PMLD LINK
sharing ideas and information

Health Matters

Winter 2016

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

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Our heartfelt thanks to Sue Turner for accepting the invitation to work with us as a Guest Editor for this edition. We believe this ‘Health Matters’ issue offers an important and very significant contribution to the PMLD field as a result of our collaboration.

GUEST EDITORIAL

Health Matters

Being healthy makes it is easier for us to live life to the full, spend time with our friends and families and enjoy our work and our leisure time. However we know that people with learning disabilities have less good health than their non-disabled peers, and that this has a significant impact on quality of life and life expectancy. Our first article by Paul Pargeter from Dimensions sets the scene and gives a broad overview of health issues for people with learning disabilities. For people with PMLD the impact is even more profound. Avoidable differences in health status are called health inequalities, and they are unjust and unfair. Therefore it is crucial that people supporting those with PMLD understand and act on the particular health issues that people with PMLD experience. Health checks are an important general reasonable adjustment of benefit to people with PMLD. The thought provoking article by Dominic Slowie and Crispin Hebron focuses on this issue, and includes some important questions to ask.

Many people with PMLD experience detrimental changes to body shape, and thus the call for a national approach to postural care launched at the Changing our Lives ‘Got My Back’ conference in September is very important We are pleased that this issue includes articles relating to the presentations on the day from Janet Robertson and colleagues regarding research and postural care, and an article about improving postural care in Lanarkshire from Michelle Morrison and colleagues. In addition there are some great practical tips about getting a good wheelchair assessment from Helen Daley, some imaginative ideas about bringing postural care together with learning in the classroom from Martin Goodwin, and a lovely example of a sensory story from Peter Wells. Scotland are doing some great work on postural care and it is good to have an update about their overall approach to people with PMLD from Angela Henderson, as well as an update from Laurence Taggart in Northern Ireland focused particularly on health checks.

With regard to specific health problems, CIPOLD noted that ‘deaths related to the nervous system, congenital and chromosomal abnormalities and the respiratory system were all more likely to be avoided by good-quality healthcare interventions’. Therefore the article on respiratory care by David Stanley is of particular importance. We also know that people with learning disabilities die of constipation, so it is great to know about work in the central Midlands from Louisa Whait. Finally, there is a very helpful article from Lisa Donaldson at SeeAbility.

The way in which services are organised and delivered has a huge impact on people with PMLD. The article by Sadie Clarke and Rebecca Crossley uses case studies to explore the impact acute liaison nurses can have when people with PMLD are in hospital. It is also good to hear from Debbi Cook about the Southern Derbyshire PMLD service and the difference it is making to the lives of people with PMLD. Being able to measure the difference services make can be difficult, so the case study from Elaine Thomas and Gwen Moulster illustrating how the Health Equality Framework has been used with someone who has PMLD, demonstrating improved outcomes is very timely. Personal Health Budgets can lead to better outcomes for people with PMLD, so we are grateful for the article from Independent Lives, which describes how these are working in West Sussex, Hampshire and Portsmouth. Finally, there is a really practical article about how to help people with PMLD manage anxiety by Clive Smith.

In summary, this issue contains lots of helpful articles on health and people with PMLD. We hope there is something in here for everyone to take away and put into practice, improving the health, and therefore the lives of people with PMLD.

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Standing up to Health Inequalities
A provider's response

Paul Pargeter

We are continually and justly advised to invest in our health. It is, more or less, unarguably good advice and some of the more eye-catching headlines aim to inspire us to stay focused on ourselves for our own sake. “Your body is your most priceless possession”, “Love yourself enough to be healthy” and “Take care of your body, it’s the only place you have to live in”.

They’re designed as a wake-up call - you lose your health; you lose everything else with it. I’m no health or fitness fanatic (I enjoy the odd slice of a Victoria sandwich, for sure), but I get it. I get that health is all important. It’s important because it is central to my happiness and wellbeing – from good health everything else can flow! So, why the difference? “What difference?” you say. Well, why is it, if it’s so important, that people with learning disabilities have poorer health than their non-disabled peers, a difference in health status that is, to an extent, avoidable?

In 2010, mortality rates among people with moderate to severe learning disabilities were reported as being three times higher than in the general population. Another statistic from that year is that one in seven adults with learning disabilities rated their health as "not good", backed up by high levels of unmet physical and mental health needs revealed by health screening. The Department of Health have continuously emphasised that NHS trusts must play a central role in meeting the health needs of people with learning disabilities, which is right. It is also right that we must all play our part and as someone that works for a support provider I believe we can play an important one.

Last year we completed our most comprehensive health survey of people we support. Topics covered, among other things, a variety of check-ups, nutrition, exercise and access to health care. Results provided yet more evidence that, although improvements are being made, meeting the health needs of people with learning disabilities has to improve on all levels.

One of the outstanding elements of this is the need to support people with regular health checks by accessing health centres and practices and…demanding a gold-plated service every time. Keeping on top of our health is really important; this is even more important for people we support as many are unable, at least easily, to directly tell us when they are feeling unwell or in any pain. Family and friends are crucial partners here as they usually know their relative or friend well enough to recognise the signs of ill health. Families are, more often than not, the support provider's heroes; equipping us with the invaluable detail and guidance that is needed to support a person with all aspects of their life. This partnership, alongside creative and personalised communication, helps all involved to keep informed and understand how every person stays healthy.

This should not be an exclusive approach to physical health though, as mental health and general wellbeing are closely connected. Research has shown that challenging behaviours (being aggressive, destructive, self-injurying and so on) in some instances result from pain or discomfort associated with untreated medical disorders. In which case they are probably more appropriately termed as coping behaviours, but I won't get into all of that just now.

In Dimensions we have the largest Behaviour Support Team of any other equivalent provider and their work has provided stark evidence that health can be a contributing factor to behaviour and mental wellbeing. In 2016, analysis of data that describes the settings and events that trigger challenging behaviour for people with profound and multiple learning disabilities found that the environmental variable that eclipsed all others was physical illness. It seems that health is being overlooked as a factor in causing challenging behaviour and that treatable conditions as well as ineffective pain management may be managed better with medical professional input or more effective support. In short, if we support people to stay healthy then they are more likely to be happy. Obvious, I know, but worth stating nonetheless.

Our role as a support provider is influential to the extent that we can help people access health professionals more regularly and consider helpful interventions to help with, for example, someone feeling more comfortable in the dentists' or going for a blood test. Moreover, we are often very present in people's lives so we can keep a constant eye on someone's health as we are supporting them in their day-to-day life. Even though we are not trained health professionals, we are supporters and advocates which makes us an enabler for better health. Together with families, friends and health professionals we have a duty and opportunity to improve the situation for people with learning disabilities. We can help people invest in their own health and feel the reward of treating your body as your most priceless possession.

Over the last 2 years Dimensions has been preparing to implement a research-based support model called Activate. In trials, Activate has produced very positive results in increasing the realisation of goals and outcomes of people we support, and significantly reducing levels of challenging behaviour. At its core, Activate has 8 quality of life domains and together they cover all aspects of a person's life. Health, quite rightly, is a domain in its own right and its use has demonstrated that if there is a focus on health-specific goals alongside clearly defined steps, people we support have a significantly better chance of staying healthy. Bringing together systematic ways to define, develop, track, and illustrate progress for people we support, families and support teams is what Activate brings. The goal? A happy, full and healthy life! Dimensions aims to implement Activate in full in 2017, so watch this space for further reports on progress.

Responding appropriately to the health inequalities faced by people with learning disabilities demands action on all fronts and support providers can help in a number of ways by:

- Improving the early identification of ill-health among people with learning disabilities by, for example, informing people of and supporting them to go to annual health checks, and cervical and breast screening.
- Helping people to communicate their health issues as well as helping them understand the importance of health and the availability of health care. Providers play a critical role in promoting healthy lifestyles among many people with learning disabilities.
- Revisiting how we interpret the Mental Capacity Act 2005. We must make reasonable adjustments so that people are guaranteed opportunities for life-style saving treatments.

Finally, we need to be strong advocates and monitor the progress towards the eradication of health inequalities faced by people with learning disabilities. The gold standards we demand for ourselves must be applied for those we support and if they are seen to drop we are well placed to say so.

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REPORT BACK

Got My Back!

On the 12th September *Changing Our Lives* held the *Got My Back* conference on postural care in Birmingham. Briefly, postural care is a way of working with people whose body shape has or is in danger of becoming distorted, to stop, limit or slow these changes. Body shape distortion can happen to anyone who has problems moving, and is an important issue for people with profound and multiple learning disabilities. Body shape distortion can lead to lots of health problems for the person including pain, respiratory problems, difficulties with eating, drinking, digestion and constipation. These problems can have a profound effect on a person's quality of life and can result in early death. Postural care helps people to maintain a better posture during the day and at night, so it includes how people sleep and how they sit. Early intervention with children who have problems moving is very important – but postural care with adults can also be very effective.

At the conference we heard about lots of examples of how postural care is working for people. The work in Scotland led by PAMIS is particularly notable as Scotland have signed up to a national strategy and pathway for postural care across Scotland, with family carers central to the development and rollout of the strategy. The work is funded by the Scottish government through The *Keys to Life Learning Disability Strategy.* Unfortunately, although there are some places providing good support with postural care in England, in most areas there is no support. This needs to change. Although there isn't good research evidence about postural care (because the research has not been done), there was more than enough evidence at the conference that postural care makes a positive difference, and thus reduces the health inequalities people with learning disabilities experience, something public services have a duty to address.

The conference called for a national approach to postural care, and David Harling, Learning Disability Lead in the Nursing Directorate for NHS Improvement, who spoke at the conference expressed his commitment to support a postural care strategy for England. *Changing Our Lives* will be bringing together key people in a national group to help take this work forward.

Further information about the conference including a report and all presentations are available here: http://www.changingourlives.org/got-my-back/

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Raising our sights, combating nihilism to improve outcomes for people with profound and multiple learning disabilities (PMLD)

Dominic Slowie and Crispin Hebron

People with learning disabilities have poorer health than the general population and the explanation for this is not necessarily straight forward or simple.

Some people have specific disabilities that are associated with physical or mental health problems, so they start out in life with additional needs for example epilepsy or heart problems. We also know that some disabilities are associated with a higher risk of certain diseases. Those people with Down's Syndrome for example have higher risks for developing thyroid gland problems, certain leukaemias and dementia, though most will not. However, and this is really important, most people with a learning disability, even profound and multiple learning disabilities (PMLD), should have expectations to be healthy. Perhaps even more importantly is that those of us who work as health professionals should also have expectations of good health for our patients with PMLD. So why are we saying this? Well arguably the biggest problem leading to poor health for people with learning disability is that many of us see a person’s disability as a disease….what has been termed a ‘medical model of disability’ and we therefore have low expectations of good health for people with PMLD. We create a self-fulfilling prophecy based on our low expectations and aspirations on behalf of those we may know or care for. We as a society, whilst noting the heroic efforts of many inspiring carers and clinicians, perhaps tell ourselves that not a lot can be done so limit our aspiration....'What's the point?'......nihilism! If we do nothing else in this article we would like to create some high aspiration for good health in people themselves, their family carers and health professionals.......because we know outcomes can be much better once this aspiration is in place.

We believe that the health inequalities that we are starting to understand in much more detail are preventable and unjust. And people with profound and multiple learning disability suffer more injustice through poorer health outcomes than the rest of the population with learning disability. It is often far harder for people with PMLD to communicate their symptoms and needs and it may be far more challenging for clinicians to elicit symptoms and signs of disease or perform relevant investigations to make a diagnosis.

In England, the Improving Health and Lives Learning Disabilities Observatory (IHaL) was set up in 2010 ; a similar observatory has subsequently been commissioned by the Scottish Government. An important element of the work of the observatory is to bring together the available evidence of the health and wellbeing of the population of people with learning disabilities, including information on inequalities.

There is evidence of increased rates of many serious health problems among people with learning disabilities provided by IHaL; regular health screenings (including the current Annual Health Check scheme in England) typically reveal high levels of unmet needs. There is evidence of increased rates of:

- Obesity
- Diabetes
- Sensory impairments (e.g. Vision and Hearing problems)
- Musculoskeletal impairments
- Epilepsy
- Poor uptake of national cancer screening programmes
- Sleep disorders
- Mental health problems (along with inappropriate and over prescribing of anti-psychotic medications)
- Difficulties eating, drinking and swallowing (dysphagia) are common and increase the risk of recurrent respiratory infections. This can also lead to poor nutrition.
- Respiratory disease
- Poor uptake of immunisations, including influenza
- Poor oral health
- Gastrointestinal problems, including cancers are proportionally higher amongst people with learning disabilities. There is high prevalence of constipation, gastro-oesophageal reflux and Helicobacter pylori, a bacterial infection associated with indigestion symptoms, stomach ulcers and some gastrointestinal cancers.

- People with learning disabilities are at increased risk of chronic pain conditions, which can be difficult for carers to recognise.

NHS England has commissioned the provision of specific learning disability data from GP information systems (known as the GP extraction system, or GPES), this data is to be analysed by Public Health England through IHaL with the first set of data due for publication in December this year. This data has the potential to provide even greater insight into the current health status of the learning disabled population.

To add to the issues of increased risks and low expectations, people with learning disabilities are more likely to be exposed to adversities such as poverty, poor housing, unemployment and social isolation. In 2010 the Marmot Review reported on evidence of the relationships between health and wider social and economic conditions, and noted the importance of national policy in achieving health improvements:

> *The causes of health inequality are complex but they do not arise by chance. The social, economic and environmental conditions in which we live strongly influence health. These conditions are known as the social determinants of health, and are largely the results of public policy.* (Marmot, 2010 pp.85-91)

Whilst there is little doubt that better participation in society, better housing and more employment opportunities will have a positive impact on health for people with all levels of learning disability we are pleased that Sir Michael Marmot and his team are now working with us to build on the work of Professors Gyles Glover and Eric Emmerson to more fully understand how these social determinants impact of the lives of people with a learning disability. The team will also look to see if there are societies who address these negative impacts more successfully so that we can determine approaches that will deliver positive results.

The Health Equalities (HEF) was published by the UK Learning Disability Consultant Nurse Consultant Network in 2013. The HEF provides a series of graphs that indicate how high or low the likely impact of each of the determinants of health inequality is for both individuals and populations in various situations. This free and easy to use tool has already been used extensively by commissioners and providers of care to map risk for individuals and within populations in such a way that the determinants of good health can be addressed in a timely and strategic manner to improve the likelihood of health equality.

So what else can be done to ensure that people with Profound and Multiple Learning Disabiliites have much better health outcomes and that we all start to share higher aspirations?

Firstly we need to share evidence of good clinical or social practice that is making a difference. This will challenge our assumptions of what is and is not possible to aspire to.

Over a number of years in Wakefield Physiotherapists and Orthopaedic Surgeons working together, have developed a joint early intervention approach, using a variety of preventative and interventionist therapies, that has led to the elimination of hip dislocation in children with cerebral palsy, some of whom will have profound learning disability. If they had not believed radical change was possible they may not have even tried. How many more examples are there of ambitious clinicians challenging assumptions and delivering change as significant and important as this? Let's hear about them.

Many NHS organisations have now pledged to employ and are successfully employing people with all levels of learning disability http://www.nhsemployers.org/your-workforce/plan/building-a-diverse-workforce/need-to-know/creating-a-diverse-workforce-learning-disability as part of the NHS Learning Disability employment strategy. This has had positive impact for both the individuals and the organisations. 60% of people with a learning disability would like to have paid employment. Only 6% do. Do we assume that by definition those with PMLD will not be able to work? Do we need to reconsider the sorts of work that people could do with the right support?

In day to day clinical practice we need to recognise that even small reasonable adjustments to how we deliver care make large differences e.g. allowing more time for an appointment. There are a number of prompts and reminders given to services on how to do this and IHAL maintains a database of Reasonable Adjustments with tools and support documents should there be a need to see if someone has solved a particular problems already. All hospital trusts should have a learning disability liaison nurses who is usually a fantastic resource to enable reasonable adjustments to be planned and delivered. If your Trust does not have one perhaps you should be asking your Trust Board directly why not, given that reducing health inequalities for people with a learning disability is one of only a limited number of priorities for the NHS at present.

For an individual with Profound and Multiple Learning Disability there are some things that should happen regularly and which they and their professional or family carers should expect and demand:

- A thorough annual health check that involves a GP at some point and addresses all of the following points:
- An offer to have relevant details shared through an 'Enriched Summary Care Record' that will then be accessible to all health professionals in hospitals or walk in centres containing relevant details specific to learning disability.
- A record of Body Mass Index with an action plan and follow up for anybody who is obeseor underweight…including screening for diabetes (There is 50% more morbid obesity in people with a learning disability). If people who are not choosing their own food are obese or underweight, such as many with PMLD, we need to be asking who is responsible for their nutrition and working with them).
- A record of blood pressure with action to address abnormal results
- A review of sensory impairments and oral/dental health care.
- A review of gastrostomy or tracheostomy functioning/management.
- Flu immunisation with nasal vaccine being used if needle vaccine cannot be used.
- Epilepsy review if indicated with seizure freedom being the aim and involvement of exhaust all therapy options to try and achieve this.
- Postural assessment and intervention. Poor posture can affect breathing, nutrition, rates of infection, pressure sores, mobility and quality of life. Sleep systems and surgical intervention can make a difference for some people so we need to keep challenging.
- A review of whether screening for the national screening programmes has happened and if not why not. Perhaps a reasonable adjustment is needed and services are prepared to make these adjustments if they know what the specific need is.
- Memory and mental health screening for particular problems.
- Review of social circumstances: support, friends, family, purposeful activity and enjoyment of life, living accommodation and choice over this and carers.
- Medication review asking is each of the medications being prescribed helping. What is it being prescribed for and if it is not clear would there be value in a trial of withdrawing the medication? This is particularly relevant for psychotropic medication which may have been started many years ago by specialists and perhaps not subsequently reviewed.

The enhanced service, whereby GPs are paid an additional sum for doing a health check, is offered to people with a learning disability from the age of 14. NHS Choices now carries information about whether your GP offers this service (and most do). If they don't, perhaps you should consider swapping to another GP. It is also the responsibility of professional carers to make sure those they care for are offered this check. So, again it is a legitimate question to ask of professional carers…."When is ……… due to have their annual health check at the GPs or is the GP going to visit to do it?" Remember that there should be a shared action plan for any priority health issues identified with agreed follow up arrangements (sometimes called a Health Action Plan)

Nationally we are developing a standardised template to be used during the check so that we can expect all the above, and more, to be offered as relevant to all people with PMLD.

Finally if you are with somebody who has PMLD as you are reading this, or the next time you meet somebody, we would ask you to try and see them with new eyes. Ask yourself whether you think they look healthy and whether you would accept the levels of health that you see them experiencing? If you wouldn't, then it is down to you to start challenging the health aspirations that everybody around that person might have, remembering small changes can make big differences. We hope some of the initiatives and information above can help.

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Postural care
What the research does (and doesn't) tell us

Janet Robertson, Chris Hatton, Susie Baines and Eric Emerson

For people with profound and multiple learning difficulties (PMLD), poor body positioning can have severe and life threatening consequences (Crawford & Stinson, 2015). There are some great examples of postural care services around the country, but they are a long way from being routinely available to everyone with PMLD who needs them (National Institute for Health and Care Excellence, 2012). When making the case for more postural care services, it is important to present an evidence-based argument. But what does the published research tell us about postural care for children and adults with PMLD?

As part of our work in the Public Health England Learning Disabilities Observatory (also known as IHaL), we did a systematic scoping review of the research evidence specifically relating to postural care and people with PMLD. We wanted to know both what the research evidence said, but also what the gaps were in the published research evidence (bearing in mind that published research can often lag behind what's happening in practice). We searched 4 electronic databases for research papers published in academic journals between January 1990 and March 2016, and sent out requests for people to tell us about newly published research papers we might not know about.

From a starting point of 1,062 possible research papers, we eventually identified only 25 research papers reporting on 23 different research projects relevant to postural care and people with PMLD. 16 of these studies reported research from the USA or UK, and the research projects typically involved small numbers of people (none of the projects involved more than 100 people). The projects used a wide range of research methods, none of them used research designs such as randomised controlled trials that are highly rated in general hierarchies of what counts as good evidence in healthcare.

To help us make sense of the research papers, we grouped them into three themes: who needs postural care? (4 studies); postural care interventions with people with PMLD (17 studies); and issues related to the provision of postural care services for people with PMLD (3 studies). In this article we're not going to reference all the research papers we discuss, but you can get a full copy of our review paper by emailing us at j.m.robertson@lancaster.ac.uk . We are also very close to publishing a Public Health England factsheet summarising the scoping review.

We found 4 research projects related to the theme of who needs postural care, although none of them tried to estimate how many people with PMLD would be likely to need postural care. Two projects (with 55 and 99 people) reported on the percentage of people with PMLD in their groups with a range of conditions, most commonly scoliosis (56%-62%), contractures (32%-42%) and dislocation of hips (24%-39%).

We found 17 research projects related to the theme of postural care interventions, although they covered a very wide range of types of intervention. Three research projects (involving 13 – 70 people in each project) concerned surgical interventions with children, mainly relating to scoliosis. Results were very mixed and there were often complications as a result of the surgery, although all the authors stated that surgery was better done earlier rather than later. Three research projects (involving 7 people in total) investigated behavioural approaches, where people who maintained a therapeutic head or body posture for longer gained a rewarding stimulus, which did generally result in people holding these postures for longer. Seven research projects (involving 4 – 30 people in each project) involved using a wide range of equipment with children and adults, including safety harnesses, varieties of standers, spinal braces and individually fitted seating systems. Overall, if the equipment was properly fitted and tailored to the person's requirements there, were a range of positive outcomes. However, professionals were less attuned than families to how practical the equipment was to use on a daily basis, and whether the person with PMLD needed periods of relaxation without the equipment. Finally, three research projects (involving 16 people in total) investigated how people were positioned (for example sidelying or sitting in a wheelchair). It seems that different positions can have an impact on things like oxygen saturation and communication, but the effect varies widely from person to person.

The third overall theme we identified was related to service-related issues concerning postural care with people with PMLD, where we found three research projects involving between 11 and 61 people per project. These projects gained the views of a wide range of professionals about postural care. Overall, there was less than optimal awareness of postural care issues and postural care services among a wide range of professionals, including teachers, short break/respite carers, and members of multi-disciplinary teams. Professional awareness of postural care issues did improve with training. However, professionals identified some quite serious practical barriers to providing good postural care in a range of places where children and adults with PMLD spend a lot of time, such as schools.

So, what does the research tell us about postural care and people with PMLD? Overall, not a huge amount, particularly in terms of the kinds of evidence that health service commissioners would pay attention to. This systematic scoping review has identified some urgent gaps in the evidence base, including:

- How many people with PMLD need what kinds of postural care?
- What kinds of postural care work well for which people (and for their families and professionals too)?
- How is postural care best provided and organised so people get good postural care?
- How can families and professional carers be supported to provide good postural care?
- What happens when postural care is provided early to prevent/minimise later problems?

The important innovations in postural care that are happening in some places with people with PMLD are generally not (yet) in the academic literature. Families, practitioners and researchers have a great opportunity to work together to generate research evidence that will have a direct impact on the lives of people with PMLD.

Janet Robertson, Chris Hatton, Susie Baines and Eric Emerson, with thanks to Sarah Clayton and Liz Goldsmith, Lancaster University and the Public Health England Learning Disabilities Observatory

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Working together to improve 24 hour postural care within NHS Lanarkshire

Michelle Morrison, Lynn Frew, Clare Boslem, Kate Jordan
and Diane Sloan

Many people with profound and multiple learning disabilities (PMLD) experience a detrimental change of body shape. This is due to a number of factors including immobility and gravity. However, good postural care can help to minimise, stop or restore body shape when everyone working with the individual has the same knowledge base. Within Lanarkshire, PAMIS, a Scottish charity supporting people with PMLD and their family carers, has been working co-productively with family carers and healthcare professionals from NHS Lanarkshire to increase knowledge on how to recognise what can cause body shape to change and how to implement good postural care alongside contributing to Community Learning Disability Physiotherapy Service postural management documentation.

Why is knowing about body shape important?

Postural Care is effective positioning to ensure good posture in all positions throughout the day and night. This is important, as children with neurological impairments, such as cerebral palsy, move in less symmetrical movement patterns due to altered tone and muscle weakness. This puts them at risk of developing postural problems (Sato et al, 2014), including:

- Hip dislocation
- Spinal scoliosis
- Joint contractures
- Functional limitations
- Pain

In addition to the above, the risk of developing other related health problems also increases, including:

- Respiratory problems and chest infections
- Digestive problems
- Circulatory and pressure problems

Repeated asymmetrical postures can become fixed unless corrected/supported. Asymmetrical postures and associated health risks can and should be prevented with effective postural care (Castle & Soundy, 2014; Hill and Goldsmith, 2010; Pountney et al, 2009 Pountney et al, 2002; Pountney et al, 2002).

Where it all began

After receiving a two day workshop on postural care from Postural Care Skills UK, attendees from Lanarkshire felt passionate about developing local information for other carers and people supporting someone with vulnerable body shape.

My family have been involved with PAMIS for many years, as our daughter is profoundly disabled with multiple health issues and severe learning difficulties. PAMIS had mentioned that there was a training opportunity coming up regarding postural management, *a two day workshop with Postural Care Skills UK. I agreed to attend as I had been to various other workshops and had found them useful, and at this time my daughter was experiencing high levels of pain and we had spent the previous twelve months adjusting pain medication to improve her quality of life. But to be honest I didn't think I would get much out of it as I had been involved with physiotherapy since my daughter was six months old (she was by this time seventeen) and thought I had a very good knowledge about body shape and being proactive in keeping my daughter's body as healthy as possible - I couldn't have been more wrong! I left the first day with a mixture of emotions - I was angry, upset and frustrated that I had never been given this information before but it also made me passionate about carrying out postural care for my daughter and also passing this valuable information and knowledge on to all parents and carers.*

I, alongside a group of parents, felt so passionate about the lack of this information that we decided, with the help and support of PAMIS, to get this information out not only for parents but for carers and anyone who works with a person with PMLD. (Kate – family carer and postural care champion)

As *Postural Care - Craig's consensus for a mainstream future* (Simple stuff Work, *2009)* reminds us, "The straightforward concepts, skills and associated issues related to protecting body shape are not intuitive." There was a need to ensure families had as much information as possible on body shape and this led to PAMIS applying for abd successfully receiving funding from NHS Lanarkshire Carers Information Strategy, for a 2 year period.

At this time, NHS Lanarkshire Community Learning Disability Physiotherapy service was reshaping their postural management protocol as they had no formal Postural Care Pathway, no standardised Postural Care Plans and no standardised Postural Care training for parents and carers. In developing these documents, the physiotherapists hoped to:

- Identify those at risk of developing hip dislocation, contractures and scoliosis,
- Provide a structured approach to postural management for those at risk,
- Ensure equitable and effective postural management for every child and adult in Lanarkshire,
- Improve awareness of postural management risks and the importance of implementing postural management plans with parents/carers,
- Improve postural management transition from child to adult services.

The Carers' aims were to:

- share their knowledge with other carers
- provide better information for carers
- ensure the opportunity to attend standardised training was given to other carers
- help families provide good postural care, in turn, improving body shape
- be recognised as an equal partner in the care of the person with PMLD

During this time, PAMIS supported partnership working between family carers and specialist Allied Health Professionals (AHPs) within NHS Lanarkshire to create information resources and contribute to developments within the physiotherapy service for people with PMLD.

What we have done

In creating information and physiotherapy documentation, it was important to ensure carers were at the heart of creating information and physiotherapy documentation. They felt that an information booklet and DVD would be the best way to get information into the family home and would be a good tool for AHPs to begin talking to families about body shape and postural care.

1. The first step was the development of the Postural Care planning group in 2013, which involved physiotherapists and an occupational therapist, with close collaboration with parents/carers and PAMIS throughout.

Before information resources could be designed, it was important to hold honest and open conversations. This included the importance of families receiving full information on body shape, including why equipment or exercises were important and the consequences of not doing them. Carers said that if they were given all the information, they could be in control of what they did with it, even if this meant that they might get upset or angry if the news was not what they had expected to hear. Carers recognised that AHPs might feel that their messages weren't being listened to but that it was important for families to be regularly reminded about body shape, especially in the early years while they are trying to manage life with their child. Families may not hear what is being said, as life often gets in the way, and postural care may not seem important. Not knowing that some of the things they were doing at home, such as loosening wheelchair straps, was detrimental to body shape left carers feeling guilty and, angry, and and that they had let their child down. The person being cared for spends at least 60% of their day at home with carers, they are the main providers of all aspects of care and, crucially, the main potential implementer of good postural care. Carers can only be in control if they have the full knowledge of what causes body shape to change, what this looks like and how it could be minimized or prevented. Can carers be in control. It is therefore essential to work co-productively with families and also crucially as a multi-disciplinary team ensuring the family isn't receiving conflicting messages.

2. A Postural Care Pathway and Checklist was developed, which provided guidance and documentation of specific postural care needs of each individual client.

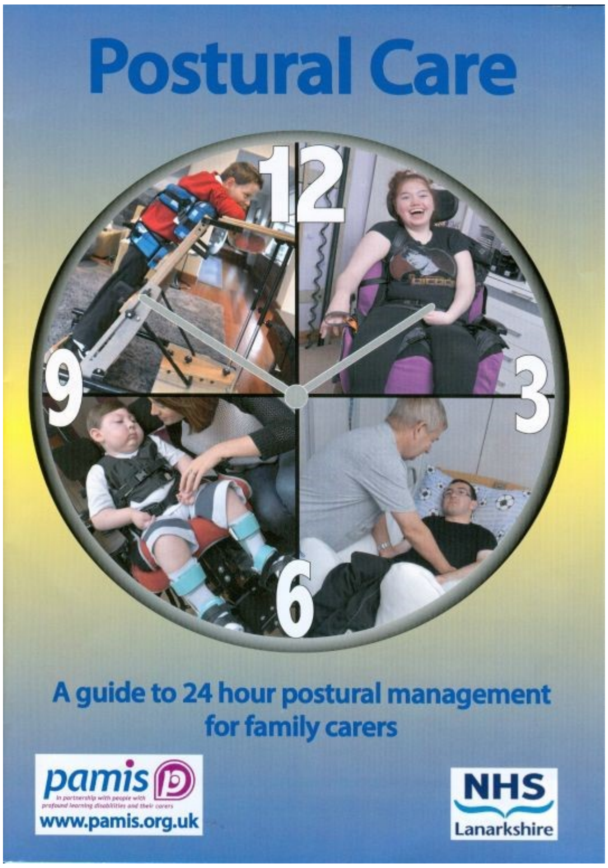
3. A Postural Care booklet was developed in 2014 to provide information and advice to parents and carers in Lanarkshire.

"We decided that the most effective medium for getting information out to families would be a booklet outlining the principles of postural care and various family stories in their own words with lots of photos to illustrate good and poor posture. We worked closely with physiotherapists and occupational therapists with Michelle from PAMIS chairing all the meetings and coordinating everyone's schedule - no small task! And although it took the best part of two years to finally publish the booklet we are very proud of the finished project and have had a lot of positive feedback from parents, carers and professionals." (Kate)

4. Standardised 24 Hour Postural Care Plans were developed in 2015 to formally document each client's postural care recommendations, and provide these recommendations to parents and carers.

5. Postural Care Training was developed by the Learning Disability Physiotherapy Service in 2016, and will be piloted in the near future before being delivered across Lanarkshire in 2017.

6. Postural Care Film recently released. This was a collaborative tool produced by PAMIS with NHS Lanarkshire AHPs and carers involved in every aspect of its creation.



"We decided that a DVD would be a valuable and accessible tool in spreading the information regarding postural care and we once again set out on a long journey with the same people who were all passionate about postural care. We applied for more funding and once we received this we hired a production company, August Pictures, and set about recording the DVD. It was very important that we as parents had a lot of input into the content and tone of the DVD, so as before we had many meetings with the allied health professionals and with the help, support and encouragement from Michelle we have managed to produce a DVD which we are all very proud of and more importantly we know will help other parents and carers in their daily lives and also provide a learning tool for health professionals and workers in the care sector." (Kate)

Influencing others

NHS Lanarkshire specialist AHPs who have been working on the creation of new documentation and information resources have been pivotal in sharing their knowledge with carers, reaching out to many people who may not have understood or heard the postural care message before.

PAMIS has been supporting carers to share their knowledge too and has helped a number of carers become Postural Care Champions. These carers have been speaking to families, professionals and addressed conferences telling people about their own experiences and how they have implemented postural care at home.

The benefits of implementing good postural care

There are many benefits that both carers and AHPs have cited when good postural care is implemented. It has a beneficial impact on the individual as they are in less pain, and better being in less pain, being able to engage with others and their environment. It helps, aid with issues around surrounding eating and drinking, digestion and good bowel health, and create reduced risk of reflux and aspiration. It can make it easier to get out of the house as; the person may tolerate sitting in their wheelchair for longer periods, and can enable them to have their personal care needs met more easily reducing their risk of exposure to social isolation. It also plays a large part in the person being included. Posture is vital in helping people take part in activities, particularly if they have difficulty with their motor skills. If the person is being well supported there is increased opportunity for functional use of their hands as well as maintaining upper body and head control which can allow them to play with a toy or communicate more effectively.

"Since implementing postural care we've been able to claim back some of our life. Kara is happy and relaxed a lot of the time. She has fewer interruptions during the night due to discomfort or pain. She hasn't had to have a change to any pain medication in the last 2 ½ years – she's not in pain now. She wakes up with a great big smile in the morning. Good postural care has improved her life immeasurably. I truly believe that by implementing postural care over twenty four hours I have improved her quality of life, reduced her pain and improved her respiratory condition considerably". (Kate)

"It can be really hard to deal with the diagnosis of your child but there is still a need to know about the importance of good postural care." (Claire – family carer)

"My sleep system keeps me in a good and comfortable position at night. It stops my legs from windsweeping and helps me to lie straight. When I'm in a good position I don't have any pain and this makes me have a more comfortable night's sleep." (Ross – young person with learning disabilities)

"In implementing postural care we're protecting Robert for the future. I feel very proud that I've learned how to do this. I'm doing the best for my family and for my son." (Frances – family carer)

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Getting a suitable wheelchair
A step by step guide

Helen Daly

This article, written by a family carer, sets out the practical steps that need to be taken to get a suitable wheelchair, and the issues that need to be considered. It includes a list of helpful questions to ask during the assessment

Getting a referral

The initial referral is usually be made by a GP, although sometimes another qualified person such as an Occupational Therapist may make the referral. The referral will lead to an assessment

Preparing for the assessment

It is important to give the assessment some thought. This is a major piece of equipment that will have long term effects on a person's life. It is a major cost whether supplied by the NHS or privately funded.

- Think about Outcomes - what does the wheelchair need to achieve?
  For example:
  - Be more comfortable
  - Help someone do the things they want to do
  - Stop someone's head from feeling heavy
- Jot down a few notes about the person's health (you could use a summary of the health action plan) such as I get chesty or I get sores on my toes Include any other equipment used etc. This is the person's health profile.
- Jot down a few notes about what the person does on a typical day, some things the person likes to do occasionally and things the person wants to do. This is the person's lifestyle profile.
- If you have some photographs of the person doing things in a chair - pick a few out and take these with you.
- Try and find out what could be available (on the internet?) - see also types of moulded seating and the section on types of wheelchair
- Include the person in all the above!

The assessment

Good assessors will be interested in the person, how they live their life and how the wheelchair will support them to do this.

The appointment is a conversation and medical assessment about your needs. Equipment such as a ceiling hoist and physio plinth should be available.
If you have complex needs you should expect:

> Enough time for the assessment - this could be two to three hours.

You will talk about the person's health and their life Some vital measurements about joint range and overall body condition should be taken. The measurements will help to provide evidence about the person's posture and movements.

For some measurements the person will probably need to get out of their chair and onto a physio plinth.

Who should be in involved in the assessment?

This will depend - but the core team should be:

- You and a familiar, skilled care giver
- A lead assessor - qualified and experienced in postural care, neurodisability and rehabilitation.
- A technician qualified in rehabilitation.

In some assessments there may also be a need for a clinical scientist, speech and language therapist and an electronics engineer. For example on a power-chair or smart-chair, it will be important to get all switches and electronics in the right place. Everything will then come together in one complete integrated system.

It is important that everyone keeps the individual's wants and needs at the forefront of the discussion. However there may be tensions between different outcomes, making the conversation difficult, and assessment, prescription and provision more complex.

Making difficult decisions

Compromises are not always about money. For people with complex needs outcomes can include:

- being comfortable
- helping ability and independence
- minimising complications - including secondary/ future complications
- supporting care giving
- the wheelchair as part of a whole lifestyle

Below are some examples of how outcomes may conflict so that difficult choices need to be made:

i) Comfort versus independence
A wheelchair may need to be tilted back for periods of time and this may inhibit the use of a switch or there may be a temptation to try and correct a posture to gain back a skill, when for comfort accommodating the current posture is best.

ii) Independence versus prevention of secondary and or future complications. This can be illustrated by someone we spoke to. They were learning to tolerate a headrest for longer. The young man was good at giving eye contact to speakers and used to looking around to fix his eyes on whoever was talking or whatever was interesting. This supported his ability to understand and communicate with the world. However, over time this could interfere with his swallowing function as his neck was becoming progressively out of line. These are really difficult issues to resolve. They illustrate why both clinicians and carers need to have open dialogue.

iii) Care givers need for a lighter chair verses the need for a robust chair because of strong spasm. Care givers themselves frequently develop problems due to physical handling - even where risk has been reduced as much as possible - a future cost to the NHS and care giver. It may be possible to solve this by providing a rigid frame, or if possible reduce the size of the frame, reposition the pushing handles - or consider a power pack to help.

After the initial assessment appointment

The assessor should write a report setting out what they found and what someone needs. The people who should get copies are: the person and appointed carer, the GP, whoever is funding the chair. When funding is agreed a prescription can be written for the chair. Some wheelchairs can be issued right away but some will need further appointments for fitting. People with complex needs may require at least three more appointments.

Appointments for people with complex needs - casting, fitting, and issue

- Casting; a person needing a moulded seating system will have a cast taken of their body. The casting appointment may take up to 2 hours. It is really important that the cast is accurate; measurements maybe checked again, the person may need time to relax and reduce spasms and the posture will need to be arranged so that the fit is comfortable. It is better for the person and the cost to the service if this is done correctly first time.

- Fitting; the cast will be used to make a moulded seat. Once the mould is made, more detailed work with the mould is done at this point.

- Some people assume there is only one type of moulded seat. There are different types of moulds to meet different needs - see below for more details on types of mould. This can take 3 or 4 hours.

- Issue; this is fine tuning and how to use the chair. The appointment may take up to two hours.

Can I have a powered-chair or smart-chair?

A powered-chair is a chair that uses a motor to move. A smart-chair is a chair that has additional electronic features. See also below. Power-chairs and smart-chairs are often used in school and childhood. They become an important part of people's independence and health. There maybe some tensions regarding the environment and the use of smart-chair/powered-chairs, particularly when previously used in the larger spaces offered by school. This maybe exacerbated by the need for a larger chair in adulthood. Serious consideration to space should be part of the assessment. Cognition is sometimes cited as a reason why they cannot be supplied to people with pmld.

However a blanket ban on smart-chairs for people with pmld could ignore article 8 of the Human Rights Act. People have a right to a private and family life. They have a right to personal development and independent movement as far as possible. Below are some points to consider:

- Have an expectation that clinicians and others should be sensitive and knowledgeable regarding the small but highly significant ways people with pmld are able to express and control their world. People will spend many hours each day waiting and being moved, anything that gives a person a sense of control over when they move and/or supports movement will be very high prized.

- Independence in this context is not about driving an electric chair unsupervised from place to place. It is nuanced and meaningful to the person involved. Fully person centred.

- A few examples how smart-chairs may be appropriate for people with pmld are sitting to standing chairs, chairs that run on track systems or have stop sensors, pre-programmed chairs to run along a specific path, chairs that allow people to be at different heights or angles. See Simpson (2005).

- A chair and switch that allows someone to experience movement and make a connection with the switch and the movement - even when this is hand on hand is an example of persons independence and development.

- Many computers and pieces of equipment are provided for all sorts of people - who may only use a few functions - this should be no different for people with pmld.

If a person qualifies for a power-chair they are also entitled to a manual chair. Both chairs must meet the needs of the person.

Sometimes other ways of introducing smart-technology should be considered.

One young man was about to have his comfy chair replaced and this was going to be fitted with an ability to have a switch added that he may/or may not be able to use to tilt his chair. This was cheaper - but offered more options if it didn't work. The wheelchair would remain small and easy to use. For this young man and his family this was the preferred option.

What options do I have if I need moulded seating?

People with complex seating needs will either have modular seating systems or moulded seating. There are many types of modular seating and families appear to be familiar with this seating.

Suppliers and therapists have many options to discuss with people and customise seating to the person. However, there may come a point when a person needs a moulded seat to manage their posture.

Custom moulded seating is used when someone has very complex seating needs. As the name implies it is seating moulded to the person's body. People who have these seats are likely to have 24 hour postural management requirements and other therapeutic input to optimise posture and health.

It can appear that moulds are inflexible, confining and made out of hard plastic. It can come as some surprise to find this is not the case.

Choice of mould can make a huge difference

There are three commonly used types of moulded seating. These can be combined - so that seating and trunk support may use different systems to get the best result. The three systems are:

- Thermoplastics
- Carved foam
- Interlocking systems - Matrix, New Matrix and Lynx

Features of thermoplastic seating

- Light weight
- Low bulk
- Difficult to adjust once made - casting must be exact and no anticipated changes to posture
- Can be hot
- Can be difficult to clean
- Finished mould feels very rigid

Features of foam Carved seating

- skilled electronic or manual carving from the cast
- foam density can be chosen to best meet comfort needs
- foam can be altered for width and minor changes
- can be hot
- can be bulky

Features of interlocking Matrix/Lynx

- Interlocking segments - (like a high tech mechano) - shaped around a cast or directly around the person

- Can be adjusted at fitting stage or if body changes due to growth or posture change - can achieve high degree of accuracy
- Gaps between segments allow for air circulation so helps with people who get hot
- Easy to clean
- New Matrix can allow for different stiffness and give
- May be heavier than some other systems
- May need higher level of maintenance and skill to make

Many people have combinations of moulded systems - for example foam carved seat for comfort and a Matrix back for accuracy and temperature control. For more information see Pope (2007)

Should I accept a voucher to get my chair?

Some people have found the voucher system very useful. Basically this is where the NHS offers a voucher towards the cost of a manual wheelchair. The scheme was introduced to give people greater choice. The East of England draft QIPP programme (Quality, Innovation, Productivity and Prevention) provides the following definition of the three choices of funding open to people via the NHS:

- **Direct Issue** – the referred individual is assessed and prescribed the wheelchair from the Approved Range of Equipment List which best meets their clinical need. This wheelchair is provided, maintained and repaired by NHS funding.
- **Partnership Voucher Scheme provision** – the referred individual chooses an alternative wheelchair, which they prefer from the Approved Range of Equipment List. A voucher is issued for the cost of the wheelchair originally prescribed - any difference in cost between that of the prescribed wheelchair and the one selected by the individual is paid for by the individual. The issued wheelchair remains the property of the Wheelchair Service and is maintained and repaired free of charge.
- **Independent Voucher Scheme Option** – the referred individual is able to approach Approved Wheelchair Suppliers, and choose a wheelchair from a range not normally supplied by the NHS. Once a wheelchair has been selected approval has to be given by a Wheelchair Service Therapist or Technician – ensuring that the chosen wheelchair meets the individuals clinical need requirements. A voucher is then issued for the cost of the wheelchair originally prescribed, any difference in cost between that of the prescribed wheelchair and the one selected by the individual is paid for by the individual. An additional amount is added for maintenance and repair costs and the wheelchair is purchased by the individual

Whatever a person is offered by the NHS, it should meet all clinical needs and legal obligations - including things like minimising future complications and taking account of carers needs. Prescriptions should comply with the law and follow best practice guidance.

Very large differences between the value of the voucher and cost of the chair of choice, for someone with complex needs may indicate either a problem with the prescription or a problem with the prescriber/supplier. Anecdotal evidence from families suggested they accepted a voucher because they could get a lighter, better looking wheelchair. People felt their children had enough barriers to acceptance. A general feeling was put into words by one Mum… 'we didn't want her sitting in a huge, ugly chair…. Our daughter loves her chair'. Worryingly one family was given a clinical need for a tilt in space chair from a consultant - but the wheelchair clinic felt the person didn't currently meet the criteria. In this instance there was a reluctance to engage in prevention.

Families and people have experienced both good and bad practice from provision in the private sector and NHS. Make sure there is a clear maintenance and repair contract in place. Modifications made on a wheelchair - even if they are clinically needed-may affect the manufacturer's warranty.

One Dad explained - 'we had an active lifestyle…the chair our child was being offered was heavy, bulky and ugly. We got a private assessment for a lightweight super chair - we paid a deposit of £2000 - the company supplying the chair went bust…by now our son was desperate for a new chair…we found another supplier…but we had to agree to accept the chair when it arrived even if it was wrong…it cost another £5000…. The chair was very wrong….Our son had to use it until the NHS chair arrived… when it broke it cost £200 for the call out. The money was bad enough - but the damage to our son's health….! I'm still very, very angry.'

What can I do if I cannot get a suitable wheelchair?

Sometimes wheelchairs arrive and there is a problem. If the chair is unsuitable:

- Go back to the wheelchair clinic - there may be very good reasons why a wheelchair needs further adjustment - despite extensive and good assessment.

- If problems persist or there are ongoing difficulties during the process of getting the chair, ask to speak to or write to the manager of the wheelchair service and make notes about has happened. Think about whether this is a complaint and there is a need to follow the complaints process.

- If you decide you want to make a complaint get a copy of the complaints process and follow it carefully.

- Wheelchair service managers want to know as soon as possible if something is wrong. Referral or prescription errors are expensive; services want to reduce this happening.

- The next step is go to the GP or consultant and ask for a second opinion - maybe there is a need for a referral to a more specialist clinic or service. There may also be other health matters that have emerged since the wheelchair assessment and other therapies could help seating - for example botox or a change in medication.

- At all points above it will be useful to have the support of a familiar community therapists, familiar and skilled carers and anyone else who can provide support from the persons network/circle.

- Other useful people to approach are the local wheelchair user group, the local Learning Disability Partnership Board (this board has to do an annual assessment of health services for people in a town or city), the local Health Watch, the councillor responsible for disability in your town/city, or the local advocacy service - the local Mencap or Scope group.

Further Reading

Raising our Sights - How to Guide 10: Wheelchairs'
https://www.mencap.org.uk/advice-and-support/pmld
- for resources and videos guides and videos

Other frequently asked questions, you may find helpful to ask at assessment

- How long should it take to get my wheelchair?
- Will it fit in my vehicle?
- Can I travel in my chair in my vehicle?
- Is there anything I can do about being too hot?
- I get sores from my chair how can you help me?
- I like to communicate using my whole body - but I also get sores where my belts are or I get myself in a bad position in my chair - what are my options?
- Do I need a harness?
- I like to look but around my headrest gets in the way - what is the best sort of head support I can have?
- My feet won't stay in the footplates what can you do to help?
- My wheelchair covers need washing for obvious reasons can I have 2 sets?
- What happens if my chair breaks/ who do I contact?
- Do I have to pay for repairs?
- Can I use my wheelchair for transporting oxygen, medicines, my peg feed (other equipment)?
- How can my communication aid/switch be fitted?
- Can I have a tray, it helps me sit up and take part in things?
- What size wheels are best to meet my lifestyle needs?
- When my wheelchair goes over a bump my back hurts, can I have a better suspension?
- Can I choose the colour?
- I am an adult now and my care givers are finding it hard to push me up slight slopes, I cannot do many things I like - that keep me active, develop and maintain my good mood and skills - can I have a lighter frame or a power pack?
- Can we explore whether I would benefit from smart technologies - for example my bowels get bunged up - could I have a seating to standing chair?
- One thing I can do on my own - with supervision—is use a head switch to go round and round in a circle. What else do you think I could learn - can I have an electric chair to help me develop my switch skills?

By Helen Daly

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PMLD LINK
sharing ideas and information

Vol. 28 No. 3 Issue 85

Get me out of my chair!

Martin Goodwin

Meeting the health needs of students with profound and multiple learning difficulties (PMLD) as part of their daily life at school or college should be an essential part of a PMLD curriculum. This edition of PMLD Link has shown the benefits of good postural care in enabling people with PMLD to have an increased chance of securing an improved quality of life.

Increasingly, schools have more freedom to scope the curriculum to address the whole life needs of people with PMLD. However, due to a number of learning priorities and practical obstacles, the physical needs of students may be overlooked and not accommodated as a regular activity. Developing the person's awareness, experience of and capacity to be in symmetrical and posturally beneficial positions is a valuable educational activity in itself and can provide much needed relaxation for a stressed or constipated learner and being engaged in these care routines can also be an opportunity to engage in fun and pleasurable activities as part of their leisure.

In my class I have been exploring a range of activities[1] that could be provided whilst the student is on mats on the floor or using other postural supports such as side lyers and in standing frames. In this article I would like to share some examples of activities that enable education opportunities when the student is out of their chair[2].

Standing Frame Activities

Pass the parcel

Pass the parcel can be a package that can be gradually stripped away or simply a box with different objects that is passed from one learner to another or better still a series of boxes of decreasing size placed inside each other (rather like a Matryoshka doll). So inside the box you could place some small interesting items to engage with like bubbles, a sparkly ball or a whoopee cushion between pieces of attractive metallic shredded paper so that the person and others in the group can have an explore before the parcel is passed on.

Board Games

Get a large piece of mounting board (or several pieces of mounting board to create a large piece) and grid into squares. Using laminated cards and Velcro find a picture for a number of the squares. These can be themed for example based on TV themes. The student can then co-actively roll the dice and count the squares whilst another member represents the number rolled by banging or tapping on a drum. The staff can then play the corresponding track such as the music from Coronation Street or the dramatic drums from East Enders. I have made some other themes for this board game based on subjects such as pop songs, Halloween and Christmas.

Object table

Being in a standing frame can provide an opportunity for some free exploration of objects. In my class I have a variety of boxes without lids (cups, plastic bottles, sweet tubes, handbags etc.) in which students can place objects, and boxes with lids (Jar with screw top, mini-bin, ring box etc.) so that students can undo/fasten and place or find objects hidden inside. It's a valuable opportunity to practice physical and cognitive skills.

Hoop

Find an unwanted hoop and firmly attach some stretchy lycra to it. Used horizontally you can have fun with bouncing or rolling objects to each other on it and engaging in parallel play. Whilst it is held vertically the hoop can be an area that you make shapes with by pressing hands, drumming fingers in a rhythm or putting your face against it.

Activities for Side Lying Boards

Keyboard Mat

Grab a bargain from the market or online market places and buy a roll out keyboard mat. When a student is placed on the mat they can roll on to the keyboard or brush their arms or feet against it and make a noise on it by intentionally or unintentionally activating the sounds or rhythms in the keyboard.

Treasure Web

Using a dressing rail get some string and make a web by spanning the string across the frame. On the string you can then attach objects. Recently my class made a Diwali treasure web where we attached pieces of coloured fabric, jewels, tinsel, wheel spoke decorators and star lights. This can be placed vertically so that a student can explore the area horizontally whilst on their side lyer by reaching or feeling the objects.

Floor Activities
Little rooms, dens, chandeliers and umbrellas
The ideas expressed by Dr Lili Nielson (2004) through the theory of active learning are of much benefit. The concept of active learning supports people who might otherwise seem passive, to voluntary explore their environment and increase their self awareness, thereby helping them towards the kind of learning that babies usually experience as a matter of course by giving feedback, contingency and control. A Little Room or BeActive Box along with homemade alternatives such as dens, chandeliers (a hoop with items attached) and umbrellas (with items attached to hang or used to project a light on) can offer stimulating and physically engaging learning opportunities.

Fabric mat
A range of interesting, visually and physically stimulating fabrics can be used with the person whilst on the floor. Fabrics can be draped across in a burst-pause fashion; you can wrap the student in the material or place it near the student so that they can explore movement. Try attaching different items of weight and size, bells and other sound makers to the fabric or playing a game of roll or hide the ball with it.

Treasure tubes
Try putting materials, fabrics or objects, or battery operated lights in a cardboard tube that is either closed at one end so that the person can scoop or feel the items within an enclosed space or leave it open so that you can build suspense and slowly reveal items from both sides playing a 'where is it' game.

[1] The author does not assert ownership of the ideas expressed on this page. They are just tried, tested and shared in order to support other practitioners. Please be aware of and assess health and safety issues in relation to your own students.

[2] Please ensure that the students' physiotherapist and occupational therapists are involved in recommending appropriate activities to meet the health needs of students

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PMLD LINK
sharing ideas and information

Vol. 28 No. 3 Issue 85

Sheldon and the Hare
A sensory story

Pete Wells

Sheldon is a slimy snail, everyone say "Hello!"
Sheldon is a slimy snail, who is very, very slow.
Hector is this hasty hare, who is very, very fast,
He's always in a hurry and he's never, ever last!

	Storyline:	**Suggested Props!**
1	One day Sheldon got a letter, there was panic on his face, The letter was from Hector Hare, a challenge to a race! Optional chorus to chant or clap: Sheldon snail is very slow, Hector Hare is very fast, Hector hare will win the race, and Sheldon will be last!	(Show letter, rustle paper)
2	Three times around the garden, then to the apple tree, The winner gets ten carrots, and a kiss from Brenda Bee!	(Taste carrot/ kiss sound on BigMack / feel bee toy)
3	Slowly Sheldon read the letter, said "Okay then, I agree! I like the taste of carrots, and I fancy Brenda Bee!"	(Taste carrot/ Wolfwhistle on BigMack)
4	Soon came the day of the big race, in the garden, quite a crowd, Everyone was cheering, it was very, very loud!	(Everyone verbalise/make noise!)
5	Brenda got it started, she said "Ready, steady go!" Hector bolted from the starting line, poor Sheldon started slow!	(Ready,Steady,“Go!” on BigMack)
6	Hector sped around the garden, at a super speedy pace! He could feel the grass beneath his feet and the wind upon his face!	(Fan individuals : switch-operated if you can!)
7	Sheldon shuffled round the garden, at a super slow snail's pace, As Hector passed him for the second time, he blew a raspberry in his face!	(Raspberry sound using a Balloon/BigMack)
8	Soon Hector Hare was tired, so took off his training shoes, "Sheldon Snail's so sluggish, I've got time for a little snooze..."	(Snore sounds / cover individuals with blanket)
9	Hector fell into a deep, deep sleep, for an awfully long time, He awoke to the sound of cheering, as Sheldon reached the finishing line!	(Feel shell/ everyone cheering!)
10	“Not so fast! I won't be beaten! Not by a slowpoke snail!" Yelled Hector in a hurry, slipping on Sheldon's slimy trail!	(Feel slime or gloop!)
11	Hector slid across the garden, bashed into the apple tree! As Sheldon crawled across the finish line. He won, hooray! Yippee!	
12	So Sheldon was the winner, he got his kiss from Brenda Bee! Everyone can be a winner, I'm sure that you agree!	(Celebratory massages all round!)

Pete Wells has been teaching amazing children in Sunderland for over twenty years. He delights in writing and sharing sensory stories ~ the grosser the better!

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

Vol. 28 No. 3 Issue 85

PMLD LINK
sharing ideas and information

Respiratory Care in People with PMLD and Complex Physical Disability

David Standley

In this article, I discuss respiratory care for people with Profound and Multiple Learning Disabilities (PMLD) and a Complex Physical Disability (CPD). CPD is an umbrella term used to describe people who have severe physical and/or neurological impairments resulting in postural abnormalities and movement disorders. Individuals require wheelchairs and assistive devices to mobilise and maintain themselves upright against gravity. The main aim of this paper is to enhance carers' and healthcare professionals' knowledge and understanding about the respiratory problems this group of people present with, and offer advice on how to improve a person's respiratory care.

Respiratory Health

People with a Complex Physical Disability (including many individuals with PMLD), are at high risk of developing respiratory problems. They are the main reason this population of people access their GP or attend hospital (Young et al. 2011), and pneumonia is the biggest cause of death (Reddihough 2001). There are a number of factors that increase the risk of this group developing respiratory problems (Figure 1). Health problems such as epilepsy and low weight also contribute to the risk indirectly. As a general rule, the more risk factors a person presents; the greater the probability of them developing respiratory complications throughout their lives.

Risk Factors
• Airway Clearance Dysfunction • Constipation • Dysphagia • Immobility • Poor Oral Hygiene • Reflux • Saliva Management Difficulties • Sleep Disordered Breathing • Thoracic Deformity

Figure 1: Factors that increase the risk of people with CPD developing respiratory problems

Signs and Symptoms

Respiratory failure tends to, but not always, follow a pattern of increasingly severe signs and symptoms (Figure 2, page 24). As these progress so does the level of medical treatment required which are known as escalations in treatment or care (Figure 3, page24). It is the signs and symptoms of respiratory compromise that affect the person's quality of life; and increase the pressures on the care network.

Respiratory Care

The aim of respiratory care is to optimise the management of a person's risk factors with the view to reducing their symptoms. It is not possible to eliminate a person's risk factors altogether because they are linked directly with the person's physical and/or neurological condition and the secondary complications of physical disability. Therefore, respiratory care is a long term approach aimed at prevention rather than cure.

Respiratory care should involve comprehensive assessment; the development of an individualised management plan; and, if indicated, honest discussions about prognosis and future care (Seddon and Khan, 2013). The latter is known as an advance care plan. For respiratory care to be effective it requires a multidisciplinary approach which starts in the community with access to specialist respiratory services as needed (Figure 4, page 24). As people with Complex Physical Disability age, their risk factors can become more difficult to manage hence a person requires close monitoring and timely access to appropriate care when their presentation changes. Figure 4: Healthcare Professionals involved in respiratory care.

Guy's and St Thomas' NHS Foundation Trust has developed an integrated respiratory pathway for people with Complex Physical Disability and learning disabilities (including many individuals with PMLD). This involves the local community health services, led by the adult with learning disability team, and Lane Fox specialist respiratory unit at St Thomas' Hospital. This pathway ensures that comprehensive respiratory care is provided and overseen within the local area. This model of working is not routinely available across the country which often leaves people with Complex Physical Disability without a co-ordinated approach to their respiratory care. In the absence of a dedicated

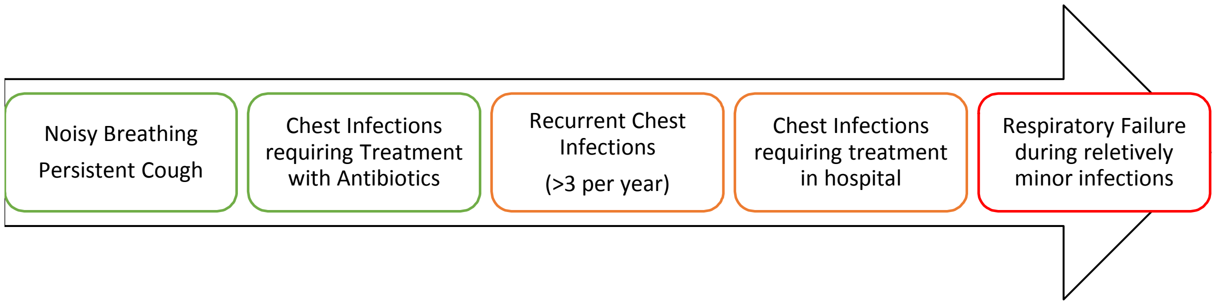

Figure 2: Pattern of respiratory symptoms

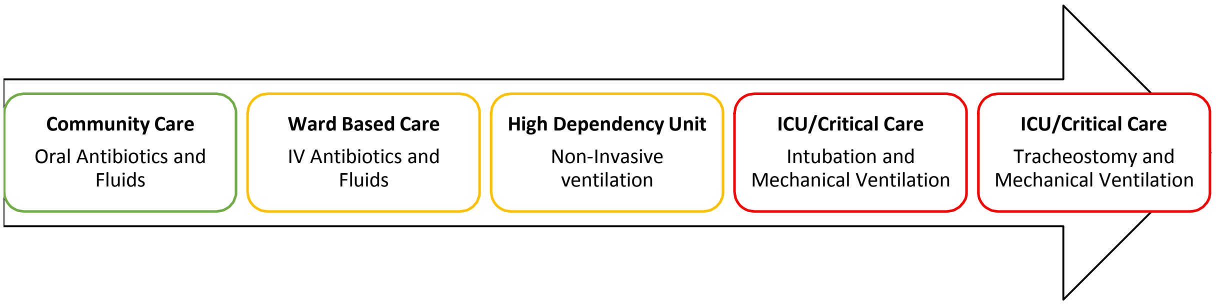

Figure 3: Escalation of care points

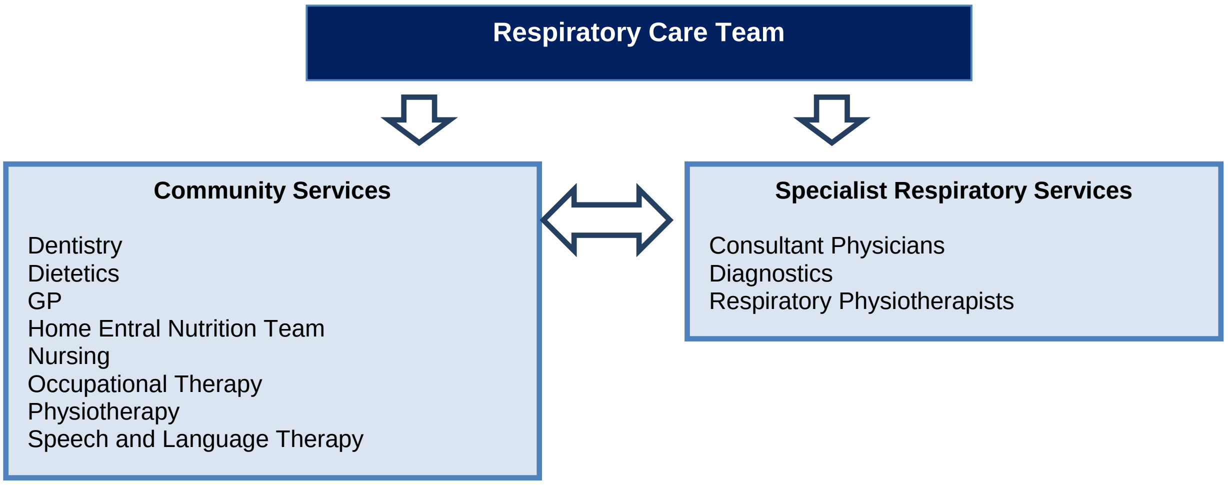

Figure 4: Healthcare Professionals involved in respiratory care

respiratory team carers and healthcare professionals need to develop an in-depth understanding about the key aspects to respiratory management. This includes the signs and symptoms of respiratory complication; the respiratory risk factors; the treatment options available, and who to consult to improve the person's management. This knowledge is often lacking which can increase the risk of people developing respiratory problems without receiving the appropriate care. Table 1 aims to provide readers with basic information about the respiratory risk factors to support them when seeking advice on how to optimise a person's care. Many of the symptoms of the respiratory risk factors are similar and they are often caused by a number of factors which can make assessment challenging. It is not uncommon for people with Complex Physical Disability to be receiving services from the entire respiratory care team at any one time. For this reason a co-ordinated multidisciplinary approach is important.

Factor	Description	Cause	Signs and Symptoms	Treatment Options	Who can help
Airway Clearance Dysfunction	A strong, effective cough is important for maintaining a clear airway and respiratory health. A strong cough loosens, moves, and clears mucus, food and/or fluid from the airway.	• Respiratory Muscle weakness • Spinal deformity • Poor coordination of the muscles involved in coughing *NB: A person's ability to cough may be effected by their health, arousal level and fatigue.*	• Chest infections • Effortful cough • Tiredness after coughing • Weak cough • Wheeze and/or crackles during breathing	• Chest physiotherapy • Postural management • Therapeutics Activities such as movement groups, rebound therapy and hydrotherapy	• Physiotherapist
				• Medications • Nebulisers	• GP
				• Oral Suction • Devices that assist coughing	• Specialist Respiratory Services (SRS)
Constipation	Constipation is defined as not passing stools regularly or being unable to completely empty the bowel. It is usually associated with hardened faeces. Roughly 55% of people with Complex Physical Disability (including many individuals with PMLD) have constipation and take regular laxatives.	• Immobility • Inadequate oral intake • Abnormal bowel function •	• Bloating • Difficulty breathing • Excessive saliva • Foul-smelling wind and stools • Increased seizure activity • Loss of appetite • Reflux • Stomach pain and discomfort	• Medication - laxatives	• GP
				• Hydration • Modify diet	• Dietician • Home Entral Nutrition Team (HEN Team) • Speech and Language Therapist (SLT)
				• Movement • Exercise • Standing	• Physiotherapy
Dysphagia	Dysphagia is the medical term for swallowing difficulties. 99% of the people with Complex Physical Disability (including many individuals with PMLD) are affected by dysphagia.	• Poor coordination and/or weakness of the muscles associated with swallowing. *NB: A person's ability to swallow may be effected by their health, arousal level and fatigue*	• Chest infections • Choking • Coughing whilst eating or drinking • Dehydration • Dribbling or drooling • Weight loss *NB: Aspiration involves inhaling secretions, vomit, or foreign bodies. 50-80% of people with* Complex Physical Disability (including many individuals with PMLD) *aspirate with 60-97% doing so without displaying signs and symptoms.*	• Review the environment, position and support provided when the person is supported to eat and drinking • Modify diet	• SLT • Physiotherapist
				• Videofluoroscopy –x-ray of the food and liquid moving from the mouth to the stomach.	• GP • SLT • Specialist respiratory Services (SRS)
				• Consider alternative feeding options such as a PEG	• Dietician • GP • SLT • SRS

Table 1: Respiratory risk factors, the treatment options, and who to consult

Factor	Description	Cause	Signs and Symptoms	Treatment Options	Who can help
Immobility	Immobility limits access physical exercise. This impairs a person's ability to maintain their fitness, breathing function and normal airway clearance.	• Neurological, Physical and/or Cognitive impairments	• Development of contractures • Poor exercise tolerance • Spinal Deformities • Weak cough	• Postural management • Therapeutic activities	• Occupational Therapist • Physiotherapist
Poor Oral Hygiene	Poor oral care increases the build-up of bacteria in the mouth. This can then enter the lungs especially if the person has saliva management difficulties and dysphagia. This increases the risk of developing pneumonia.	• Excessive sugary foods or drinks • Poor oral care • Reduced or non-oral intake • Reflux • Saliva management difficulties	• Bad breath • Pain • Plaques and discoloured teeth	• Individualised oral care plan • Regular oral care	• Dentist
				• Review diet	• Dietician • Speech and Language Therapist (SLT)
Reflux also known as Gastro-esophageal reflux disease	Reflux occurs when stomach contents are regurgitated into the oesophagus and potentially the lungs. Gastric contents contains bacteria and acidic substances which can be a contributory factor in the development of pneumonia. 48%-90% of people with Complex Physical Disability (including many individuals with PMLD) have reflux.	• Constipation • Immobility • Mechanical changes or weakness of the Lower Oesophageal Sphincter • Severe scoliosis • Slow digestion	• Bad Breath • Burping • Cough when not eating • Coughing on lying from sitting • *NB: Coughing can also be due to saliva management difficulties* • Excess salivation • Finger sucking • Food refusal • Pain • Poor oral hygiene • Postnasal drip • Recurrent Chest infections	• Medication • Surgery	• GP • Specialist respiratory Services (SRS)
				• Positioning • *NB: The optimal position required to minimise reflux needs to be individually assessed.*	• Physiotherapist
				• Diet • Weight management	• Dietician
				• Review feeding rate and type	• Home Entral Nutrition Team (HEN Team)
				• Review eating and drinking guidelines	• SLT

Factor	Description	Cause	Signs and Symptoms	Treatment Options	Who can help
Saliva Management Difficulties	Saliva management difficulties results in the person either drooling or having to swallow large volumes of saliva. Saliva contains bacteria and yeast which increases risk of developing chest infections. 37% to 58% of people withComplex Physical Disability (including many individuals with PMLD) have saliva management problems. The combination of saliva management difficulties, dysphagia and poor oral hygiene increases the risk of aspiration and development of chest infections.	Dysphagia Constipation Difficulties moving saliva to the back of the throat Poor mouth closure Reflux Tongue thrusting *NB: Drooling can be made worse by:* • *A lack of head control and poor posture* • *Excitement* • *Lack of sensation around the mouth* • *Mouth breathing*	• Choking • Chronic cough • Coughing on Lying • Cough when not eating *NB: Coughing may also be due to reflux* • Damp and soiled clothes • Interference with speech • Irritated chapped skin around mouth and chin • Recurrent chest infections • Unpleasant odour • Visual Drooling • Wet/ Gurgly Voice	• Medications *NB: Medications used in the management of saliva can cause thick saliva which is difficult to manage and increases seizure activity.*	• GP • Specialist respiratory Services (SRS)
				• Oral hygiene	• Dentist • Speech and Language Therapist (SLT)
				• Botox • Surgery	• SRS
				• Assessment of oral function and dysphagia	• SLT
				• Positioning • Oral Suction	• Physiotherapy
Sleep Disordered Breathing	The estimated prevalence of sleep problems in adults with learning disabilities varies from 8.5% to 34.1%. Sleep problems may be due to: • Challenging behaviour • Medication • Psychiatric conditions • Sleep disordered breathing • Visual impairment Sleep disordered breathing refers to a group of respiratory disorders that occur in sleep or are made worse during sleep.	• Central apnoea – pauses in breathing due the brain being slow to respond to changes in the oxygen and carbon dioxide levels. • Hypoventilation – breathing at an abnormally slow rate which results in the build-up of carbon dioxide in the blood. • Obstructive sleep apnoea – pauses in breathing due to obstruction of the upper airway.	• Broken sleep patterns • Loud Snoring • Morning head aches • Reduce carer quality of Life • Reduce quality of Life • Sleeping during the day • Pauses in breathing at night	• Positioning •	• Physiotherapist
				• Medications	• GP • SRS • Sleep Disorder Clinics
				• Non-invasive ventilation •	• SRS • Sleep Disorder Clinics
Thoracic Deformity	Spinal deformities have an effect on the shape of the rib cage which can make it harder to expand the chest wall. This increases the work of breathing even when the lungs themselves are completely healthy	• Abnormal movement patterns • Poor postural management • Reduced muscle strength • Static postures	Contractures Curvature of the spine Increased chest infections Pain Stiffness on movement	• Postural Management	• Occupational Therapy • Physiotherapy • Wheelchair services
				• Bracing	• Orthotist
				• Surgery	• Orthopaedic Surgeons

References: Braverman, 2001; Koumbourilis, 2006; Marks, 2008; Yoneyama 2002.

Summary

There is overwhelming evidence that people with Complex Physical Disability (including many individuals with PMLD) are at high risk of developing respiratory problems. They often have a number of risk factors that require specific management plans provided by a range of community and specialist healthcare professionals. Ideally this should be managed by a dedicated respiratory team; however, in the absence of this, it is important that care providers and healthcare professionals working with people with Complex Physical Disability can recognise the signs of respiratory compromise and have an understanding of how to access respiratory care. This, in turn, can reduce the symptoms and can significantly improve a person's overall health and quality of life.

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

Louisa Whait

People with learning disabilities are at a higher risk of having constipation and for people with profound and multiple learning disabilities the risk is still higher. This is not surprising when you look at the reasons for constipation which include: inadequate diet and fluid intake, side effects of certain medications, reduced mobility and lack of exercise and anxiety or depression.

We know that people with learning disabilities often have poorer diets and take less exercise than their non-disabled peers. They are also more likely to be on medication and experience mental health problems. People who are non-ambulant are at greater risk again, and it has been suggested that there is a link between constipation and body shape distortion and/or abnormal muscle tone, although the evidence is more anecdotal.

Environmental factors also play a part. Lack of privacy, inadequate facilities and changes to routine can all increase the likelihood of constipation.

Constipation is often thought of as a minor health problem, and for the majority of people this is true if it is treated promptly. However chronic constipation can lead to more serious health problems including:

- Rectal bleeding, which may be the result of anal fissures, haemorrhoids or rectal prolapse.
- Abdominal pain, cramps and bloating
- Loss of appetite
- Nausea
- Overflow diarrhoea
- Faecal impaction
- Faecal vomiting
- Twisting of the bowel leading to ischaemia and septicaemia

The impact of quality of life should not be underestimated, and constipation should be considered if there are unexplained changes to an individual's behaviour, including self-harm. In extreme cases, chronic constipation can lead to death.

In order to raise awareness of constipation and people with learning disabilities, the learning disabilities public health observatory published a guide in 2016 called Making reasonable adjustments for people with learning disabilities in the management of constipation. The guide gives more details about the reasons for constipation, the treatment of constipation, links to accessible information about constipation and examples of reasonable adjustments that can be used with people with learning disabilities. The guide can be downloaded here: https://goo.gl/Sn1NSI

The learning disabilities observatory also ran an event on constipation to raise awareness. Louisa Whait, the Regional Learning Disability Network Officer for the Central Midlands was at the event and describes what she did next.

After hearing a Mum talk about her son and the impact of constipation on his life and some stark facts about the prevalence of constipation in people with a learning disability I wanted to do something about it. I wondered how many people are in Assessment and Treatment Units because of constipation. How many people are now on a myriad of drugs to "manage" their behaviour when the cause - easily treatable-is constipation.
I sent out a general message to my networks, which includes people from social care, providers, nurses, family carers and self-advocates, to see if anyone could work with me. I was blown away by the response – 20 people stepped forward in less than 24 hours. This in itself told me that Constipation is a huge concern particularly amongst nurses, occupational therapists and physiotherapists. People working in Children and Adults services came forward, all saying they have seen first hand the impact (no pun intended) of constipation on quality of life and the consequences of long term use of laxatives.

The group has met twice so far. We are thinking about how to raise awareness of constipation and the effect it has on quality of life. What could we do to reduce the prevalence of constipation in one in three people with a learning disability? What could we do to reduce the prevalence of constipation in three in four people with complex needs living in institutional settings? What could we do to raise awareness of alternative treatments which are less damaging than long term use of laxatives? Whilst a serious issue, the meeting provided lots of giggles – we don't talk about bodily functions do we? Even people who will have dealt with bodily fluids throughout their career got a little childish glint in their eye as we talked about poo. The innuendo which flew around the room was brilliant. It really did bring home to us how little we talk about it – that is part of the problem. It is not considered polite to ask someone about their bowel movements – although I have to say far more people are telling me about their own movements when I tell them about this work!

We have agreed that we are going to:

- Develop some simple messages about constipation to help people understand more about it – and talk about it

- Raise awareness of different interventions such as posture care and bowel massage

- Develop a "Risk of Constipation" (ROC) tool to support families, people with learning disabilities, health and social care staff. The aim of the ROC tool is to raise awareness of the causes and impact of constipation, provide details of preventative measures and holistic, evidence based management and treatment.

- Write some short training sessions that anyone can deliver

We would like more people to work with us. If you can't get to meetings you can still help us do some of the work – we can email or speak on the phone. I would really like to hear from families and their experiences of support around constipation.

The guide can be downloaded here:
http://tinyurl.com/j954ltk

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Everyone deserves an equal right to sight

Lisa Donaldson

SeeAbility, the national charity supporting people with sight loss and multiple disabilities, has been working for a number of years to help people with learning disabilities look after their eyesight.

Fortunately many sight problems are easily treatable, and regular sight tests are the gateway to getting the right prescription glasses through to identifying and treating serious sight threatening conditions such as glaucoma.

Unfortunately people with learning disabilities are many times more likely to suffer sight problems and are also much less likely to get the eye care they need. Research has found adults are 10 times more likely to have a serious sight problem and six in ten adults will need glasses.

Readers of this journal may also already know that the more profound and complex a person's learning disability is, the more likely they are to have a serious sight problem. This means vision problems will be high in settings supporting people with more profound needs. Some researchers have even suggested that everyone with severe or profound learning disabilities, and all older adults with Down's syndrome, should be considered visually impaired until proven otherwise.

From my work in special schools, I know that children with learning disabilities are 28 times more likely to have serious sight problems. Our data shows 50% of children in these schools have a problem with their vision, and we know about 4 in 10 have never had a sight test.

As with other aspects of healthcare, the familiar barriers experienced by people with profound and multiple learning disabilities exist. Supporters may have their questions too. How do you establish what someone can see if they cannot tell you? What if the person would struggle to cope in an optical practice, or get used to wearing glasses?

As an optometrist working with children and adults with learning disabilities through my work with SeeAbility, I'm aiming to answer some of these questions and bust a few myths in the process.

No one is 'too disabled' to have a sight test

The first myth is that sight tests involve speaking, reading and sitting still in a dark room. But as optometrists we can use different techniques, for example:

- When someone is unable to sign or communicate, I can use observation techniques instead. How does the individual use their vision – can they track a moving object, do they notice objects in their peripheral vision, can they distinguish pictures and colours on some of the materials we use? This tells me a lot.

- When someone does not like the dark, or would find it difficult for me to get close to them, we can still do a sight test. I can still look at how well a person might be focussing from a distance using a specialist instrument (a retinoscope) and lenses. So if they need glasses to correct an eye focussing problem, they can be prescribed even if they are unable to communicate what they can see.

- It is also possible to assess how well someone can control his or her eye movements, whether they have restricted eye movements and if they have problems with 3D (binocular) vision.

All this is possible, but obviously helping someone feel comfortable is vital. Being able to gather information prior to when I meet someone for their eye test is really helpful; this includes finding out about their eye care and health history and learning more about how someone communicates and what makes them feel at ease. We use an 'about me and my eyes' pre-test questionnaire to build up a picture before we meet someone for their eye test.

During the test having someone present who is familiar with the person is a great help too. In special schools we use music, favourite toys and we operate in sensory rooms or cosy corners of classrooms. Demonstrating and explaining everything I am going to do before I try to do it often really helps too.

Getting used to glasses is another common concern. If you have always lived your life in a blur because you are very short sighted, suddenly seeing all these people and objects around you can be too much.

There is no doubt that you do sometimes have to be patient when it comes to glasses. From our work in special schools and with adults we have tried the following techniques:

- Sometimes we introduce the strength of the prescription in stages over many months.
- Support plans can be adapted to help someone get used to their glasses for example by building up to using them for longer periods of time each day or to help them identify which glasses are for which activity (distance or near).
- Understanding how new glasses change a person's vision can aid supporters in helping them to get used to them. For example, if someone is long sighted and loves the iPad, then glasses should help to make it clearer, but if the person is short sighted they may not notice any improvement to their vision with the glasses and so in this case it may be better to start off watching TV or going outside (of course it still needs to be a favoured activity!)

Another real concern is that the person would not cope in an optical practice. These days, they feel very much like other retail environments and can be very overwhelming.

Aside from the fact that eye care settings should be aware of their duty to provide reasonable adjustments, including information in an accessible format, it is still helpful and advisable to talk to the optometrist or the people in the practice first, so they know what adjustments are needed and can pave the way to a good experience. Completing SeeAbility's pre-test questionnaire "About me and my eyes" and giving it to the practice in advance will be really helpful for the optometrist and dispensing optician to prepare.

Readers may also be interested to know that some optometrists will offer domiciliary sight tests (at home, in a residential setting, and in day centres). The rules state that the person must be unable to leave their home unaccompanied due to illness or disability.

SeeAbility keeps a list of optometrists who have told the charity that they can offer domiciliary sight testing or have experience and tools to support a person with a learning disability in an optical practice.

Lastly understanding the result of an eye test can be confusing for anyone – what does a prescription mean? What is my eye condition? What are the next steps for treatment? SeeAbility has a number of easy read resources for people with learning disabilities, and information for supporters too.

This includes support and advice in helping someone to get serious but life changing treatment, such as surgery for cataracts.

Being aware of vision

At SeeAbility we recognise (and indeed parents of children with PMLD often tell us) that eye care can drop off the list of critical priorities, especially when an individual can be living with other complex health needs.

For anyone reading this article, and supporting someone with PMLD, just being aware of tell tale signs of a problem with vision could be the first step in making sure that person's sight is tested.

Symptoms such as eye rubbing, having discomfort with bright lights, being hesitant in poorly lit environments, losing interest in social activities, or bumping into furniture or being alarmed at an unfamiliar noise or when approached, even significant changes in general behaviour, for example challenging behaviour or withdrawal, may also be triggered by a sudden deterioration in vision.

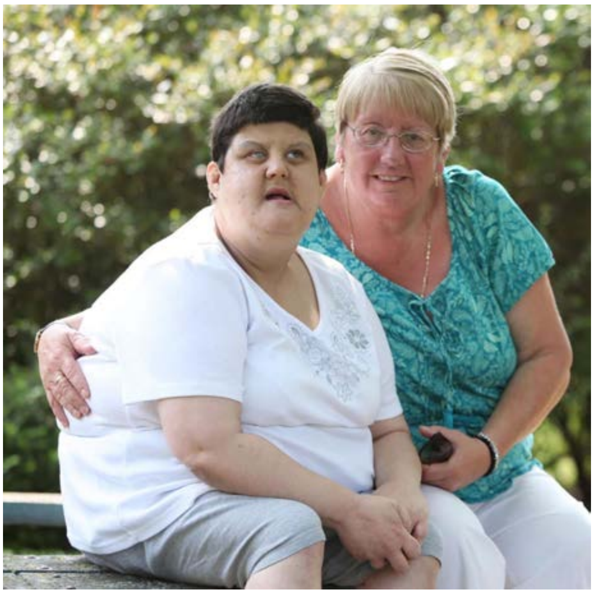
Carers and supporters are key in helping the person wear prescribed glasses, so it is important to be with the person to collect their glasses, and look out for tell-tale signs of ill-fitting glasses such as marks on a person's nose or ears or reluctance to wear them.

Certain conditions associated with learning disabilities can also come with different sight problems. Being aware of this can be helpful (resources and support).

Sally's story

Sally has 18-P Syndrome which is associated with learning disabilities. Some years ago Sally started rubbing her eyes and described an 'itch' on her head, her way of saying she had a headache. An optometrist visited Sally at home, and found she had seriously high pressures in her eyes, due to glaucoma. In fact 18-P Syndrome comes with a higher risk of glaucoma, something that mum Maureen hadn't been told about before.

Sadly despite urgent treatment Sally had already lost much of her sight. Maureen was determined this wouldn't happen to others so she has campaigned to establish better eye care services in her local area, through the 'Bridge to Vision' project, where



optometrists visit Sally's day centre, to sight test, dispense glasses and where serious sight problems have been identified and treated. The project also raises awareness locally about the risks of sight problems amongst people with learning disabilities.

Contact Details

Lisa Donaldson, Optometrist and Clinical Lead:
Children in Focus, at SeeAbility
Email:

Campaigning for an equal right to sight

NHS England operates a national sight testing contract and funding system. But it was never designed with people with learning disabilities in mind.

For example, some high risk groups are listed to get their sight tests free on the NHS at any age – not so people with learning disabilities.

And an optometrist working in a day centre, or in a special school will be paid exactly the same standard fee paid by the NHS for 'high street' sight tests of £21.31. That's hardly recognition of the flexible tests, familiarisation sessions, repeat visits or longer appointments that some people with PMLD will need.

The result is that a few local commissioners and services have stepped in to fill the gap with targeted pathways of eye care. SeeAbility fundraises to do its work in special schools. But this is unfair to those not lucky enough to live in these areas.

What is needed is NHS England to reform its contract and funding system and ensure that there is a national programme of sight testing in special schools, and a national pathway of eye care for people with learning disabilities in the community.

You can read our full recommendations for reform and support our equal right to sight campaign here www.seeability.org/equalrighttosight

SeeAbility is a UK charity supporting people with sight loss and multiple disabilities. We are one of the oldest visual impairment organisations in the world and were founded in 1799. As well as providing specialist support, housing and social care, we have expanded our work in recent years to raise awareness of the high risk of sight problems in children and adults with learning disabilities. We have a wealth of information including free easy read factsheets about eye care and eye health and a simple to use database of opticians who can support people with learning disabilities to have an eye test and access good eye care. We also offer training in eye care and vision.

List of SeeAbility resources and support

SeeAbility's accessible easy read information on sight tests and glasses for use by people with learning disabilities, supporters and community optical practices www.seeability.org/myeyecare

SeeAbility's database of opticians helps people understand where they might go www.seeability.org/find-an-optician

SeeAbility's Functional Vision Assessment tool and our training opportunities such as our Eye Care and Vision Charter, or joining our Peer Educator Network are here www.seeability.org/our-services/advisory-services

SeeAbility's eye surgery support plan www.seeability.org/uploads/files/PDFs_Books_Easy_Read_/ESSP_full.pdf

Read more about SeeAbility's Children in Focus Campaign including videos, research reports and easy read forms
https://www.seeability.org/children-in-focus
Read more about the links between different conditions and links with sight problems
https://www.seeability.org/children-in-focus/?article=disability-and-vision-links

PMLD LINK
sharing ideas and information
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Southern Derbyshire Service for People with Profound and Multiple Learning Disability

Debbi Cook

In Southern Derbyshire we have 5 locality teams serving the Adult Learning Disabled population. We take people from transition at 18 to the end of life. Each team has a nurse, a physiotherapist, an occupational therapist, a speech and language therapist and a psychologist. Our PMLD population is a small percentage of our overall work, but some of the most complex and rewarding work we do. The service we provide for our clients is based solely on the principle of being Person Centred. This is never more self-evident than in the work we do with our profound and multiply disabled clients.

In our experience the PMLD clients we see:

- Have a profound learning disability
- Have a severe physical disability
- Need skilled carers to understand and interpret their communication
- May have difficulties with eating and drinking and may be PEG (Percutaneous Endoscopic Gastrostomy) fed
- Often have additional sensory problems e.g. sight and hearing.
- Often need exceptionally high levels of support with all aspects of their care due to their multiple complex health needs
- May have episodes of behaviour that are difficult to understand, interpret and manage.
- Often have epilepsy
- May have autism and/or additional syndromes

Currently in Southern Derbyshire, there are approximately 159 clients with PMLD. These numbers reflect those who are permanent wheelchair users and those who are ambulant (often with assistance i.e. gait trainers and walking frames). While these numbers do not seem particularly high, the amount of input these clients need is exceptional as they often have complex, multiple, life-limiting conditions, and many are still being cared for at home by family. Prospective numbers coming into the service are high, increasing rapidly, and the conditions people present with are more complex. Over the last 20 years neo-natal care has improved and children with conditions that would have previously precluded them from surviving into their teens are now being managed effectively, prolonging their survival. Services need to consider the resource implication of so many children with complex needs coming into Adult services.

The motivation for all our work

The driver for all our work with this client group is that we value them for being themselves, not for what they can do, not for what we wish they could do, not for what society thinks they should do. Our service hinges on the ability to respond and communicate with our clients on the most instinctive level, using techniques such as Intensive Interaction to create a bond of acceptance that allows us to provide an empathetic and compassionate service that meets their individual highly complex needs. This client group depends on total care and support given by others and is therefore the most vulnerable group of people the service provides for.

We also engage and support the carers, both families and professionals as they are the lynch pin in identifying, treating and supporting this very special client group. Professional carers need intensive training and support to keep their clients safe and healthy. Parental and familial carers need even more support and understanding of the care they provide. Parents, siblings and other relatives are often providing cradle to grave care for this client group and dealing on a daily basis with emotional, often distressing and physically draining activity. They need our assistance and understanding to manage the enormity of the tasks they undertake, twenty four hours a day, 365 days a year.

‘Families caring for a son or daughter with profound intellectual and multiple disabilities face an exceptionally heavy responsibility of care’. Mansell (2010)

Within the Learning Disability Service, we operate in episodes of care. This means that clinicians work on specific goals and once these goals have been achieved they will be discharged. However, due to the complexity of the needs of people with PMLD we work differently, and individuals often remain open to us for a substantial period of time. Clients with PMLD are often supported by our staff for the whole of their lives as their health needs are ever changing and their wellness hangs in a balance that can be tipped into life-limiting by something as simple as a small misjudgement in giving a drink or even a change of weather. This has a profound effect on staff that consequently need the close support of their fellow team members to help them cope with the emotional highs and lows that arise from dealing with this client group.

The community teams work closely with other agencies e.g. Social Services, Primary and Secondary Health care to provide seamless, optimal care. We also have the Complex Needs Clinic for clients with PMLD. The Complex Needs Clinic was started in 1999 and was required because most clients with PMLD were seeing multiple medical practitioners both from Primary and Secondary care and there was a lack of communication between Medical Services. The clients with PMLD were also not having a regular "overall" review, which in view of their complex health needs was deemed essential. The Clinic is now seen as a National example of Good Practice.

The Clinic is run on a weekly basis by Dr Xia Lin, Consultant in Rehabilitation medicine, and clients with PMLD from all over Southern Derbyshire are reviewed yearly or more often if appropriate. Clients are supported by carers or family and staff from the Learning Disability team, usually the Physiotherapist or the Nurse. Dr Lin looks at all aspects of the client's health from management of conditions like epilepsy, spasticity and orthopaedic problems, to aspects of basic care such as bowel management and posture. The Service has proved invaluable over the years as Dr Lin is able to "fast-track" clients into appropriate departments, and also monitors their on-going health problems.

Outcomes of an internal audit

In November 2013 the Service undertook an internal audit. This revealed that hospital admissions in Southern Derbyshire among this group of clients, with such complex needs, were significantly lower than in other parts of the country (10.5/1000 as opposed to the National Average of 70/1000). The Health needs of this client group are varied, multifactorial and often life-limiting. For example, if a client has a dislocated hip they may be unable to side-lie, so they can't have their chest treated on that side.

If they get a chest infection the coughing increases their spasticity, making their back deformity worse, which misaligns their head so that when they drink they become distressed and aspirate. Their treatment often involves the whole team supporting the client and their carer, with overlapping roles in order to maximise the efficiency and efficacy of service delivery.

The intended overall outcome for all PMLD clients is for them to be Healthy, Happy and Safe. All Services for this group, regardless of profession have this as an end goal. The fact that we have much smaller numbers than the National Average being admitted to Hospital in Southern Derbyshire proves that the Service is effective in maintaining the health of these people with such multi-faceted life-limiting conditions.

What must be taken into consideration when looking at Outcomes is that for PMLD clients we are looking at 24 hours a day, on-going life-long management of complex life- limiting conditions. Services are predominantly provided through carers and families with support from the appropriate professionals.

We pride ourselves in Southern Derbyshire with working closely with client, families and paid carers to provide the best service we possibly can for this small but important group of people.

Our treatments need to be flexible, individual, compassionate and creative, holding the client at the centre.

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PMLD LINK
sharing ideas and information

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Acute Liaison Nurse Role

Sadie Clarke and Rebecca Crossley

In 2007 Mencap published a report called *Death by indifference*, which highlighted the preventable deaths of six individuals with learning disabilities owing to failings within the NHS. The barriers in accessing health services for people with learning disabilities were documented in an Independent Inquiry Healthcare For All ((Michael, 2008), which included the recommendation to implement a confidential inquiry into the premature deaths of people with learning disabilities (CIPOLD). The inquiry (Helsop *et al.*, 2013) reviewed the deaths of 247 people with learning disabilities over a two year period, and found that on average men with a learning disability died 13 years earlier that the general public and women with learning disabilities died 20 years earlier.

The investigation highlighted that many premature deaths were due to significant difficulty or delay in diagnosis, further investigation or specialist referrals, often as a direct result of unrecognised care needs and problems with coordinating care. People with profound intellectual and multiple disabilities (PMLD) have substantial, sustained, complicated health care needs (Mansell,2010). Recent research estimates that there are just over 16,000 adults with profound intellectual and multiple disabilities in England (Emerson2009).

CIPOLD found that people with learning disabilities experience institutional discrimination with the NHS, and the needs of people with profound intellectual and multiple disabilities were poorly understood. General health services, have failed to make sufficient reasonable adjustments for people with learning disabilities (Michael, J cited in Mansell 2010, p.5) It has been well documented that people with learning disabilities are significantly more likely to experience poorer health outcomes as a direct result of unmet health needs.

The James Paget University Hospital (JPUH) challenges the inequalities that people with learning disabilities often experience, by regarding them as a high priority owing to their often complex and unmet health needs. A flagging system is used within the hospital to identify and respond to the needs of people with learning disabilities. The system records data of:

- Future planned activities (elective procedures),
- Current inpatient activity,
- Cancelled appointments,
- Frequent attenders,
- Mortality statistics.

This provides an opportunity for the Acute Learning Disability and Autism Liaison Nurse (LDLN) to plan care and ensure reasonable adjustments are made to promote equal access to healthcare and a good quality of life. However, all staff that work within the hospital should be aware of patients that have learning disabilities and the additional support they may require. JPUH uses a hospital alert system that notifies all staff that reasonable adjustments may be required to improve health outcomes for people with learning disabilities and/or autism.

The following reflections are from personal practice experience. All patient details have been changed to ensure that patient confidentiality is maintained. This account aims to demonstrate skill development, professional awareness, opportunistic learning and critical incident analysis that promote new insight into nursing.

Future Planned Activity (Elective Procedures)

The increase of Annual Health Checks for people with learning disabilities has resulted in more people with learning disabilities accessing secondary health services to screen and treat preventable illness. Patients with learning disabilities attend JPUH for a variety of outpatient appointments; the most common are endoscopy, colonoscopy, and community dental treatment under general anaesthetic. The JPUH hospital flagging system records information regarding future planned activity and elective procedures for all people with a learning disability. This information is used to contact the individual to determine the level of support needed and requirement of reasonable adjustments. The use of a hospital alert system ensures that all professionals involved are notified that this individual has a learning disability and/or autism and may require reasonable adjustments to improve health outcomes during pre-planned admissions.

Reasonable adjustments are a legal requirement of The Equality Act (2010) and of course The Autism Act (2009) to ensure that disabled people are able to access mainstream services that they would not be able to access without adjustments. Data collected at JPUH proves that a lack of reasonable adjustments to support patients during elective procedures has resulted in people not attending hospital or arriving at hospital unprepared, so that the procedure cannot go ahead. Non-attendance is not only detrimental to an individual's health but high levels of non-attendances cause significant cost implications for the hospital. Improved pathways have be shown to support people with learning disabilities and/or autism to gain equal access to health services. Examples of reasonable adjustments for elective admissions may include; desensitisation work to reduce anxiety, a fast track process, a quiet room and easy read information to aid understanding.

Case Example

Jonny requires a dental extraction under general anaesthetic as previous attempts have been unsuccessful and any further attempts would cause unnecessary distress. Jonny is a young man with profound intellectual and multiple disabilities which includes autism and can become anxious in unfamiliar surroundings. Some admissions to hospital may be complex and it may be appropriate to arrange a pre-admission planning meeting. This provides an opportunity for all involved to agree on plans and responsibilities for the admission and outline plans for discharge. Those involved in a planning meeting may include the individual, family, community learning disability team, allied healthcare professionals, anaesthetic consultants, medical consultant, Independent Mental Capacity Advocates (IMCA) and any other support staff. Planning meetings also provide an opportunity to assess capacity to consent to treatment and the appropriateness of a best interest decision. A planning meeting was scheduled for Jonny and those attending were as follows:

- Jonny (Patient)
- Jonny's Family (Mother and Sister)
- Familiar Carer
- Consultant Anaesthetist
- Community Dental Nurse
- Learning Disability and Autism Liaison Nurse
- Reasonable adjustments agreed (see table below)

Capacity considerations

People with profound intellectual and multiple disabilities have great difficulty communicating; they typically have very limited understanding and express themselves through non-verbal means, or at most through using a few words or symbols (Mansell 2010:3). A capacity assessment "Green Sticker" (Image 1) was completed during the planning meeting in which all members attending the meeting agreed that Jonny lacked capacity to make an informed decision regarding his procedure as he was unable to understand information presented in accessible format and was unable to weigh up and retain the information long enough to be able to make an informed choice.

Jonny was experiencing pain which caused him significant distress. All persons present at the meeting agreed that the procedure was in the best interests of Jonny and a consent form 4 (Image 2) (consent form for those who lack capacity recently updated to include legislative changes was completed).

Additional Support Needs	Reasonable Adjustment Required
Jonny has significant behavioural needs. He does not like big crowds, bright lights or noises and will become anxious in these environments.	1. Arrive at the appointment as late as possible to avoid waiting. 2. Jonny's sister and support worker have a strong therapeutic relationship with him and are confident in their ability to manage his anxiety during the admission to hospital. 3. Jonny will be prescribed an anti-anxiety medication to help him stay calm prior to the procedure which he agreed to have. 4. It is essential that Jonny has a side room for his procedure as he will not manage the busy environment of a bay. 5. Minimal staffing in the room during induction of anaesthesia to reduce anxiety.
Jonny's daily routine is based around meal times and a change to this may be difficult for him	6. Arrange a morning appointment and to be first on the procedure list.
Jonny may not tolerate a gas induction of anaesthesia as he doesn't like things in his face	7. Jonny is used to having his blood taken and does not have anxiety of needles, an intra-venous (IV) induction is recommended. 8. Emla cream will be prescribed to be applied (Support Staff or Family) 1 hour prior to cannulation to suppress the pain of the needle insertion.
Jonny does not have a history of swallowing difficulties, however, he does not chew tablets.	9. Liquid analgesia for post-operative pain.
Jonny has a diagnosis of epilepsy and has tonic clonic seizures that are controlled with medication.	10. Jonny will not consume any food from midnight prior to the procedure and can have clear fluids up to 2 hours before. All medications can be taken as normal.

Current inpatient activity

CIPOLD (2013) recommended that there should be clear identification of people with a learning disability within healthcare systems so that reasonable adjustments can be put in place.

Poor risk assessment and management has been identified as the root cause of death for people with learning disabilities in hospitals. The flagging system allows the LDLN to monitor and assess all inpatient activity to ensure that their health needs are being met. This is achieved by completing a rapid risk assessment to support identification of specific risk areas and need for extra support. Areas to be assessed are as follows:

Personal Safety

In 2009 the Ombudsman's report stated that people with intellectual disabilities have a significantly higher risk of adverse events happening to them in hospital (Six Lives, Parliamentary and Health Service Ombudsman, 2009). Some people may be unable to maintain their own safety due to their level of learning disability. Unfamiliar environments can cause distress and agitation, for this reason people may become non-compliant with interventions and remove medical devices. Patients that are unable to manage their posture and position are at increased risk of pressure area breakdown. Other patients that wander or attempt to abscond are at high risk of falls. Serious incidents that result from a lack of assessment regarding personal safety can significantly affect the length of stay in hospital.

Case Example
Nathen is a young man who has profound and multiple learning disabilities, his needs are complex and he requires additional support in unfamiliar environments. In the community Nathen is funded for 1:1 support 12 hours per day, however, it was identified that due to the level of Nathen's disability he is unable to identify risks in his environment and may become distressed around people that don't understand his additional needs. The JPUH can provide a carer's contract which allows familiar carers to support individuals during their admission to hospital to prevent risks associated with personal safety. As Nathen already has funding for 12 hours of 1:1 support the ward provided an addition 12 hours of funding to allow his familiar carers to provide 24 hour of 1:1 support to ensure Nathens' family and Nathen receive the best outcomes during their stay. The funding stream comes from the ward budget which is agreed with the matron from the admitting ward following completion of the risk assessment.

Swallowing, nutrition and hydration

Dysphagia is a condition that effects approximately 1 in 3 people with a learning disability (Howesman, 2013). Poor management of dysphagia can lead to avoidable deaths (Helsop et al, 2013). CIPOLD identified that poor record keeping contributed to the premature deaths of people with learning disabilities. Of the deaths reviewed, little attention was given to preventing potential problems such as swallowing difficulties and nutrition within the hospital environment. All staff should note and respond to the alert on the system to signify individual additional needs and be able to access agreed plans and any other information provided such as the hospital passport. This processes advocates an environment that is proactive to potential difficulties and challenges rather than reactive, as this will ultimately improve patient experience.

Case Example
Jo along with her profound and multiple learning disabilities has a severe anxiety of hospitals; this was heightened by nursing uniforms and scrubs. When staff attempted to support Jo during meal times she became significantly distressed which caused her to aspirate her food, increasing her risk of aspiration pneumonia. Initially 1:1 support was funded to assist her during meal times; following this nursing staff were provided with a plain t-shirt to cover their uniform whilst supporting Jo. This reasonable adjustment enabled Jo to establish good therapeutic relationships with the staff and reduced her risk of aspiration as a result of becoming distressed.

Communication

Communication is key to nursing patients with a learning disability, however, it is common for people with learning disabilities to have communication difficulties and they may rely on others interpreting their non-verbal behaviours. Hospital passports aim to help staff to understand and interpret choices, preferences, likes and dislikes, and provide specific information about how to communicate with an individual.

Case Example
Annie attended A+E with a laceration to her left leg, her mother reported that this was a deliberate act of self-harm. Annie has autism and has no verbal communication along with cerebral palsy. The Doctor felt that a referral to CAMHS (Child and Adolescent Mental Health Services) was appropriate for Annie. However Intensive interaction was used to develop an understanding of her behaviours, and it was thought that she could be indicating stomach pain.. After a discussion with her mother it was discovered that she had recently been prescribed movicol to soften her stool to increase bowel motion. However the GP had not advised the mother on when to stop the medication and it was now causing Annie to experience cramping and bowel discomfort. The mediation was stopped and after a few days Annie's self-harming behaviours ceased. Diagnostic over shadowing could have resulted Annie's pain and discomfort being unresolved without specialist advice on

communication which may have resulted in an inappropriate referral to child Mental Services.

Mental Capacity

Learning disability liaison nurses must educate other health professionals on the Mental Capacity Act 2005 which states that people must be assumed to have capacity unless otherwise stated. To have capacity an individual must be able to comprehend and retain information regarding the decision, especially as to the consequences of having or not having the intervention, weigh up the information in the decision making process and relay the information back by using their preferred methods of communication.

When a person lacks capacity to consent to treatment then these best interest decisions should be considered. According to the Nursing and Midwifery Council Code (NMC, 2015) nurses should act in best interest of people at all times, all of the following should be considered when making decisions in the best interests of another individual:

- Past and present expressed wishes and feelings.
- Religious beliefs and values.
- Any other factors that the individual would express if they were able to do so.

Case Example
Louise has a profound learning disability and cerebral palsy. When she is acutely unwell she experiences increased difficulty with verbal communication. Unfortunately because of her physical disabilities healthcare professionals often make a judgement on levels of understanding and capacity to consent. After completing a rapid risk assessment with Louise, it was observed that her level of understanding was in fact in question and a two stage capacity assessment (Green Sticker) needed to be completed with regard to escalation to ITU (Intensive care unit). As Louise had no family or legal representative an IMCA (Independent Mental Capacity Advocate) needed to be instructed to ensure the proposal to escalate Louise to the Intensive Care Unit was in her best interests. The design and implementation of the "Green Sticker" a formal way of documenting and auditing adherence to the Mental Capacity Act 2005 has proved extremely useful to medical and nursing colleagues, where assumptions are sometimes made the "Green Sticker" supports the clinician and patient through the assessment process as well as documenting this coherently along with the outcome. At the James Paget Hospital treatment options are available in accessible format .

Epilepsy

Epilepsy is a significant co-morbidity for people with learning disabilities. It accounts for a large number of acute hospital admissions and increases the risk of physical injuries, aspiration and deprivation of oxygen. All staff should be aware of the risk, triggers and management of a person with epilepsy. All inpatient seizure activity should be recorded and monitored. Specialist professionals should be involved in any changes in medication or management regimes.

Case Example
Matthew was admitted to hospital with a dislodged PEG. Although this can usually be reinserted within the community, his stoma site had closed which meant that he would require an endoscopy under sedation to reinsert it. All of Jonny's nutrition and hydration is administered via his PEG site therefore; he was not receiving any nutrition and had IV fluid running to ensure he was kept hydrated. Matthew has severe tonic clonic seizures controlled by medication. All of his medication is administered via his PEG and as his seizure activity is increased by illness, anxiety and high temperature, this makes him at high risk of having a seizure. Since his last seizure he has significantly deteriorated, placing emphasis on preventing any other unnecessary seizures. The doctors were able to administer some of his medication via intra venous cannulation, however, his support staff were concerned that he had not had all of his usual medication. This triggered a conversation with the pharmacist about Jonny's risk of seizures who then reviewed his medication to ensure that risk of seizures was prevented. This information was shared with the consultant who reinserted the PEG as a priority. This is a demonstration of effective care coordination and information sharing to improve health outcomes.

Behaviours and Anxieties

The NMC (2015) states that nurses should recognise when people are anxious or in distress and respond compassionately and politely. The hospital can be a difficult environment for many people with a learning disability. The change of routine for some people can be very distressing and this will become apparent in the hospital environment. These behaviours and anxieties can be reduced for pre-planned admissions with the use of desensitisation work, however, this can be challenging for people during emergency admissions. The rapid risk assessment provides an opportunity to assess the level of risk by gathering information and providing care that is proactive in preventing unnecessary situations.

Case Example
Sam who has profound and multiple disabilities was admitted in an emergency, presenting with symptomatic pain caused by an axilla abscess. He had completed a course of anti-biotics which was unsuccessful in

eliminating the infection; the decision was made in Sam's best interest following completion of capacity assessment to have the procedure to drain the abscess to reduce discomfort and to prevent a possibility secondary cause of sepsis. Sam is currently experiencing difficulties with his mental health; he appears very low in mood and has displayed severe anxiety that caused him to become vocally aggressive and tearful when in hospital. Sam's social worker notified the liaison service of a recent safeguarding issue that has resulted in Sam having to be moved into emergency respite care. Sam did not understand why he couldn't go "home" and was clearly very distressed. Unfortunately because of the seriousness of the safeguard concern there was no time to prepare Sam for such a significant life changing event.

Sam needed his abscess drained to reduce the pain and prevent further complications; however, previous negative hospitals experiences have caused him to feel anxious in the theatre department. Following some desensitisation work and continuous reassurance, it became apparent that asking Sam to go to the theatre department for anaesthetic would cause him unnecessary distress. It was agreed that the consultant anaesthetist would sedate Sam in the side room of the ward to prevent any further negative hospital experiences. During the morning Sam was distracted by 1:1 support, when his agitation and anxiety started to increase staff distracted him by taking him for a walk.. Sam's procedure was successful and it was achieved in a calm environment. Following his discharge, a referral was made to community learning disability team to support Sam with his low mood and anxiety. The liaison service worked collaboratively with the community learning disability social worker to ensure further support was given during placement transfers and discharge to prevent any further distress to Sam. Liaison continued with the emergency respite home to make them aware of his current anxieties and referrals made.

Repeat Admissions

As previously discussed people with learning disabilities are likely to have poorer health than that of the general public, therefore, their admissions to hospital will be significantly higher. However, admissions to hospital should be planned and well-co-ordinated where possible. If an individual is attending A+E it is likely to be in an emergency situation or their health needs are not being met in the community. JPUH gathers data on all repeat admissions and shares information with community learning disability teams and GP's to promote continuity of care and raise safeguarding concerns.

Case Example
Sophie is a 23 year old lady with profound and multiple disabilities who is known to the community learning disability service and lives in a supported living environment. She was admitted to hospital with an injury to her right hand. Analysing the data I could see that she had attended A+E over ten occasions with trauma injuries, in the last three years. I made a referral to the JPUH safeguarding team, notified the community learning disability team and had a discussion with her GP. From the discussions I had with other professionals and Sophie it did not appear that she was experiencing abuse however further examinations found an auto immune deficiency. I was able to share this information with the community learning disability team who will now monitor and assess her needs within the community as it is possible that her support needs will be changing and she will regular more regular health monitoring and staff supporting will require more training.

Contact Details

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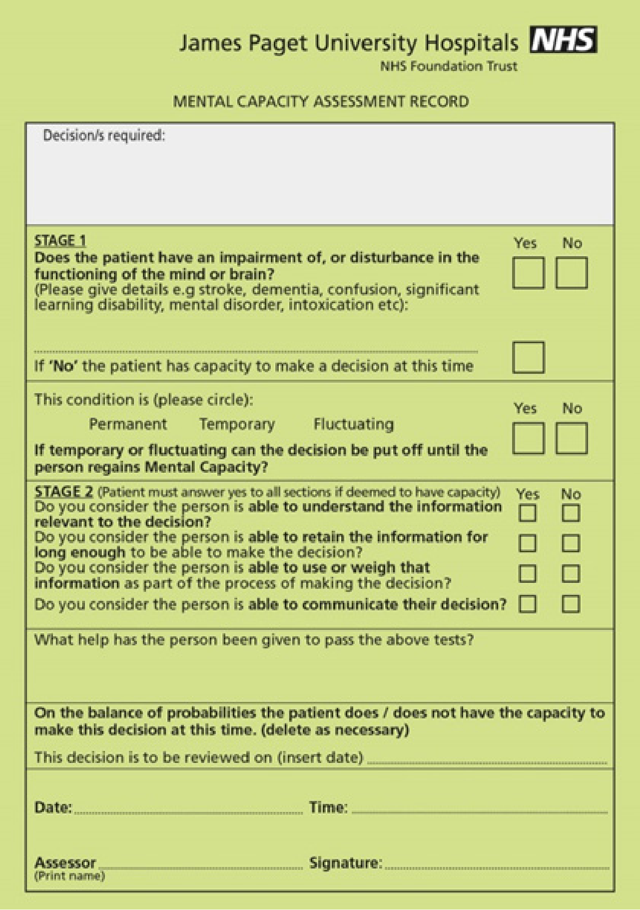


James Paget University Hospitals NHS
NHS Foundation Trust

MENTAL CAPACITY ASSESSMENT RECORD

Decision/s required:

STAGE 1

Does the patient have an impairment of, or disturbance in the functioning of the mind or brain? Yes ☐ No ☐

(Please give details e.g stroke, dementia, confusion, significant learning disability, mental disorder, intoxication etc):

If '**No**' the patient has capacity to make a decision at this time ☐

This condition is (please circle):

Permanent Temporary Fluctuating

If temporary or fluctuating can the decision be put off until the person regains Mental Capacity? Yes ☐ No ☐

STAGE 2 (Patient must answer yes to all sections if deemed to have capacity)

	Yes	No
Do you consider the person is **able to understand the information relevant to the decision?**	☐	☐
Do you consider the person is **able to retain the information for long enough** to be able to make the decision?	☐	☐
Do you consider the person is **able to use or weigh that information** as part of the process of making the decision?	☐	☐
Do you consider the person is **able to communicate their decision?**	☐	☐

What help has the person been given to pass the above tests?

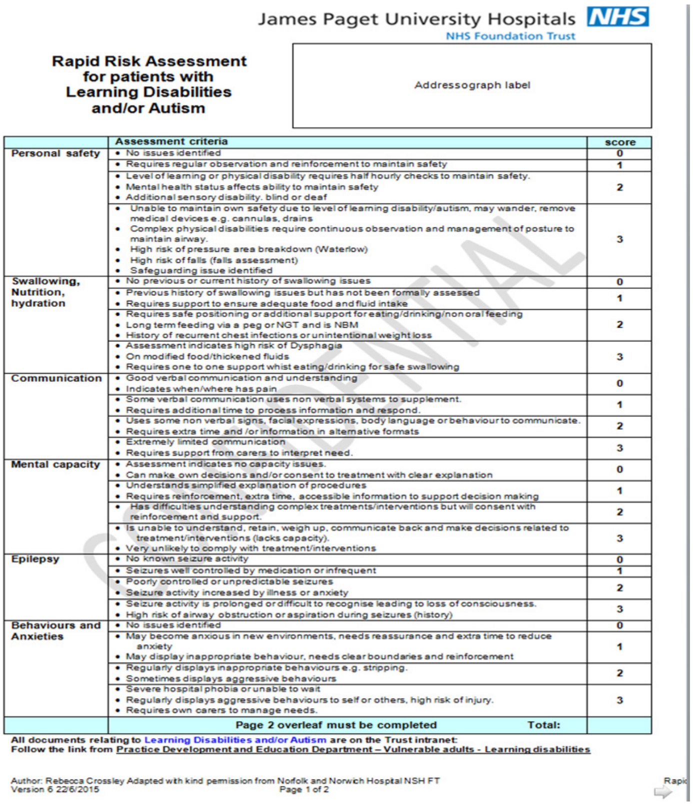
On the balance of probabilities the patient does / does not have the capacity to make this decision at this time. (delete as necessary)

This decision is to be reviewed on (insert date) ....

Date: .... **Time:** ....

Assessor .... **Signature:** ....
(Print name)

Image 1



James Paget University Hospitals NHS
NHS Foundation Trust

Rapid Risk Assessment for patients with Learning Disabilities and/or Autism

Addressograph label

	Assessment criteria	score
Personal safety	• No issues identified	0
	• Requires regular observation and reinforcement to maintain safety	1
	• Level of learning or physical disability requires half hourly checks to maintain safety. • Mental health status affects ability to maintain safety • Additional sensory disability. blind or deaf	2
	• Unable to maintain own safety due to level of learning disability/autism, may wander, remove medical devices e.g. cannulas, drains • Complex physical disabilities require continuous observation and management of posture to maintain airway. • High risk of pressure area breakdown (Waterlow) • High risk of falls (falls assessment) • Safeguarding issue identified	3
Swallowing, Nutrition, hydration	• No previous or current history of swallowing issues	0
	• Previous history of swallowing issues but has not been formally assessed • Requires support to ensure adequate food and fluid intake	1
	• Requires safe positioning or additional support for eating/drinking/non oral feeding • Long term feeding via a peg or NGT and is NBM • History of recurrent chest infections or unintentional weight loss	2
	• Assessment indicates high risk of Dysphagia • On modified food/thickened fluids • Requires one to one support whist eating/drinking for safe swallowing	3
Communication	• Good verbal communication and understanding • Indicates when/where has pain	0
	• Some verbal communication uses non verbal systems to supplement. • Requires additional time to process information and respond.	1
	• Uses some non verbal signs, facial expressions, body language or behaviour to communicate. • Requires extra time and /or information in alternative formats	2
	• Extremely limited communication • Requires support from carers to interpret need.	3
Mental capacity	• Assessment indicates no capacity issues. • Can make own decisions and/or consent to treatment with clear explanation	0
	• Understands simplified explanation of procedures • Requires reinforcement, extra time, accessible information to support decision making	1
	• Has difficulties understanding complex treatments/interventions but will consent with reinforcement and support.	2
	• Is unable to understand, retain, weigh up, communicate back and make decisions related to treatment/interventions (lacks capacity). • Very unlikely to comply with treatment/interventions	3
Epilepsy	• No known seizure activity	0
	• Seizures well controlled by medication or infrequent	1
	• Poorly controlled or unpredictable seizures • Seizure activity increased by illness or anxiety	2
	• Seizure activity is prolonged or difficult to recognise leading to loss of consciousness. • High risk of airway obstruction or aspiration during seizures (history)	3
Behaviours and Anxieties	• No issues identified	0
	• May become anxious in new environments, needs reassurance and extra time to reduce anxiety • May display inappropriate behaviour, needs clear boundaries and reinforcement	1
	• Regularly displays inappropriate behaviours e.g. stripping. • Sometimes displays aggressive behaviours	2
	• Severe hospital phobia or unable to wait • Regularly displays aggressive behaviours to self or others, high risk of injury. • Requires own carers to manage needs.	3
	Page 2 overleaf must be completed Total:	

All documents relating to Learning Disabilities and/or Autism are on the Trust intranet:
Follow the link from Practice Development and Education Department – Vulnerable adults - Learning disabilities

Author: Rebecca Crossley Adapted with kind permission from Norfolk and Norwich Hospital NSH FT
Version 6 22/6/2015 Page 1 of 2 Rapi

Image 2

PMLD LINK
sharing ideas and information

Vol. 28 No. 3 Issue 85

Using the Health Equalities Framework (HEF) to improve health and well-being A case study

Elaine Thomas and Gwen Moulster

The Health Equalities Framework (HEF) was originally developed by a group of four consultant learning disability nurses in 2013 and updated in 2015 to help learning disability nurses demonstrate whether the care they provide makes a difference. It is now regularly used by other professionals and carers and is also a useful tool for families who can use it to check how their loved ones are doing. It was created in response to concerns that people with learning disabilities experience reduced healthy life expectancy, premature and avoidable mortality, and significantly compromised quality of life when experiencing ill health.

Using the Health Equalities Framework (HEF) to improve The HEF is based on the known determinants of health inequality experienced by people who have learning disabilities. Using the HEF enables people to identify priorities for care and support and to measure how much impact health inequalities are having on a person.

The HEF doesn't measure illness, it measures things like how and where someone is living, their opportunities to access good health and social care and the quality of help they get. The HEF produces a graph and tables demonstrating the level of health inequality before and after intervention.

Case study

Sam (not his real name) is 42 years of age and has a diagnosis of a severe learning disability and cerebral palsy. He has limited verbal communication using occasional words but he communicates mostly through his facial expressions and body language.

Sam is usually a happy person he loves listening to music and looking at magazines with others. He particularly enjoys being with his family. He usually engages with care staff and initiates interactions, although at times he does like to sit quietly.

Due to cerebral palsy Sam's limbs are contracted most of the time but with gentle touch he can be encouraged to relax. Sam loves his food and has a very good appetite even when poorly although he may then refuse part of his meal. Sam has recurrent urinary tract infections (UTIs) and has had recent major abdominal surgery. He uses a wheelchair, is unable to weight bear and uses a hoist for all transfers.

Sam is unable to reliably indicate when he is in pain. He is usually very cooperative but on occasion he shouts out especially during personal care or whilst being hoisted. His family and carers also report that sometimes he pulls faces, they don't think he likes being moved.

Sam sleeps in a high low bed and prefers to be on his right side. Sam's dad says he fidgets a lot when uncomfortable and on the last two occasions that Sam was diagnosed with a UTI he initially didn't sleep well.

When Sam is unwell he often sleeps deeply, his carers think this is because he is exhausted.

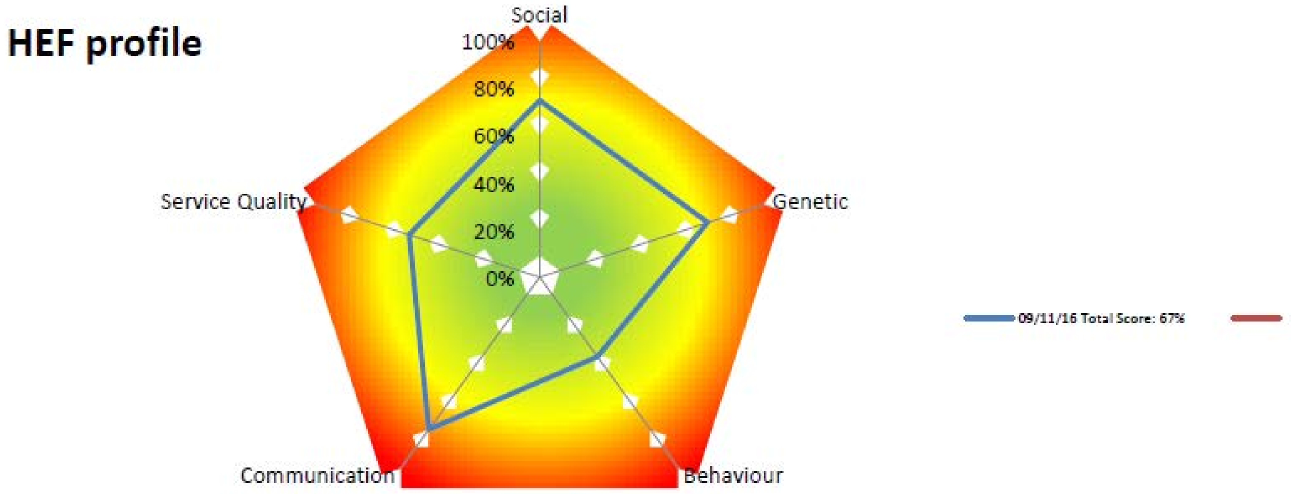
Sometimes Sam becomes pale and clammy which is unusual for him because he normally has pink cheeks. He is often sweaty even when it's cold and usually sweats profusely for no apparent reason.

The ideal HEF profile will show a low score in all areas (see figure 1). Figure 1 demonstrating Sam's Initial HEF Profile. Unfortunately limited space prevents sharing illustrative HEF tables here'

The HEF profile created at initial contact with Sam shows the health inequalities he experienced were causing a very high impact on his health and wellbeing with an overall score of 67%. A high score at this level indicates risks of long term serious health problems and high risk of premature death.

Sam had had an increasing number of admissions to the acute hospital through A & E. By utilising the HEF it was possible to establish that there was no clear known indication of pain or any pain intervention plan in place to support Sam.

Figure 1: Initial HEF profile



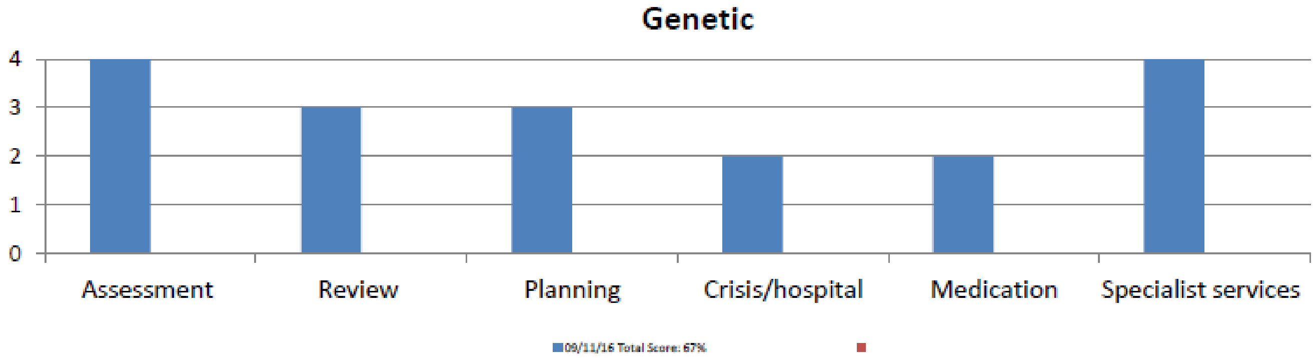


Table 1: Example of Initial HEF Profile - Genetics

Following admission to a specialist assessment and treatment unit for people with learning disabilities with PMLD and complex health needs, using the information collated through the HEF, a pain assessment was completed and a person-centred intervention plan and robust care plans were developed.

In response to the development of the Pain Picture regular non-opioid pain relief was prescribed for the post-operative period following Sam's abdominal surgery. The carers supported Sam with position changes, therapeutic massage, hand on hand simple touch and verbal encouragement during physical interventions and identified the need to test for possible UTI's. Where significant indicators were present, prompt contact was made with the GP.

Following the interventions made, the impact of the health inequalities Sam experienced had dramatically reduced, with the total score dropping to 35%. It is particularly notable that the scores related to communication and genetic determinants of health inequalities were significantly lower.

Using the HEF helped the practitioners to prioritise early identification of possible pain and illness, leading to timely treatment and reducing the risks of further ill health. Sam's hospital admissions significantly reduced and referrals were made to other health professionals i.e. Physiotherapy and the Tissue Viability Nurse.

Although Sam's family and carers know him well, they hadn't connected everything they knew about him to formulate an early picture of when things might be going wrong. The Pain picture helped them to do this by capturing their knowledge and documenting it in a very person centred way that helps everyone see how he is responding. The HEF profile helped demonstrate the difference made to Sam's health and wellbeing.

Figure 2: Pain Picture (Moulster, 2015)

Pain Picture - Known indicators of pain		
Indicator	Family Observation Normal	Family Observation Pain
Skin colour	Pink no unusual features	Can become pale / very white may also have red / crimson cheeks especially if pain is severe
Sweating	Often warm even when the environment is cool. May sweat.	Sweats profusely (clammy) Forehead and hair gets wet, also chest and sweaty palms
Absence of contentment/ facial expression	Normally happy, smiling, relaxed, engages with staff, making eye contact, interested in his environment. For short periods of time it is normal for him not to engage but these periods are not persistent (less than 10 mins)	Shuts eyes (often mistaken by carers for sleep), withdrawn, unsettled. Grimaces
Aggression	None, amenable, wanting to please, becomes upset when others display behaviours of concern	Can become frustrated, may hit out during personal care although not targeted at an individual. Occasionally punches his let palm with right fist.
Breathing	Rate between 16-18 per min	Noisy breathing, fast and raspy rate above 18 per min
Behaviour e.g. eating, sleeping, behaviour patterns	Eats well Generally, sleeps well but broken pattern at this time due to frequent episodes of personal care	More irregularity in sleep Tends to sleep heavily through exhaustion May eat but may not finish a meal
Body tension	Body quite rigid, cooperative with encouragement.	Limbs and torso becomes increasingly rigid, reluctant to move.
Increased vocalisation	Will engage at normal volume	May shout 'stop it', May shout "stop it" with increased volume and may refuse to engage altogether
Crying	Never cries	Never known to cry

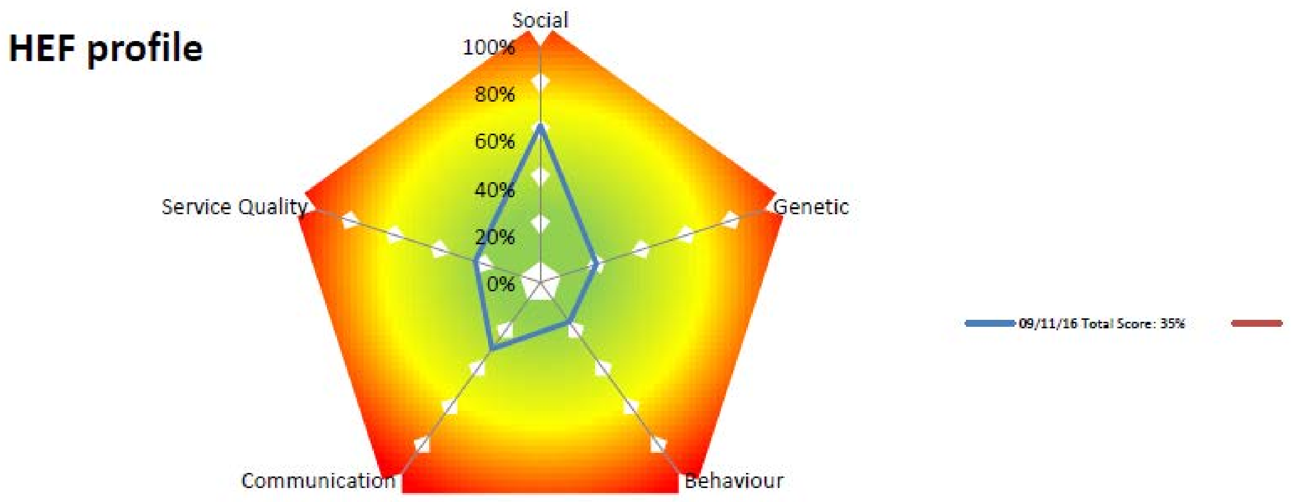
Pain Management Recommendations:

Green Little or no pain identified, no need for extra clinical intervention, maintain interventions that reduce likelihood of pain. Regular movement to help change position. Massage legs, feet and hands as per care plan.

Amber Evidence of some pain, consider pain relief, including therapeutic approaches known to be helpful e.g. massage, change of position, administration of simple non-opioid analgesia currently 500mg x 2 tabs QDS of paracetamol as prescription. Benefits from hand on hand soothing touch, verbal reassurance
If UTI is suspected (see care plan), obtain a urine sample and on result treat as directed by GP.

Red: Evidence of significant pain, continue as above AND contact GP, or 999 for medical emergency

Figure 3: Follow up HEF profile



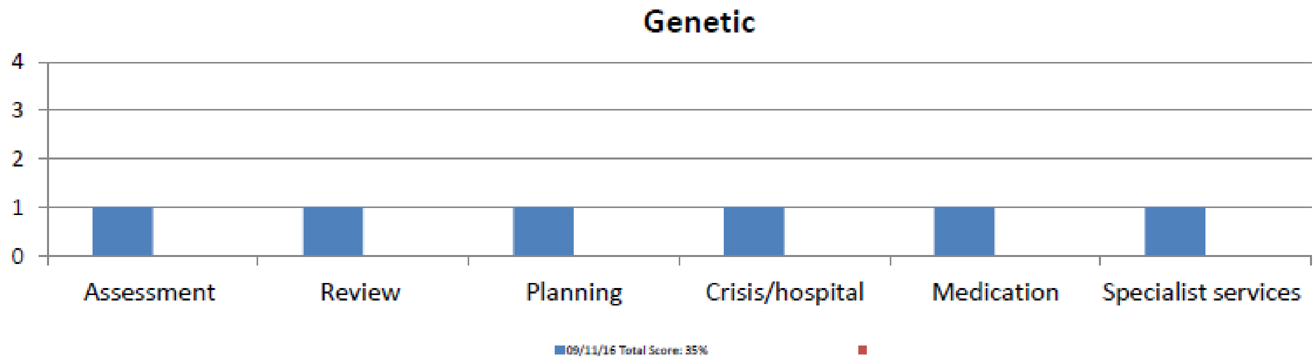


Table 2: Example of Follow up HEF Profile – Genetics

Footnote:

Limited space in this article prevents sharing illustrative examples of the more detailed HEF tables. Please contact the author for further information . More information on the evidence base that underpins the HEF can be found in the Complete Practitioners Guide (Atkinson et al 2013) and in the data collected on health inequalities by the Learning Disabilities Public Health Observatory (2011, 2012).

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Personal Health Budgets

Glenys Newman

‘We offer personal health budgets, but people generally don’t want to take them up as they are a lot of work’.

This comment was made by a manager of Continuing Care team and is likely to be one of the reasons that the take up of personal health budgets remains low – but is it true? This article is jointly written with Independent Lives and Glenys Newman, a user led charity that provides one to one support on how to use a personal health budget, and if needed advice and guidance regarding the employment of staff. The article briefly sets out what personal health budgets are, how they work and what Independent Lives does to support individuals and their families. The article includes a case study showing how a personal health budget is working for one young woman with profound and multiple learning disabilities.

What are personal health budgets?

Personal health budgets aim to give people with long-term conditions and disabilities more choice and control over the healthcare and support they receive. Following an assessment, an amount of money is allocated to support an individual’s identified health and wellbeing needs, planned and agreed between the person and/or the family and the local NHS team. Since October 2014, adults on NHS Continuing Health Care and children in receipt of Continuing Care have had a right to have a personal health budget. The NHS can also offer personal health budgets to people with long term health conditions or those with mental health problems.

How do personal health budgets work?

National Guidance on Direct Payments for Health Care Regulations 2013 explain how personal health budgets can be managed in a number of different ways.

- Firstly, an individual may wish to receive a ‘Direct Payment’. In this case the money will be paid to them or their representative directly. Individuals can then purchase the care and support they need in conjunction to what is agreed in their support plan.
- Secondly, individuals could receive a ‘Notional Budget’. In this case the NHS will hold the money and will buy the goods or services chosen to meet health and well-being needs.
- Finally, the money could be managed as a ‘Third Party Budget’. The money is paid to an organisation or trust that holds the money on people’s behalf and will help support them to remain in control but provide more in-depth practical support to arrange their care. Lack of capacity to manage a personal health budget should not be a barrier because of this option.

Personal Health Budget advisors at organisations such as Independent Lives help people to decide which management method will work best for them.

Person centred support planning

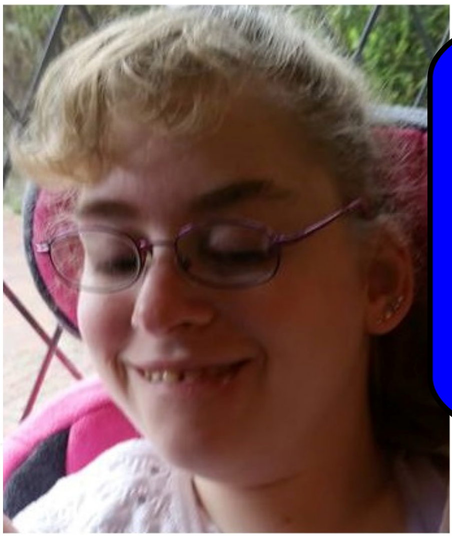
At the heart of personal health budgets are good, person centred conversations, helping to acknowledge what is important for and to the person so they remain healthy. Advisors guide people and their families through these conversations, and the information is captured in a support plan; this can be written together with the individual, their family, the personal health budget advisor and health care professional. Independent Lives provides a support planning and Direct Payment service specifically for people in West Sussex, Hampshire and Portsmouth who are eligible for a personal health budget. They help people to look at their needs holistically in order for them to receive the best, most appropriately tailored and coordinated package of care. The three advisors at Independent Lives all support their own family members with a personal health budget, so talk from personal experience.

Once a personal health budget advisor is assigned, the individual will receive one-to-one support from that same advisor for as long as they receive a personal health budget. They’ll work closely with them, family and the NHS to ensure that the support plan is still working as well as it should be, and will help to rewrite the plan if it is recognised that something could be working better.

Support to train Personal Assistants (PAs)

When people employ their own PAs, advisors can support them to access appropriate training. The Independent Lives clinical nurse training

Natasha



What people like and admire about me…

I am a kind, sensitive and caring young lady.

My smile lights up a room but I need to feel comfortable with you for you to see it – if you are really lucky I will poke my tongue out at you!

My giggles are infectious and I have a wicked sense of humor – so enjoy a funny story or two.

I am very brave and only cry if I am in a lot of pain.

How best to support me…

I communicate using a yes/no response and a Communication book but I need time, a quiet environment and to feel secure with you.

My vision is poor so things need to be shown to me up close and images need to be clear for me to see them. I wear glasses all the time. I am also very light sensitive so need my glasses (the lenses darken) and lots of factor 50 when outside as I burn VERY EASILY.

When moving and handling please be aware of my high anxiety levels and osteoporosis. Speak to me calmly and ensure I feel secure otherwise I will panic and spasm. I dislike lying flat on my back so will need a pillow under my head and reassurance at times.

I rely on others for all my care needs and have drinks and feed through my button. I can have pureed food and tasters of thickened fluid but you need to refer to my feed guidance sheet. I enjoy a bit of chocolate or mashed cake!

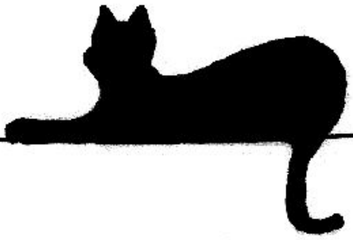
It is important that medication is given on time – to ensure I remain comfortable and healthy.

What's Important to me…

My family – mum, dad, brother Mat and his wife Claire and my three cats – Monty, Rosie & Jim.

I love to look pretty so enjoy being helped to choose nice clothes to wear, make-up and having my nails done. I like to be around others and dislike being alone – I am one of life's observers. I need to feel safe and need a lot of reassurance, both verbal and physical. I like to have calm approach and dislike sudden loud noises. I am unable to change position for myself and need frequent position changes to keep me comfortable and free from sores. My muscles are very stiff and this can cause me pain and discomfort which can make it hard for me to communicate. Please don't assume that I don't understand what is going on around me or forget to include me in discussions.

Although I rely on others to help me do things, I soon become bored so need lots of stimulation. I enjoy my music and stories and have lots of things on my iPod to listen to. My favourite films are musicals like Pete's Dragon, Walking on Sunshine and Mary Poppins, though I have lots more! I am not as delicate as I seem and love to dance and move in my chair with assistance. I also love physical activities such as rebound therapy, riding my trike and hydrotherapy.



service 'Your Training Your Way' has been developed to support the training and development of PAs. Examples of training includes essential skills to undertake a range of clinical tasks which can be safely delegated such as enteral feeding and tracheostomy care to ensure they know how to support people safely and in a person centred way. This also provides PAs a chance to develop new skills, increase confidence and support their career as a PA. A personal health budget holder who recently trained their PAs using the project said: The Nurse team are really personable; they listen to the needs, and have been so responsive in finding options that work for us and that will fit into a busy schedule. It feels like a true partnership approach.

How a personal health budget is working for one young woman with profound and multiple learning disabilities

Natasha left full-time education at the age of 19 and is now supported to remain living in the family home with her mum and dad. Mum manages a Personal Health Budget on behalf of Natasha, employing a team of four PAs to help care for her four days a week. As well as providing all of Natasha's care, PAs accompany her to a wide range of activities which are also funded through her personal health budget, ranging from rebound therapy, music and drama at a local College, hydrotherapy and a variety of other activities at her local Lifeskills Centre including ICT, yoga, cookery and sensory art.

All PAs have received external training through Independent Lives in generic tasks such as manual handling and first aid, in addition to specialised clinical training through the Nurse Training Service in tasks such as catheterisation and gastrostomy care and feeding. The Personal Health Budget is also used to pay for respite away from the home one night per week and some weekends. Natasha's PAs recently accompanied the whole family on a cruise. This meant the family could relax and enjoy their holiday together.

Only when you read the detail do you realise she has considerable health needs.

Conclusion

With the right support, personal health budgets can work very well for people with profound and multiple learning disabilities and their families. Good information is a crucial first step, with a clear explanation of what personal health budgets are and the potential benefits. Being able to talk to knowledgeable people with experience of managing personal health budgets, such as those who are family carers themselves, builds confidence and can help people think beyond traditional services so that people get better lives.
This article describes what is happening in one area, although there is no reason why it shouldn't happen everywhere. However, support for personal health budgets varies across the country. It will be important to find out what is happening locally.

It is key that we keep families and children/young people central, so that good practice regarding support planning and overall personal health budget implementation is not lost as pilot initiatives move to being mainstreamed and the number of personal health budget increases.

You can find out more about Personal Health Budgets and clinical training at:
http://www.independentlives.org/clinical-training-for-personal-assistants

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NEXT ISSUE

Spring Vol. 29 No. 1 Issue 86

Sharing Perspectives

Do you have any stories to share?

If so, contact the editors:

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Copy date 10th March 2017

Managing anxiety and developing relaxation skills - a sensory perspective

Clive Smith

Anxiety is a state that precious few can claim to have no experience of. So, for the majority, it is a state that we have common experience of. What though is anxiety in physical terms? What effect does it have on individuals and, most importantly, what is the impact for those we support with special needs?

A dictionary definition of anxiety identifies it as "a feeling of worry, nervousness, or unease about something with an uncertain outcome". Now, for many of our students they live in a perpetual state of anxiety, with little or no control over their environment or lives. This manifests itself in physical transformations - a chain reaction of hormonal surges, most notably, cortisol the stress hormone. If not acted upon, the body then releases adrenalin (known as epiephrine in the USA.) This is the 'fight or flight' hormone, preparing the body to survive. People less likely to display these extremes are those who have developed fundamental life skills, including communication, sensory regulation, coping strategies and social skills. Chief amongst the coping strategies is the ability to relax.

There is no great secret to relaxing, anyone who has been involved in drama or yoga knows the fundamentals - deep and regular breathing. We often hear people say to children, "take a deep breath", or "breathe slowly". There isn't space in this article to explain the chemistry behind this, but if you are interested have a look at this web link: http://www.nopanic.org.uk/important-breathe-properly-help-anxiety.

The fundamental problem is how do we train our children to breathe properly to help them relax? Any training around breathing must obviously be a part of general activities, and not attempted when the individual is having a meltdown. So, make the following activities part of all your regular fun sensory sessions. The basic principle is - first, get them to exhale. Any activities that make them exhale, have to be then followed by a deeper inhalation. There are loads of sensory activities that include blowing out -for example blowing bubbles, painting with straws, blowing streamers, sound makers, party blowers, using microphones or sound effects units. But whenever the individual is blowing out, model the language "breathe out" and when they have to inhale, then model the language "breathe in". Make these activities short and regular. Try also to include these activities at stressful times of the day, to improve the oxygen/carbon dioxide balance.

A key element for those practicing relaxation with yoga or drama is the use of visualisations - a tool to imagine a calm and peaceful environment that accompanies deep breathing exercises. Now, whilst the vast majority of the individuals that we work with will not be up to using self-visualisations to calm themselves down, they do have their own alternatives - videos, DVD's and clips on YouTube. Often watching the same clip over and over again is a process that we may see as obsessive. In fact, they creating a very predictable world for themselves, one in which they know exactly what is going to happen every minute and every second. Don't discount the use of these favourite clips as a tool to help keep them calm or calm them down after an incident.

Our sensory room, or our sensory curriculum, can become a key element in managing anxiety and developing relaxation skills. Much of the equipment we utilise has an inherently calming effect: bubble tubes, fibre optics or slow rotating images on a projector. We can use these calming pieces of equipment to improve the individual's state of relaxation. The reason behind this is twofold. The first is the repetitive movement of all the effects, creating a state of predictability - the man in the moon will come around on the projector, time after time. The bubbles will continue to flow and the colours in the fibre optics will slowly change in sequence. The second reason is the calming effect of the pastel shades and slow movement. As a complete contrast, for example, night clubs will use very fast changing strong lights to stimulate our senses and films will use short, quick edits to create uncertainty and increase tension. However, please remember communication about what is going to happen is essential in all of these activities to maintain a calm environment: “We are going to the sensory room”, “we are switching out the lights”, “we are switching on the projector” etc.

Much has been written on the concept of ‘Deep Pressure’, for example the work by Patricia Wilbarger (1991). The use of weighted blankets and jackets is now widespread. Although there is not space in this article to explain the biological process in detail, touch in general is a positive experience and releases certain feel good hormones within the body. However, with the cognitive issues facing many of the individuals that we work with, touch without full communication and understanding, can be a very negative experience. So non-human deep pressure can be therapeutic, such as the use of weighted blankets. If you observe your students, you may find them seeking out deep pressure themselves. Temple Grandin (2009) talks famously about squeezing herself behind the sofa to reduce panic attacks. This led to her famous ‘squeeze box’ that she used to control her anxiety. We can see the individuals that we work with seeking out deep pressure in many ways - hugging bubble tubes or squeezing themselves into corners on soft mats. I have had in the past, children grab my hands and make me squeeze them on their temples. Many students and young children in general will often indulge in tip-toe walking, which is in essence, applying deep pressure to their joints.

A key element to helping individuals to relax better is to develop a sensory profile, which can highlight not only the sensory inputs that provoke negative responses, but can also identify those that individual responds well to. By choosing some of the preferred sensory experiences and by working in an anxiety free area, we can teach the individuals that we work with that valuable life skill - how to relax. Again, use the sensory room if available to begin relaxation training as we can effectively control all sensory inputs. Make yourself familiar with the environmental elements that can increase stress and anxiety. These may be noise in the room, bright lights, too much visual clutter and obviously other individuals in the living or working space. I am not, however, advocating that we strip out all of the things that may be negative, our whole purpose is to teach those that we support to cope with the world as it stands - with bright lights, noises, people and all. We need to create instead safe sanctuaries where the individual can retreat to. Pop up tents have been used regularly with great success, are easy to store and easy to put up, but maybe not so easy to put away! Distraction free areas, a blank corner of the room - even better with black or dark coloured surrounds. Lilli Neilsen, a Danish psychologist working fundamentally with deaf-blind children, took inspiration from prams and cots and created ‘the Little Room,’ a three sided box with a Perspex lid that provided a safe and secure environment within which a child could explore toys or other artefacts (Nielsen 1992).

There is no one element to developing relaxation skills in those we work with, but if we focus on providing a secure and predictable environment to reduce the scope for anxiety, we can then use some of the strategies discussed above to promote relaxation & a sense of wellbeing.

Contact details

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FUTURE FOCUS

Sharing Perspectives

The Spring issue of PMLD LINK will be a general edition, Sharing Perspectives. There is no overarching theme, allowing us to consider a wide variety of relevant topics under one cover - whatever is of most interest to you, our readers.

Over the last few years the journal has covered a wide range of themes - the advancement of technology, art and culture, leisure and pleasure and in this edition, health. All of these are significant issues for people with PMLD. Are we missing anything?

The Spring 2016 edition of PMLD LINK started with a 'call to arms' where Michael Fullerton's article highlighted the necessity of awareness and attention to 'detail' when considering the lives of people with PMLD. We hope that a general edition allows us to address these details. We feel strongly that we need to allow contributors the opportunities to present ideas that may not be easily 'squeezed' into a themed edition. This is an opportunity for us to share articles and information reflecting the idiosyncratic nature of people with PMLD and their lives. Our last general issue was Summer 2011 and had a very eclectic range of articles – discussions about communication, around health and welfare, some musings from a teaching assistant and useful information relating to the process of becoming a legal deputy.

Another article shared the developments of the Department for Education's Complex Learning Difficulties and Disabilities Project including a focus on the Engagement Profile. This particular resource has recently come back to the fore within the education of pupils with PMLD. This approach to assessing progress was one of the many recommendations made to government by The Rochford Review: Final Report (October 2016) when commenting on statutory duties of assessment in schools. What will be the significance of this to learners with PMLD? Are you an educator, a policy maker or a parent, who feels strongly about this issue?

Is there is anything you feel PMLD LINK has not covered recently- or at all? Is there something you would like to share, whether it is something which had a really good outcome, or perhaps a problem you have not been able to solve; a new approach you have come across or would like to find out more about; a response to one of the articles you have read; or a follow up of topics covered in a past issue? If so, or if you have a burning topic that you want to air, now is your chance!

Contributions can be any length up to 2000 words. Short or long, they are equally welcome and remember – you can write about any topic you feel is relevant!

Please send articles and other contributions **by Friday 10th March 2016 t**o Wendy Newby or Jillian Pawlyn, Guest Editors of the Spring issue
wennewby@aol.comm or Pawlynjv@gmail.com

PMLD Link wishes you 'good health' – see the new Health Resources on our website!

It is well known that people with a learning disability face greater and more complicated complex health challenges than those who do not who have a learning disability. People face discrimination, inequality of access and 'diagnostic overshadowing', these challenges are compounded for individuals who have a profound and multiple learning disability.

Our Health section includes a range of practical resources such as screening tools, assessment tools, examples of good practice guides, health passport, hospital checklist and examples of good communication. We hope these resources will help you when supporting people to achieve their optimum health.
We wish you 'good health!
www.pmldlink.org.uk

IN THE NEWS

Christian Raphael is awarded MBE for his services to people with profound learning disabilities and complex needs

Christian and his sister Marie-Claire at the palace

You may recognise Christian from the front cover of PMLD Link in the Summer of 2013. For many years Christian has been a member of the National Learning Disability Board - formerly the Learning Disability Programme Board. He has supported the work of iHAL and supported a number of other national initiatives. In particular Christian has championed personalised support including involvement in one of the Raising Our Sights guides. All this as well as featuring in issues of PMLD Link!

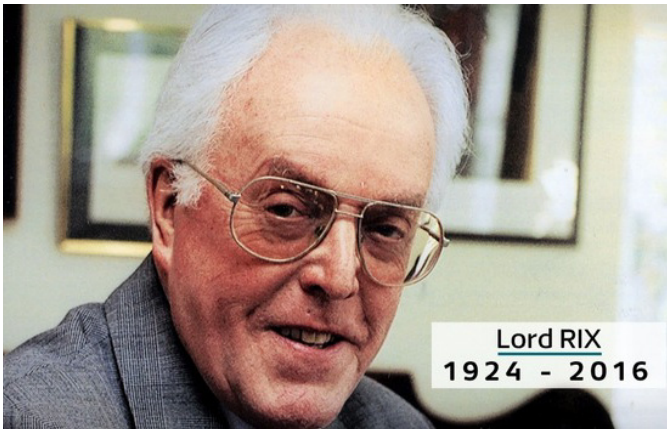
Update on the Learning Disabilities Death Review (LeDeR) programme

The Learning Disabilities Death Review (LeDeR) programme has just published its first annual report. This covers the 'set up' activities for the new programme, the challenges faced in establishing a process for local reviews of deaths, and ways in which they are working through these challenges. It also provides information about the progress made in the series of additional projects and activities that the programme team have engaged with, alongside establishing a process for local reviews of deaths. There is an easy read version and both reports can be downloaded at www.bristol.ac.uk/sps/leder/news/2016/public-facing-summaries.html

A key part of the LeDeR Programme is to support local areas to review the deaths of people with learning disabilities aged 4 – 74 years. The programme is piloting and then rolling out reviews of deaths of people with learning disabilities across the four NHS England regions:

- NHS England North: the North East and Cumbria was the original pilot site for the LeDeR programme. This pilot site reported its work at a Learning and Sharing event in Durham in July 2016. The reviews of deaths of people with learning disabilities are now being rolled out across the rest of the North region.
- NHS England Midlands and the East: the pilot site for this region is Leicester, Leicestershire and Rutland, which is now receiving notifications of deaths.
- NHS England South: the pilot site for the South is Wessex, which is now receiving notifications of deaths.
- NHS London: five pilot sites have been identified for London and they are currently establishing governance and other arrangements for the work.

More information about the programme and the review process can be found on their website www.bristol.ac.uk/sps/leder/



Lord Rix

Brian Rix, Lord Rix, who has died aged 92, devoted his life almost equally to stage farce – as one of the most brilliant comic actors in the postwar years – and to campaigning for people with learning disabilities. He was successful at both. In the theatre, both in management and on stage, his name became synonymous with the "Whitehall farces", named after the London venue and with plotlines usually involving a lie, a comic deception and someone being caught with his trousers around his ankles. Rix also ran repertory companies and presented more than 90 farces on television in the 1960s – to huge audiences – starring the big names of the day, such as Dora Bryan, Sid James, Sheila Hancock and John Le Mesurier.

Then, as the father of a child with Down's syndrome, he changed the direction of his life and became a campaigner and fundraiser for people with learning disability, in particular for the charity Mencap. He was its secretary general for seven years from 1980, and by the time he left the role, Mencap – and learning disability in general – had a much higher profile in the UK. He served as Mencap's chairman, 1988-98, then its president until his death. (https://www.theguardian.com/stage/2016/aug/21/lord-rix-obituary)

Did Lord Brian Rix make a difference to your life or to the life of someone close to you? Share your story using the hashtag #LordRixMemories on Facebook, Twitter or Instagram and you can find them here https://storify.com/mencap_charity/lord-brian-rix-1924-2016

PAMIS Conference - Promoting Inclusion, Transforming Lives

14-16 June 2017, Dundee

The first PITL (Promoting Inclusion, Transforming Lives) International Conference in June 2017 will attract more than 200 national and international delegates to Dundee and Angus for a 3 day conference.

Profound means deep, wise, expert and if we recognise that people with profound and complex healthcare needs are some of the best educators in teaching compassion, care and facilitators of working together as teams to create inclusive and meaningful lives, we have the tools to do something very special.

This conference will provide an interface for research, practice and policy that supports this concept but for a wider population of people who are excluded from communities and an opportunity to share work and ideas that transform lives and communities.

Our themes for this conference are:

- Inclusive life transitions, and
- Inclusive spaces (physical, environmental, cultural, emotional, social)

Prepare to be challenged, to be creative, to be involved and most of all to take forward the learning from this conference and apply it back into practice and life.

If you are interested in attending and presenting at this conference, please go to www.pitl.org.uk to submit your abstracts.

If you are interested…'Reasonable Adjustments' http://tinyurl.com/jsbugxv

Changing Together – a new research project gets off the ground

Change is an inevitable part of life for everyone, but even small changes can have an enormous impact on the lives of people with profound and learning multiple disabilities (PMLD). Children and young people in particular encounter many changes through the course of their education – from subtle, day to day changes in their classroom through to some of the big transitions, like starting school or moving on into adult services. These changes can often seem very small in nature but may have a big impact and even cause distress if not well planned or handled sensitively.

This small scale project plans to find out about the best ways of helping learners with PMLD prepare and respond positively to changes. By working in a small number of settings over the next eight months, the project hopes to capture what works well to support learners cope with change. They will be working with people who know these individuals best – their families and familiar school staff. The project team also plan to share and develop some new ideas, exploring how we can prepare more effectively to improve the experiences of change for learners with PMLD. Some practical guidance and resources will be developed as an outcome from the project, hopefully available at the end of the school year.

Jill Davies and Annie Fergusson from the project team would welcome ideas on sharing information and positive examples of preparing and supporting transitions and smaller change for individuals with PMLD – please get in touch!

Contact Jill: jdavies@learningdisabilities.org.uk or

Annie : ann.fergusson@northampton.ac.uk

Reasonable Adjustments resources

The Public Health England Learning Disability Observatory (PHELDO) writes reports focused on reasonable adjustments in particular service areas. All the reports have some relevance to people with profound and multiple learning disabilities. Each report includes:

- A summary of any relevant evidence and research relating to the service area under consideration
- A brief description of relevant policy and guidance
- A table of resources
- Good practice examples setting out how local areas are implementing reasonable adjustments

To date we have written reports on the following service areas:

- Management of constipation
- Weight management
- Dysphagia management
- Cancer screening
- Epilepsy services
- End of life care
- Primary care services – Annual health checks
- Dementia services
- Diabetes service
- Eye care
- Dentistry

All the above reports can be downloaded from the following website page:
www.improvinghealthandlives.org.uk/projects/reasonableadjustments/reasonableadjustmentsreports

Three further reports are planned this financial year. One on substance misuse, one on taking bloods and injections and one on pharmacy and giving medicines.

Health Leaflets

PAMIS has produced a series of practical information sheets on health topics that are particularly relevant to people with PMLD.

- Managing Bowels and Bladders
- Understanding and Managing Epilepsy
- Respiratory Health
- Understanding and Managing Nutrition
- Responding to the Mental and Emotional Needs
- Oral Health Care

Download from:
http://www.pamis.org.uk/_page.php?id=30

SHORT COURSES & CONFERENCES

January

Title:	Sensory engagement
Date:	3rd
Location:	Cornwall
Provider:	Joanna Grace
Contact:	http://jo.element42.org/

Title:	Curriculum and Assessment for Children and Young People with SLD and PMLD
Date:	16th
Location:	Manchester
Provider:	EQUALS
Contact:	www.equals.co.uk

February

Title:	Sensory stories
Date:	10th
Location:	Cambridgeshire
Provider:	Joanna Grace
Contact:	http://jo.element42.org/

Title:	Enabling Environments for Communication
Date:	13th
Location:	Manchester
Provider:	Course Beetle with ARC
Contact:	http://coursebeetle.co.uk/cpd-essentials/

Title:	Sensory stories
Date:	16th
Location:	Walsall
Provider:	Joanna Grace
Contact:	http://jo.element42.org/

Title:	Sensory engagement
Date:	17th
Location:	Walsall
Provider:	Joanna Grace
Contact:	http://jo.element42.org/

Title:	Sensory approaches to challenging behaviour
Date:	27th
Location:	Manchester
Provider:	Hirstwood Training
Contact:	richardhirstwood@gmail.com

Title:	Sensory approaches to challenging behaviour
Date:	28th
Location:	Birmingham
Provider:	Hirstwood Training
Contact:	richardhirstwood@gmail.com

March

Title:	Sensory approaches to challenging behaviour
Date:	3rd
Location:	London
Provider:	Hirstwood Training
Contact:	richardhirstwood@gmail.com

Title:	Learning Outside the Classroom- Taking the Curriculum Outside
Date:	6th
Location:	Birmingham
Provider:	Concept Training
Contact:	info@concept-training.co.uk

Title:	Learning Outside the Classroom- Taking the Curriculum Outside Woodland Trainer 1 Day Course
Date:	17th
	East Sussex
Provider:	EQUALS
Contact:	www.equals.co.uk

Title:	Advanced Woodland Trainer 2 Day
Dates:	31st and 1st April
	North Wales
Provider:	EQUALS
Contact:	www.equals.co.uk

April

Title:	"No they don't" presentation at the Words Count UK Conference
Date:	27th
Location:	Lincolnshire
Contact:	http://jo.element42.org/

Title:	Accredited Rebound Therapy for SEN, Open College Network Level 2
Date:	27th and 28th
Location:	Birmingham
Provider:	EQUALS
Contact:	www.equals.co.uk

Title:	Title: An Introduction to Sherborne Developmental Movement – Certificate Level 1
Date:	18th May
Location:	Derby
Provider:	EQUALS
Contact:	www.equals.co.uk

PMLD LINK
sharing ideas and information

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Sort Code:	40-39-06

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Account to be debited: ……………………………………………………………………………………………

Account No. ………………………………………

Signature(s): ………………………………………………………………………………………………………

Date: ……………………………………………

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PMLD LINK
sharing ideas and information

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

About Us

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

Rob Ashdown	Former teacher of pupils with severe and profound and multiple learning difficulties and special school Headteacher.
Jeanne Carlin	Disability Retired Disability Consultant and a parent of a young woman with PMLD.
Helen Daly	Mum to a young Adult with PMLD, previous career in Further Education for 20 years - including Curriculum Team Manager for Inclusive Learning and Developing an Improving Choice Programme for people with Complex Needs. Currently involved in carers groups in the Eastern Region, Learning Disability Partnership Board and associated projects.
Jill Davies	Research Programme Manager for the Foundation for People with Learning Disabilities. Jill recently completed a Dept. of Health project on Meeting the needs of children with complex health needs. She facilitates the UK Health and Learning Disability Network.
Beverley Dawkins	Beverley Dawkins, OBE, has worked with children and adults with a learning disability and their families for over 30 years. She is a qualified Speech and Language Therapist and has an MA in ‘Applied Psychology of Learning Disability Services’. Before becoming Chief Executive Officer of Generate she worked for Royal Society Mencap, campaigning for the rights of people with PMLD.
Ann Fergusson	Annie is a senior lecturer in the SEN & Inclusion team at the University of Northampton, teaching on undergraduate and postgraduate courses relating to severe, profound and multiple learning disabilities. Her research interests relate to person-centred working, meaningful participation and the voice of the individual in promoting positive mental health and wellbeing. She works one day a week in a special school with a role for training and looking at impact. Annie has a brother with a learning disability. She is a family member of the Learning Disabilities Mortality Review Programme Advisory Group.
Martin Goodwin	Martin is a teacher of pupils with PMLD and a Regional Tutor/Visiting Lecturer for the Severe and Profound Multiple Learning Disabilities course at the University of Birmingham. Martin has specialised in approaches to improve interaction, communication and participation of people with severe and profound learning disabilities. Martin has experience of working in play and leisure, education, residential and advocacy.
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
Becky Loney	Becky has a background in running creative services for adults with PMLD within the voluntary and statutory sector and she established the Lambeth Mencap Carousel project. Becky is passionate about intensive interaction and sensory storytelling, and spreads the word by training staff teams in high quality activities and creative approaches.
Wendy Newby	Deputy Headteacher at The Shrubberies School, Stonehouse, Gloucestershire. This is a school for students with Severe and Profound Learning Difficulties
Jill Pawlyn	Jillian Pawlyn has a background in Learning/ Intellectual Disabilities Nursing and is an enthusiast and advocate of Technology Enhanced Learning. During her years as a registered nurse Jillian has developed a specialist interest in the health needs of people with a learning/ intellectual disability in particular those individuals who have Profound Intellectual and/or Multiple Disabilities (PIMD/ PMLD). She is a member of both the national and local PMLD Networks
Sue Thurman	Former NHS Speech and Language Therapist for adults with learning disabilities with a particular interest in PMLD. Now writes and trains about communication and is a Registered Intermediary assisting vulnerable witnesses to communicate at police stations and courts.
Bella Travis	Policy Lead, Mencap

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

PMLD LINK

sharing ideas and information

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

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