

PMLD LINK



sharing ideas and information

Well-being

Winter 2013



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

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This issue of PMLD Link is sponsored in memory of a much loved sister

GUEST EDITORIAL

Well-being

This Winter issue is the third issue in our year of celebration of 25 years of PMLD Link. This issue has the theme of 'Well-being' which dictionaries tend to define as the state of being happy, healthy, and prosperous. However, the articles presented here have more to do with the quality of life and this is not to be confused with the concept of 'standard of living', which is based primarily on income. We are not so much concerned here with wealth and employment but rather with the built environment, physical and mental health, access to health services, opportunities for education, recreation and leisure, and ways of fostering social belonging. There are a range of articles in this issue, predominantly concerned with physical health and mental health, but they all admirably reflect this desire to establish a good quality of life for people with PMLD.

We asked for reflections on the mental health needs of people with PMLD. In Spring 2004 (Issue 47) Barry Carpenter reported on the outcomes of an inquiry into the mental health needs of young people with learning disabilities. In Winter 2005 (Issue 52) Loretto Lambe and Maureen Phillips summarised the outcomes of the surveys and the training delivered by a follow-up 'Well-being Project'. In the current issue we have fresh insights a decade later from both Barry Carpenter and Maureen Phillips.

We approached a range of people for information about health and welfare matters and have been almost overwhelmed with the response. Therefore, we are pleased to report that we have a range of important and interesting articles here: an investigation into invasive care procedures in Scotland; the appropriate development and use of do not resuscitate orders; the value of regular health checks by GPs in identifying previously unrecognised health needs; the development of a more inclusive health care system; the development of reasonable adjustments to primary care services from GP practices with support from volunteer 'champions' with learning disabilities and their mentors; the value of truly integrated therapy services; the absolute necessity for good postural care; and the value of NHS continuing health care. All these authors provide yet more references for other documents and websites with the potential to influence practices.

Of course, we must not forget about the well-being of those people who care for, educate and support people with PMLD and Julia Barnes frankly discusses the issue of bereavement and the approach of one class team to remembering a student who died. There are also relevant items in the news and resources pages. The final article by Vicky Hubbard is about the Sounds of Intent approach to enhancing the contribution of musical activities to children's lives and she presents a 'Music Bill of Rights'.

Good news

PMLD LINK has been awarded a grant to engage a freelance worker for one day a week to assist with creating greater awareness of the journal and the management of subscriptions. Full details will appear in the Spring issue and on the website at the same time but if you believe you have relevant skills and can work from home, please email rob.ashdown@ntlworld.com for further information and to express interest now, giving **brief** details of your suitability for the role.

You will find within news items and details about some good books and resources. We hope that you will pay particular attention to the piece about the Raising our Sights How to Guides which are on the Mencap website. These include two important guides on health-related issues.

Our final thought is that there is evidence of a significant increase in recent years in the numbers of children with PMLD in special schools in, particularly those with complex health needs and so-called 'life-limiting conditions'. We do query whether adult services for people with learning disabilities are sufficiently prepared to meet this new wave of children when they enter their adult years. This just serves to emphasise the need to adopt the practices referenced in the articles in this issue and we hope to read more about developments in all services in future issues.

Enjoy your reading and do share the enthusiasms of these writers with other people who may not have access to the journal. Our best wishes to you for 2014.

Jeanne Carlin and Rob Ashdown

NEXT ISSUE

Spring Vol. 26 No. 1 Issue 77

- Making Sense of the World -

Do you have any stories to share?

If so, contact the editors:

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The copy date for all articles, information and news for the
Spring issue is the 14th February

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Improving the emotional and mental well-being of people with profound and multiple learning disabilities How far have we come?

Maureen Phillip

In 2005 the 'Making Us Count' report (Phillip, Lambe and Hogg, 2005) highlighted that people with profound and multiple learning disabilities experience a wide range of emotional problems like the rest of us. Research undertaken for the report by Professor James Hogg, Loretto Lambe and Maureen Phillip for the 'Foundation for People with Learning Disabilities' looked at how family carers identified changes in the emotional and mental well-being of their daughters/sons.

Families who participated in the research highlighted a number of internal and external causes of changes in the mental and emotional well-being of their daughters/sons. From the reported causes in the research a

workshop programme was designed, developed and delivered by family carers. These workshops included the use of family stories as a way of understanding the causes and effects of changes in emotional well-being of

people with PMLD and the impact this has on both the life of the person with PMLD and the person caring for them. The workshops were delivered throughout Scotland and a training pack for the UK was developed by the Foundation for People with Learning Disabilities (Phillip, Lambe, Hogg and Alcoe 2005).

Healthy Lifestyles Project

In 2008 the workshops formed a part of a PAMIS 'Healthy Lifestyles Project'. This three year project started in 2006. Health and leisure workshops were designed and delivered in all PAMIS areas. The emotional and mental well-being workshop programme was titled 'The Well-being Workshop' and was an integral part of the Healthy Lifestyles project. Through the Healthy Lifestyles Project PAMIS was able to widely distribute the research based workshops on emotional and mental well-being. The health workshops enabled PAMIS to share the information with families and staff working with people with PMLD and the leisure workshops offered the opportunity to discuss the benefits of improved emotional health and well-being in relation to the provision of intellectually and physically accessible leisure pursuits for people with PMLD. The health workshop was designed and developed to enable understanding of how deteriorating physical health impacts on emotional well-being but equally deterioration in emotional well-being can impact on physical health. Leisure workshops were developed to emphasise the importance of physical exercise for improved emotional and mental well-being as well as for improved physical health.

Other identified causes of changes to emotional and mental wellbeing in the research were loss and bereavement and life transitions, such as moving from education to adult services. PAMIS was committed to help address this gap in provision and subsequently secured funding to undertake further work in both these areas.

Loss and Bereavement

A learning resource pack for loss and bereavement has been developed and is due for publication soon. The resource has been developed in two sections. One section shares the bereavement experiences of people with profound and multiple learning disabilities, from the perspective of parents and carers. It notes the barriers that exist which prevent people with PMLD from fully engaging with the bereavement process and describes a range of approaches for support. The other section discusses how to support a person with PMLD through the grieving process. The bereavement and loss project also involved a practical element which engaged the project workers in developing a multi-sensory memory box for a PAMIS family. Collaboration with international colleagues in Germany has enabled the work to be



shared with others working in the field of learning disabilities.

In addition to the two separate sections in the learning resource pack, there are two DVDs. One features parents talking about the effects of bereavement on their daughter/son with PMLD who have in the past been bereaved. They also talk about their plans and aspirations for how their child will be supported in the event of their death. The other features parents who have themselves been bereaved by the loss of their son or daughter. Both are powerful DVDs.

Future Choices Project

Life transitions also caused significant changes in the emotional and mental well-being of people with PMLD. PAMIS secured funding to develop the 'Future Choices Project'. This project provides families with 1:1 support through the difficult transition process from education to adult services. An important central element of this project is that it offers training and information events, aimed at providing the information necessary to enable family carers to develop personal support plans for their daughters/sons. Provision of practical tools such as the bereavement and loss learning resource pack and the training offered in the Future Choices Project, provides parents with the tools necessary to negotiate difficult times. Having access to practical information that empowers family carers at times like transition from education to adult services, may help to prevent problems that could lead to deterioration in emotional well-being, by enabling the family carer to understand the process and to feel more in control of the situation. The practical advice given in both projects goes a considerable way to alleviating stress and helps combat some of the problems that

might inevitably lead to changes in mental and emotional well-being for both the young person and the family carer.

Video Interaction Guidance

Another way in which PAMIS has helped raise awareness of the mental and emotional well-being of people with PMLD is through the use of 'Video Interaction Guidance' (VIG) and 'Video Enhanced Reflective Practice' (VERP). PAMIS are fortunate to work with Sandra Strathie of 'Glen Strathie Partnership' (<http://www.verp.uk.com>). Sandra is a VIG supervisor, trainer and AVIGuk™ accreditor for the method. Video Interaction Guidance is a technique that aims to improve positive interaction and communication. The technique was developed by Biemans (1990) in the Netherlands and is based on Colwyn Trevarthen's, 'Theory of Intersubjectivity'. VIG works under the premise that attuned responses to the initiatives of others are the building block of attuned interaction patterns. The approach is based on a coaching relationship as opposed to didactic teaching methods. Using VIG enables open discussion about the emotional and mental well-being of people with PMLD.

VIG is undertaken in three steps using a set of contact principles as a framework:

- Step 1: The video is taken and the guider edits the film, selecting good positive moments of interaction
- Step 2: The review session is next. Here the guider and the individual staff member/family carer undertaking VIG, looks together at the video to identify positive communication and interaction.
- Step 3: Discussions around attuned responses to initiatives and interactions are then undertaken and scaffolding of learning takes place through the shared review process. VIG offers the opportunity to discuss communication and interaction.

The sessions take place in the person's day to day environment. The positive reflection process offers people working with individuals with PMLD the opportunity to discuss any changes they have noticed in the person's mental and emotional well-being. VIG is a practical, person centred method that offers the opportunity to work with people with PMLD in a holistic way that allows emotional well-being to be discussed as an integral part of the learning process.

The resources alluded to in this article are a few of the ways in which PAMIS has responded to the findings of the 2005 research. These resources help people to understand and support individuals with PMLD and while there may still be a lack of identification and understanding of the mental and emotional well-being of people with PMLD, there have been a number of

initiatives undertaken by PAMIS since the report in 2005 that offer the opportunity to actively and creatively understand, engage with, and respond to the mental and emotional and wellbeing of people with PMLD in an informative and practical way.

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People with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services

(United Nations, 1994)

Mental Health and Emotional Wellbeing in Students with Profound, Multiple and Complex Learning Disabilities

Barry Carpenter

What must it be like to be a 15 year old young woman with PMLD whose every intimate care need must today be dealt with by another? What does that do for your self-image? To be an 8 year old boy with a profound Autistic Spectrum Disorder (ASD), arriving in the playground of your primary school, eager to join in the games of your peers, but you cannot, you do not, understand the rules of the game. What does that do for your self-confidence? Emotional resilience is key to emotional well-being. Schools should focus on this as a vital component in the armour a child will need to face the life challenges ahead. What must it be like to live every day of childhood with a profound disability, a special need, a complex learning difficulty?

Clearly the mental health and emotional wellbeing of our young people is at risk, as recent findings have highlighted. If we turn our attention to young people with intellectual disabilities and complex need, the findings are even more concerning. Children and young people with complex learning difficulties and disabilities (CLDD) include:

“those with co-existing conditions (e.g. autism and attention deficit/hyperactivity disorder (ADHD)) or profound and multiple learning disabilities. However, they also include children who have newly begun to populate our schools – among them those who have difficulties arising from premature birth, have survived infancy due to advanced medical interventions, have disabilities arising from parental substance and alcohol abuse, and/or have rare chromosomal disorders. Many may also be affected by compounding factors such as multisensory impairment or mental ill-health, or require invasive procedures, such as supported nutrition, assisted ventilation and rescue medication”

(Carpenter et al. 2011, p.3)

Emerson (2003) noted that children with an intellectual disability were over seven times more likely to have a diagnosed psychiatric disorder than their non-intellectually disabled peers. Not only this but the co-

existence of more than one mental health difficulty was common, with 50% of Emerson’s study population having more than one diagnosis. This finding was also emphasized in the ‘Complex Learning Difficulties and Disabilities Research Project’ which stated that “mental health is the most pervasive and co-occurring need to compound and complicate children’s special educational needs and disabilities” (Carpenter et al. 2011, p.9).

Each school and each teaching professional has a vital role to play in the promotion of emotional wellbeing in our young students. Bailey notes that “...all teachers of children with special educational needs or disabilities ... are inadvertent agents of change in the promotion of the core aims to promote wellbeing in classrooms and the onus is on delivering better outcomes for our most vulnerable children” (Bailey 2012, p.11). Emotional resilience, a clear focus on how we keep our young people with PMLD emotionally strong, is key to this process.

However this cannot be tackled solely by schools. This level of complex need requires the contribution of a transdisciplinary team able to deliver multi-dimensional assessment which defines behavioural problems, development disorders and mental illness, and, through evidence-based intervention, promotes development and positive mental health in young people with a range of complex special needs and disabilities, (Dossetor, White

and Watson 2011).

There is a major imperative for schools to seize the initiative around curriculum development in relation to the emotional well-being of their students with complex CLLD. It is still too often the case that the mental health needs of young people with CLLD go unnoticed until the problems are severe and entrenched. Indeed, such an initiative may bring benefits to a wider group of students in any school when considering the World Health Organisation's estimate that worldwide 10-20% of children and adolescents experience a mental health disorder (http://www.who.int/mental_health/women_children/child_adolescent/en). This has to be set against the broader prediction (also from the World Health Organisation) which estimates that depression will become the single greatest burden of disease in the world by 2030.

We must not underestimate the key role that relationships have to play in indicating both the difficulties in the positive adjustment of a child's mental health state and the potential for a decline in that state. Indeed, Dossetor (2012) cites the eminent child psychologist, Professor Sir Michael Rutter, who would often observe that poor peer relationships are the best measure of childhood adjustment, and the best predictor in childhood mental health problems. Dossetor goes on to state that "the quality of relationships in the context of a mental disorder has more effect than medical treatment" (Dossetor 2012, p2). Teachers need to remind themselves that teaching is a relationship based profession. For students with PMLD may be hyper sensitive to the slightest nuance of emotional response from the teacher. The ethos of the school, the atmosphere of the classroom, the dynamics of the group, all set the context for the relationships in which the vulnerable child with profound and complex needs may identify how they are valued (or not) as a human being in that setting.

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An Apology to Our Subscribers

A number of people have reported that they are having difficulty with accessing the Members Area of the PMLD Link website. We apologise for this. Our technical advisers have been trying for some time to identify the problem and we are now consulting the original website designers so hope to have it resolved soon.

We intend to transfer much of the archived material to the public part of the website with the exception of issues from the preceding two or three years. It will take a little while to achieve this.

In the meantime, any queries about the content of back issues not in public areas should be addressed to Rob Ashdown. E-mail: rob.ashdown@ntlworld.com

Delivering Invasive Health Care Procedures to People with Profound Intellectual and Multiple disability: From Research to Policy

James Hogg, Brenda Garrard and Loretto Lambe

Lack of equity in health care for people with learning disabilities has become an increasing concern with respect to national policy in Scotland (Scottish Executive 2002), while research has shown that this situation exists at all levels of the health care system (Hogg 2001). People with PMLD have been shown to be particularly vulnerable to poor health and health care provision, disadvantaged by complex conditions affecting their neurological state, their physical conditions, ability to eat and drink (dysphagia) and their respiration. As well as the detrimental impact of this multiplicity of conditions on their quality of life and that of their families, mortality is well in excess of other people with learning disabilities and the wider population, with over 20% of children and adults dying prematurely in any 10 year period (Hogg et al, 2007).

Several specific health care needs of children and adults with PMLD require intensive and regular intervention. With respect to neurological problems: epilepsy may be managed through the administration of Rectal Diazepam and/or Midazolam through the administration of buccal/nasal administration; severe spasticity may require Baclofen implants to alleviate spasms, while dysphagia may necessitate non-oral feeding (gastric and nasogastric) and respiratory problems may have to be dealt with through the use of ventilators and deep suctioning to maintain breathing.

These and other health care procedures are widely viewed as highly invasive, and contributing to the lack of equity noted above. Also, there is evidence from a number of sources that their delivery can be problematical. The present study supported by the Scottish Government set out to identify which conditions are viewed by family and paid carers as being invasive, and the extent to which they judge that there are specific barriers to their delivery that lead to non-delivery in service settings. Following a conference and consensus workshops that set the framework for subsequent research (Garrard, Lambe and Hogg 2009), a questionnaire survey was undertaken with the principal aims of the study being to:

- I. determine, from the perspective of paid and family carers as to what constituted an invasive procedure
- II. establish the extent to which barriers exist which precluded the delivery of such procedures in service settings and what these barriers were
- III. identify ways in which barriers may be overcome, and:
- IV. more broadly, to describe examples of good practice in which barriers have been overcome.

The survey was conducted in Aberdeen, Aberdeenshire, Angus, Dundee, Edinburgh, Fife, Glasgow, Highland, Orkney, Perth and Kinross, Shetland, South Lanarkshire and the Western Isles. 200 care settings were approached including: adult resource centres; community services; supported accommodation; schools and colleges; residential and nursing care homes; and respite facilities. In addition, family carers were also invited to complete the questionnaire (Garrard, Lambe and Hogg 2010).

Pilot work led to the identification of 20 procedures that might be considered invasive. Respondents were asked to judge which they considered invasive, and which

barriers they considered made difficult or precluded the delivery of each procedure. They were also invited to comment on their judgements and provide illustrations.

The invasive procedures were:

1. Nasogastric tube feeding
2. Gastrostomy
3. Jejunostomy
4. Tracheal suctioning
5. Tracheal tube replacement
6. Postural drainage
7. Nebulising;
8. Oxygen delivery
9. Short-term intermittent ventilation
10. Long-term intermittent ventilation
11. Manual bowel evacuation
12. Delivery of enemas
13. Delivery of suppositories
14. Colostomy/Illeostomy care
15. Urethral catheterisation
16. Supra-pubic catheterisation
17. Delivery of pessaries
18. Injections
19. Applying skin creams
20. Oral/Nasal suctioning.

There was highly significant agreement as to whether a given procedure was invasive, despite the lack of any formal definition of this term. In addition, agreement on their relative invasiveness between paid and family carers was also highly significant.

Barriers considered in relation to each procedures were:

1. Limited staff resources (insufficient time available to administer procedure)
2. Staff competence (staff lack the necessary training to administer the procedure)
3. Staff attitude (staff do not consider the task comes within their job specification whether competence or not)
4. Service agencies' policies and operating procedures
5. Service agency commissioners' operating procedures
6. Consent issues
7. Care plan precluding a service provider administering an invasive procedure
8. Union interventions
9. Health and safety

The percentage of both paid staff and family carers reporting that one or more of these nine barriers precluded or made difficult the delivery of each of the 20 procedures was computed, and written comments coded with respect to both difficulties and possible solutions. The findings demonstrated that at all levels of the

system, delivery of such procedures can, in varying degrees, be obstructed by one or more of the barriers. All barriers explored were to some extent cited by some staff members as obstacles to the delivery of every procedure, though this effect was strongest for the procedures judged most invasive. Lack of staff competence and staff attitudes were most strongly cited as significantly precluding the delivery of a number of procedures, particularly those regarded as most invasive. Although competence and attitude were implicated as barriers, it is important to emphasise that wider factors such as policy and union interventions might set the conditions for staff's inability to deliver a procedures.

A corollary of these findings is that in some facilities in Scotland, all procedures are being delivered unobstructed by these barriers, i.e. it is possible to make effective provision in educational, day service and other facilities. Specific examples of good practice are cited. Nevertheless, where barriers do preclude delivery, the impact on the individual with PMLD and their family is profound, as reported in family carers' written comments of. Non-delivery of a procedure by staff could lead to anxiety and lack of confidence on the part of family carers, exclusion from services, and demands on family members to undertake the procedures themselves.

In general, family members cited fewer barriers than did staff. In part this may be lack of awareness of wider issues in service delivery, e.g. the role of commissioners, but as pointed out by some of them, family members deliver all of these invasive procedures in their own homes year in and year out. Family carers emphasised the importance of their involvement in both training staff and care planning.

These findings were explored further through detailed interviews with 10 of the survey respondents who had indicated that they were successfully delivering invasive procedures. The interviews explored the ways in which interagency agreements were established, the management and operational procedures within the settings, and details of staff training as well as day to day to delivery and monitoring.

In the light of these findings, the Scottish Government set up a short-life working group to develop a national quality framework. The group's vision for this framework was: "No person will be excluded from any service because of an inability to deliver an essential invasive procedure. Every child and adult with profound and multiple learning disabilities in Scotland will receive competent and comprehensive care through the delivery of essential invasive health care procedures in all settings in which they receive support. No person will be excluded from any service because of an inability to deliver a necessary invasive procedure."

The framework is based on an ecological model focussed on the individual with PMLD and the family, working out through the immediate service setting, to agency policies, commissioners' responsibility and a range of agencies and organisation with an important role to play in realising the short-life working group's vision (Scottish Government Short Life Working group 2013). The framework is undergoing a period of consultation with stakeholders leading to a national policy enshrined in the recent Scottish Government learning disability policy document, *The Keys to Life: Improving quality of life for people with learning disabilities* (Scottish Government 2013). Here Recommendation 43: states: "That all stakeholders involved with people with PMLD commit to the implementation of the Scottish Quality framework for the delivery of invasive procedures...." (p.103).

This process is now underway, facilitated by the development of an online toolkit that makes available good practice in the delivery of invasive procedures as exemplified in the work of those who have contributed to this initiative, as well as wider national and international practice. PAMIS would welcome further examples from readers of PMLD LINK of ways in which barriers may be overcome, and the aspirations of one mother fully realised:

"People with profound and multiple learning disabilities are already heavily disadvantaged and do not need to be further disabled through a society not providing the care, service and resources required to enable them to leave the confines of their home. Living day in and day out within the same four walls results in their, and their families', lives and health being adversely affected."

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Healthcare - How Should We Influence the Current Changes?

Janet Cobb

There is an urgency to influence and engage with commissioners and family doctors (GPs) in relation to the new NHS structures if we are to change the existing position for people with complex health needs and the poor outcomes experienced by many people with profound and multiple disabilities.

One can identify two key Issues which arise as a result of the current way that the NHS engages with families.

- The current system is not inclusive and therefore does not facilitate relationship building between the family GP, primary health care team and the family and child.
- There are serious systemic issues and outcomes that result from disengaging children with disabilities from primary health care systems.

Primary health care systems need to STOP disengaging children with their family GPs and primary care practitioners and ensure health care systems are:

1. Inclusive
2. Make reasonable adjustments
3. Commission future health care services based on evidence of what health supports work and outcomes for the individual.

What happens now?

As soon as a disability is identified a child is fast tracked to the care of a paediatrician and 'specialist' health care team. This allows the family GP and primary care team to relinquish responsibility to secondary 'specialist' child health care services. This 'specialist' child health care system is often isolated from mainstream primary health care, marginalised, underfunded and often the services provided have a poor evidence base leading to poor health outcomes in adulthood. We can see some of the results in documents such as Healthcare for All (Micahel 2008) and the confidential enquiry into premature deaths of people with a learning disability (CIPOLD Team 2013). As a result of poor contact with primary care systems there is a dearth of data on disabled children nationally so we do not know the basics

such as the numbers of disabled children within individual GP practices or their associated health care needs making it almost impossible to commission appropriate health services intelligently.

What can we do?

It is imperative that the new commissioning arrangements in clinical commissioning groups (CCGs) take account of the health needs of disabled children especially those with complex associated needs. In order to do this we need to

- Gather robust data to establish a national profile of the health needs and commissioning requirements for people with PMLD.
- Strengthen and support individual GPs and primary health care practitioners to develop their confidence and competence to support families and have local and personal knowledge of their 'patients' with PMLD.
- Ensure the specialist knowledge, expertise and experience that is currently in specialist services is not lost by bringing these services alongside primary health care.
- Develop child centred health plans that may be supported by a personal health budget with a focus on inclusive health care that is evidence based and produces tangible outcomes.

The focus should be on primary care with support from specialist services NOT the opposite way around as it is at present. All effort should be put into prevention and treatment at the earliest level not a quick transfer into specialist secondary or tertiary care.

The relationship between Health and Education

The 'specialist' child health system is often wrapped around the 'special' school system creating an inherent obstacle to any disabled child wanting to attend

Key health commissioning arrangements for children and young people must include:

- Postural care
- Community epilepsy services
- Pain and distress recognition / services / training
- Communication and dysphagia support services
- Behavioural / mental health / emotional support services
- Individualised support / personal health budgets especially for young people with complex and continuing health care needs.

a mainstream school. This is especially relevant to children with severe or profound disabilities and more complex associated healthcare needs.

What happens now?

Segregated education is the last bastion of discrimination against disabled children and leads to a lifetime of disadvantage in terms of:

Work opportunities. We know that disabled people are less likely to gain full time paid work and the education system has created an expectancy of dependency across society despite disabled people wishing to have the same work opportunities as everyone else.

Health status. Once a child is segregated from mainstream healthcare services the more complex the health issues the more likely a poor outcome - the ultimate one being premature death. I am not saying that specialist health care is not needed but that this support should be integrated within an inclusive primary health care system and based on evidence based practice. This could lead to a major investment in preventative health care services such as epilepsy support, postural care, dysphagia services, pain and distress recognition and prevention, behavioural support, safe acute hospital provision and much more.

Citizenship. Often disabled children have no-one in their lives other than families, paid workers or other disabled children. The consequences are far reaching for both disabled people and society as a whole. We know disability hate crime is increasing, we know the media can pedal false beliefs - this would all be so much more difficult if disabled children were supported into mainstream schools. The first step to friendships with non disabled children is to create the opportunity and we take this away from disabled children by separating them at school.

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We are all sensitive to our physical environment. The sights and sounds, colours and shapes, the light and the dark, the walls, ceilings and furniture, the 'atmosphere' around us. Young people with complex needs are almost certainly even more sensitive than most not only because they may have additional sensory impairments, but also because in the main the physical environment which surrounds them is usually created by someone else, and someone who doesn't share their unique outlook on the world.

(Andrew Colley, teacher at the Granta School, from his article for PMLD Link Spring 2014)

The Importance of Good Primary Healthcare for People with Learning Disabilities

Fiona Richards

I am a Mum. I have 4 children, one of whom has PMLD. I work as a GP in Barnsley, and have been in my practice for 20 years now. In work, I am the Learning Disability (LD) lead and safeguarding lead. At home, I am Mum and carer.

I did a 'Partners in Policymaking' course some years ago now and through that fabulous course I met many dedicated wonderful people. I learnt so much. I then went on to do an 'All Together Better' course for professionals and carers. [For more information about these and other course go to <http://www.in-control.org.uk>]. In my practice, I compiled our LD register, principally from personal knowledge, and by searching case histories which contained some dreadful, outdated terms, which included 'Mental Retardation', and 'Educationally Subnormal'. That was then, we have moved on a lot.

Why is Good Primary Healthcare So Important?

People with learning disabilities have poorer health than their non-disabled peers, differences in health status that are, to an extent, avoidable. Emerson et al (2010) show that these differences represent health inequalities. The key point is that people with learning disabilities have health problems that are often unrecognised and unmet.

People with learning disabilities also have a shorter life expectancy. Recurrent respiratory tract infections are very common, and are actually the commonest cause of death in people with learning disabilities. Examples of health problems commonly missed are:

- Hypothyroidism and coeliac disease in Down's syndrome,
- Sensory impairment, including common simple problems like ear wax, glue ear, ear infections.
- Mental health problems, including depression and anxiety.
- Dementia
- Constipation
- Gastro-oesophageal reflux
- Poor oral health

The term 'diagnostic overshadowing' is important to understand. It means, attributing symptoms and behaviour associated with illness to the learning disability, so the actual illness is overlooked. It is vital to watch out for new behaviour, or any changes in behaviour, including physical, mental and social.

Why Do People with Learning Disabilities Have Poorer Health?

1. Greater risk of exposure to the social determinants of poor health, including unemployment, poor housing, social exclusion.
2. Increased risk with specific genetic and biological causes of learning disabilities, for example congenital heart disease in people with Down's syndrome.
3. Chronic health problems are more common, including epilepsy, diabetes, obesity.
4. Communication difficulties, due to problems with hearing, vision, reading and understanding invitations to health checks.

There are also deficiencies in access to, and quality of healthcare.

All GP practices should make reasonable adjustments including;

- seeing the same doctor for continuity,
- making appointments either early in the day, or later on, when it is quieter in surgery, if patients are anxious, and
- making the appointment time long enough, so there is plenty of time to see the patient.

Make sure that your practice is accessible for all.

Annual Health Checks

Annual health checks aim to detect unmet, unrecognised and potentially treatable health conditions, and to target actions to address these health

needs. The evidence is clear in indicating that health checks are effective in identifying previously undetected health conditions in people with learning disabilities (Robertson, Roberts and Emerson 2010). For example, using the Cardiff Health Check on people in GP settings, Baxter et al (2006) found that:

- 51% of patients with learning disabilities had new health needs identified
- Of these patients, 37% had two or more health needs
- 9% of these patients had a serious health problem, including asthma, diabetes, hypothyroidism and cancer.

Matt Hoghton, Lead for Learning Disability for the Royal College of General Practitioners, and the Learning Disability Group have authored a guide to health checks for people with learning disabilities (Hoghton 2010) which recommends that GP practices should:

- Identify clinical leads, which should include a doctor, a nurse, and administration, to organise invites and appointments. The community Learning Disability team should also be contacted and involved, as needed.
- Use a template for the annual health check, the most commonly used is the Cardiff Health check template, but different computer systems will have their own templates. [We use System 1 in my practice.]
- Organise, ideally, annual blood tests the week before the health check appointment, so the results can be reviewed and acted upon as necessary.
- Conduct an annual thyroid function blood test all people with Down's syndrome.

Elements of the Annual Health Check

General:

- How are they, any changes in medication, health, circumstances?
- Height, weight, waist circumference, Body Mass Index.
- Smoking status, alcohol consumption.

It is a good idea to discuss diet and lifestyle with the person and their carers. Bear in mind that the person with learning disabilities may not be the one who is buying and cooking their food, so advising the carer is very important.

Mobility and Musculoskeletal - including postural care, wheelchair and night-time positioning, sleep systems, if used.

Cardiovascular - check pulse, blood pressure, heart sounds, checking for murmurs

Respiratory - listen to the chest, to exclude any infection, or breathing problems.

Abdominal - check for any lumps, tenderness, ask about

and address any problems with constipation, or urinary problems.

Inviting ladies for a smear, if needed and advising about the procedure, with leaflets to read through, so informed consent can be obtained.

Advise men to check for testicular lumps and swellings. Remember, to check whether people in the right age group, 60 to 69 years, have been invited to take part in the national bowel screening programme.

Skin - check for infection, spots, eczema, any pressure areas that might need attention.

Breast checks - advise the person, and /or their carer about breast self-examination, and check that they have been invited for a mammogram, as appropriate, generally, ladies over the age of 50 years, unless there is any significant family history.

Mental Health - ask about their mood, any anxieties or worries, and treat or refer on as appropriate

Vision - advise them to get an eye check, if needed.

Hearing - check their ears, refer for testing if needed.

Oral health - remind them to see their dentist.

Top Tips on Helping People with Learning Disabilities Hoghton (2010) recommends:

- Make extra time
- Communicate with the person with LD first
- Use language that they understand.

Communication is the key. It's important. It matters. It can make a big difference to people's health and wellbeing. Make time.

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NHS Continuing Healthcare: What's It All About?

Alison Giraud-Saunders

NHS Continuing Healthcare (NHS CHC) is one of the ways that adults with profound intellectual and multiple disabilities may have support funded. It is governed by some specific rules; it is important to understand these to make sure that the system works as well as possible for people with learning disabilities and their families. More detail is given in the guide I wrote for family carers.

This article is about NHS CHC in England, and for adults. The system is different for children and young people up to the age of 18.

What is NHS CHC?

Many people get their support funded through social care, or jointly funded by health and social care. However, some people are entitled to have a complete package of health and social care paid for by the NHS. This is called NHS CHC (DoH 2012). The funding can be used to support someone wherever they live and it can be awarded as a 'personal health budget' (see below).

A person may be eligible for NHS CHC if they are assessed as having a 'primary health need'. This depends on four aspects of their needs:

- the nature (including the impact on the person and the types of care required)
- the complexity (and the skills required to care for them)
- the intensity (both quantity and degree of needs)
- the unpredictability of their needs and the responses required.

Eligibility for NHS CHC is usually assessed in two stages, using tools that have been set nationally:

- the Checklist: if this suggests the person might be eligible, they will go on to the second stage
- the Decision Support Tool, which guides the assessor to look at a person's needs against 12 health 'domains' (e.g. behaviour, communication, mobility).

There is a 'fast track' process for people who need an urgent decision, for example as part of their end of life care.

Anyone can ask for eligibility to be assessed; usually this is suggested by a health professional or social worker who is involved in the person's care. Arrangements for assessments vary from area to area, but typically the assessor will be a nurse from the local NHS CHC team (not necessarily someone familiar with people with learning disabilities).

The guidance is clear about the importance of involving the person themselves, in whatever ways are possible for them, and people who are providing care or know the person well – particularly if the person lacks capacity to consent to the assessment or the planning processes that are likely to follow. The assessment should be person centred; however, it is important to distinguish between the assessment of eligibility and the process of planning and organising personalised support.

If a person is found eligible for NHS CHC, the NHS becomes responsible for agreeing the care plan and funding all the agreed care and support. Any funding from the council will usually stop, so it is really important to make sure that the care plan covers all the types of support the person may need, not just their health care. Some benefits may also be affected, depending on whether the person lives at home or in residential care.

Some families assume that their relative will get better funded support if they become eligible for NHS CHC. This cannot be assumed: the NHS has the power to decide on the package of support that "is appropriate for the individual's needs" (DoH 2012 para 167). The guidance is clear that support should be personalised and "reflect the individual's preferences, as far as possible" (DoH 2012 para 169). Furthermore, "unnecessary changes of provider or of care package [should] not take place purely because the responsible commissioner has changed" (DoH 2012 para 170).

All Clinical Commissioning Groups (CCGs) now have the

power to offer NHS funding as a personal health budget (PHB), including as a direct payment. (PHBs can be managed in three ways: as a 'notional' budget [the NHS commissions in line with the individual's plan]; by a 'third party', such as a support provider or an independent user trust, or as a direct payment.) From April 2014 anyone eligible for NHS CHC will have the right to ask for it as a PHB, and from October 2014 they will have the right to have NHS CHC as a PHB (subject to certain rules) (Lamb 2013). The announcement of this new right emphasises that it should enable people to continue with support that is working satisfactorily for them (including people who previously had a social care direct payment).

Examples of practice, good and poor

I have heard some examples of excellent practice. For example:

- In Cornwall a young woman with complex health needs who was in transition to adult services was told she would be eligible for NHS CHC. Her family were worried about how this would work. She had a case manager allocated who understood person centred approaches and was willing to work with the young woman and her circle to try different things: "I never had the sense of her trying to fit anyone into a box"
- A mother from the North East described the importance of family and staff working together to support her son. For example, they "wrote the book together" to make sure everyone knew how to support him and organised work patterns to suit his activities. She said, "Listen to your families!"
- Thomas' story is on the website of the peer network (Peoplehub 2012). When he became 18 and was eligible for NHS CHC his family "... contacted the National Peer Network for PHBs, who provided invaluable support and practical advice and information from people who had lived experience of PHBs ...we were able to produce a detailed proposal and care plan, which contained processes and protocols and, importantly, measureable outcomes and clear roles and responsibilities for Commissioners, Thomas' Representatives, Third Party Provider and Care Staff to ensure Thomas is safe and receives the best possible care. Our proposals were fully supported by Healthwatch and approved by the local NHS Team."

Unfortunately I have also heard examples of poor practice that have left families feeling confused, alarmed and angry. For example:

- The family who told me about a nurse turning up to assess their son, who had very complex needs. She did not seem to have met someone with learning

disabilities before and did not make any effort to engage directly with him. She only wanted to talk about his health needs and did not know what to do with the person centred plan and health action plan his family showed her. She assumed they would want him to go into residential care

- The family who were told their daughter (in her mid -20s) would have to go into a nursing home 60 miles away "because that's where people on NHS CHC go".
- Several families who were unaware their relative was being assessed for NHS CHC and did not have the potential implications explained to them – so by the time they found out they were upset and cross.

Families want to feel supported by the health professionals involved with their relatives; they do not want to hear "the NHS doesn't fund that" or "NHS rules won't allow that".

There is sometimes confusion about what a NHS CHC package covers. For example, some NHS services may refuse to become involved, saying the service should have been built into the package (e.g. equipment, supplies or access to a specialist team). The guidance is clear, however, that entitlement to NHS CHC does not affect entitlement to other NHS services. It is also quite common for families to report that social care withdraws completely once their relative becomes eligible for NHS CHC; the Department of Health issued new Directions in April 2013 to remind local authorities of their continuing responsibilities to work in partnership with the NHS even when a person has been assessed as eligible for full NHS funding.

What helps?

- Good information for the person and their family or other supporters about how NHS CHC works, the implications of this funding, the availability of PHBs and the options for accommodation and support.
- Commissioners and case co-ordinators who understand the Mental Capacity Act and personalisation principles and are able to work with the person, their family and other supporters to engage in creative support planning.
- Availability of local services that can provide PHB support, such as brokerage and a range of support with employment of personal assistants (PAs).
- Availability of both people interested in working as PAs and support providers that can deliver personalised support, including managing a range of health problems, and agreements with health staff about training and delegation of responsibility for invasive interventions where appropriate.
- Agreements with NHS CHC staff and community learning disability staff that they will work together

and contribute their skills as appropriate to the individual's person-centred support.

- Person- and family-centred arrangements for supply of 'consumables' such as continence products and feeding tubes.
- Agreement between the NHS commissioners and the local authority about how they will deal with any uncertainty or dispute about who pays for what (including aids and equipment), and agreement about joint funding for people who have complex needs but do not meet the full NHS funding criteria.
- Very clear information and transitional arrangements for:
- young people who are moving from children's services, whether or not they received children's continuing care funding
- people who have been receiving social care direct payments.

Contact Details

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We Welcome any Contributions to PMLD-Link

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

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

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

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

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

Postural Care

We've a mountain to climb and we've only just got our boots on!

Sarah Clayton

I am a married mum with four wonderful children. I grew up in a house in which 'Postural Care' and protection of body shape dominated many things, the working day for both my parents, conversations around the dinner table and I'm pretty sure I was the only person in school whose friends had all had their body symmetry measured. I began working with families supporting children who use Postural Care in the late 1990s and I have been addicted ever since. At that time the concepts of 'coproduction', 'positive deviance' and 'outcome focussed' service provision, which I will go on to discuss, simply did not feature. In 2007 my world fell apart when my eldest daughter Abi was diagnosed with a malignant brain tumour at just 6 years old. By the time we knew what was happening it had spread throughout the ventricles of her brain and down her spinal cord. It has been a devastating journey for Abi but she, like her mother, is a stubborn little madam and continues to face every day with courage and humour.

The Postural Care mountain – where are we now?

Postural Care is a gentle way of protecting a person's body shape. Any person who finds it difficult to move or to change position effectively may benefit from Postural Care. Changes in body shape happen silently, mostly when we are asleep in our beds, at a time we would imagine we and those we love were safe from harm. The danger comes from gravity and so no matter what age the person is we must never lower our guard (Hill and Goldsmith 2010). Ultimately, body shape distortion is a killer, it is an enemy we must treat with the reverence and respect it deserves.

The 'Confidential Inquiry into Premature Death of People with Learning Disabilities' (Heslop et al 2013) was published in March 2013 and is a harrowing read. The team recommended that adults with learning disabilities are "to be considered a high-risk group for deaths from respiratory problems". They went on to recommend that alongside access to seasonal flu and pneumonia vaccinations "...CCGs [Clinical Commissioning Groups] must ensure they are commissioning sufficient, and sufficiently expert, preventative services for people with learning disabilities regarding their high risk of

respiratory illness. This would include expert, proactive postural care support, aggressive treatment of gastro-oesophageal reflux, the ready availability of speech and language therapists or other suitably qualified nurses able to undertake swallowing assessments, the development of clear clinical pathways for gastrostomy insertion, and the frequent review of patients waiting for a gastrostomy procedure to protect them from risk of aspirating."

(Heslop et al 2013, p.114)

I would like to introduce an analogy at this point as we start to think about Postural Care provision in the UK. I have always imagined the ultimate goal, eradication of body shape distortion, as being the summit of a huge mountain. Just take a moment to imagine this goal, think about a world in which hip dislocation in young children is seen as the glaring exception and not an accepted norm, a world in which young people rarely undergo radical spinal surgery because they just don't need to, a world in which people can get on and live their lives with minimal chronic pain and discomfort. The view would be amazing wouldn't it?

If we go back 25 years we can safely say that the vast majority of people did not even know this mountain

existed but thanks to awareness raising work such as the wonderful Postural Care Campaign (Postural Care Action Group, no date) I hope that we have now acknowledged its existence and recognised its sheer enormity. There is a sense now however that some service providers, despite their best efforts have become stuck in the foothills. I am privileged to work both in the UK and overseas and I am struck by the common difficulties faced by practitioners who are working hard to improve outcomes. There is frustration at the misconception by some commissioners that provision of a piece of specialist equipment must mean an improved outcome. It is as though practitioners have some of the tools they need “we provide sleep systems in this area” and they might be in possession of a map “we have a care pathway in place” but are they really striking out towards the summit and, if they are, what are their local commissioners doing to support them? What do sufficient, and sufficiently expert, preventative services look like? What are the key outcomes that they should aspire to achieve and, if a service is to describe itself as expert and proactive, where is the transparency and sharing of comparable outcomes with other service providers?

We will only ever reach the top together

Postural Care is about making sure that people who are at risk of developing changes in their body shape are supported as symmetrically as possible, as comfortably as possible, 24 hours a day. It involves equipment such as wheelchairs, walking aids, standers, alternative seating, orthotics and night time positioning equipment, it is helped by active therapy and encouraging movement and it is directed by measurement of body symmetry. Most importantly Postural Care involves individuals, their families and personal assistants working alongside health and social care practitioners to ‘coproduce’ effective, person centred solutions to often complex challenges. Over the past 25 years we have come to understand how and why the body changes shape, we have developed incredible equipment and technology, we know that people need timely access to this equipment and have the Community Equipment Code of Practice Scheme (CECOPS 2012) but we have only just begun to grapple with the concept of coproduction. Henry Ford is quoted as saying that “Quality means doing it right when no-one is looking” and this couldn’t be more true of Postural Care provision. We don’t see amazing results because a therapist has a Masters level qualification or a Doctorate; we see amazing results when we enable, inspire, motivate and trust families and personal assistants.

Working in partnership with families, personal assistants and practitioners is for me the most exciting part of this journey. The biomechanics, the equipment, the technology – they are all very interesting and helpful but

there is nothing that compares to the buzz of seeing people succeed, of supporting a parent to fashion a solution that best suits their circumstances, of seeing a family whose happiness, health and wellbeing are inextricably linked to one another doing well. It is this passion, this drive and this sheer determination that exists within families that practitioners need somehow to capture, to embrace and to nurture if we are to ensure that at 2am the pillow, towel or teddy bear is in exactly the right place. Clair Lewis’ poem ‘Mother – Care’ gives a sense of this commitment and drive: here is an extract:

I am her MOTHER
her full time adorer
who explodes when she smiles
whose heart breaks when she cries
who worries constantly
and continually sheds
the tears which cushion her
ride through this mess
I'm here because I love her
how about you?
don't compare my contribution
to what you do.

(Lewis 1999)

Positive Deviance and Outcome Focused Postural Care

The concept of ‘Positive Deviance’ is one that we as an organisation have embraced wholeheartedly (see Living University of Postural Care website below). There is a wealth of information about Positive Deviance available and this is not the place to go in to too much detail however, put simply, it is about looking for the people who achieve a better outcome than the majority when faced with the same problem. In the UK we are actively searching for the services, families and organisations that achieve great results in relation to Postural Care and we are asking them two simple questions, what have you done and how have you done it? My experience as a parent of a child that has undergone treatment for cancer has taught me what it is like to be supported by an outward looking team. What do I mean by this? I mean that the world of paediatric oncology is one in which a collaborative approach, a sharing and acknowledgement of better results, leads to improved services for children like mine. The team supporting us as a family are constantly talking to, working with and supporting other teams from around the world to improve treatment outcomes. It is a model that we as an organisation aspire to and hope we can support by sharing results from around the world.

A wonderful example of Positive Deviance can be found in Wakefield. There are a total of 274 children and young people aged between 0 and 18 who access the

GMFCS Gross Motor Function Classification Scale	1 Children who can walk, run, jump and climb stairs but who have some impairment of speed, balance and/or coordination	2 Children who can walk in and outdoors and climb stairs but have some difficulties with such things as uneven ground or crowds 3 Children who use walking aids but use wheelchairs for long distances	4 Children who use walking aids for short distances but use wheelchairs most of the time 5 Children who use wheelchairs for all mobility and need postural support in order to be able to sit comfortably	Total number of children and young people aged 0-18 supported by the service	Hips dislocated 75% Migration over 75% of femoral head uncovered by acetabulum
Wakefield	122	106	46	274	0

Table 1: Outcome data for physiotherapy services in Wakefield district

physiotherapy service in Wakefield led by Suzanne Carter. Of these 122 have a Gross Motor Function Classification Scale (GMFCS) of 1, 106 have a GMFCS of 2 or 3 and 46 have a GMFCS of 4 or 5. (See Table 1) In answer to the question ‘What have you done?’ they have reached the summit. Not a single child or young person accessing this service has a dislocated hip and in the past 12 months only 4 have undergone preventative soft tissue surgery.

The response to the second question (How have you done it?) is more complicated (Carter, no date) but in essence they are wholly ‘outcome focussed’. Over the past 25 years a culture of impunity has developed in which basic, person-centred outcomes are not being recorded, collated or shared. If you want to know how successful a school is in teaching maths you don’t ask how many maths lessons each child receives – you look at the results and compare them with similar schools. The work in Wakefield gives individuals and their families, commissioners and service providers a benchmark. Surely if we are to see improvements in services we have to be asking each and every area what are their outcomes and how do they compare? In Suzanne’s own words

“This service hasn’t happened overnight, it has developed over the last 9 years to give us the successful outcomes of today. The important points to stress are that it is by giving the families some control and positive expectations for their children that go more than halfway

to bringing them success. Also, this has been a result of long term, dedicated staff who are happy to work alongside each other to develop a service giving our children the right to expect these positive outcomes.” (Carter, no date, p.3).

Whilst Suzanne and her team have achieved a great deal working in partnership with families they are also very aware that their service is vulnerable to change, she continues to work closely with the local commissioning team to ensure everyone understands the outcomes they are being paid to deliver.

I come back to the idea of our mountain, of how far we have to go and of the summit. 25 years into the future we will live in a world in which hip dislocation in young children is seen as the glaring exception and not an accepted norm, a world in which young people rarely undergo radical spinal surgery because they just don’t need to, a world in which people can get on and live their lives with minimal chronic pain and discomfort. They are already having a cup of tea and looking out at the view in Wakefield so if your initial reaction to this vision was scepticism this is an opportunity to reflect, a chance to reconsider what might be possible if only we were brave enough to look up.

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The Living University of Postural Care is a Positive Deviance initiative registered with Tufts University Boston. It provides a platform to celebrate and learn from improved outcomes in protecting and restoring body shape. Website <http://www.posturalcareskills.com/living-university>

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NEXT ISSUE

Spring Vol. 26 No. 1 Issue 77

- Making Sense of the World -

Do you have any stories to share?

If so, contact the editors:

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The copy date for all articles, information and news for the
**Spring issue is the
14th February**

Do Not Resuscitate Decisions in People with Learning Disabilities Whose Best Interest?

Claud Regnard, Dorothy Matthews and Lynn Gibson

Stephen is a 57 year old gentleman with Down's syndrome and diagnosed with dementia. As his dementia progressed and his cognitive and functional abilities deteriorated he was admitted into a nursing home. He had physical complications associated with dementia caused by postural distortion with contractures resulting from increased tone and poor active movement. This meant he needed full assistance for daily living tasks including hoisting for transfers and specialist equipment, but he found it difficult to cooperate with interventions from the care staff. Stephen also had issues with eating and drinking and was assessed as needing a modified diet but he often refused nutrition. This resulted in admission to hospital with dehydration and pneumonia where he was actively treated with IV fluids and medication.

A Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form had been completed in the emergency department and was still in place upon discharge when it was presented to the community team by ambulance staff. This form had been completed with no input from family or wider care team. The reasons given for the DNACPR decision were that cardiopulmonary resuscitation (CPR) could not succeed because of "a) low baseline function, b) doubly incontinent and c) hoisted for transfers". This DNACPR form was invalid for two reasons:

- None of the clinical conditions stated could affect the success of CPR.
- Stephen did not have the capacity to make a CPR decision, but there was no indication that a best interest process (as required by the 2005 Mental Capacity Act) had been used to make the DNACPR decision.

Mencap's updated report 'Death by Indifference: 74 deaths and counting' made the following observation:

"The inappropriate use of DNR orders has remained a constant feature of many Mencap cases. There have been circumstances where DNR notices have been applied without the knowledge or agreement of families, and applied hastily in inappropriate situations, solely on the basis of the person's learning disability."
(Mencap 2012 p.15)

In recent years many organisations have revised their policies on cardiopulmonary resuscitation (CPR) and several regions have created unified DNACPR (Do Not Attempt CPR) policies. Unfortunately several problems have beset such policies:

1. A primary focus on preventing unnecessary CPR. This is understandable when CPR cannot work (e.g. end stage cancer) when any attempt at CPR will be distressing and undignified for all those present. But, in the rush to condemn inappropriate CPR, the issue of inappropriate CPR decisions has been ignored. It is interesting that none of the CPR-related court cases to date have been about inappropriate CPR; all have been about inappropriate DNACPR decisions, some in people with learning disability.
2. Failing to make DNACPR policies concordant or compliant with capacity legislation. For example, in England and Wales, only one DNACPR form is concordant with the 2005 Mental capacity Act (CNNE 2013). Many use old terminology such as 'mentally competent' to describe capacity. In particular, it is rare for policies or DNACPR forms to make clear what is meant by the term 'best interests' as defined by capacity legislation.
3. The lack of understanding of the Mental Capacity Act. This exists amongst professionals but also national bodies. For example, in several Department of Health policies there is no mention of the Act: the

Essence of Care (DoH 2010); the Mandate to NHS Health Commissioning Boards (DoH 2012a) or the Helping people make informed choices about health and social care (DoH 2013). Even the Winterbourne Transforming Care report and concordat documents (DoH 2012b) initially failed to mention the Act.

4. Failing to make clear that CPR is only one of many decisions that an individual may wish to make or have made for them. Advance care planning and shared decision making are not usually part of CPR policies and useful documents such as Emergency Health Care Plans are often restricted to paediatrics. The irony of this is that learning disabilities services have for many years pioneered shared decisions making, understandable information and documents such as health passports.
5. Having different policies and documentation for children and adults. This makes transitions even more difficult. Only one DNACPR document in the UK applies to all ages (CNNE 2013).
6. Advice to make CPR decisions in all acute admissions creates problems. In 2012 NCEPOD (National Confidential Enquiry into Patient Outcome and Death) produced a report on CPR. The first recommendation is as follows: "CPR status must be considered and recorded for all acute admissions, ideally during the initial admission process and definitely at the initial consultant review when an explicit decision should be made in this group of patients, and clearly documented (for CPR or DNACPR)." (NCEPOD 2012 p.9). While none of us would have a problem with considering CPR in all acute admissions, the requirement to make an explicit decision in all patients is a serious concern. The fact that this includes patients in whom an arrest is not anticipated breaches existing national guidance, but also makes discriminatory decisions more likely.

These problems expose vulnerable individuals to poor decision-making. This is despite capacity legislation in Scotland, England and Wales and national CPR guidance (BMA 2007) providing excellent frameworks for making these decisions. Misunderstanding and ignorance of these frameworks account for many of the problems. For example, the term 'best interests' is perhaps the most abused term in health and social care and the trap is that a professional thinks that their 'holistic' assessment is in the individual's best interests. It is essential that national bodies and all professionals understand that the correct application of best interests is a legislative requirement, not simply a personal opinion. Many parents, partners and relatives do not realise this and are often left isolated in their belief that an individual's CPR decision is wrong. No-one is suggesting that there should be more CPR, but the process of making every DNACPR decision should be compliant with capacity legislation.

Stephen (continued)

The reasons stated for the DNACPR suggested it had been completed using assumptions rather than clinical reasoning. Since the DNACPR was invalid this was cancelled. As Stephen had been previously assessed as not having the capacity to consent to complex decisions, a 'best interests' meeting was held that followed the nine point checklist required as a minimum by the Mental Capacity Act. Taking all the issues into account, it was decided by professionals and family together that CPR would not be in Stephen's best interests should he develop pneumonia again. An emergency health care plan was completed to inform future care. Stephen remains in the nursing home with appropriate decisions in place.

Mary

This 53 year old lady with learning disability was supported by community services for many years. She was diagnosed with acute myeloid leukaemia with a poor prognosis, a diagnosis that required a specific regime of treatment to be considered. This resulted in a formal assessment of Mary's capacity to consent for this treatment which showed that she did not have capacity for this specific decision. A 'best interests' meeting was arranged that followed the nine point checklist required as a minimum by the Mental Capacity Act. This included input from an independent mental capacity advocate (IMCA) and the community support team. Discussion with all stakeholders included information that treatment would involve intense chemotherapy during which time Mary would have to be hospitalised. If the treatment was successful a remission of up to one year could be expected, followed by further chemotherapy and possibly a bone marrow transplant. Mary's prognosis with treatment could be up to two years but without treatment it would be months. Using the information available the decision was that it was not in Mary's best interests to pursue active treatment. Mary died at home seven months after diagnosis with agreed and appropriate decisions in place which prevented crisis interventions and allowed proactive, quality care to the end of her life.

Conclusion

For people who do not have the capacity, shared decisions should be made in partnership with good communication between health professionals and family and carers, compliant with legislation and avoiding unnecessary or unacceptably distressing treatment. This was the case for Mary from the outset but not for Stephen. However, Stephen was fortunate that the problems were picked up by professionals who understood the issues. Others are not so fortunate. In the North East of England an initiative called Deciding right has been established since 2011 to enable

individuals and organisations to be compliant with current national legal and clinical frameworks (CNNE 2013). The Mental Capacity Act and national guidance on advance care planning and cardiopulmonary resuscitation decisions are at its core resulting in unified documentation in all care settings. This initiative has now been extended into Cumbria, has just been adopted by the Wirral in the North West and is a model for other areas.

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But to be truly accepted in society means being treated equally and fairly in other ways. It means having a health service that recognises and redresses the stark fact that people with learning disabilities still die 20 years earlier than the general population.....We need to ensure that all those who work in health care understand the health needs of people with learning disabilities, how these can differ from the general population and to respond appropriately and positively. This is not always about the application of knowledge but about an attitudinal and cultural shift in supporting individuals to lead healthier and happier lives.

(Michael Matheson, Scottish Minister for Health, in Foreword to the *Keys to Life*, Scottish Government, 2013)

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Getting it Right at GP Surgeries Matters

Rhea Sinha

This article reflects on the volunteers and the pilot healthcare project 'Getting it Right - From the Start' (GIRFTS) which is based on partnership working between Mencap and four clinical commissioning groups.

The main aim of our three-year volunteer-led project, which started in August 2011, is to make reasonable adjustments to primary care services for people with a learning disability. This will improve the quality of service at GP practices. The project is being piloted by four clinical commissioning groups: East Surrey, Exeter and Mid Devon, Northamptonshire, and North Tyneside. Each locality is supported by a locality co-ordinator, a lead GP and a multi agency steering group that meets regularly.

Volunteer Champions who have a learning disability and Mentors in each area are instrumental in taking the pilot project forward. It is key to point out here that the

outcomes for the volunteers within these pilots are just as important as the outcomes for primary care. The amount of commitment and involvement in a three year project, along with the willingness to train and learn and take part in planning and reviews, is not a small ask from volunteers.

At present, 62 regular and dedicated Volunteer Champions are working with 72 GP surgeries across four areas. Our volunteers are supported by the locality co-ordinator to build their relationship with the individual GP surgeries and be the key players in delivering workshops on learning disability awareness to these surgeries.

How does the project work?

- We recruit Volunteer Champions, who have a learning disability, and Volunteer Mentors, who provide support to the Champions.
- We invite 20 GP surgeries in each of the pilot localities to engage with the volunteers.
- The volunteers provide an Action Plan to the GP surgeries about what 'reasonable adjustments' can be made and how they can be made.
- The volunteers deliver learning disability awareness workshops to staff at GP surgeries in each locality.
- The GP surgeries are given advice on creating easy read documents to help people with a learning disability understand their health.
- Volunteers re-visit GP practices six to nine months later to review their progress and the impact of the workshop.

The results of our workshops

The workshops are attended by surgery staff including GPs, nurses, practice managers, registrars, medical secretaries, receptionists and patient participation group members. Staff are given advice about communicating well with patients and how they can make information easy for people to read, so that people with a learning disability can understand more about their health. Staff operating in all areas of a GP practice found the sessions useful as demonstrated by the following feedback:

95% of practice staff said they would recommend our workshops. Some of the feedback below is evidence of the success of the project.

A GP from East Surrey says "I felt the workshop was delivered with excellence. I clearly understood the readers and felt challenged to improve my practice."

A practice manager from North Tyneside says, it "was very simple, I enjoyed participating in the learning which was clear and concise."

An assistant practice manager from Devon says, "This has made me more aware how to send letters out to patients. We will do an Easy Read Information booklet."

A receptionist at a Devon GP Practice says, "It was lovely seeing volunteer Lesley so confident in addressing the meeting; I personally dislike those type of situations - well done Lesley."

"I found the workshop interesting and found it covered some obstacles which people with learning disability have made me understand better" says a receptionist from Northamptonshire GP surgery

"It helped to hear of people's experience first hand. I really enjoyed it. Thank you" says a dispenser from a Mid Devon surgery.



Dr Clare Scarlett, NHS North Tyneside CCG Clinical Lead for Learning Disability, who is also one of our GP leads giving us guidance, speaks highly about our project. In Clare's words, "Practices in North Tyneside that have taken part in Mencap's 'Getting it Right - From the Start' have described deriving new insight into the needs of people with a learning disability. Just as significant, perhaps even more so, is the impact of having training delivered by some one with a learning disability. Medical and administrative staff training can be viewed as complex and technical: but this project underlines the benefit of making sometimes simple but highly effective adjustments that easy read text and uncomplicated vocabulary are as powerful as the most complicated communication. It has been impressive to see the volunteers grow in confidence and the quality of their work; it is pleasing that GP Practices can recognise how staff competencies have improved through taking part in the workshops."

Volunteer Journeys So Far

Volunteer Champion Sedley Wilson joined the East Surrey pilot when the group was formed in January 2012. He is very involved in a number of learning disability projects where he lives in Addiscombe, Croydon. This includes the 'Better Understanding Group' (BUG). They look at information from the Council

and give their views on how easy to understand the information is and what changes to make. Sedley has been working with three surgeries in East Surrey and has also been a great help in spreading word about the project in Croydon. He is a member of the steering group and has given a huge amount of time and support to moving our work forward.

Sedley talks about his experience of the project, "Since I started this project I have come a long way. I have never really done much reading, but now I read a lot more. Getting ready for the workshops has made a big difference to my reading. I have learnt a lot and this has helped me in the other things that I do locally. It has been a real eye-opener to find how our GP surgeries work. Our group of mentors and champions is great. As champions we all have different sorts of disabilities but we get on really well and support each other. It has been very positive working with my mentor Charles and doing something new for both of us. We are making progress and everyone is doing what they can in the surgeries to improve things."

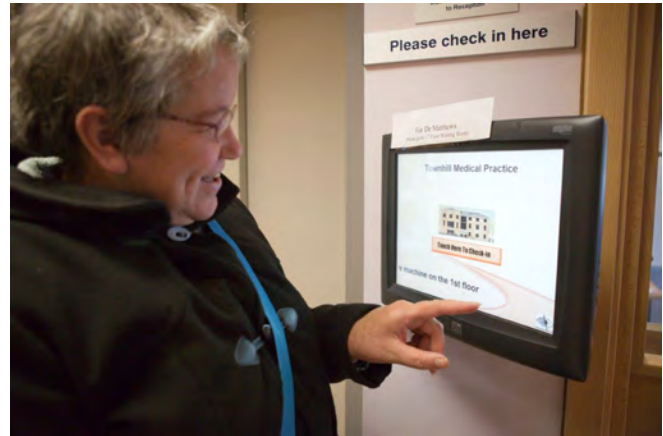
Husband and wife volunteers, Ross and Jennifer, work on this project with their mentor, Vicky, in the Mid Devon and Exeter locality. Vicky has this to say: "Delivering training with skill and flair, developing a rhythm with each other that shows how supportive this young couple are of each other and how they enable one another to shine. Together possessing a strong understanding of the purpose of the project the couple are able to deliver workshops with real professionalism and aplomb. Jen also helped to write the content and slides she and Ross co-presented in London for the Learning Disability Health Network in July 2013. They did a fantastic job co-presenting in London and were delighted with the response from the delegates there."

Jen says, "I feel proud to be part of the project. I believe this could benefit so many people." In Ross' words, "I fell like we are accomplishing something with this project and that makes me happy."

Mentor Vicky says, "I am extremely proud to support Jennifer and Ross. They have a talent for training and presenting. I believe they should be paid for it."

The GIRFTS project has strongly re-enforced our belief in the role of volunteers with a learning disability as health advocates in primary care settings. Other local health organisations, local councils, out of hours GP services, neighbouring clinical commissioning groups are showing great interest in our workshops on learning disability delivered by our volunteers.

We are looking to offer our volunteer resources and to deliver as many workshops and easy read advice sessions



in the localities as possible before the GIRFTS project ends in August 2014. Our volunteers are promoting our project, speaking about the project to staff in housing associations, day centres, and local sharing events.

It is not easy to capture the parameters of our work in a few lines, our project web page <http://www.mencap.org.uk/what-we-do/our-projects/getting-it-right-start>

provides a good overview. We hope that professionals who read this publication will feel inspired by this article and keen to find out more.

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Faced with such undeniable need, why is it that people with profound intellectual and multiple disabilities have such difficulty getting help? The evidence from families themselves is that prejudice, discrimination and low expectations underlie their plight.

(Jim Mansell, in Raising Our Sights, 2010)

Delivering Effective Therapeutic Assessment and Interventions for People with PMLD Using an Integrated Multidisciplinary Approach

Helen Campbell, Sarah Ballard and Helen Booth

This report is a brief overview of an integrated sensory assessment service for people with PMLD. The service is a partnership between Occupational Therapy and Physiotherapy from North Staffs Combined Healthcare NHS Trust (Community Learning Disabilities and Mental Health Trust) and Speech and Language Therapy from Staffordshire and Stoke on Trent Partnership NHS Trust. The aim of the service is to complete a full assessment of the person's skills, identify the potential to maximise these skills and then the empowerment of carers to maintain and promote these skills.

We offer full assessment from point of referral in a holistic manner. The assessment is completed at home and in any day placement that the client accesses. We offer both individual and group assessment sessions in a sensory room on NHS premises. More recently we have used council resources to reflect demand on the service from clients using council run day provision. We also complete observations as required to meet assessment needs. Sessions run in blocks of six weeks followed by a review period with goal setting. Once assessment is completed we then offer formal training and support to the parents, carers and staff teams working with the client.

The integrated assessment service has developed to meet the needs of individuals with more complex needs, limited or no formal communication skills and restricted access to opportunities in the community. The service uses a sensory approach in a therapeutic environment to address needs related to communication, engagement, mobility and posture.

The interventions described were originally designed and planned to meet the requirements of 'Valuing People' (DoH 2001) and 'Valuing People Now' (DoH 2009) which advised that learning disability specialists working in close collaboration is recognised as best practice. More recently, the work reflects the recommendations in the Health and Social Care Act 2012, specifically the duty to encourage integrated working.

The national context for this work with people who have learning disabilities and complex needs is a changing one. In March 2010 Professor Jim Mansell published his report 'Raising Our Sights: Services for Adults with Profound Intellectual and Multiple Disabilities' (Mansell 2010). Recurring themes within this report were the obstacles to implementation of policies for support which are prejudice, discrimination and low expectations. The report outlines 33 recommendations for the government and policy development. The importance of these recommendations is highlighted acutely by the shocking findings of the Winterbourne Inquiry (DoH 2012) which resulted in several criminal convictions and the closure of a service delivering care to people with learning disabilities. The recommendations from this inquiry include drivers to ensure people have access to person centred care in their local community, with emphasis on quality of care and standards of practice to achieve better outcomes. The Mid Staffordshire Foundation Trust Public Inquiry (2013) re-emphasised the need for commitment to common values. Emphasis was placed on keeping the patient at the centre of the work, communication and co-ordination of care.

Our target client group are the most cognitively and physically disabled in our society. Enderby and Davies (1989) state that up to 90% of people with a learning disability have communication difficulties. The majority of people with PMLD have extremely limited communication ability, restricted to behaviours such as eye gazing and changes in facial expression. Therefore

people with PMLD are often dependent on other people interpreting their non-verbal communication. This is difficult even when the person interpreting the communication is familiar. However many people with PMLD depend on paid carers who are often unfamiliar and may have varying levels of experience. This can lead the person with PMLD to have limited communication opportunities and to be misinterpreted and misrepresented. The very nature of their disabilities leads to these adults being one of the most vulnerable groups in society due to the total dependence on others for even the most very basic care needs, let alone leisure and fun activities.

The Specialised Clinical Team

The integrated service is delivered by three specialist clinicians, an Occupational Therapist (OT), a Speech and Language Therapist (SLT) and a Physiotherapist (PT).

Occupational Therapists

When working with people with learning disabilities, OTs consider the impact of the

person's learning disability on their occupational performance, with interventions focusing on engagement in occupation and enabling independence. Collaborative working is considered essential in order to effectively meet the needs of the person with a learning disability (College of Occupational Therapists 2013). This work is summarised in the following quote from the College of Occupational Therapists (2009):

“The purpose of Occupational Therapy is to enable people to fulfil, or work towards fulfilling, their potential as occupational beings. Occupational Therapists promote function, quality of life and the realisation of potential in people who are experiencing occupational deprivation, imbalance or alienation, they believe that activity can be an effective medium for remediating dysfunction, facilitating adaptation and recreating identity.”

Speech and Language Therapists

Speech and Language Therapists are the lead experts within the multidisciplinary team regarding

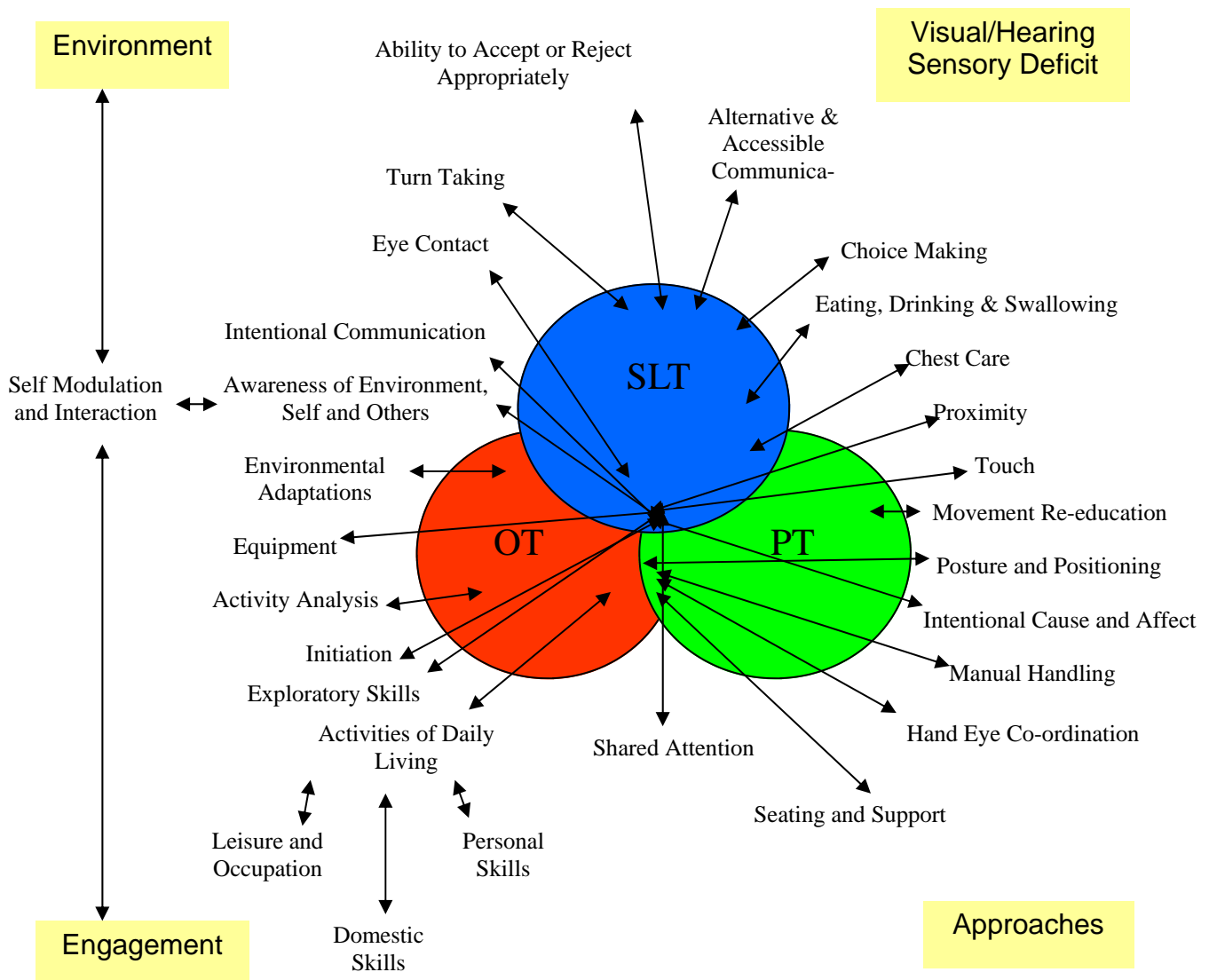


Figure 1

communication and dysphagia (swallowing difficulties). The Royal College of Speech and Language Therapists (RCSLT) (2006) state that SLT's role when working with people with learning disabilities is promotion of communication skills for independence, choice, inclusion and rights and the enablement of maximum involvement of the individual within these four domains. The College's 'Adult Learning Disabilities Position Paper' (Baker et al 2010) states that the profession recognises that work with adult learning disability is cutting edge "characterised by progressive strategic thinking, partnership working and embracing the social model of disability."

Physiotherapists

Physiotherapy is a healthcare profession concerned with human function, movement and maximising potential. It uses physical approaches to promote, maintain and restore physical, psychological and social wellbeing, taking account of variations in health status. It is science based, committed to extending, applying, evaluating and reviewing the evidence that underpins and informs its practice and delivery. The exercise of clinical judgement and informed interpretation is at its core (Chartered Society of Physiotherapy, 2002). Physiotherapists assess, diagnose and treat disorders of movement which may be musculoskeletal, neurological or respiratory in origin. These may include rehabilitation of specific physical causes of the presenting problem, developing compensation strategies to overcome physical limitations and enabling clients to maintain their physical skills.

Integration of Professional Roles

Figure 1 (page 29) has been developed specifically for this integrated therapy assessment service and shows the interface between the three professions, demonstrating where roles are shared and complement one another. This also demonstrates the importance of individual expertise in ensuring a comprehensive delivery of integrated clinical service.

Clinical Pathway

A single set of person centred, bespoke goals tailored to each individual are set collaboratively utilising the East Kent Outcome System (EKOS) to ensure objective measurement of clinical interventions. This is a health benefit based system where measurable targets are set to predict the anticipated health gain in an episode of

therapy. (For further information on this please contact the authors.) Outcomes are regularly reviewed against the goals set, with updated goals set as clinically indicated. Clients are enabled to maintain their outcomes by provision of highly personalised intensive training and support to families, carers, the wider multidisciplinary team and staff from outside agencies. Integrated multi-professional records are kept for each client using the service reflecting the expert intervention of each professional specialism whilst maintaining an integrated consistent approach towards achieving the EKOS goals.

Continuous evaluation and evolution of the service is driven by government initiatives & guidelines, emerging research and evidence, feedback from service users, their families, the multidisciplinary team and commissioners.

Figure 2 below is a flow chart that demonstrates the pathway followed for each client accessing the service.

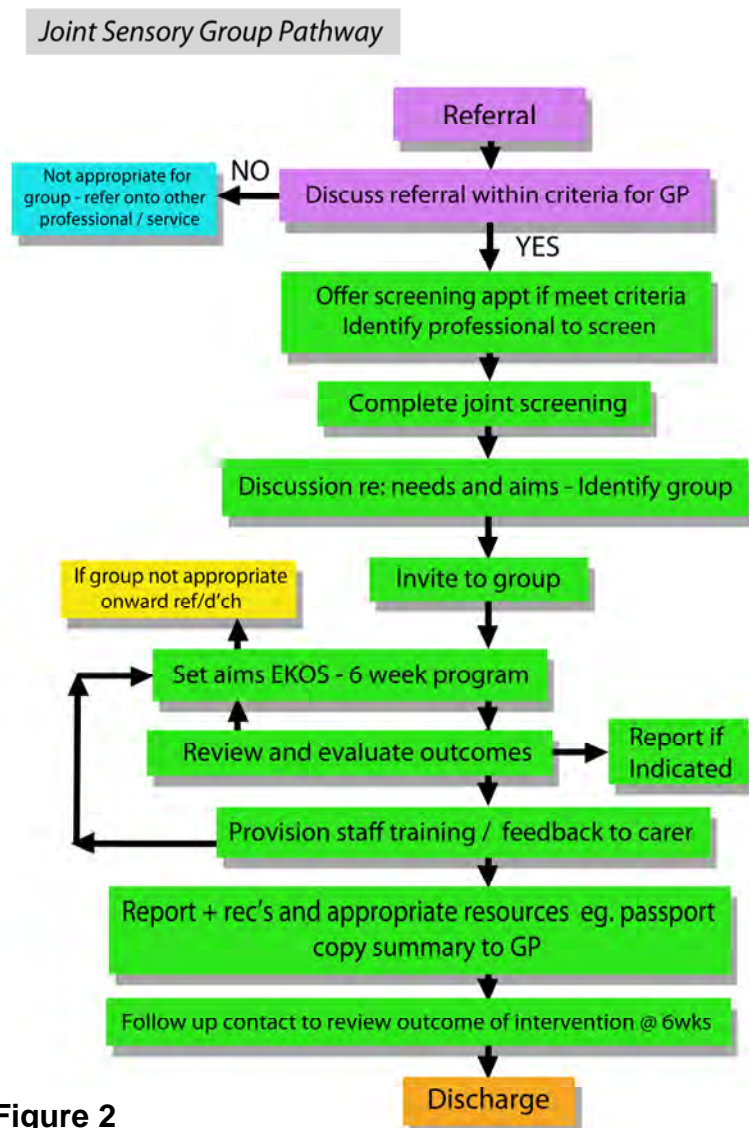


Figure 2

Outcomes of the Integrated Approach

Prior to the development of this service, the SLT, OT and PT found they were receiving similar referrals and were working uni-professionally with the same clients. On reflection it was identified that this was not a maximally efficient way to achieve a holistic approach, as each professional intervention was performed on a different day, at different times, with client treatment reliant upon time consuming liaison across organisations.

Joint working has made the service provision for this client group for our organisations more efficient and streamlined - the client attends one appointment instead of three, allowing a more intensive, cohesive approach with less liaison time required between professionals. Resources are shared including accommodation, equipment, clinical documentation and training materials.

Integrated working has enabled our clients to achieve a wider range of clinical and functional outcomes than would have been possible with uni-professional working. Individual outcomes have also been achieved more quickly and at a higher level than previously when this support was delivered uni-professionally. Objective measurement of these outcomes is much more robust due to all professions being involved in setting and evaluating aims. This has also facilitated maintenance of achieved goals by the use of integrated training and professional support.

Joint working provides opportunities for integrated clinical supervision, support and teaching across the multidisciplinary team for professional peers, new staff and students, as opposed to a traditional model of performing this solely in professional silos. This has helped enhance the evidence base for interventions for this client group within the local health economy by sharing good practice.

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“SALLY!”

Mark Whiting

Just over a year ago I took up a very exciting appointment as the WellChild Professor of Community Children’s Nursing at the University of Hertfordshire. To the best of my knowledge it is the only Chair in Community Children Nursing anywhere in the world. As part of my ‘induction’ to the University I was invited to provide an inaugural lecture and this provided an opportunity to reflect on the journey travelled so far.....

The first ever community nursing service specifically concerned with the provision of care to children was established in 1888 as a private nursing service based in Great Ormond Street, London. The service operated for almost sixty years, up until the establishment of the National Health Service in 1948. The service was concerned largely with the care of children (whose parents could afford to pay) in their own homes and was offered as an alternative to in-patient care and the nurses often ‘lived-in’ with their young charges – sometimes over a period of several months. Like many of the services which were to follow in the footsteps of these pioneering nursing sisters, the work of community children’s nurses has often focussed upon children who require ‘hands-on’ clinical care, including:

- Children with acute paediatric medical conditions, such as gastro-enteritis
- Supporting children with long term conditions such as asthma, diabetes
- Children who are technology dependent, for example children who have tracheostomies or who require continuous gastrostomy feeds
- Children who have life-limiting or life-threatening conditions including end-of-life care

In the autumn of 1998 (perhaps around 100 years to the day after the first community nurse set off from Great Ormond Street Hospital), I was working as a Community Children’s Nurse in North London. I received a referral from one of my Community Paediatrician colleagues requesting that I visit a child whom she had seen in school and who needed dressings to wounds on her wrists where she had been self-harming. Sally (a pseudonym), who was 14 years of age, attended one of the local schools for children with severe learning disabilities and had

missed most of the last year at school. When she did attend, she was described as ‘unkempt, dirty and with very challenging behaviour.’

I visited Sally at home. By this time I was aware that her wounds had been caused by Sally picking away at the flesh on her forearms exposing underlying tissues and with some evidence of infection. Sally lived with her mother and two younger brothers. Her house looked as though it had been hit by a tornado. The tornado was Sally! She had removed the doors from every room and cupboard in the house, she had torn, bitten, chewed and eaten her own clothing, her mother’s clothes, her bed linen and mattress. Her mother reported that she had no recollection of whether or when any health or social care professional had ever visited the house. Sally’s father had walked out on the family several years previously. Her brothers were both receiving support from local educational psychology and mental health services. Sally’s mother was distraught - in extremis. I had been asked to apply the proverbial ‘sticking plaster’ to a wound which clearly needed rather more than my nursing skills could manage.

I did dress Sally’s wounds, though she immediately started to chew at the bandages. I also made a multitude of telephone calls and referrals in order to try to engage a whole series of services, many of whom had no prior knowledge of Sally or her family. I visited Sally on a number of occasions over the course of several weeks – the healing of her physical wounds was a testament to the powers of recovery of the human body, but the necessary healing of the larger wounds for Sally and her family will have taken many years. I am sad to record that soon after my final visit – to apply dry dressings to her arms - I lost touch with the family.

But 'Sally' stayed with me. As my career progressed through a series of roles, each focussed on different aspects of community children's nursing – clinical care, management, education and research – my thoughts often returned to Sally. Sally represented a group of children who often remain hidden, almost invisible..... and it was that first visit to Sally which prompted me to undertake my own PhD study "Is this my life?" (Whiting, 2009) in which I explored and sought to find areas of consistency or of difference in the experience of parents of three sub-groups of children:

- 'children with a life-limiting or life-threatening illness';
- 'children with a technology dependence'; and a third group
- 'children (like Sally) with a disability that was neither technology-dependent nor life-limiting/life-threatening'

I wanted to try to better understand why children such as Sally were often times invisible to Community Children's Nursing Teams...

The major frame of reference for my study was my own experience in community children's nursing. Although nursing often describes itself as 'holistic', looking after the whole person, my experience suggested that children with disabilities would only come to the attention of local community children's nursing teams if they required specific 'clinical' care in the community – perhaps in symptom management/support for a child with a life-limiting illness or in order to support parents with practical aspects of caring for a child who has a tracheostomy or is fed via a gastrostomy tube. I wanted to try to develop my understanding of whether the needs, problems and issues faced by families in all three study sub-groups were present regardless of whether the child had a particular diagnosis or technology dependent.

What the study uncovered was, I suspect, not at all surprising. Although the numbers of families whom I interviewed was relatively small (33 families – 11 in each sub-group), it was clearly evident from the research that many elements of parental experience were consistent throughout the study population:

- The ways in which parents make sense of their situation has a pivotal role to play in relation to how they perceive the impact of the child's disability or complex health need upon family

life and consequently how they experience the need for help and support.

- Impact of childhood disability within the family is a complex phenomenon. In large part impact cannot simply be defined or described in the context of a particular 'medical' diagnosis or prognosis. Many elements of impact do not appear to be specifically related to whether a child has a life-threatening or life-limiting illness or is technology-dependent.
- Parents reported enormous differences in the level and nature of professional support which they had experienced, with very few identifying that they had experienced the support of a Lead Professional or Key Worker.
- Parents did, however, describe a wide range of personal characteristics and helping behaviours which they had found helpful in their engagement with professional staff
- Parents reported that the greatest area of unmet need was for respite, a break from caring.
- Parents described their experience as a 'battle ground' in which they often felt the need to put on their body armour before engaging with professionals.

In a short article such as this, it is only possible to provide a brief snap-shot of the overall study. However, even in these selected, summary findings, I hope that I have been able to provide some evidence to suggest that the time is perhaps right for Community Children's Nurses (and maybe for other professionals) to look more closely at their practice, to challenge historical ways of working and to actively seek out children like Sally who, in the absence of the 'right' diagnosis or who don't actually require specific 'clinical' care, may slip below the RADAR.

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Remembering Larry

Julia Barnes

During the half term holiday of October 2011, 15 year old Larry (a pseudonym) died unexpectedly. He was a real character with a fabulous smile, a contagious laugh and an amazing determination. Larry didn't speak but his vocalisations, gestures and facial expressions left you in no doubt at all as to what he was thinking! He was the king of 'if looks could kill' if you offered him something he didn't like but would also reach out to give you a full blown hug if he felt like it.

Hearing of his death was a shock – it wasn't believable, he had been so full of life and joy. It was hard for the staff to understand but how to explain it to his peers? As a special needs school we have to confront death more frequently than a mainstream school would expect to. As a staff we are necessarily resilient and can be philosophical over the vulnerability of many of the young people we work with. Even after ten years of working in a special school it is still something I find very difficult. During the school week I spend significantly more time with my pupils than I do with members of my own family. This time is not solely spent 'educating' but also caring; ensuring that our pupils with more complex needs are comfortable, pain free, not hungry or thirsty and are feeling happy, valued and respected. In these circumstances strong bonds are formed between staff and pupils. But it is still very, very difficult; a colleague discussed how we have to juggle our 'personal' response with our 'professional' response. All the time we are grieving we are mindful of how to respect pupils' responses, and sometimes accept a lack of them. I can feel myself welling up as I write this over two years on.

Our school caters for 138 pupils with a wide range of special educational needs, including moderate, severe and complex learning difficulties, profound and multiple learning difficulties, autistic spectrum disorders, sensory impairment, and physical disabilities. Students are in mixed ability pastoral groups of the same chronological age and attend some lessons in their pastoral groups and others in ability based groups.

The pupils in Larry's pastoral group had been supported to help them understand the deaths of

other pupils and were familiar with some of the language we use. One pupil pointed out that; "Larry will now be able to walk and talk, as heaven is a wonderful place". But it was the students with PMLD whom I felt more concerned about. A classmate, Carl (a pseudonym) who had shared the same lessons for most of their past 3 years appeared to be looking for him. Carl seemed quieter than usual, resting his head on the table rather than joining in with some of his favourite activities.

I searched for guidance on how to support young people with PMLD deal with the bereavement of a friend but there was very little information out there. It was a matter of doing what came naturally. In his book 'My Right to Play', Robert Orr described using the empty wheelchair of a recently departed peer to help to explain their absence to an individual with complex needs. In our Sensory Lesson Larry had often used his standing frame. We brought it into the room and encouraged the five remaining pupils to look and touch it to recognise that Larry was no longer there. We also found his favourite toy, a keyboard with a demo that Larry used to play and replay, which we all must have heard hundreds of times! I'm unsure how meaningful exploring the empty standing frame was but again two pupils looked around when hearing the familiar tune on the keyboard as if they were looking for Larry. Perhaps we helped to confirm a feeling of puzzlement rather than loss? One of Larry's classmates with severe learning difficulties used Larry's standing frame as an item for reverence. On more than one occasion he visited it and sat on the floor next to it; when asked what was the matter, he replied; "He's gone".

During the same lesson we read 'I'll Always Love You' (Wilhelm 2003), a children's book about a young boy whose dog dies and goes to heaven and misses his owner just as his owner is missing him. We have used this book successfully to support other pupils accept and deal with the death of a friend but somehow it didn't appear to reach this group of pupils with more complex needs. It went 'over their heads' and I could see pupils 'glazing over' appearing lost in the volume of text, while we adults didn't have a dry eye between us.

Crying and feeling sad was something we did not avoid, we cried in front of students, explaining that we were feeling sad because we were missing Larry. Although the students with PMLD did not cry with us they did gently try to comfort us in their own way, leaning onto us and resting their heads against us. I am quite convinced that they understood that something sad had occurred.

During the following week I racked my brain over what we could do that would meaningfully support pupils to understand the loss of Larry. I didn't want us to simply have a single session of 'missing' Larry and that be it. As described by Penny Lacey (2009), introducing new activities, not even concepts, to our group of pupils with complex needs takes many, many repetitions before they can recognise what is happening and join in. I felt we would have to remember and show we were missing Larry many times before pupils would understand he really had gone. Not on holiday, not off poorly, but that he had died and 'gone' and would not be coming back.

In a supermarket I saw some tete-a-tete mini daffodil bulbs and bought a pot for each pupil in the group. I printed photos of Larry looking at his happiest, smiling and laughing. During the next lesson pupils were supported to look at and select photos of Larry and we glued them to the outside of the pots. Whilst we were looking at his photos and talking about him we played The Three Tenors, one of his favourite albums. Although it was a sad time it felt a more meaningful activity than sharing the story had done the week before.

The pots sat on the windowsill of the classroom and during each week's lesson we would play The Three Tenors, lift the pots down, look at the photos of Larry and water the bulbs. The bulbs sprouted,

grew leaves, buds and then flowers. Over the weeks I looked forward to tending the bulbs and talking about Larry. Although poignant, it became a less sad time. Some of the pupils in the group who use spoken language would look towards the pots and talk about "Larry's daffodils".

As spring became summer the flowers died and we planted the bulbs on the hillside directly outside the classroom window. The change to the routine from lifting 'Larry's Daffodils' off the windowsill to water them to taking them outside, removing them from the pots and planting them in the grass seemed to be a little unsettling or perhaps unexpected for some of the pupils. We then removed Larry's photos and recycled the plant pots and the curriculum carried on. We did not make a point of talking about Larry from then on but we did mention him each time something such as a wobbling jelly reminded us of him!

When Larry's family were ready the School Chaplain held a whole school memorial assembly to celebrate Larry's life which his Mum, Dad and younger brother attended. Photographs of Larry were shown and his family were presented with his Record Achievement. It was an emotional occasion for his family and for many of the staff and pupils but provided a definitive occasion in which to say goodbye to him.

A year passed from Larry's death and spring returned again. The daffodils poked their heads up above the grass and bloomed. I found that many members of the school community had been aware of our 'remembering Larry' project and people came into the classroom to look out of the window at the bulbs and chat about Larry, his life and to share fond memories. We remembered how his death had been a shock and hard to accept but a year later it seemed easier to be philosophical about losing him.

The pupils who had tended the daffodils in pots found looking out onto the hillside difficult due to the height of the windows and individual's visual preferences so we went out to look and touch them whilst remembering Larry. Students appeared to recognise the activity and repeated the familiar language about Larry 'gone' which we had used when tending the daffodils the previous year.

While I am not suggesting that the events I have described were the right way, they did help me and the other staff deal with the death of Larry. Neither am I suggesting that the activities helped the pupils understand that Larry had died but it did provide us with a regular opportunity to discuss him and his absence. At first, pupils saw and felt our grief and we were able to acknowledge their sadness or 'quiet feelings'. Over the weeks that followed we were able to talk about Larry with happier voices, without tears and I believe pupils felt this shift in our grief. It was also reassuring to know that our 'remembering Larry' project was acknowledged and supported by members of the wider school community and provided them with opportunities to talk about Larry and celebrate his life.

Since the 'Remembering Larry' project I have discovered Erica Brown's book; 'Loss Change and Grief - An Educational Perspective' which explores the subject of bereavement in the mainstream and special school. I would recommend it to special needs teachers who feel they need extra

information to support themselves or pupils dealing with death, not solely to cope at the time but to plan so that you are able to offer the most appropriate opportunities for pupils, staff members and families.

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Developing a Personalised Music Curriculum for Pupils with Complex Needs through ‘Sounds of Intent’

Vicky Hubbard

Music plays a powerful role in most people’s lives: it has a unique capacity to touch our emotions, change our behaviour and improve our general wellbeing, regardless of our personal preferences. However, for individuals with complex needs it can be even more: a unique universal language with the potential for enabling communication, shared social enjoyment and an opportunity to express themselves as individuals and musicians. It is because music is processed largely on the right-hand side of the brain, linking it closely with emotion rather than the areas associated with cognition, that it enables individuals with profound cognitive delay to understand music at the same, and in some cases higher levels, than ‘typically’ developing people (Corke 2002). Yet until recently despite this exceptional potential there has been little research into how children and young people with complex needs develop musically, and an absence of a suitable music curriculum and assessment tool to teach and monitor progress in this area.

In 2010, I began the role of music-coordinator at St Luke’s Primary School in Scunthorpe, a special school for one hundred and twenty pupils aged between three and eleven years of age with profound, moderate and severe learning difficulties. The school, like many, celebrated the value of music and it was used widely across the curriculum. However, the music schemes of work didn’t reflect the requirements of the children with the most complex needs and the staff lacked confidence to deliver music, with many associating it with the role of a ‘music specialist.’ As part of a dissertation project for an MA in Education, I began a journey with a small focus group of staff to improve the opportunities we provided in musical development for these pupils and ‘Sounds of Intent’ (Sol) provided the structure for our work.

Sol is a free online curriculum framework and resource for mapping musical development in children and adults with SEN and is available to all at www.soundsofintent.org. It is based on research with typically developing children and over six-

hundred observations of people with SEN engaging in musical activity. The Sol team have written about its early foundations (Ockelford et al. 2010) and since then it has developed into a fantastic online resource. The framework segments musical development into three domains: Reactive (how individuals respond to sound and music), Proactive (how individuals create and produce sounds and music) and Interactive (how individuals learn to communicate and interact through music). Within each of these three domains the framework is divided into six levels, with each level then split again into four smaller elements, giving a total of seventy-two elements that can be used for assessment and target setting. It encompasses every stage of musical progress from no responses and engagement with sound, to recognising the skills of an accomplished ensemble performer.

In the preliminary stage of my research I used Sol as a structure to train the focus group; this enabled me to research what they currently knew about early paths of musical development. We found it

interesting that while many of them initially lacked confidence in their own musical ability, they had a wealth of knowledge in other developmental areas such as speech and language which follows an almost identical route to music at the early stages. The most useful aspect of the training came from exploring the Sol website which they found to be an invaluable resource as it provided detailed descriptions of each of the elements and practical strategies for delivering them within many different settings. They particularly enjoyed viewing some of the many hundreds of video examples which provided a great stimulus for moderation and discussion about our own musical practices as well as inspiring teaching ideas. The website also offered a number of downloadable resources, including activity cards and mp3 tracks which they later began to use in their own music sessions. Through these experiences they began to gain confidence and a sense of how easy it could be to deliver music and Sol, even if they had no musical experience.

To build staff confidence further and improve pupils' opportunities for musical development, I trialled a research methodology that focused only on discovering and building on our current successes ('Appreciative Inquiry'). I asked each of the participants to take a photo of a positive musical developmental experience with a child with PMLD, each of which they then discussed and analysed as a group. From these lively debates the group extracted many key themes within their musical work. Through validation with the wider school staff they decided upon five final themes they wished to improve to evolve our music practice:

1. Communication
2. Group work and allowing time
3. Staff skills and confidence
4. Resources
5. Multisensory

For each of these themes they used what they had learnt from Sol and their own experiences to envisage what our ideal practice would look like, and set these out within written positive ethos statements. The final stage involved devising action plans to help these statements become a reality which I was then able to synthesise into a 'Music Bill of Rights for Pupils with Complex Needs'.

Over the last two years we have begun to put this Bill of Rights into action. We have trained additional teaching assistants in Sol giving them the knowledge to be able to baseline pupils using the simple online assessment tool available on the website. These staff then used the resources and the framework to set individual targets and write individual programmes which were delivered in one-to-one sessions, and also incorporated into group music lessons. What became apparent was that the staff were becoming more conscious of pupil's musical intent enabling them to recognise the next steps and push for these through creative and innovative musical activities. The benefits of the online assessment system enabled them to measure and record even the smallest of reactions or slightest amount of progress towards any one of the Sol elements. The periodic records could then be easily transformed with a couple of mouse clicks into a simple graph or table celebrating the pupil's achievements. These could then be shared with professionals and parents or transferred easily to other assessment software.

The pupils have benefited greatly from working on Sol and all appear to enjoy their sessions immensely. Through engaging in musical play we have a number of students who have improved their musical interaction skills. One nursery aged pupil had previously made no vocalisations, but developed this skill in his Sol session and is now generalising this with communicative intent in the classroom environment. Other children who previously appeared to show no responses to sound are now reacting though systematic presentations and they are even beginning to demonstrate some preference to certain types of sound. One teaching assistant working with a pupil with complex needs reported to me that by using Sol "he has learnt to interact with others by playing musical games on the drums, listen to motivating CDs and through singing, before he didn't pay any attention to us." With another child she worked with who has a visual impairment and complex needs, she reported how he previously wouldn't like to be independent in his work or sound making; "he would often take my hand to prompt me to make sounds, now he loves to sit at the piano developing fine motor skills, playing, and looking intently at his individual fingers as he creates and reproduces short motifs."

Music Bill of Rights for Pupils with Complex Needs

To improve opportunities for musical development each child has the right to...

an individual music programme devised from the Sounds of Intent framework.

an individual programme that makes reference to Routes for Learning, communication, records of preferences and ACC

a lead TA skilled in recognising & developing communicative musicality.

Groupings & Time

work one-to-one with their lead TA on their individual music programme.

work in small groups and as part of a whole class.

flexibility in lessons to lead their own learning and be given the time that they need to respond.

a lead TA for music based within their class who is highly trained and confident with Sounds of Intent, and can support other staff, parents and carers.

work with enthusiastic confident staff who are all trained in:

1. Sounds of Intent
2. the best use of music resources
3. the Soundbeam
4. the multisensory studio.

access to one-to-one and small group music sessions based on the theories of intensive interaction and interactive music.

Communication

consistency in the delivery of their programme.
consistency in who they work with.

a lead TA who will ensure that consistency remains during periods of transition.

Resources

well designed high quality music resources created and maintained by a designated resource coordinator.

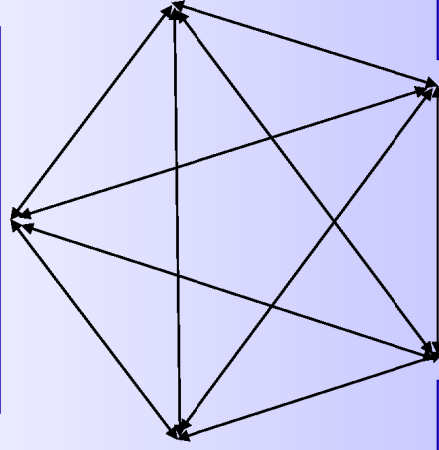
practice their ICT skills with music technology during multisensory sessions.

Multisensory

access a multisensory musical learning environment (the studio) once a week to work on their individual programmes.

access to the multisensory benefits of the Soundbeam.

access to well maintained multisensory music topic boxes.



Staff Skills

work with newly appointed staff who have been trained as part of their induction.

thorough assessment maintained by their lead TA on the Sol framework.

work with staff who regularly update their musical skills through observation, discussion and sharing workshops with colleagues.

The benefits have also been seen across the curriculum in other subject areas. Some teachers have used the interactive domain as a means of recording Intensive Interaction sessions. Additionally, the activities have proved useful for informing planning for early listening and phonics skills in Literacy sessions. Links can also easily be made to 'Routes for Learning' (Qualifications and Curriculum Group 2006) and ICT work, for example when using the Soundbeam or iPads.

Although my MA research was initially aimed at improving opportunities for pupils with complex needs it has proved to have had an impact on other groups of students too. Being aware of musical developmental pathways has enabled the staff to recognise a number of students who are musically gifted and support them to develop their talents, which have included some starting instrumental lessons. The great thing about Sol is that it can be used with any student, any age, and be delivered by anyone in any setting. Indeed Ofsted have recently recognised Sol as an example of good practice in their report 'Wider Still and Wider' (Ofsted 2012). By focusing on improving opportunities for musical development with pupils with complex needs we have developed a positive music environment for all with confident enthusiastic staff and pupils who are making progress not just in musical ability but right across the curriculum through Sol.

Sol is already being used by a number of SEN schools and organisations across the country and the hope is that this can be increased and expanded. The Sol team have also recently published a mainstream version called 'Sounds of Intent in the Early Years'. Soundabout are the charity leading the dissemination of Sol across the UK. They are currently able to offer schools and SEN organisations a free one day INSET introduction to Sol. If you would like to find out more, or book a day please contact me at victoriahubbard@soundabout.org.uk. To keep up to date with the latest developments and to see videos of Sol in action please 'like' our Facebook page at www.facebook.com/SoundsOfIntent.

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Good health begins with promoting well-being and preventing ill-health and this is the same for people with learning disabilities; healthy active lifestyles have to be the starting point for all.

Valuing People Now (Department of Health, 2010)

Top websites for this issue

<http://www.in-control.org.uk/>

In Control is a national charity whose mission is to create a fairer society where everyone needing additional support has the right, responsibility and freedom to control that support. It was founded in 2003 for local families with disabled members in Wigan. The website has details about 'Partners in Health' which is a course aimed at people with disabilities or long term health needs, family carers, and professionals, including commissioners, providers and clinicians who wish to make positive changes at a local and national level. The website also has information about 'Partners in Policymaking' and 'All Together Better' courses.

<http://www.improvinghealthandlives.org.uk>

The Improving Health and Lives Learning Disabilities Observatory is a collaboration between the three organisations: Public Health England, the Centre for Disability Research at the University of Lancaster and the National Development Team for Inclusion. Since April 1st 2013 it has been operated by Public Health England, the Government Organisation overseeing all public health work in England. The website carries reports called 'health profiles' for the areas of Local Authorities that run Adult Social Services. They are used by planners in health services and social services but are also interesting for self-advocates and family carers.

<http://www.cnne.org.uk>

This is the website for the Clinical Networks Northern England. It covers north east England, north Cumbria and the Hambleton and Richmondshire area of North Yorkshire which has patient flows into Teesside.

<http://www.rcn.org.uk>

The Royal College of Nursing (RCN) is the largest professional association for nursing in the UK. It promotes excellence in practice and helps shape health policies.

<http://www.rcgp.org.uk>

The Royal College of General Practitioners is the professional membership body for family doctors in the UK and overseas. The RCGP is committed to improving patient care, clinical standards and GP training.

<http://www.peoplehub.org.uk>

'Peoplehub' is the Personal Health Budgets Network. It has been set up to seek out and present the people's experiences of personal health budgets. The website states: "We believe that being connected to like-minded people in the development of personal health budgets will create confidence by showing people they are not on their own, and also provide a valuable opportunity to learn from each other."

<http://www.familycarers.org.uk>

The National Family Carer Network is an umbrella organisation that aims to promote the voice and rights of family carers supporting a person with a learning disabilities. Its membership comprises both organisations and individuals.

FUTURE FOCUS

Making Sense of the World

The first issue of the new year, Spring 2014 has the theme 'Making sense of the World' and we would like to be able to publish accounts of absolutely any opportunities that you feel have enabled children or adults with PMLD to get information about anything and everything, including themselves.

Getting information about themselves, their own self-awareness and how they might gain insight into themselves and their place in the social world; have there been any occasions where someone has demonstrated their uniqueness, their special qualities, their personality. I will always remember a parent's school diary entry for her sixteen year daughter which read something like this, 'Today is a great day! Catherine has finally managed to push her cornflakes bowl off her tray. She's been trying for years and today she finally did it. She laughed and we laughed and told her how clever she is!' We would like to hear about any moments where you believe there has been an opportunity for someone to be self aware and/or to realise that they have had an effect on other people.

The theme also invites us to think about contingency-sensitive environments. Do you have an example of, or have undertaken research on a particularly responsive environment for adults or children with PMLD where their communicative intent is more easily noticed and responded to, so that they are encouraged to continue. Perhaps you have set up an environment where their actions create an effect which they really enjoy and are motivated to repeat to prolong their pleasure.

We had a number of articles on iPads etc. in our Winter 2012 Technology issue and so it would also be good to hear about any low-tech, creative ideas, including resources which open doors to and 'make sense of' the arts, enabling people to appreciate and become emotionally involved for example, in stories, poems, plays, music. There are also the regular experiences any of us may have; being engaged in a physical activity, going to a gig or a concert, exploring a town – or simply shopping, being in the country or by the sea, somewhere cold or somewhere hot, those times when all our senses are alert and giving us pleasurable or sometimes not so pleasurable information about our world.

On the other hand, examples of how someone is helped to know what is going to happen next in their day are particularly relevant to this group of people, enriching their lives by contributing to their confidence. Also, how

can we as carers, families and professionals get information from them and understand them better.

Sharing the experiences of people with PMLD and your ideas, knowledge and enthusiasm can be inspirational to others and we look forward to hearing that you are interested in contributing and to a deluge of articles!

The copy deadline for all articles, information and news for the Spring 2014 issue is the **14th February**.

Please email

Chris Fuller: fuller.chris@hotmail.com

or

Rachel Hughes: rmparry@hotmail.co.uk

Good news

PMLD LINK has been awarded a grant to engage a freelance worker for one day a week to assist with creating greater awareness of the journal and the management of subscriptions. Full details will appear in the Spring issue and on the website at the same time but if you believe you have relevant skills and can work from home, please email rob.ashdown@ntlworld.com for further information and to express interest now, giving **brief** details of your suitability for the role.

REVIEWS

Title: Personalised Learning for Young People with Profound and Multiple Learning Difficulties

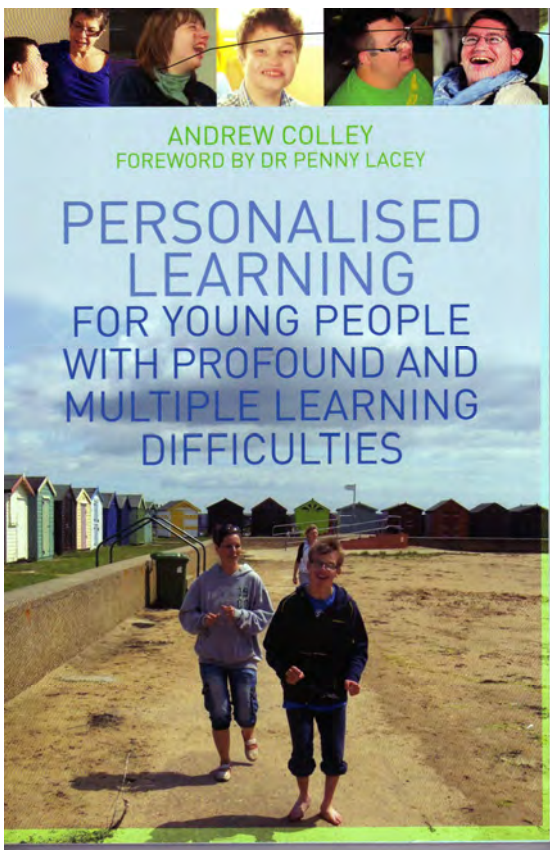
Author: Andrew Colley

Publisher: Jessica Kingsley Publishers

Date: 2013

Price: £19.99

Pages: 168



Andrew Colley's book will be of real interest to anybody involved in the education of young people with PMLD aged from about 14 years upwards. The young people he writes about mostly do not have profound physical impairments but they present many challenges. Andrew is a real wordsmith and this is a very readable book indeed. In his book Andrew articulates well his enthusiasm about teaching these students and his personal philosophy about the nature of the curriculum and teaching and the provision that is most appropriate to the needs of these young people.

The book starts conventionally enough with introductory descriptions of several of Andrew's students, whom the reader again encounters at other points in the book, and discussion of labelling, definitions of PMLD, prevalence and, importantly, the guiding principles underpinning his own teaching. The second chapter provides some very brief definitions of common syndromes which have an impact on teaching and learning and the need for thorough assessment through dialogue with people who know the young person well and extended observation and interaction with them. His description of an hour-long interaction with a new 'difficult' student is an entertaining example of how Andrew tries to learn about his students and the importance of this information for designing their personalised curriculum. The third chapter is about Andrew's positive approach to managing the challenging behaviours his students can show: "Above all, we should try not to view young people's everyday behaviours through the prism of our own social and cultural conditioning." Andrew wants to convince us that we should accept these young people as they are, although there is ring of realism in whatever he writes and he makes suggestions for strategies for promoting more acceptable behavior and avoiding situations getting out of control. In the next chapter, Andrew articulates his approach to personalising the curriculum and what he means by teaching and learning. His answer to the question "What do you actually teach them?" is that he teaches them what they truly need and in a way that suits them. His goal is to teach them to be happy, to communicate a little better and to be as independent as possible – three concepts that he seeks to clarify. These have to be learned in a personalised way: for Andrew: "The curriculum is the student: the student is the curriculum". Other chapters address the design of the learning environment, the expectations of staff, timetabling issues, meaningful target setting and assessment. There is a chapter on transition to adult services which includes an extended case study of the approach to personalised learning in a college setting. Finally, he shows how the personalisation process is used to create a unique curriculum for one student.

This is not an "academic" text. There are no extended discussions of what research has gleaned. This is a down-to-earth, commonsense book that will appeal to practitioners and many parents. You will not find lengthy expositions of 'intensive interaction', 'augmentative communication systems', 'transition planning' although he provides some useful references at the end of the book. What comes across clearly is Andrew's own humane and realistic views but he also includes painstaking presentations of the views of parents and a range of professionals so that it is not only his voice that you hear. This book is both thought-provoking and uplifting.

Title: Supporting Children with Learning Difficulties: Holistic Solutions for Severe, Profound and Multiple Disabilities

Authors: Christine Turner

Publisher: Continuum

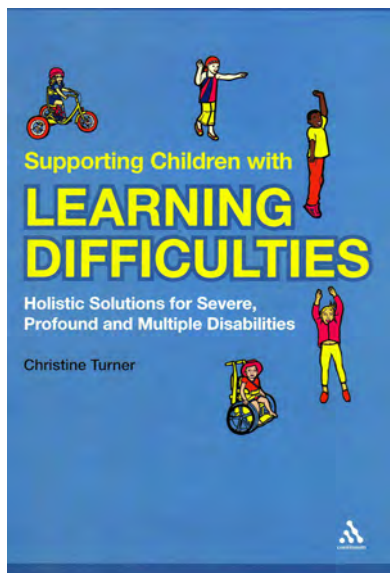
Date: 2011, reprinted 2012

ISBN: 978-1-4411-2177-6

Cost: £19.99 in paperback

Pages: 161 plus xiii

This book is aimed primarily at all those involved in teaching children and young people with severe, profound or multiple learning disabilities. However, its easy-to-read style makes it accessible for parents, carers and anyone else with an interest in the education or care of children with learning difficulties. It covers many



aspects of learning from the simplest forms of non-verbal communication to key skills that may be learned in the context of history and mathematics lessons. In every chapter, the author describes strategies and makes available practical tips and suggestions.

The book illustrates how the curriculum can be adapted to meet the individual needs of each child regardless of their level of disability. It explains how to develop their use of the senses, especially vision, hearing and touch. The need for consistency and routine, how to break tasks down to ensure success and how the environment can affect learning are among a range of the topics that are discussed. Movingly, the author makes plain the ways that a learning disability affects not only the child but also their family.

Christine Turner has real depth of experience in teaching children with severe, profound and multiple disabilities. Her stated intention is to give relatively inexperienced colleagues easily accessible information about these children and approaches to teaching them. She aims to

encourage readers to 'place themselves in the shoes' of the child as well as to explore educational approaches. In this she succeeds admirably. The book gives practical, sensible and genuinely helpful advice and is easy to read. There is no jargon and the text is further enlivened by case studies.

This kind of text should be useful both for encouraging interest in this sector of education and for supporting new entrants. This is most helpful at a time when many experienced professionals are approaching retirement and schools are faced by the looming problem of a relative dearth of people with relevant knowledge and skills. Of course, the book cannot cover in depth all that needs to be known about how children with severe, profound and multiple disabilities think and learn. Even though she illustrates well the relevance of some specific approaches, there is not the space to review in detail which approaches are effective and why. This knowledge can only come with comprehensive mentoring and professional development opportunities which schools and various agencies must provide. However, in this context it is worth noting that the book provides guidance for further reading and details about organisations and relevant websites. As an inspirational, practical and informal guide, this is a book well worth having and sharing.

Title: Fetal Alcohol Spectrum Disorders: Interdisciplinary Perspectives

Authors: Barry Carpenter, Carolyn Blackburn and Jo Egerton (editors)

Publisher: Routledge

Date: 2013

ISBN: 978-0-415-67016-6

Cost: £34.99 in paperback

Pages: 328 plus xxii

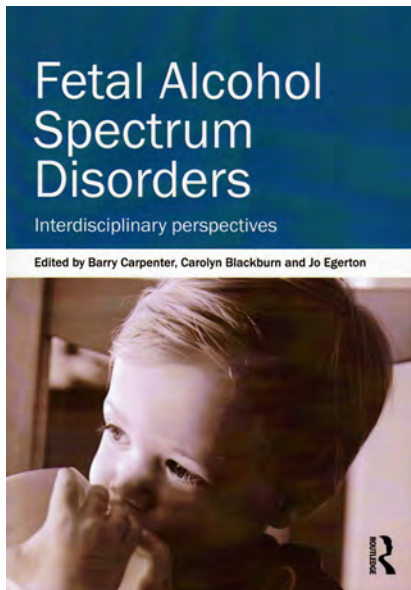
The message in this book is blunt: consuming alcohol during pregnancy is very likely to be harmful to the baby. Even moderate drinking carries a risk despite equivocation in UK government guidelines. The safest thing for women to do is to consume no alcohol at all when they know that they are pregnant or are planning to have a baby. This book dispels many myths. Much is now known about the effects of alcohol on the development of the unborn child, although some children may be unaffected for reasons that are complex and not well understood. Alcohol kills brain cells in the

vulnerable foetus at any stage in its development. Its effects are more harmful and long lasting than those of smoking and use of hard drugs such as heroin, cocaine, etc.

This book contains much useful information about what have become known as 'fetal alcohol

spectrum disorders' (FASDs). Estimates of prevalence vary but there could be as many as 1 in 100 children with FASDs. Diagnosis is not straightforward because there are only subtle physical manifestations and accurate diagnosis depends upon good case histories and investigations. Diagnosis is not helped by the fact that children with FASDs can show cognitive and social-emotional problems which are also associated with mood disorders, autistic spectrum disorders and attention deficit hyperactivity disorder. What is unclear from the book is the extent to which consuming alcohol in pregnancy could result in profound learning difficulties, although it is known to be implicated in miscarriages and sensory and physical problems.

A strength of this book is that it contains contributions by 30 authors from a variety of disciplines (health, education, social care, law) and from several different



countries. There are also contributions from people who have adopted or cared for children with FASDs. The choice of chapter authors reflects the editors' view that an inter-agency approach to prevention, diagnosis, educational intervention and social care is required and each chapter brings a genuinely interesting perspective and insights. This book is not about blaming mothers who drink in pregnancy – indeed it stresses that many women may not realise they are pregnant during the early stages of the foetus' development and that there has been much misleading advice. This book recognises the support that mothers need from fathers, family and friends to maintain abstinence and from midwives and others for their education, guidance and counselling. Worryingly, this book shows that so many key health and other professionals lack knowledge about the effects of alcohol and appropriate advice and support to give, but it does provide the latest information from research and good models for their training. In the final chapter the editors helpfully provide overviews of each chapter and reiterate key messages for service development.

This is a scholarly book that is invaluable for articulating knowledge about, and initiatives in relation to, FASDs. There is no mention specifically about children and young people with PMLD and there are many causes of disabilities besides, but it would be wrong to assume that this book has no relevance. It provides important information for professionals from all services and organisations who may be engaging, knowingly or unknowingly, with children and young people with FASDs and their families. The editors have also co-authored a book called Educating Children and Young People with Fetal Alcohol Spectrum Disorders published in 2012 by Routledge.

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IN THE NEWS

Paying tribute to Alan Parrish

Ann Norman

I am sad to report that Alan Parrish, a pioneer in the field of learning disability nursing, has died. Alan was the adviser for learning disability nursing for the Royal College of Nursing (RCN) from 1983 until his retirement in 1999, and was instrumental in achieving recognition for prison nursing and for vulnerable people who came into contact with justice services. He was intolerant of injustice and helped nurses to speak out where it existed both in learning disability nursing and prison nursing.

Alan was a keen writer and was very well respected for his views, not only in nursing but across professional boundaries. He was especially skilled in providing opportunities for other nurses to shine and articulate their perspectives, always happy to step back from the limelight and give others a voice. I will always remember Alan as a genuine, kind and compassionate man who really epitomised the very best of nursing.

Paying tribute to Alan, Dr Peter Carter, RCN Chief Executive and General Secretary, said: "Alan was a hugely respected and much loved RCN adviser and a true leader in the field of learning disability nursing. I knew Alan from my previous roles in the NHS and you could always trust Alan to tell you the things you absolutely needed to hear, however difficult. He was a gentle, charming colleague with a great sense of humour and a talent for bringing out the best in people. He inspired many, many people to choose this branch of nursing.

"Alan changed the face of learning disability nursing and was known the length and breadth of the UK for his pioneering work. Above all, he was a champion for the rights of people with learning disabilities to receive excellent care and take their rightful place in society."

Contact Details

Ann Norman, RCN Learning Disability and Criminal Justice Nursing Adviser
e-mail: ann.norman@rcn.org.uk



New Website for Comparing Adult Social Care Services

Adult Social Care Outcomes Framework (ASCOF) data is now presented on a website that allows people to find out more about care services. On the website you can select your local authority from the map or drop-down menu, or type in your postcode, to find out how carers and people receiving local authority funded care and support in your area rate factors such as, quality of their life, satisfaction with care services and feeling safe. The Department of Health has worked with the Health and Social Care Information Centre to produce this website. To visit the website, go to: <http://ascof.hscic.gov.uk>

A Tribute to Victoria Willson

26 June 1970 – 22 Sept 2013

Centre 404 in Islington has paid tribute to Victoria Willson, beloved daughter of Jean and Norman and sister of Tara [see *Family Carers Update*, Autumn 2013, Issue 18, pages 6 and 7, available at <http://www.centre404.org.uk>. Victoria passed away peacefully on Sunday 22nd September in her own home surrounded by family and friends.



“Over the years Jean and Victoria Willson have launched many campaigns such as ‘Save a Baby’, ‘Treat me Right’, ‘Death by Indifference’, ‘Stand by Me’ and ‘Changing Places’ that have contributed to improving the lives of people with multiple and complex needs. As a pioneer and innovator from a very early age, Victoria became the face for people with high support needs. She raised awareness of the learning disability community’s identity, needs and wishes, to a wider audience, in her own unique way. In 2011, Victoria was chosen by Mencap as one of the top twenty people with a learning disability who have made a huge difference in society.

“Dame Philippa Russell the Chair of the Government’s Standing Commission on Carers (who is also a carer for her 50 year old son) has kindly written a few words about Victoria.

“I first met Victoria at a Kith and Kids event in Coram Fields nearly forty years ago. We had just come back from living in Central Africa and I remember thinking how drab and gray England was – until I saw Victoria! But as her mother Jean said, when Victoria smiled, you felt there was a sunburst in the room. As a woman without words, she nonetheless communicated with everyone. I remember her bright pink dress glowing against the faint drizzle of an English Autumn afternoon, a flower in her hair and thinking that here was someone who truly enjoyed life! I soon learnt that Victoria had a powerful personality – matched by the love, the passion and support of her family. Victoria was a trail-blazer. When she was born, disabled children were still being placed in long- stay hospital wards. There were many negative views about the ability of the world to cope with complex needs but Victoria proved the world wrong. She moved to Field End House and then to that place we all want, a home of her own.

“Victoria loved life. The local market, the shopkeepers and their neighbours all knew her out and about. She had fantastic parties (I so wish I could have gone to the Hawaiian one). She and her family never knew the meaning of the word ‘can’t and she and Jean, Norman and Tara were indeed an inspirational family to other parents like ourselves who maybe did not have the creativity, the vision and the sheer determination of the Willsons behind them!

“As Jean said at Victoria’s funeral, she had a real ability to attract and demand total commitment from people in every walk of life. She was a role model for ‘personalisation’ because she loved her life and she was loved in return. Victoria enjoyed life – everything from seeing a police raid at Euston Station (so many dogs and so much excitement!), her music, her food, the pattern of light and shade in the trees.

Continued on page 48

"I well remember my seven year old daughter looking at Victoria admiringly in Coram Fields and saying 'she looks fun!' Victoria was fun. But she was more than fun. She, Jean, Norman and Tara together were a fantastic team. They were an iconic family and always warm and generous in their support of others. As I wrote to them on hearing so sadly about Victoria's death, I said that Victoria had enjoyed such a good (and valued) life. Life was often cruel. She had illness, she had pain but the spirit survived. Victoria reminded all of us that life is ALWAYS worth living. She enriched the lives of all who knew her. She was much loved and she will be remembered."

[Jean and Victoria have featured in the PMLD Link Journal, most recently in last year's Summer 2012 Issue, Volume 24 (2) pages 2 and 3, when Jean talked about transitions in Victoria's life.]

Frozen Light tour dates announced!

Hello again from Frozen Light, a theatre company creating multi-sensory performances for audiences with PMLD. In 2014 we are touring our production Tunnels for teenagers with PMLD across the UK. Join Lana on an exciting adventure as she searches for the light that has mysteriously disappeared from her city. Tunnels is an enchanting multi-sensory production that fuses live music, sign and movement.

Tunnels hits the road on 24th January at the New Wolsey theatre in Ipswich where we are an associate company. The show will then journey to venues across the UK including: Arlington Arts Centre* (Newbury); Gulbenkian Theatre* (Canterbury); Cambridge Junction*; Colchester Arts Centre*; Phoenix Theatre* (Bordon); Conerstone Arts Centre* (Didcot); Zinc Arts* (Chipping Ongar); Central Studio Theatre* (Basingstoke); Norwich Arts Centre*; Harlow Playhouse*; Derby Theatre; Theatre Royal Plymouth; Galeri (Caenarfon) and Dundee Rep Theatre. For further information on the tour please visit frozenlighttheatre.com

We can't wait to get this show on the road!

house are enabling Tunnels at these venues. house is an initiative by Arts Council England to improve range, quality and scale of theatre presented across the east and south east of England.



Raising Our Sights Guides

As reported in the last issue of PMLD Link, Mencap and the PMLD Network have produced a series of 'how-to guides' and associated films to help local areas meet the needs of people with PMLD, funded by the Department of Health. The guides are aimed at families, commissioners and others who are responsible for supporting or developing services for people with PMLD. Raising our Sights, by the late Professor Jim Mansell, was published in March 2010 with recommendations that aim to make sure people with PMLD and their families get the support and services they need, and do not miss out on opportunities for more choice and control over their lives. Since this issue has the theme of Well-Being, your attention is drawn particularly to two of the guides:

'How-to guide 2' is on clinical procedures. Jeanne Carlin, disability consultant and parent carer, was the lead author for this guide. Raising our Sights identified that many people with PMLD are being denied services or access to certain opportunities and activities, because some agencies are preventing their staff from undertaking clinical procedures or using medical devices to sustain or support life. This clinical procedures guide is intended to help local areas implement these recommendations and ensure the inclusion of people with PMLD. It focuses on what needs to be in place to meet their needs, sharing examples of good practice.

'How-to guide 4' is about understanding and meeting the health needs of people with PMLD. Jill Pawlyn, registered nurse (learning disabilities) and lecturer, was the lead author for this guide. People with a learning disability are four times more likely to die of preventable causes than people in the general population, and 2.5 times more likely to have health problems. Raising our Sights identified specific problems where services for adults are often not sufficiently well developed to recognise and intervene effectively, e.g. postural care, dysphagia, and epilepsy. It identifies what needs to be in place to meet the health needs of people with PMLD, including how to improve access to health services most of us take for granted. It provides case studies and links to more information and resources.

The guides and films can be accessed at: <http://www.mencap.org.uk/all-about-learning-disability/information-professionals/pmlD/raising-our-sights-guides>

University of Kent awarded Queen's Anniversary Prize

The University of Kent has been awarded a prestigious Queen's Anniversary Prize for Higher and Further Education for the work of its Tizard Centre. The Queen's Anniversary Prizes are awarded, within the honours system, for exceptional contributions by institutions in the higher and further education sectors and will be presented by The Queen at Buckingham Palace on 27 February 2014.

For more than 30 years, the Tizard Centre has worked to improve the lives of people with Intellectual and Developmental Disabilities (IDD) and their families, focusing on the relationship between policy, management and practice to bring about improvements in the quality of their lives.

In a joint statement the Centre's Co-Directors, Professor Glynis Murphy and Professor Peter McGill, said: 'We are very honoured to receive such a prestigious award. The Prize not only acknowledges the work of both the staff and students at the Centre, it reflects the legacy of its founder, the late Professor Jim Mansell.'

'It is also recognition at the highest level that people with IDD deserve the best possible quality of life. All too frequently, they are at a real disadvantage in society with nine out of ten experiencing disability hate crime. We hope this award signals the need for a step change by policy-makers and the wider society.'

The Tizard Centre has an international reputation for its cutting-edge research and practice. Over the years, it has trained hundreds of practitioners through distinctive practice-based undergraduate and postgraduate programmes and regularly advises government on issues relating to challenging and offending behaviour, profound multiple disability and sexual abuse among people with IDD. The Centre's impact is world-wide, extending to East and Central Europe, where it has undertaken vital work on 'deinstitutionalisation', as well as to Ireland, Japan, Australia and New Zealand.

The National Family Carer Network is Promoting Family-led Support

For many years family carers have designed, developed and managed support for their learning disabled relatives. Their intimate experience of what good support looks like, their energy and passion, and their lifelong commitment to their relatives means that they are often best placed to lead this process. Family-led support comes in various shapes and sizes; it can be 'hands-on' or 'arms-length'. It includes:

- Leading planning
- Managing a relative's direct payment to pay for personal assistants
- Coordinating 'pooled funding' on behalf of several people with learning disabilities
- Setting up a service
- Working in partnership with an agency.

Changes to the way that support for people with learning disabilities is funded and purchased means that families will have an even more important role to ensuring their relatives get good quality support. However, many families never consider the option of 'doing it themselves' because they do not know what it would involve, what the benefits are, or where they could get help. Over the next two years the National Family Carer Network will be working to promote family-led support. The Network wants to:

- Understand more about the experiences of families that have developed their own support;
- Find out family carers views family-led support and what help they would like to consider it as an option;
- Develop practical resources that provide families with the information, advice and assistance they need when thinking about arranging support themselves.

The National Family Carer Network would be grateful if you would help by filling in a survey telling them about your current involvement in your relative's support and your views about what might happen in the future.

To take part in the survey online go to the website for the Network (see address below). It is hoped that the survey will find out more about what the National Family Carer Network can do to help support family carers who would like to arrange support themselves.

To find out more about this activity or request a paper copy of the survey, please contact Paul Swift: Mob: 07740 946564; Tel: 0117 9294365; mail to: paulswift.research@gmail.com

For more information about the National Family Carer Network go to: <http://www.familycarers.org.uk>

EHRC's Disability Committee: end in sight for influencing legislation

Disability Now raises fears about the future of disability rights in the light of the Equality and Human Rights Commission's (EHRC) plan to disband its statutory body, the Disability Committee. There is a proposal to replace the statutory body with an advisory one with no legal powers to make decisions on disability-related matters. In contrast, an independent review carried out by disabled activist and former member of the Disability Rights Committee, Agnes Fletcher, recommended retaining the statutory status of the Disability Committee for another four years. Retaining its status, according to Fletcher, would have provided disabled people with the confidence that rights were being safeguarded at the highest level. Agnes Fletcher said that she was disappointed with the EHRC's stance. For more details, read the full article on the Disability Now website. Go to: <http://www.disabilitynow.org.uk/article/ehrcs-disability-committee-end-sight-influencing-legislation>

SHORT COURSES & CONFERENCES

Providers Details

Concept Training

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

EQUALS

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

Hirstwood Training

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

Sense

Jackie Bishop and Rachel Johns
Tel: 01179 670 008
Email: jackie.bishop@sense.org.uk
rachel.johns@sense.org.uk

January 2014

Title: **Learners with pmld/profound autism: how we sense, learn & begin to learn**

Dates: 14th Birmingham, 17th Manchester, 20th Nottingham

Provider: Flo Longhorn Les Staves

Contact: florencealonghorn@gmail.com

Title: **Emergent Literacy & Drama Workshop**

Dates: January 23rd London, February 6th Nottingham

Provider: Keith Park Flo Longhorn
Andrea Muir Sarah Hall

Contact: florencealonghorn@gmail.com

Title: **Complex learning difficulties and disabilities: Children of today – adults of tomorrow**

Date: 22nd - 23rd

Location: London

Provider: The Royal Society of Medicine

Contact: Chanel Roachford
Tel: 020 7290 3942
intellectualdisability@rsm.ac.uk

Title: **Lifting the lid on curriculum for pmld learners**

Dates: January 27th Bristol, February 3rd Manchester

Provider: Peter Imray Flo Longhorn

Contact: florencealonghorn@gmail.com

Title: **iPads in SEN**

Dates: 27th London, 29th Birmingham, 31st Manchester

Provider: Hirstwood Training

Contact: See provider details

Title: **Complex learning difficulties and disabilities: impact of visual impairment**

Date: 29th

Location: London

Provider: SSAT (The Schools Network) Ltd

Contact: events@ssatuk.co.uk

Tel: 020 7802 0660

Title: **Literacy for Today in Special Schools**

Date: 30th

Location: Manchester

Provider: EQUALS

Contact: See provider details

February 2014

Title:	Ipads apps switches and sensory magic!
Date:	10 th
Location:	Manchester
Provider:	Ian Bean Flo Longhorn
Contact:	florencealonghorn@gmail.com
Title:	Practical & Effective Ways of Using Multi Sensory Equipment
Dates:	<u>February</u> 11 th Liverpool, <u>March</u> 3 rd London, 4 th Eastbourne, 12 th Nelson, 18 th Birmingham, <u>April</u> 29 th Glasgow, <u>May</u> 5 th
Provider:	Cambridge, 20 th London
Contact:	Concept Training See provider details
Title:	Tools for Inclusion – person centred planning facilitator training 5 day course
Date:	<u>February</u> 12 th 13 th 14 th , <u>March</u> 20 th 21 st
Location:	Leeds
Provider:	Connect
Contact:	Sarah Wheatley: sarah@citn.org.uk Tel: 0113 2703233
Title:	Inclusive and Creative Computing
Date:	27 th
Location:	York
Provider:	EQUALS
Contact:	See provider details
Title:	Introducing an easy and effective Target Setting System
Dates:	<u>February</u> 28 th Edinburgh, <u>March</u> 24 th Manchester, 26 th Birmingham, 28 th London
Provider:	Hirstwood Training
Contact:	See provider details

March 2014

Title:	PMLD: Profound and Multiple Learning Disability – engaging children in learning
Dates:	3 rd London. 6 th Manchester, 17 th Brighton
Provider:	Concept Training
Contact:	See provider details
Title:	Making sense of sensory learning
Dates:	3 rd London, 5 th Birmingham, 6 th Manchester
Provider:	Hirstwood Training
Contact:	See provider details
Title:	Intensive Interaction: Building relationships with people who have profound learning disabilities and complex needs
Dates:	Jane Gurney 4 th Cardiff, 19 th London, 21 st
Provider:	Belfast
Contact:	Concept Training See provider details
Title:	Learning and Progression in the Multi-Sensory Classroom
Dates:	4 th Birmingham, 10 th London
Provider:	Concept Training
Contact:	See provider details
Title:	Creative Minds Conference
Date:	delivered and presented by learning disabled artists 10 th
Location:	Brighton
Contact:	www.creativemindsproject.org.uk
Title:	7th Biennial Scientific Conference: Breakthrough to Excellence
Date:	11 th -14 th
Location:	Hunter Valley, Australia
Provider:	Australasian Academy of Cerebral Palsy and Developmental Medicine
Contact:	ausacpdm2014@dcconferences.com.au

Title: Pedagogy, Curriculum and Assessing Pupil Progress for Children and Young People with SLD and PMLD
Date: 14th
Location: Manchester
Provider: EQUALS
Contact: See provider details

Title: Developing Special Needs Practice in Early Years Foundation Stage
Date: 20th
Location: London
Provider: Concept training
Contact: See provider details

Title: Seminars and Exhibition: Kidz in the Middle
Date: 27th
Location: Coventry
Provider: Kidz in the Middle
Contact: Tel: Disabled Living 0161 607 8200

Title: Conference: Broadening our Horizons
Date: 28th - 29th
Location: Melbourne
Provider: Intensive Interaction Down Under 3 (IID3)
Contact: Tel: +61(0)3 9372 7182
 Email: iid3@ammp.com.au
 Web: www.ammp.com.au/iid3

April 2014

Title: Conference: Bridging Research and Practice in Early Childhood Intervention
Date: 3 - 6th
Location: Antalya, Turkey
Contact: Website: <http://www.iceci2014.com/eng/kayit.php>

May 2014

Title: Interactive and Multi-Sensory Storytelling
Dates: 2nd Manchester, 9th Birmingham, 16th London
Provider: Concept training
Contact: See provider details

Title: 2014 BILD Positive Behaviour Support Conference
Date: 8th - 9th
Location: Scotland
Contact: Email: learning@bild.org.uk

Title: Learning Outside the Classroom
Date: 12th
Location: London
Provider: Concept Training
Contact: See provider details

Title: Open Day for Professionals at The Children's Trust
Date: May 15th, November 13th
Location: Tadworth, Surrey
Contact: opendays@thechildrenstrust.org.uk
 Tel: 01737 365890

Title: Atypical Developmental Pathways: 4th Paediatric Neuropsychology Symposium
Date: 19th - 23rd
Location: London: UCL Institute of Child Health
Contact: Magdalena Pytlarz
m.pytlarz@ucl.ac.uk

Danille Dansey
d.dansey@ucl.ac.uk

Title: Play for People on the Autism Spectrum
Date: 20th
Location: Chorley
Provider: Concept Training
Contact: See provider details

LONGER COURSES (with Creditation)

MA Education

Pupils with Severe and Profound and Multiple Learning Difficulties (P1: Contexts & Understanding P2: Curriculum & Teaching)
The modules address the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards
The course provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with severe and profound and multiple learning difficulties.

For further Details: The University of Northampton. Tel: 08003582232 Email: study@northampton.ac.uk

MA Education Physical Disabilities (P1: Contexts & Interventions P2: Curriculum Issues)

The first module (P1) provides opportunities for those with QTS and professional qualifications and experience in services for children, to engage in structured critical reflection, exploration of key substantive issues and overarching policy determinants in respect of children and young people with physical disabilities. The second module (P2) provides students with opportunities to investigate, critique and evaluate a range of curriculum approaches in the field of physical disabilities. It engages students in debates concerning the relevance and practical efficacy of recent guidance and legislation in physical disability-related issues, and offers an in-depth series of curriculum-focused activity which is intended to enhance both the understanding and the practice of those working with children and young people with physical disabilities.

For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

MA Education Understanding Multi-Sensory Impairment

This module addresses the requirements of the Teacher Development Agency (TDA) National Special Educational Needs Standards (Extension 2.i – 2.iv.). It is directly related to Pupils with Multi Sensory Impairment (MSI) The module provides students with an opportunity to gain an understanding of those influences which impact upon the learning, development and management of pupils with multi sensory impairment. It provides professional development for teachers and other professional colleagues working in an area of low incidence need and addresses priorities established by Local Authorities, individual teachers and others working with children and young people who experience MSI.

For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

Certificate in Higher Education (CHESL): Supporting Learners with SLD/PMLD

This course aimed at Teaching Assistants will look in detail at the needs of learners who are known to have severe or profound and multiple learning difficulties. These learners may also have other additional or associated disabilities, such as physical or sensory impairments. The course will examine topics of both a theoretical and practical nature to provide students with a greater understanding about this group of learners, together with a broad range of strategies and approaches that can be applied to practice. The sessions will include lectures, workshop activities, discussion and some visiting speakers.

For further Details: The University of Northampton. Tel: 0800 358 2232 Email: study@northampton.ac.uk

BPhil, PGDip and MEd Inclusion and SEN

Year 1 Learning Difficulties and Disabilities (Severe, Profound and Complex) Year 2

Autism (Children) or Autism (Adults)

Distance Education

This two/ three year course contains 6 modules and students study the required number from this list for their chosen award plus a dissertation.

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

MEd includes a research methods module and a dissertation

For further details: The University of Birmingham, Penny Lacey p.j.lacey@bham.ac.uk or Helen Bradley h.bradley.2@bham.ac.uk

BSc in Professional Practice

BSc in Professional Practice - includes forensic, mental health/learning disability, challenging behaviour, older person with LD and epilepsy modules. Students will be provided with an educational experience, tailored to their particular requirements, so as to gain professional experience. This will enable them to work collaboratively and flexibly within health and social care systems.

For further details: University of Chester Tel: 01244 511000 Email: enquiries@chester.ac.uk

MSc in Advanced Practice

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

For further details: University of Chester Tel: 01244 511 000 Email: enquiries@chester.ac.uk

Postgraduate Courses in Profound and Complex Learning Disability

The course is studied by distance learning plus attendance at an Autumn Study School at the University of Manchester.

The course accent is on moving towards increasing choice; developing community presence and participation; and increasing respect for individuals with complex needs. This approach underpins all aspects of course delivery. The course has three aims:

- To support the professional development of people working with children and adults with complex disabilities.
- To empower course participants to advocate for people with profound and complex learning disabilities.
- To enable course participants to develop knowledge and understanding of key issues in the field.

For further details: The University of Manchester, Lesley Jenkins Phone: 0161 275 33337 Email: pld.distance@manchester.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.

Learning Difficulties and Disabilities (Severe, Profound and Complex)
Distance Education

This distance education programme has been developed for the range of staff who work with people with severe, profound and complex learning difficulties, for example teachers and lecturers, nurses, therapists, psychologists and support staff. It is primarily about the learning and development of children and adults with severe, profound and complex learning difficulties, particularly in the areas of cognition and communication. Education, in its broadest sense, is seen as a key topic but other areas covered include health, therapy and social care. An important central theme is multi-agency collaboration and course participants will be expected to develop and reflect on their collaborative work as part of course. All the course assignments are grounded in reflective and evidence-based practice and are driven by the individual professional development needs of participants.

For further details: University of Birmingham Dr Penny Lacey, phone: 0121 414 4878 or email: p.j.lacey@bham.ac.uk

AdCert, BPhil, PGCert, PGDip, MEd.

Multisensory Impairment (Deafblindness) - *Distance Learning*

This programme enables teachers and others working in education related fields to work more effectively with learners who are deafblind (multisensory impaired). Some students are teachers working with children or adults, but others are from social services, medical, or residential work. A one-year programme can lead to the awards of Advanced Certificate or Postgraduate Certificate.

- A two-year programme can lead to the award of BPhil, or Postgraduate Diploma.
- A two-year programme with a dissertation can lead to the award of an MEd.

Students working on BPhil or Postgraduate Diploma programmes with some additional activities can, on successful completion, be recognised as meeting the requirements of the DfES for the mandatory qualification for teachers of children with multisensory impairments.

For further details: University of Birmingham Dr Liz Hodges on 0121-414 4873 or email: e.m.hodges@bham.ac.uk

Adults with learning disabilities who have significant and complex needs

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

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

The programme leads to further qualifications at Diploma and Masters level.

For further details: University of St. Andrews <http://psy.st-andrews.ac.uk/people/personal/mc1/> Dr Martin Campbell email: mc1@st-andrews.ac.uk



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

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

About Us

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

Rob Ashdown	Former teacher and special school head teacher specialising in the needs of pupils with severe and profound and multiple learning difficulties
Alice Bradley	Has worked in schools, universities, health and social care settings in the UK, Canada, Thailand and various countries in Africa and Asia. Currently working in international development and as a volunteer with some UK charities.
Jeanne Carlin	Disability Consultant (freelance) 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.
Beverley Dawkins	Policy manager - profound and multiple learning disabilities, Mencap
Ann Fergusson	Researcher and tutor for severe learning difficulties and PMLD courses at The University of Northampton. Trustee of National Family Carers Network. Ann also has a family member with a learning disability
Chris Fuller	Founder and former Director of Bag Books: multi-sensory stories for people with PMLD, and previously special education teacher
Rachel Parry Hughes	Lecturer in Social Work, Goldsmiths, University of London, researcher in the field of profound and multiple learning disabilities
Penny Lacey	Coordinator of the University of Birmingham course in severe, profound and multiple learning difficulties; freelance consultant; Penny has a family member with severe learning difficulties
Loretto Lambe	Director of PAMIS an organisation in Scotland working with people with PMLD, their family carers and professionals who support them
Wendy Newby	Teacher and curriculum coordinator St. Rose's School, Stroud, a school for children with physical disabilities and complex health needs
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.

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PMLD LINK

sharing ideas and information

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

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