides, which are short leaflets, include the following:

- A Guide to Health Checks - for Families, Supporters & Social Care Providers
- A Guide to Health Checks - For Commissioners, GPs

& Specialist Health Professionals

- Easy Read - Annual Health Checks: for young people with learning disabilities, their families and supporters
- Annual Health Checks & Coronavirus
- The NDTi has also made available 'A Comprehensive List of Resources' split into four sections as follows:
- Resources for people with learning disabilities and families,
- Resources for young people with learning disabilities and families
- Resources for social care providers
- Resources for commissioners, GPs and specialist health professionals

To view these and find out more, go to: <https://www.ndti.org.uk/resources/useful-tools/health-check-resources>

Archived Reasonable Adjustments Guidance for Health Services from IHaL: Improving Health and Lives (IHaL) was set up to provide high quality data and information about the health and healthcare of people with learning disabilities. The information aimed to help commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare. The IHaL website has now been archived and will no longer be updated. However, its resources continue to be available on the national archive. New information that is published by the learning disability team at Public Health England (PHE) will most likely be published on www.gov.uk and can be found by searching 'learning disability'. The results can be filtered, e.g. by selecting 'health and social care' in the 'topic' drop-down list.

EVENTS UPDATE

Inevitably, the people who offer training continue to face challenges created by Covid -19 and this means that we cannot publicise any events with any degree of certainty that they will occur as originally planned. Some are no longer running face-to-face or in-house training courses, but there are now some excellent online training opportunities available. Here is a list of regular and relevant providers together with their contact details. We suggest that you regularly visit their websites to see what may be on offer.

The Seashell Trust is a charity which is dedicated to providing a creative, happy and secure environment for children and young people with complex and severe learning disabilities which include little or no language abilities. <http://www.seashelltrust.org.uk/events/training-development>

Us in a Bus is a charity which offers practical workshops for individuals, groups and organisations about Intensive Interaction. usinabus.org.uk/events/training-dates

The Story Massage Programme combines the benefits of positive touch with the fun and creativity of words. The charity offers a range of courses. <https://www.storymassage.co.uk/training>

The Social Care Institute for Excellence (SCIE) aims to improve the lives of people of all ages by co-producing, sharing, and supporting the use of the best available knowledge and evidence about what works in practice. <https://www.scie.org.uk/training>

The Goldsmith Centre offers training courses relevant to people with complex disabilities; including postural care, specialist seating and sensory engagement. <https://thegoldsmithcentre.com/>

Simple Stuff Works also offers products and training designed to help people manage postural care and is associated with the Goldsmith Centre. <https://www.simplestuffworks.com>

Born at the Right Time offers a range of digital training provided by Rachel Wright. The training is aimed at practitioners who care for families of children/adults with complex needs. For more information email: training@bornattherighttime.com. <https://www.bornattherighttime.com/>

Posture Positive is a new project funded by NHS England and lead by Simple Stuff Works and Born at the Right Time. It seeks to imagine and develop excellence in

postural care for people with learning disabilities. For more information follow on Facebook a Posture Positive Collective, go to www.posturepositive.co.uk or email contact@posturepositive.co.uk.

The Intensive Interaction Institute is dedicated to providing training and a range of publications and videos from accredited trainers in Intensive Interaction 5th February and 12th March - Introduction to Intensive Interaction Taster Course : Half Day Online Workshop via Zoom
Details and application form: <https://www.intensiveinteraction.org/>

EQUALS is a charity committed to supporting the work of schools and parents/carers of pupils with with SLD/PMLD through provision of curriculum materials, guidance, workshops and conferences. <https://equals.co.uk>
There will be opportunities to join a selection of 'online training sessions' from 4-6 pm weekdays. For further information contact Paul Buskin at paul@equalsoffice.co.uk

Sensory Spectacle aims to create a better awareness and understanding of auditory, visual, tactile, smell, taste, proprioceptive and vestibular difficulties. It has created a range of online training courses from mini courses to full inset days. <https://www.sensoryspectacle.co.uk/>

The Sensory Projects seek to show how with the right knowledge and a little creativity people can use inexpensive items as effective sensory tools for inclusion. <http://www.thesensoryprojects.co.uk> To be notified when events go live pop an email to sensorystory@gmail.com

Concept Training is a group of experts who aim to provide training to help people to better understand those with special needs and learning disabilities. They are currently delivering their courses via live video conferencing <https://www.concept-training.co.uk>

Hirstwood Training has a team of consultants whose mission it is to share the best sensory approaches to breaking down barriers to learning for all learners. Aside from face to face training there are also online training packages and free taster courses. <https://online.hirstwood.com>

Together Matters helps in a number of ways including provision of training for support staff and/or managers on supporting people to have a good life as they get older including a set of resources they have developed published by Pavilion Publishing. <https://www.togethermatters.org.uk>

Learning Disability England (LDE) exists to make life better with people with learning disabilities and their families. LDE offers an effective and representative voice of people with learning disabilities. Its services include planned webinars, as well as archived webinars, for sharing information.

www.learningdisabilityengland.org.uk/?s=webinars

PAMIS is the Scottish charity supporting people with profound and multiple learning disabilities - their families, carers and professionals. PAMIS have adapted their learning and development resources so that they can be delivered online. For more information please contact Fiona Harper at PAMIS – f.k.harper@dundee.ac.uk. <http://pamis.org.uk/services/training/>

Rebound Therapy training has been offered by its originators for many years and is now offering face to face and online courses. <https://reboundtherapy.org/courses>

Institute of Imagination offers activities for children and young people, families, schools, adults and educators across London and online. <https://ioi.london/whats-on/>

The Enham Trust offers training in-house or online to enable people to deliver the MOVE programme of activity based practice that enables disabled children and young adults to gain independent movement. www.enhamtrust.org.uk/the-move-programme

PCPLD Network (palliative care for people with learning disabilities) are offering a monthly free webinar as well as making past webinars available as recordings. They also offer podcasts. <https://www.pcpld.org/events-and-conferences/>

Amber Ward teaches yoga to people with PMLD and their carers, via Zoom. Suitable for adults and young people with cerebral palsy, PMLD and other neurological and physical differences, who require 1 to 1 support from a carer. Yoga students and their carers are guided through a series of movements and breathing practices to help. For more info and bookings e-mail: ambertheward@hotmail.com and go to <https://www.facebook.com/Yoga-With-A-Difference-536908303486558/>

Disabled Living offer information about services for disabled individuals, older people, and those that support them. This includes advice about products and equipment, services that support those with bladder and bowel problems, providing sensory rooms, exhibitions across the UK (Kidz to Adultz Exhibitions), equipment solutions, training courses and an online shop. <https://www.kidzexhibitions.co.uk>

Storysharing is an approach to enabling individuals with PMLD to actively take part in sharing their own stories. You can find out more on the new website which has information, resources and upcoming events and training. Visit www.storysharing.org.uk for details about skill sharing webinars for 2021.

Personal stories and story massage

Personal stories and story massage workshop will focus on ways of combining the Story Massage Programme (www.storymassage.org.uk) and Storysharing®. Provisional date: 7 January, 2021, 4.30-5.30 on Zoom.

Sharing stories with signers who have learning disabilities

Sharing stories with signers who have learning disabilities Provisional date: 21 January, 2021, 4.30-5.30 on Zoom/

Online Sensory Story and Rhyme Sessions from Wigtown Book Festival

Until April the Wigtown Book Festival are delighted to announce that they will be releasing free monthly online Sensory Story and Rhyme sessions and accompanying downloadable scripts. Ailie Finlay (Storyteller for the project) says that these sessions will be suitable for children with complex additional needs and are designed so that they are easy to join in with from home or school. (Any sensory props used will be ordinary household objects!) To join in the fun go to: www.wigtownbookfestival.com/library/a-sensory-story

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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.
- Ann Fergusson** Annie has been the main advocate for her brother (with profound and multiple learning disabilities) for almost 20 years. Retired from a long career as a practitioner and university lecturer in the special education and learning disability field. She is a member of Advisory Groups for the national Learning Disabilities Mortality Review (LeDeR) programme and NHS England Seldom Heard Voices project and has a role as a family associate with Dimensions, a social care provider. Annie was one of the team who developed the PMLD Standards.
- Michael Fullerton** Michael is Director of Health & Wellbeing with Achieve Together, a social care provider supporting adults with profound and multiple learning disabilities. Michael is a registered learning disability nurse and leads a health team focused on the quality of life of people with profound and multiple learning disabilities. Michael was one of the team who developed the PMLD Standards.
- Martin Goodwin** Martin is a teacher of pupils with PMLD and a Regional Tutor/Visiting Lecturer for the Severe and Profound Multiple Learning Disabilities course at the University of Birmingham. Martin has specialised in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities. He has experience of working in the fields of play and leisure, education, residential and advocacy.
- Rachel Parry Hughes** Lecturer in Social Work, Goldsmiths, University of London. Rachel is a researcher in the field of profound and multiple learning disabilities.
- Becky Loney** Becky has supported people with profound and multiple learning disabilities and their families for almost 30 years. She currently works as an independent advocate, an involvement worker and a LeDeR Reviewer for the Learning Disability Mortality Review and uses creative communication approaches and sensory storytelling throughout her different roles. Becky is a member of the Advisory Group for the NHS England Seldom Heard Voices project.
- Wendy Newby** Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties .
- Maureen Phillip** Maureen is the Senior Family Support and Development Director for the Scottish charity PAMIS (promoting a more inclusive society). This wide and varied position means she works in partnership with people with profound and multiple learning disabilities to support communities to recognise that people with profound and multiple learning disabilities are the best educators, as they teach us what it is to be human.
- Sue Thurman** Sue worked for many years in the NHS as a Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. She now spends most of her time as a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts. Sue is also a governor at a local special school.
- Bella Travis** Now a policy manager at Mencap, Bella was part of Mencap's former national PMLD Team. She was involved in campaigns and developing key publications and resources including the 'Raising Our Sights' How-to guide series. More recently she worked with Ann Fergusson on a joint-produced hospital resource for people with profound and multiple learning disabilities. Bella helped co-produce the PMLD Standards.

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sharing ideas and information

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

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Vol 32 No 3. Issue 97

ISSN 2042-5619