

PMLD LINK

sharing ideas and information

Transition

Summer 2014



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

www.pmldlink.org.uk

GUEST EDITORIAL

Transition

Transition, far from being a once in a life time fixed event is an ongoing series of changes that occur throughout life. From home to school, class to class, the move to “big school”, college, adulthood, a place to live, relationships and the ultimate transition of end of life care; we all pass through many transitions in our lives. What unites them all is that each create challenges as well as exciting opportunities. For people with PMLD, the navigation though often bewildering and emotionally demanding times of transition can be particularly challenging.

Approaching the task of editing this issue has had many similarities with issues faced by anyone approaching transition. There has been lots of information to find out, but it has been hard to track down and, once found, potentially confusing. There have been encouraging tales of good practice, and yet growing despondency as the reality of cuts to services and diminishing resources hits home. The gap between research findings and policy promises seems as wide as ever and if anything widening. For those with the good fortune of a well informed and empowered parent or carer and good use of local resources, there are amazing stories of what can be achieved but there are far too many examples of potential unfulfilled lives or worse. There are many new opportunities that should be available as the result of new legislation such as the Children and Families Act 2014 and the Care Act 2014. Maybe we should plan another transition issue in five years to review the impact?

So this issue is one to dip into and return to when you need encouragement from positive stories, signposting to places or people that may assist; a place where you need ammunition to fuel your fight for whatever transition you or someone you care about is facing. Rob Ashdown’s article sets the scene with reflections on articles on transition that have appeared in the journal since 2000. The first in a series of articles we hope to publish to increase awareness of the Raising our Sights guides written by Charlotte East, explains some important principles of commissioning. Angie Ingleton offers some top tips for going through the ‘Transition Pathway’. There are different approaches to smoothing the path of transition. Sarah Townsend describes the training approach that she has developed and Chris Cooper and Jo Lawson describe some outcomes of a transition project they undertook with in their school. If like us you like to hear some real life stories, read the articles from Elizabeth McBride and Linda Campbell to learn more about Ryan, Jill Davies’ account of Amy’s party and Frances Pett’s moving account of M. There are some thoughtful reflections on transition from another school in the article by Shana Mozeka, and yet another story; this time about Gilly in the article by Caroline Garner. Felicity Court tells us about some new guidance on transition due in 2016 and this leads into a packed section on news and resources. You will definitely need at least a cup of coffee and a comfy chair to read and digest all that is to be found here at your leisure.

The most powerful stories of good transition we have encountered during our work on this issue have all had one thing in common. The person in transition has been supported by others with a strong commitment to putting that person at the centre of the process. That must be our strongest wish for anybody going through any transition; that they are accompanied on that journey by support, resources and opportunities, but more than anything, by people who love and care for them.

Helen Daly & Sue Thurman

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Managing Transitions

Rob Ashdown

The first issue of PMLD LINK with the theme of 'transitions' appeared in Autumn 2000 (Issue 37 Vol. 12.3) and in the fifteen years since that issue there has been just a smattering of articles in the journal about efforts aimed at improving transition processes. In the best of circumstances, change can cause bewilderment, anxiety and uncertainty about what is going to happen in the future for children and young people with PMLD and their families and this article focuses on the resources and strategies that are already available to mitigate the more disruptive and disturbing effects of changes for 0-25 year olds.

We live in straightened times with services being exhorted to work harder and smarter to keep costs down as much as possible, even to make substantial cuts, and still to ensure positive outcomes for children and young people with PMLD. There have been major changes to funding regimes for schools, colleges, local authorities and NHS community and hospital services. Following 2 years of consultation, debate and experimentation by pathfinder authorities, a far-reaching Children and Families Bill received Royal Assent on 13th March. The resultant Children and Families Act 2014 introduces a number of changes to the way disabled children and young people and those with special educational needs (SEN) receive support going into the future (Petersen, 2014). Given the current turbulence engendered by these reforms, this particular issue of the PMLD LINK journal is timely for considering current good practice.

The Transition Pathway

The 'transition pathway' may be described as the journey that children and young people with PMLD take from birth through to adulthood. There are identifiable periods in their lives that are called transitions, although it is important to stress that a transition is a process and not a single event and it can take place over several months or years. Inevitably, these different transitions require the involvement of different resources and different teams and as we all know from experience the outcomes for the child or young person and their families depends greatly the enthusiasms, motivation and ability of individuals as well as the level of coherent organisation in the systems that are in place. There is a need for clear information about the options available at each transition, so it may help that from September 2014 local authorities are supposed to provide details of all the services that they offer. This information is contained in the 'local offer' and should be available on each local authority's website.

From birth to 3 years, the emphasis has to be upon supporting smooth transitions from pregnancy, birth and the first few weeks into early years services and schools. Thus, for instance, it is a statutory requirement for all children to have a two year old progress check and, since young children with PMLD tend to be identified from birth, support should be available from children's therapy services, paediatricians and other health professionals. Early support for families may be available from home visiting services, like a Portage service; to see if you have a Portage service near you, check your local authority's local offer, or the National Portage Association's website (<http://www.portage.org.uk/>). Early education funding can be accessed for 2, 3 and 4 year olds. The local authority may also operate an Early Support Programme for parents and carers of disabled children and young people from birth to adulthood. The Council for Disabled Children (CDC) holds the national Early Support information resource for parent and carers as well as for professionals working with them (<http://www.councilfordisabledchildren.org.uk/what-we-do/networks-campaigning/early-support/resources/information-resources>).

The period from 3 – 5 to years is marked by entry into early years education settings. Children with PMLD will mostly be placed in a special school and, probably, a teacher from the school will arrange a home visit, perhaps with a professional who already knows the child and parents. Parents should be given the information they need about the school, their rights, home-school transport, etc. and the teacher should get the information the school requires about the parents' hopes for their child, their child's needs and interests, health care strategies, contact persons, etc. There should be continuing support from various health services and special educational needs officers and specialist teachers will become involved. There may be a need for the school

to become involved in, and even take a lead, for any activities already initiated under the Common Assessment framework or instituted as part of an Early Support Programme. A child of this age with PMLD should have a statement of SEN and parents and carers will experience the first annual review.

Between the ages of 5 and 7 years there may begin to be access to organised short breaks. These may include childcare, school holiday and after school activities, access to community facilities (often leisure and arts facilities) and perhaps access to adult learning for parents and carers. Typically, these will only be accessible after assessment of need and the development of some kind of plan detailing need and what will be offered.

Not all children with PMLD go to all-age special schools: in many areas there are separate primary and secondary special schools. In these areas, when children are aged about 10 years, they and their family should be supported to visit and to choose a secondary school. There should be information about options available and the primary and secondary school should plan transition arrangements, including familiarisation visits for staff of the receiving school and the pupil (for an example see Ashdown, Lee and Darlington 2008).

The secondary phase of education should be marked throughout by 'preparation for adult life'. In the year that they have their thirteenth birthday, planning arrangements for transition to post-16 provision must start at the annual review of the statement. However, the probability is that many students with PMLD will stay on at the special school rather than leave at 16 years because usually they cannot benefit from the provision in local Further Education (FE) colleges, although in some areas there is good provision in the FE sector as evidenced in a recent discussion on the PMLD Network Forum (PMLD LINK 2012); also see Colley (2013). During their final few years of school, schools up and down the country will be trying to provide some access to appropriate day services that they will experience as part of the service provision operated by the local authority services for adults with learning disabilities. A decade or more ago this may have entailed only liaison with specific day centres but now the opportunities that are available for young adults with PMLD between the ages of 19 and 25 years are much less certain. Professor Jim Mansell identified elements of good services and detailed the obstacles that have to be surmounted to ensure that good quality of life is experienced by adults with PMLD and their families (Mansell 2010). In this context, it is worth reminding ourselves of the various 'how to guides' produced by Mencap and the PMLD Network and aimed at families, local authority officers, healthcare commissioners and others who are responsible for supporting or developing services for people with PMLD

(<http://www.mencap.org.uk/all-about-learning-disability/information-professionals/pmld/raising-our-sights-guides>). They challenge strategic planners to improve services radically and end situations where too many people with PMLD are living restricted lives.

The transition of young people into adult life involves not just supporting them through provision of appropriate continuing education but also through provision of appropriate housing, transport, leisure and social activities. Their families require accessible, consistent and specialist information, advice and guidance about what they may do to prepare for adulthood and about the options available to them locally. However, we know that the process of transition from child to adult services can be problematic: for instance, a report from Social Policy Research Unit at the University of York documents problems in provision of appropriate services to support transition (Sloper et al 2010); and a digest of discussions on the PMLD Network between February and May 2011 shows continuing dissatisfaction with some people feeling that there have been few improvements despite all of the reports and initiatives and legislation and some feeling that things are going from bad to worse (PMLD LINK 2011). We are told that, for young people with PMLD, the transition to adult services can be abrupt, delayed or restricted because of a lack of local options and appropriate planning. The fact that the Children and Families Act 2014 will extend the SEN system from birth to 25 may be helpful but does not guarantee a smooth transition from school.

A range of resources are available. Several SEND (special educational needs and disabilities) Pathfinder Information Packs were re-launched by the Government in May 2014 (<http://www.sendpathfinder.co.uk/infopacks/>). One of these, the Preparing for Adulthood information pack, provides guidance and case studies of transitions to adult services developed in North Yorkshire and Hertfordshire. The 'Transition Information Network' (TIN) (<http://transitioninfonetwork.org.uk>) is an alliance of organisations and individuals that provides general information and examples of good practice though nothing specific to young people with PMLD. TIN produces an e-bulletin called 'Getting a Life' which sets out policy and practice developments affecting disabled young people in transition. A transitions guide for services (Wheatley and Winters 2007) also may be found on the TIN website (<http://www.transitioninfonetwork.org.uk/publications/a-transition-guide.aspx>). There is a Mencap guide for parents and carers (<http://www.mencap.org.uk/all-about-learning-disability/transition-and-further-education/transition>) and the PMLD Network also has resources about transition (<http://www.pmldnetwork.org.uk/resources/index.htm#eight>). Of course, all of these guides will require updating because of the introduction of a new SEN Code of Practice due for implementation

this year. The CDC which presents itself as an umbrella body for the disabled children's sector (<http://www.councilfordisabledchildren.org.uk/>) has been singled out by the Department for Education as a partner for promoting the SEND reforms.

Multi-Agency Working

There has been much statutory guidance and legislation targeted at developing multi-agency transition services which bring together a range of resources with the aim of helping to reduce duplication of effort and assessments, improve sharing of information with young people and their families, better communication between professionals and better co-ordination in managing individual cases. However, a recent survey of provision in local authorities identified only 34 multi-agency transition services for disabled young people and many of these were at an early stage in their development (Sloper et al 2010). Surveys and follow-up interviews with disabled young people and their carers found that the key factors associated with better outcomes were having a transition worker who supported the young person and parents, the family having a written transition plan and the manager of the transition service having strategic level involvement. Unfortunately, transition services were found to be unlikely to reduce stress for the majority of the parents and over a third felt that contact with the transition service increased their stress. This study highlights the importance of properly resourced services that can provide direct support to young people and their carers, and timely and clear information, until they are settled in adult services.

Involving Children and Young People in Developing Provision

Then there is the need to ensure that the children and young adults themselves can be as fully involved as possible given their obvious difficulties with understanding and communication. 'Involve Me' was a three-year project run by Mencap in partnership with the British Institute of Learning Disabilities (BILD) about how to creatively involve people with PMLD in decision making. The project resulted in a book and a DVD with many resources about encouraging adults to make choices and express preferences (<http://www.mencap.org.uk/what-we-do/our-projects/involve-me/resources-involve-me>). Another resource downloadable from the same site is a book about communication and people with the most complex needs (Goldbart and Caton, 2010). These are resources for people working with adults but they have relevance for people working with younger people too: and, of course, there have been many books that in a similar vein address communication with children with PMLD (e.g. Coupe O'Kane and Goldbart, 1998; Imray and Hinchcliffe, 2014; Nind and Hewett, 2004; Ockelford, 2002). It is not that the knowledge about what to do is lacking: the

challenges to schools and other services lie in finding time, amid everything else that they do, to fully develop participation, training for staff around the strategies available and how to deliver them, engaging parents and other families to support them so that they too can involve their children and young people at times of transition and making or providing appropriate resources. Yet, none of these problems are insurmountable.

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How-to guide 11 commissioning

For people with profound and multiple learning disabilities

Raising
our Sights



Raising Our Sights Commissioning Guide

Charlotte East

The Raising Our Sights Commissioning Guide is aimed at Commissioners and other people responsible for planning and commissioning health and social care services at the local level. It is also useful for organisations that provide health or social care services for people with PMLD, to deliver services that people with PMLD want and benefit from, and to demonstrate this to commissioners and funders. The guide can be used by others, including family carers, user-led organisations and Partnership Boards to help evaluate your local services and make recommendations for change.

Raising Our Sights included a large number of recommendations for local commissioning. These recommendations and the Commissioning Guide, are useful tools for lobbying for changes services. Families can check that their local Commissioner has read the guide, and ask them how they are involving people with

PMLD in the commissioning of services.

The guide focuses on ways to evaluate what services are needed locally and how to ensure these services are good quality. It includes a number of practical tools to help develop high quality services for people with PMLD including:

- A **PMLD screening tool** in Section 6
- The **commissioning checklist** in Section 12 containing suggested actions from this guide, based on the recommendations from Raising Our Sights that relate to local commissioning
- A **checklist for service providers** in Section 13
- A **topic checklist** for Commissioners from each of the other How-to guides in section 14.

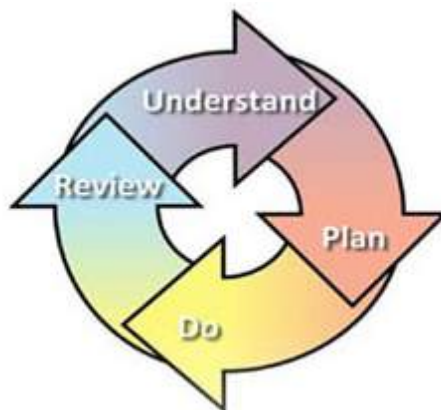
The guide also contains sections on:

- Prevention and enablement services for people with PMLD – an area where they are often overlooked;
- Meeting the needs of people with PMLD within mainstream services
- Specialist services for people with PMLD
- Measuring outcomes and value for money

What is commissioning?

Commissioning determines where public money is spent, on health, adult social care, children’s services etc. Commissioners act on behalf of the public to provide the services they need, today and in the future, using a step by step process called the Commissioning Cycle. The Commissioning Cycle has 4 steps:

- Understanding what people’s needs are
- Planning how services can meet these needs
- Doing - Putting these services into place
- Reviewing whether the services have been effective and if people’s needs have been met.



Commissioners must involve the people who have an interest in the services in the Commissioning Cycle. This includes the public, providers or potential providers, other people or organisations who have an interest in the decision (e.g. education services or health services), and most importantly, people with PMLD and their families, who should be involved at every step of the commissioning process.

Many Commissioners and service providers struggle to involve people with PMLD in planning services. There are lots of approaches that can be used, outlined in section 11 of the guide:

Involving people with PMLD and the family and friends in the commissioning of services

Involving and coproducing services with people with PMLD has particular challenges. Similar to the creative ways that can be used to measure the satisfaction of someone with PMLD, there are a number of ways that people with PMLD and their families can be actively involved in providing feedback and coproducing services.

Information about the satisfaction of people with PMLD can be used to guide commissioning. Families of people with PMLD can be actively involved in coproducing services, representing both their own views and those of the person with PMLD that they support within meetings, and other common methods of customer involvement and coproduction.

People with PMLD should be engaged directly to give their views using creative methods of communication to demonstrate the barriers they experience in everyday life, express their likes and dislikes, and express what is important to them. Alternatively information can be collected from individual’s support plans and person centred plans. Information collected from these various methods can be collated and used for service planning and evaluations. The methods used to support people with PMLD to express their views must be meaningful, in order that the information collected is meaningful. This means that the work to engage people with PMLD will take time and require intensive facilitation.

Some approaches were explored in the Involve Me project, that looked at a number of creative methods of engaging people with PMLD to be involved in decision making and consultation. More information about the project is available on the website: <http://www.mencap.org.uk/involveMe>

Involve Me looked at 4 ways of communicating with people with PMLD

- creative communication
- sharing stories
- multimedia advocacy
- peer advocacy

More information about these methods are available on the Involve Me website. The **Communication guide** also contains more suggestions on how to communicate with people with PMLD.



Working Together For Change is a method of using person centred information from reviews, support plans and person centred plans to inform commissioning. It sets out to provide:

- An effective approach to ensuring co-production with people using services
- A model for ensuring effective community engagement in the Joint Strategic Needs Assessment
- A way of understanding and measuring the impact of personalisation.

Information about each individual from the plans is translated into useable information about what is working and what is not working and the top three goals for the person. Information from each individual is then clustered around themes, analysed, and commissioning actions planned from the information that emerges from each cluster.

More information about Working Together for Change is available via:
<http://www.thinklocalactpersonal.org.uk/Browse/commissioning/coproducing/?parent=8566&child=5802>

Some electronic case recording and person centred planning programs will collate the goals and barriers of customers at the touch of a button. Iplanit is an electronic person centred planning tool that is being used by many organisations supporting people with learning disabilities.
<http://www.paradigm-uk.org/content/iplanitHome.aspx>

Information about the needs and wishes of people with PMLD can be collected via supported self expression/ creative communication sessions, which could be commissioned through self advocacy services or as a day activity for people with PMLD.

Increasingly, support providers will have access to this information through their electronic case recording and planning systems, such as Iplanit. Providers can be asked to provide aggregated information from customers support plans and person centred plans, either voluntarily or via contracting arrangements. In these cases, it is important to take steps to be assured that the information provided is the views of the person with PMLD rather than the support provider, and also to ensure that the views of people with PMLD who do not use these support providers are also heard.

Outcomes and Value for Money

Local Authorities and Healthcare Commissioners have to demonstrate that the services they commission provide value for money. A value for money judgement **must assess the benefits to the quality of life of a person** receiving the service or goods, even if the quality of life improvement cannot be given a monetary value.

There is no published research about value for money in services for people with PMLD. Services for people with PMLD need a high level support staff, and so will always be high cost. To establish the value for money of service for people with PMLD, the focus needs to be on:

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

rather than lower costs of the package of care.

The value for money of many services for people with PMLD can be measured in terms of the prevention of issues that would negatively affect quality of life or would require more expensive interventions. Health services in particular can be measured in this way, as can services to support carers and social care services that facilitate participation and wellbeing in the person with PMLD.

These areas of value for money can be demonstrated through outcomes. It is important that service providers, and people who are receiving a personal budget and arranging their own support, can demonstrate the outcomes that people are achieving. Even in situations when Commissioners and Social Workers are not currently asking about outcomes for people with PMLD, they are very likely to start doing this soon. Having information about the outcomes that people are



achieving is a good way to demonstrate the benefit of a service on a person's life, and helps guard against cuts and changes to that service.

It is important that outcomes are personalised for each individual, to demonstrate what is important to each individual. Individual outcomes could be measured using Scales of Engagement, tracking how the person's life has changed or using a quality of life measure. Pictures and videos are a powerful way to demonstrate how much a person values an activity.

Additionally, service providers and Commissioners are likely to want to set a number of additional outcomes to collect data on, to demonstrate the overall impact of the service. The Raising our Sights Commissioning Guide contains a number of suggested outcome areas and possible indicators that can be used for service outcomes.

Most outcomes can be measured within services for people with PMLD; the method of measuring the outcomes may be different to other services and may include collecting feedback from carers and support workers or tracking outcomes via changes in individuals' lives over time. It is also important to set outcome indicators that ensure the specific needs of people with

PMLD are being met.

People with PMLD, their families, and other stakeholders should be involved in determining outcome indicators for commissioned services.

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The Disabled Young People's Transition Pathway and Top Tips

Angela Ingleton

Stage 1 - Approaching Adolescence (12 - 13 yrs)

Every young person should be supported by an identified key worker to prepare for the move onto adult services from their 14th birthday through use of the team around the person approach. Parents and carers should be supported and informed about person centred approaches, and given tools to enable to plan with their young person to attend the yr 9 transition review. This will empower the young person to have a 'voice' and be supported to make decisions about their future in terms of education and in the community.

Top Tips! Start thinking about their gifts and skills! Ask about parent carer's assessment! Do they have siblings? Ask about a young carer's assessment!

Stage 2 - Proactive Planning (14 yrs)

Every young person has a right to plan proactively for their future and should lead the planning by being placed at the centre of the process. Identification of those young people who are likely to meet FACS will be made by adult social care. The head teacher will arrange and inform the young person and their family about the year 9 review, it is essential that the young person and the parent/carers prepare and feel confident.

Top Tips! Start to plan circles of support and ensure that actions agreed are time bound and followed through!

Stage 3 - On Going Planning (15-16 yrs)

Every young person has a timely multi-agency plan for an active transition process to take place within an agreed and reviewed time frame. A coordinated all about me support plan is developed to meet the young person's individual needs. Key workers are designated and identified to work alongside the family to facilitate this process.

Any decisions that need to be made at 16 years plus, must consider The Mental Capacity Act and Best Interest Decisions may need to be made.

Top Tips! Health – the young person may be entitled to health funding, ask about the 'checklist' to find out!

<https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

!Ask about The Mental Capacity Act! <http://www.mencap.org.uk/mental-capacity-act-resource>

Stage 4 - Settling into Adult Social Care (17 to 18 yrs)

The young person is appropriately supported in adult services with multi-agency and multi-disciplinary team fully engaged in facilitating care, support and independence. There is confidence and understanding from the young person, family and professional perspective in the future plan. The young person may want to continue education into college, or pursue employment opportunities. You should be offered a personal budget it is important that you develop a person centred holistic support plan, your circle should be supporting with making decisions and helping the young person to have 'tester' days so that they are fully engaged with the process and decision making

Top Tips! There are many employment programmes for young people with disabilities ask about these! Be confident to look at 'bespoke' support that is wrapped around the young person, be innovative! When the young person is enjoying an activity it is good to record this by using pictures and video clips this is really good evidence for funding panels and recording good outcomes!

Stage 5 - Transfer to Adult Social Care

The young person will transfer to Adult Social Care when they reach 18 years of age.

Benefits change when the young person reaches 18 yrs please ask for advice and guidance. If the young person is in residential care please ask for information about deprivation of liberty information: <http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/MentalCapacity/MentalCapacityActDeprivationofLibertySafeguards/index.htm#jumpTo7>

Advocacy and IMCA's (Independent Mental Capacity Advocates) the young person may need an advocate to support them with decisions

<http://www.bild.org.uk/about-bild/advocacy/advocacy-types/>

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Getting it right – training that counts

Sarah Townsend

I have worked in different roles within education for the past 30 years, mainly with adults with learning disabilities which include those with PMLD. From this experience I know that the transition from children services to adult services is not always a smooth one. Children services appear better resourced with access to much better training opportunities.

For much of my career I have been involved in curriculum development, mentoring training and support staff to effectively meet the needs of the individuals they are working with. I am now a freelance trainer and consultant, fortunate to work with many different organisations and staff teams.

My belief is that staff are the most important resource available to services, having well trained staff who understand the needs of individuals with PMLD is paramount to creating a responsive service. (Mansell, 2010). Throughout my career I have worked with many talented people but have also witnessed some poor practices when it comes to supporting adults with PMLD, yet when looking for training opportunities for staff in the adult sector there is limited choice. Despite the recommendation of the Raising Our Sights Report 'for the introduction of new kinds of qualification and the delivery of induction and in-service training reflect the needs of adults with profound intellectual and multiple disabilities more fully than has been the case in the past' (Mansell, 2010:18), the development of new short courses that are nationally recognised and approved by Ofqual has been minimal.

Development of the course

Realising there was a need to develop a nationally recognised short course that covered the key topics, when supporting a person with PMLD, I investigated ways to make it happen. It was easier than I thought, yes there was a lot of paperwork and it took longer than anticipated but there was no cost involved only time. NOCN who are an awarding body that promote the development of courses to support people with diverse needs were keen to get the qualification developed, as long as I could prove a need and demonstrate that at least 100 registrations per year. Once this information was gathered and course aims and specification were written there was a long wait to see if Ofqual would register the qualification. Finally it was agreed and the very first nationally recognised award, aimed purely at people supporting those with PMLD, was born! The Award in Supporting the Need of Individuals for Profound and Multiple Learning Disabilities is a course

that is designed to run for 14 – 16 hours at level 2 or level 3 and gives those who are successful two learning credits. This qualification is now approved by NOCN and OCN – London and I am registered as a Centre with both to deliver the qualifications. To see the full course details visit my website

The course

The course was developed on the following premise: Overall, the task is to develop our understanding of the needs of children and adults with PMLD and to design services that are truly inclusive of their particular needs. Only then will we be able to respond to the challenge of 'enabling extraordinary people to live ordinary lives.' (McConkey 1998)

A large part of this course focuses on communication and the importance of the staff role in understanding and responding to all forms of communication as they become the voice of the person they are supporting (Grove, Bunning, Porter and Olsson 1999). Staff need to learn to seize every opportunity to interpret communication and encourage a response. Raising awareness of the potential meaning of non-verbal communication can help staff to identify a person's unique communication repertoire and give them confidence to interact. Other elements of the course include looking at attitudes and values and the impact of legislation as well as the importance of providing meaningful activities for individuals including sensory stories.

Below is part of an extract on a student's reflections on the course

'The day itself was very well formatted into the history and how people were treated right through to devising and doing a practical sensory story with our colleagues-such fun to get practical!!! Sarah explained that we have to get used to being and having fun ourselves otherwise how can this transfer onto our service user's learning? **I just wished this day had been devised and taught years and years ago!!!!** I have really enjoyed studying for the NOCN PMLD - I had no idea that there was so much research out there. I will

certainly be looking up the studies "Raising our Sights" and other pieces of research and suggest we print them out for work so that as a staff team we have access to them. I have already been questioning my colleagues on choices and that we should be promoting choices. Some of my colleagues question the value as they feel the service user is not really choosing and it is just a tokenistic gesture on our part. We have agreed that we need to look at how these choices are presented.

I will be doing more garden groups so I will be planning better for each individual plus this course has made me more confident in speaking up for service users and for myself as I feel I have more knowledge behind me'.

Sylvia Owen Surrey County.

These courses are often run as staff training days within an organisation or individual people can attend open workshops for which a 15% discount is given for individual places on one of the following course for anyone from PMLD LINK.

Our next open workshops are:
London 28th October 2014
Derby 20th November 2014

Why is it important to have courses that are nationally recognised?

It is true training can be effective with or without a qualification but I feel it is essential to validate people's learning and acknowledge their achievement through a course that leads to a national recognised qualification. There are many other benefits, one of which is funding, on the Skills for Care website they state 'Adult social care employers can reclaim some of the cost of Diplomas, Awards and Certificates units through our Workforce Development Fund. Myself and Francis Pett delivered a two day training course in the London Borough of Newham where their Quality and Workforce Development Officer Moira Storrar used this fund to subsidise the cost of the course for care staff. For more information about funding see the following link. <http://www.skillsforcare.org.uk/Funding/Funding.aspx>

Future developments

Having been involved in developing this qualification, I am now working with others to look at designing new qualifications and would love to know peoples' thoughts about what is needed. Have you been looking for accredited courses but can't find anything suitable? If so I would love to hear from you. If I can prove there is a gap in the market, demonstrate a need and show that 100 people a year will register for the course then it is likely that a nationally recognised qualification could be set up. The only challenge then is to persuade organisations to invest in staff development.



A participant on the course exploring the relevance of objects of reference when using them with individuals with PMLD.

I am also hoping to do further research into the impact training has on staff and would love to hear from people who might be willing to share their thoughts on staff development. From time to time I like to share resources I have developed to help support staff, please visit my website to download a free copy of A User's Guide to Non Verbal Communication.

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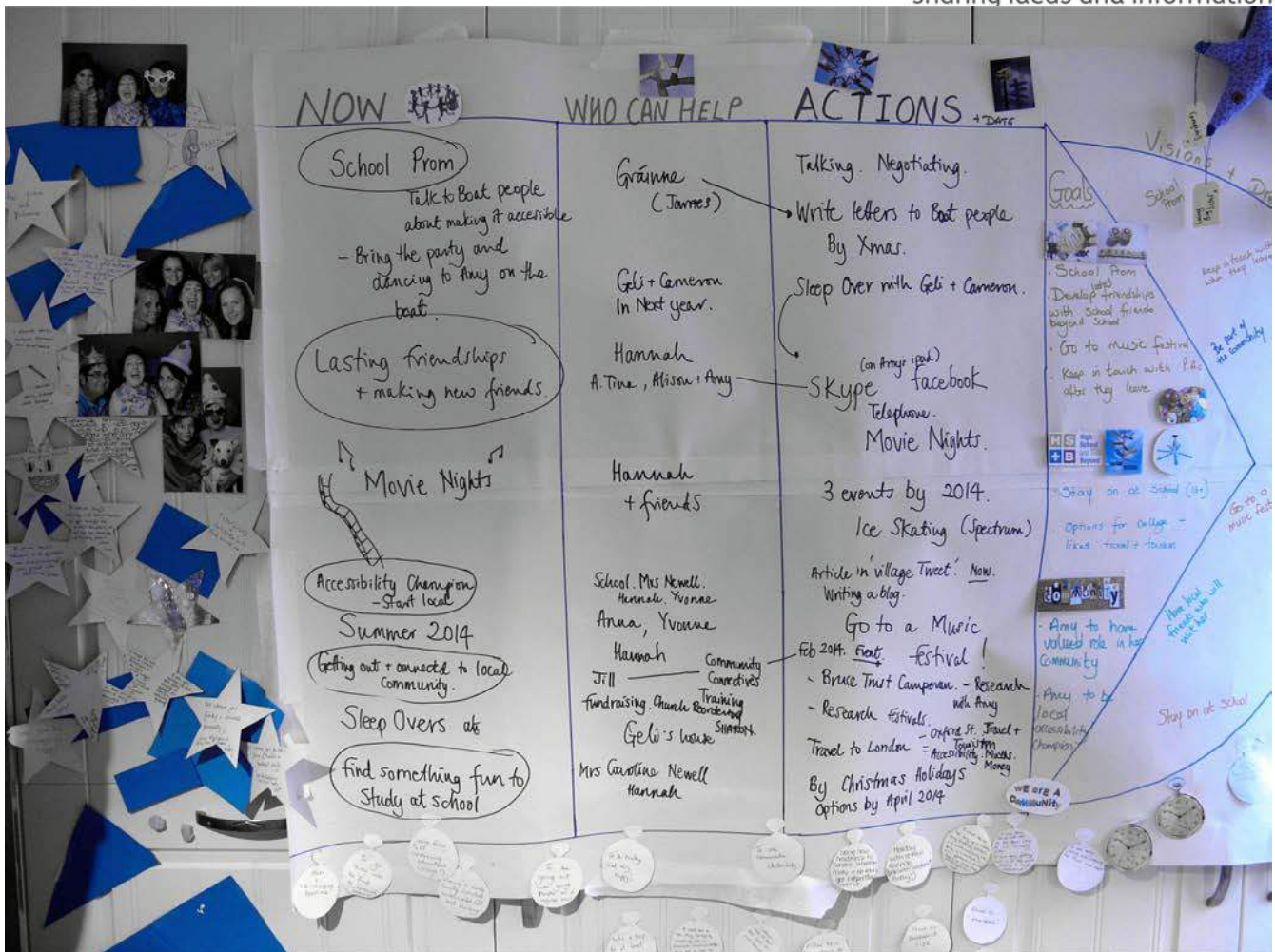
Amy's party

Jill Davies

Turning 16 is a milestone age but when you have a child with complex health needs this milestone is even more significant. For parents who never thought their child would reach their first birthday let alone their 16th it is a time to reflect. One family I know wanted to celebrate their daughter's special birthday by holding a big party. As well as sharing this birthday with friends and family they decided to use these important people in her life to help set goals to increase their daughter's independence. I was lucky enough to be invited and my role was to co-facilitate an action plan based on the principles of person centred planning.

My involvement stemmed from running a project by the Foundation for People with Learning Disabilities looking at how we can be more person centred in the way we support children and young people with complex health needs (for more information about the project see below and at www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life). In order to prepare for the party I visited the young lady called Amy on several

occasions to get to know her and to start the person centred process. Amy and her family described the important people in her life, her hopes and dreams for the next few years and began to list what is important to her. Ahead of the party Amy's personal assistants and mum helped her to design an invitation and cut out star shapes and clocks because they wanted people to think about what they admire about Amy and what their dreams were for her future.



On her actual birthday, Amy’s mum expected around 30 people to attend but in fact it was around 60. Everyone had been diligent and brought their stars and clocks and we kicked off the planning process by reading out people’s contributions. People’s dreams were very much in line with Amy’s and those of her family and close friends – to start doing more things without her parents, to go to a music festival, have a funky haircut, go on a weekend trip with friends and to go shopping in Oxford Street. Following this we did some action planning and some people present were able to sign themselves up to help Amy plan for the future. For example, three of her personal assistants agreed to work with Amy to plan to attend a music festival and a member of the school staff agreed to help Amy look at options in and out of the school now that she has turned 16. The main areas of focus were to maintain and develop new friendships, look at ways in which she can be an active member of her local community and explore options around her education.

I left feeling uplifted by the whole experience. Not only was it a great party and a celebration of Amy’s life, but some foundations were laid to help her achieve her hopes and dreams. Many of these actions were the responsibility of others, not just her mum and dad, and

this is a sign that her circle are looking at her as a young woman in her own right.

The work was part of the Foundation for People with Learning Disabilities three year project “An ordinary life” which looked at how person centred support can improve the opportunities and raise awareness of the aspirations of children with complex needs and their families. They have also launched a package of new support materials which include:

- A one stop booklet for parents, Children and young people with complex health needs
- A briefing for commissioners, health and education professionals
- An easy read person centred planning template My Health and Person Centred Plan
- Three handy factsheets: Leisure, Flying and Financial Benefits
- One page profile template for children with complex needs

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Outcomes of a Transition Planning Project

Chris Cooper and Jo Lawson

This article details work undertaken within St Luke's School, a community primary special school in Scunthorpe, which derives from projects we were involved in for our local authority North Lincolnshire Council. Those projects were 'How best to collect the views of disabled children and young people within North Lincolnshire' (North Lincolnshire Council 2007) and 'Transition Planning Project – How best to collect the views of children and young people with LDD about transition, and involve them in personalised planning' (North Lincolnshire Council 2010). [LDD means Learning Difficulties and Disabilities.]

The second of these projects was aimed at finding ways to support young people with special educational needs (SEN) in having a voice in the transition between primary and secondary education settings. The project included pupils within both mainstream and specialist settings but for the purpose of this audience we have chosen to summarise the work undertaken with pupils who had more profound and multiple learning difficulties and those with most severe communication difficulties including autism. Whilst the primary aim was to develop strategies to embed good pupil participation models for all pupils, a secondary aim developed in relation to gathering important information needed to produce successful personalised transition plans to support the pupil or pupils within their own transition experiences, and to highlight the benefits of this to all adults involved in the process of transition. The final feedback from those who took part in this project highlighted the need to include all pupils more fully in the transition process and what it might mean to them?

The first project (North Lincolnshire Council 2007) is now some seven years old and ways of consulting and resources involved in carrying information have progressed further (see Mencap 2011 for examples). Nevertheless, the good practice developed during the project is still relevant. As stressed in a new draft SEN code of practice local authorities **must** have regard to 'the importance of the child or young person, and their parents, participating as fully as possible in decisions; and being provided with the information and support necessary to enable participation in those decisions' (DfE 2013, p.12).

A large part of the first project centred on research to determine what good practice was being implemented elsewhere and, knowing the pupils we were working with, how we could ensure that their voices were heard, recognised and referred to when decisions were being made about their future in education. In order to promote good practice in pupil participation, which would become embedded into everyday practice, we realised it had to be delivered in a way that could fit smoothly into working practice, rather than be seen as yet another additional session in an already full and constrained school timetable. And consequently our next step became sharing ideas, developments and concerns about how the studies could be undertaken within the present curriculum and which forms of communication support strategies would benefit each individual pupil. Through the first research project we developed some ideas of how we could take information gained through long term knowledge of individual pupils, understanding how they communicated with the world around them, and place it in a more formal recorded response which could validate their voice and opinions when decisions were being made for and about them and their future in education. The idea of having a personal passport or profile that travelled with an individual to inform all who engaged with said individual was very much in our minds. Since clear communication between an individual pupil and those working with that pupil is a challenge, consistency in presentation, understanding, expression, support systems are key to all communication being effective and worthwhile.

The subsequent guidance we produced to support our personal profiles gave information about what a passport/profile would contain and what would be its purpose (NLSPFCT, 2008). As noted by Millar and Aitken

(2003), making a passport is an enriching process and a learning experience, not just the creation of an end-product. Our profiles took on the following format:

- Title page. This includes the date of production
- Involved professionals and parent/carer consent for information to be shared
- Personal details/family members
- Key sections –health, communication, physical, personal and social, daily living, other

The information contained in these sections is intended to be general; if required it should be supported with more specialist information and sections may be deleted as appropriate to the individual. The guidance specified that the profile should be accessible at ALL times. Any adults supporting individuals who have a profile should have access to information and training to ensure they understand the purpose of the profile and how it should be used. The profile can be supported by other documents that give further information e.g. Record of Preferences, Visual Support Systems (NLSPFCT, 2008). A lot of research was undertaken into how personal passports or profiles were being used elsewhere and, with support from other key professionals and most importantly parents, a format was devised which we felt would carry the key information needed not only to support the individual child across all aspects of their interactions with others, but also to support and inform any new setting or school the pupil was moving to. We have two special schools in North Lincolnshire and key to the success of smooth transition for our pupils between the two schools is the collaborative work undertaken between them with the support of other professionals from health and social care who work across both schools. The group of people involved in the transition project (North Lincolnshire Council 2010) came up with a series of questions which they felt covered the key points from a pupil's perspective on transition from primary to secondary education:

1. Things I like
2. What do I find easy at school
3. What do I find difficult at school
4. What would I like to do better
5. Is there anything I am worried about
6. What will I find helpful to know about my new school
7. What will be the same - what will change
8. Who do I know who has gone to secondary school/
Who will I know there who knows me?

For our group of pupils with more profound and multiple difficulties and those with more severe communication difficulties including autism, we felt we needed to do more than try to find answers to one-off questions. And so we turned to another key strategy developed during

the first research project (North Lincolnshire Council 2007) to record a pupil's responses to key experiences and analyse them in order to fully understand their likes, dislikes for activities, interactions, and experiences. We produced guidance to give purpose and definition to the 'Records of Preferences' that we devised and use (NLSPFCT, 2008). For individuals with significant learning, language and communication needs the Record of Preferences is a valuable tool for identifying how 'like' and 'dislike' preferences are shown along with responses to a range of experiences and sensory activities. For these individuals their responses and signs can be difficult to identify and interpret, particularly for adults who are less familiar. The Record of Preferences can also be used to for the following:

- Information to support transition
- Support objective and target setting
- Mould and shape responses in order to support expressive communication
- Ideas for spending time with individuals
- Rewarding and motivating activities
- Support the individuals expression of their views and feeling
- Support participation and consultation

The documentation includes sheets for:

- Sensory responses – auditory, tactile, taste, visual, olfactory
- Environmental and leisure activities
- Summary sheet – which details a child or young person's consistent like or dislike responses to the full range of experiences they have so far had, and also gives information about what those experiences were.

This Record can then be an integral part of an individual's voice which could be heard during transition planning meetings. An additional means of showing an individual's views on what is happening to and around them was to use a power point presentation showing the individual in everyday school life giving a true pictorial account of how they communicated with others, their likes and dislikes and how successful they could be when they felt comfortable and secure in their environment and the adults working with them.

Following on from these experiences we have continued to use and develop these resources, along with other published resources, to ensure the voices, views and opinions of all pupils continued to be recognised, respected and included throughout all aspects of school life and as part of the decision records made with and for them.

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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
Winter issue is the 24th October 2014



Future Choices: Training Courses and Support for Family Carers Project 2013 -2016

Elizabeth McBride and Linda Campbell

Over the last 10 years PAMIS has provided independent transition support to family carers who have a relative with profound and multiple learning disabilities (PMLD) across five geographical areas, Greater Glasgow & Clyde, South Lanarkshire, Tayside, Fife and Grampian, covering 14 local authorities.

The Futures Project was operating in Glasgow City when the local authority implemented Self-Directed Support (SDS) in the summer of 2010 for young people in transition. At this time family carers requested additional 1:1 support and training in relation to SDS as many felt overwhelmed at the enormity of the decisions they faced through SDS. Family carers told us that they lacked essential knowledge and information on personalisation and SDS, the assessment process and the terminology used within the assessment. Many of them felt disadvantaged as they lacked essential information about post educational opportunities and were not in a position to make informed choices and decisions on behalf of their son or daughter.

Future Choices: Training Courses and Support for Family Carers Project

In February 2013 PAMIS successfully secured a three year grant from the Big Lottery fund (totalling £380,000) to provide transition support to family carers who have a relative with PMLD between the age of 15 – 18 who are approaching transition or preparing for transition from education to adult services.

The project worked across Glasgow City in Year One - April 2013 to March 2014 - to develop independent support strategies for family carers to assist them in transition planning and to gain their input to enable the project to develop a robust training package to raise family carers' awareness of transitional issues prior to the project being rolled out in April 2014 to all PAMIS

areas.

The Future Choices Project provides the following training workshops to all families involved in the project:

- Welfare and Financial Guardianship – under the Adults with Incapacity (Scotland) Act 2000
- Self Directed Support - legislation, the processes and implications
- Employment legislation – the role and responsibilities of being an employer
- Welfare Reform and Benefits and the impact of this on family finances

In conjunction with the above formal training workshops, project staff provide direct 1:1 support to family carers. The level of support provided is determined by family carers needs. Project staff work in partnership with education, health and social work and provide family carers with support in:

- Identifying solicitors, raising awareness on legal aid, participating in guardianship meetings and the application process
- Planning meetings in preparation for formal meetings
- Meetings with professionals and formal review meetings
- Identifying potential post educational services and providers
- Self Directed Support assessments and support planning for post education
- Participating in welfare benefits assessments and applying for new benefits
- Negotiating post education activity and support plans

Case study

Ryan leaves school at the end of May. He is 17 years old and has profound and multiple learning disabilities. He is blind and has significant health care needs. He lives with his Dad and younger sister. Ryan's mum died 7 years ago.

He had a social worker from the Children and Families team but there has been little contact. Ryan has support from iCare (Health) and a Personal Assistant (PA) for 6 hours a week. He also goes to a day support service for young people on a Saturday. He has residential respite and has been going there since he was a baby. The PAMIS Future Choices worker met with his dad about a year before he was due to leave school. We talked through Ryan's support needs, the support offered through the Future Choices Project and made plans to complete a communication passport for him.

On following home visits we went through the process of

Self Directed Support (SDS) and the paperwork involved. We talked about options for post school services, what was important for Ryan and what his life would be like after school. We arranged to visit various day services and also respite services for adults.

The worker spent time in school, getting to know Ryan, observing how he is supported and spoke with teaching staff, classroom assistants and the school nurse. Ryan has a Functional Movement Programme and standing frame, set by his physiotherapist, which is carried out daily by school staff. His respiratory condition and scoliosis has significantly improved since using these programmes. Ryan's Dad already had Welfare and Financial Guardianship for him.

He employs a PA for Ryan through Direct Payments. He gained knowledge and confidence through attending training on being an employer arranged by Future Choices.

A Transition Social Worker who was allocated in November moved to another post in January. She had completed a Carers Assessment.

The Future Choices worker completed a mock Self Evaluation Questionnaire (SEQ). We also started to complete an Outcome Based Support Plan so that Ryan's Dad knew what to expect and the ideal support package for him. The worker allocated costs to the services in this package so that he knew what his ideal budget allocation would be.

A Social Worker from the Adult Team was allocated in March. She completed the Self Evaluation Questionnaire and presented at the Resource Allocation Screening Group (RASG). A fairly low indicative budget was allocated.

The Outcome Based Support Plan was finalised and was re-presented at the RASG in April with the Carers Assessment. The budget was greatly increased. Ryan's Dad was pleased that he will be able to arrange services and support as he had planned. Ryan will attend a building based day service and have personal assistants at other times. He can also have residential respite.

There was further negotiation with allied professionals to ensure that there would be a standing frame, movement programme and training for staff in the new adult services from the Children's Physiotherapy service. Arrangements were made to have a proper transition crossover between school and services along with health professionals and although there was less than a month left everyone worked together to make this happen. Ryan's new services will start the week after he leaves school.

The case study details the level of intensive support provided to a family carer to take him and his son through the transition process. There has been a positive outcome in this situation with post educational services identified and funding secured prior to the young person leaving school. Through effective transition planning the new staff team have been identified and can gain invaluable information on the young person's support and health care needs prior to him leaving school. Unfortunately this is not the case for all families who are going through transition. Even with support and input from PAMIS Future Choices Project families continue to find the physical transition from education to adult service provision an extremely stressful and protracted process. This process is further hindered by the failure to appoint a social worker from the adult team within the required time frames; resulting in transition planning coming to a halt as budgets and service provision cannot be secured without their vital input.

Research has shown that there is a catalogue of shortcomings in the way transitions are planned (Heslop 2002). Among these are failings in:

Communication: A lack of effective communication between health, education and social services resulting from current detailed information not being shared with appropriate professionals in a timely fashion to enable effective planning.

Co-ordination: A lack of joint assessment procedures between health, education and social work to facilitate effective interagency collaboration and cohesive strategic approaches to day service and health care provision.

Continuity: There is usually not a designated person to fully support the young person and their family through the transition process, particularly in post education planning. Therefore, the transition is often disjointed, causing great anxiety and stress to those involved, particularly family carers.

Choice: Young people and their families are not always fully involved in the process and don't have access to all of the options that are available post school to enable them to make informed choices and have an effective transition plan that encompasses health, education and social work.

Acknowledging the re-occurring negative themes around transition which, at the time, could be characterised as disillusionment, distress and disappointment PAMIS developed a Transition Planner. This is a tool that can be used for gathering, recording and sharing information specific to the individual with PMLD. In conjunction with the Transition Planner PAMIS developed a Personal



Communication Passport; a small, personalised, easily accessible document which provides a positive overview of the individual with PMLD. It aims to share vital information with new people, and staff teams, encouraging the development of positive relationships. To date these tools continue to be used predominantly with families who find them an invaluable resource for gathering, documenting and sharing information, especially at times of transition.

Getting it Right for Every Child (Scottish Government 2011) is a model of practice that promotes a shared approach towards building solutions with and around young people and families, enabling them to get the multi-agency support they require when they need it. Despite this model of excellent practice being in place it is apparent that this has not been fully implemented, resulting in young people not having adequate transition planning and appropriate adult service provision. PAMIS Future Choices Project is a member of the Scottish Transition Forum; this forum aims to improve the experiences of people with additional support needs, particularly those with PMLD as they go through life transitions especially from school or college to adult life. The forum has developed a document: The Principles of Good Transition 2 (2014).



The most recent review of the transition process, the Doran review (2012) states:

“Effective management of transitions from one stage of education to another and on to life after school is a key component to effectively meeting the needs of all children and young people. It is crucial when considering any changes for those children and young people with complex additional support needs. The review regularly heard concerns about all transitions including; into school, from primary to secondary, from one kind of school to another and particularly from school to adult services. Adequate time for planning and preparation, full involvement of the child and family and coordination of professionals were identified as contributing to successful transitions. When any of these are not properly addressed problems arise. By far the greatest concern for parents was about the move to adult services and the fear of the young person falling into a “black hole” where there was no direct accountability for continuing services”.

The Future Choices Project supported 26 families in Year 1 within Glasgow City. Intensive 1:1 support was provided to family carers in the following areas:

- 69 home visits to discuss general transition issues
- 20 guardianship support meetings to raise awareness of the issue, prepare families for meetings with solicitors, provide support to families to meet with solicitors and begin the application process, and provide 1:1 support to meet with Mental Health Officers
- 13 visits and meetings to post educational establishments and adult service providers to gain information on the service they provide to enable family carers to make informed choices and

decisions in relation to the SDS budget and outcome based support plan

- 21 SDS meetings to raise awareness of the legislation, the 4 options available, the assessment process - ensuring family carers were familiar with the language and terminology used within this, providing independent support to break down the allocated budget and devise an outcome based support plan
- 6 welfare benefit awareness raising meetings, signposting family carers to local area welfare rights officers; and co-ordinating meetings to facilitate benefit checks to be carried out and ensure that family benefits were maximised
- 20 personal communication passports which are used as a valuable tool to new staff teams to assist them in getting to know the young person and gain a greater understanding of their personality, support needs, likes, dislikes and hobbies as in most cases young people cannot provide this information to staff verbally
- 64 meetings with professionals to raise awareness of the Future Choices Project and gain referrals

In conjunction with the above work activities preparatory work was conducted within Greater Glasgow & Clyde, South Lanarkshire, Tayside, Fife and Grampian for the roll out of Year 2 of the project. Project staff have now been recruited and Future Choices: Training and Support for Family Carers is now in operation in all five PAMIS areas until March 2016. To date an additional 39 families have been identified to gain transition support from the project.

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So long, farewell, auf wiedersehen, goodbye.....

Shana Mozejko

Recently, I was asked to participate in a project run by a well-known national charity who had acquired funding to look into the transition process and put together a package or a plan to guide young people with multisensory impairment and their families through the process. Turning up to the first meeting, I honestly thought I would be sat at the back, listening to other people's views and experiences, successes and failures. As it turns out, I think I ended up doing the majority of the talking which illustrated to me that yes I do have quite a few strong feelings and opinions on transition and how it is implemented for students with a wide range of special educational needs, particularly those with multi-sensory impairments, and also how their families are affected at the same time.

Having taught in special education and with predominantly Post 16 learners for several years, I have been witness to some good, very good and not so good practises with regards transition, from all sides of the coin- school, parents, social services and other service providers. Some of these transitions I have assisted in and some merely observed. It is probably a good idea to highlight at this point that the school in which I work is a generic special school for students with severe, profound and multiple learning difficulties, aged 2 to 19 years old, and therefore, we look to transition our young people at 19. It is also a good idea to note that the transition from children's services to adult services is at 18. Unfortunately, this does mean that for those students who access respite facilities, they have to endure two transitions in a short space of time.

One of the best transitions that springs to mind, and of which I was involved in was with a young lady called Sarah. Sarah had been attending our school since she was eleven years old. Therefore, she was extremely familiar with the staff and students both in her class and the department, and also the environment and the structure of the school day. We had an extremely good relationship with the parents and carers of Sarah and we all worked together to make the transition as smooth as possible. Sarah had a multisensory impairment and other learning difficulties and worked at around the P2(ii) level. Sarah was due to transition to a centre run by the previously mentioned well known charity based organisation close to the school. I felt that this transition ran smoothly for a number of reasons.

Firstly, her parents and carers were all very well equipped beforehand with the knowledge and experience they needed to fully understand the transition process and to be able to fight and persevere with tricky questions or situations on Sarah's behalf. They were very definite and united in what they felt would be the best life path for Sarah to follow and were clear about the reasons why every other place would be unsuitable. Plans for Sarah's future had been discussed well in advance at person centred annual reviews within school and a person centred plan was in place, of which her parents and carers, and all other persons concerned were very much in agreement with.

Secondly, the main issue of funding was agreed quite soon within the whole process and so we were able to meet with the other provider and make plans well in advance of the transition. Meetings and the transfer of information took place and was meaningful to the process.

Good communication links were crucial. Sarah was visited at school and at home by the people she would be working with, a detailed Communication Passport was compiled and Sarah and a familiar teaching assistant visited the new base on a weekly basis for at least 3 months before she left so that she could become more familiar with the new environment alongside someone with whom she felt secure. As a school, we provided training and advice in how best to use Sarah's standing frame and other equipment, and also in very specific activities that we knew Sarah appreciated and could not

be replicated without detailed training, which was provided by a specialist music teacher.

The only niggle that we came across on the whole was that despite it being very obvious where Sarah needed to go after leaving school, her parents and carers still had to go and visit other providers in the area and they also sent in their tutors to meet Sarah just so they could 'check' whether or not they could meet our needs. It would have been nice if they could just have taken ours and her parents and carers word for it. Unfortunately things don't work like that.

I find it hard to be able to pinpoint just one less positive experience to talk about as I feel that there are points from several that add up to what needs to be said. Several transitions I have observed or experienced have involved funding issues which has cast shadows on how positive we can make the whole experience for the young person and their families. Either families have been told the funding will definitely be agreed and then when it has gone to panel, normally late in the day, it is not and they have had to rethink and the transition is then very rushed or non-existent, or when the funding is agreed, but again very late in the day (the last day of June when they leave mid-July) and so the transition is again, not very meaningful.

What seems to be forgotten is that young people with profound and multiple learning difficulties need a lot more time to learn about new people and places and if funding is not agreed at least 6 months in advance then the process becomes very rushed. Regard and respect is not given to the pace with which such learners learn to recall new voices, adapt to new environments and make links between the people and the places. Saying that, funding does seem to be an easier process if there are no extra respite needs involved but that is rarely the case.

To achieve the perfect transition, for some young people, in terms of learning about the people and the environment of a new service provider should take at least six months in my humble opinion. This gives time to develop relationships and ensure that the young person is fully aware of or feels secure in the new environment and is engaging with the new people in their life, so that the 'old' lot are not as easily missed. This part of the process however should only be completed if the funding has been agreed and so it would be beneficial for parents to have made an informed choice before their young person turns 18, so that the chase for funding can commence as soon as possible. I am very much aware though that however early a family and the young person decides on their ideal destination, it all depends on when social services will begin the process and that varies from county to county.

Communication is so important and planning for the changes ahead should ideally begin at age 14, with person centred reviews and all key parties involved. Families need to be given the correct information from the outset, particularly regarding the transition from children to adult services. Adult services is a whole different ball game from children's services and that subject could require an article of its own and yet families, no matter how much we try to advise them, really do not expect the change to be as huge as it is! Also, a good transition requires direct communication between the new provider and the old. Meetings should take place before any contact with the young person between the people who know the young person best and the new provider. The young person should be observed at their best but also when struggling so that there are no surprises for the new provider. Communication passports should be working documents that accompany the young person but exchanging information as soon as possible is of paramount importance so that any new equipment can be bought in advance or planning can be put in place for the activities the young person enjoys.

Transition for the young people who are leaving our school this year has become a whole lot more difficult recently as the providers available in the county are very limited, particularly for those with profound and multiple learning difficulties; cuts are being made and day services reduced. There is a lot of movement within the transition team of social services and they have huge caseloads to attend to. As a consequence applications are going to panel later and later in the day with no guarantees of being granted, however much evidence is put forward that this is what the young person needs.

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Circles of Support and Gilly's Story

Caroline Garner

Circles Network is a UK wide voluntary organisation based in Warwickshire, renowned for building inclusive communities on the foundations of justice, advocacy, empowerment and friendships.

Working with people of any age who are isolated or at risk of isolation, this organisation has ground breaking expertise in the development of Circles of Support, Independent and Collective Advocacy, Person Centred Planning and Inclusion into the mainstream of life. Circles Network has supported disabled young people and families, particularly those in transition from children's to adult services since the organisation's inception 20 years ago.

Circles Network have been an integral part of the transition process for many young people especially those with profound and multiple disabilities. Families have said the expertise in the use of Person Centred Planning tools and approaches makes Circles different from any other approaches.

It is proven that by using a person centred approach individuals are more in control and families feel better supported. In the past, Person Centred Planning, whilst recognised as best practice, has commonly been viewed as an added resource or luxury but not essential.

Circles Network has extensive experience in supporting young disabled people to access personal budgets and to use direct payments effectively and creatively. By focusing on a person's gifts, qualities, likes and aspirations and truly listening to the person, a facilitator is able to support them in planning a life that they really want.

With the introduction of Support Planning in Local Authorities, the process has now become a requirement rather than a luxury in order to help someone plan how they might use their personal budget. This is particularly so for people with pml, it is difficult to see how outcomes with multiple complex components can be achieved without ongoing detailed planning, monitoring and multiple layers of support.

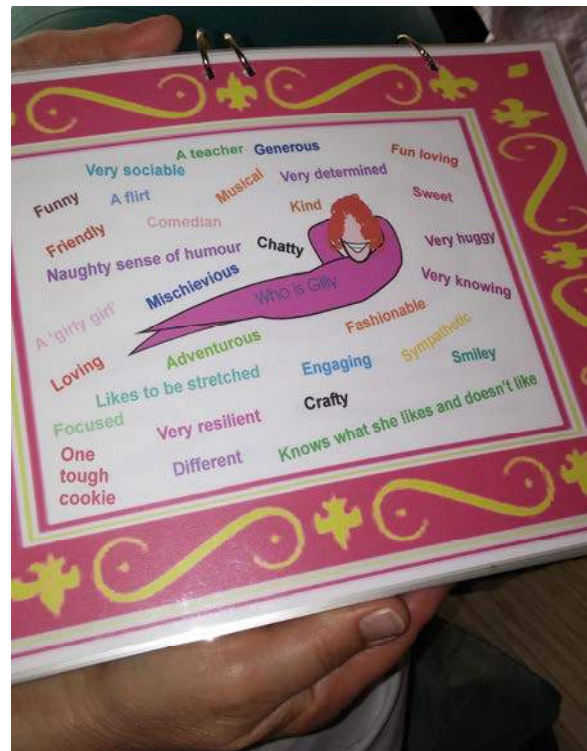
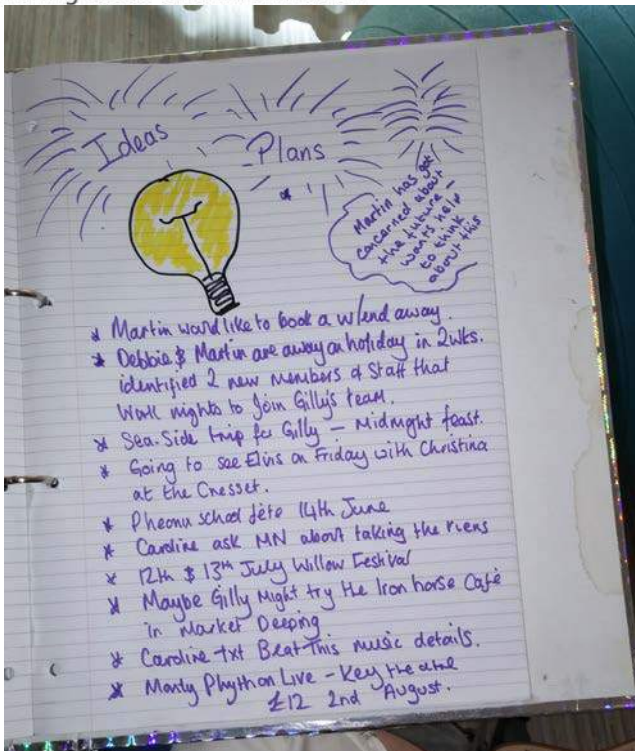
Circles of Support have always been a powerful tool in Person Centred Planning. This approach is particularly empowering for young people with profound and multiple disabilities. Often professionals struggle to "hear the voice" of a young person that cannot communicate in an ordinary way. The members of a Circle of Support are

able to come together and because of their love, fondness and knowledge of the focus person are able to advocate on their behalf, building up a rich picture of who they are and what their future aspirations might be.

The help of Circle members can be incredibly supportive to parents. It can take some of the pressure of the enormous task of planning their young person's future and is also a sounding board for ideas. Often parents find out new things about their young person from members of the Circle as the members are diverse and know them from different environments and settings. Ideally a Circle of Support would start to plan with a young person at around the age of 14. This then allows time for a comprehensive plan to be devised and gives adult social care an idea of the kind of resources and facilities needed for the young person once they turn 18 years of age.

A Circle of Support is a simple concept that is not exclusive and is transferable to adapt to different environments, ages and abilities. There are key elements to a Circle of Support that are as follows;

- A focus person for whom the Circle is for who wants to engage in the process and is not forced to do so.
- Belief from those involved that they are coming together in support of the focus person without their own agenda.
- Commitment from those involved in the Circle. The process is that of a journey and those involved should be prepared for highs and lows and should not expect to be able to provide a "quick fix".
- Circles of support work better if the members of the Circle are natural people in the focus person's life rather than professionals. When professionals do attend it is encouraging if they do so in a voluntary capacity. Sometimes paid people may be the only supporters an individual has in their life and this is a good starting point with a view to the outcomes of the process encouraging inclusion and increasing opportunities for natural people to form friendships with the focus person and ultimately become a member of their Circle.



- An independent facilitator is useful particularly during the development and early stages of a Circle of support. The skillset of a facilitator of Person Centred Planning is diverse. A good guide can be found on line that was produced by the University of Minnesota. - <http://rtc.umn.edu/docs/pcpmanual1.pdf>
- Circles of Support are not a substitute to paid support or help from key professionals but are an important addition.

Gilly's story

Gilly was introduced to Circles Network in 2001. Gilly and her parents' lives were monopolised by medical appointments, doctors, nurses, social workers etc. Whilst these people and environments were essential for Gilly in terms of her health she was becoming in other people's eyes a patient, a receiver of services and the real person that is Gilly was at risk of being lost.

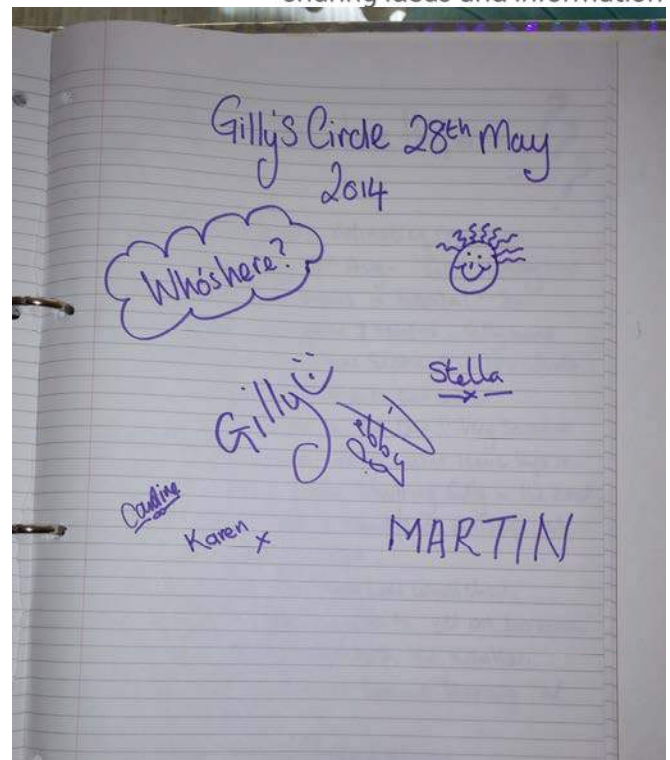
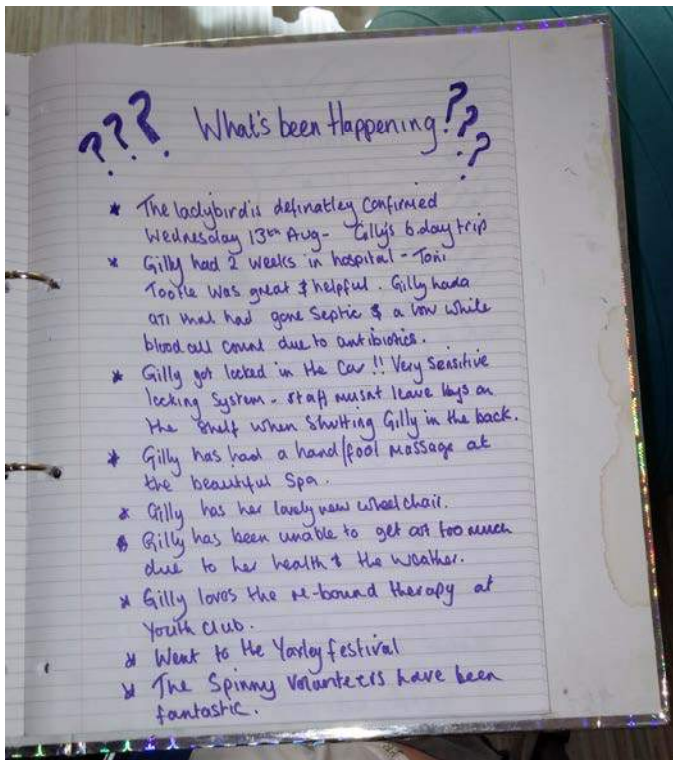
Circles Network helped Gilly to develop her Circle of Support by using a tool called a relationship map to identify the key people in Gilly's life and those that have a fondness and love for her. Her Circle was formed and together with her friends Gilly was able to discover who she was and where she would like to get to in the future. Gilly loved having her favourite people around her, getting hugs on demand and hearing people suggest ideas about opportunities that she might like. Everyone learnt that Gilly could make some decisions for herself and be clear at the Circle if she felt something was a good idea or something she would like to do. There were other

things that she was not able to make decisions on so the members of the Circle helped her to have a go at new activities and visit new places gauging her reaction and feeding back to the group the next time. This enabled the picture of who Gilly is and what she enjoys to develop and grow into a young woman.

At the heart of Gilly's transition into adulthood and ongoing transitions is Gilly's Circle of Support. It was the Circle of support that built Gilly's support plan to provide the evidence for Gilly's life, her well-being, Gilly as citizen. Loved, cherished, important.

Gilly is a great teacher. Gilly taught us that her Circle needed to be dynamic because things change, including Gilly. Circles differ and some will run on their own after a while – without the facilitator. In Gilly's case the Circle needs continued support from the facilitator.

Gilly's Circle of support still meets every 6-8 weeks. Over the years people have come and gone but there are still some members that were around 13 years ago. The members of the Circle, support Gilly with new ideas, and come up with a list of things that are going on locally and further afield that she could be involved in that are fun, safe and community based. The members of the Circle also support Gilly in reviews and at meetings to act in an advocacy role and to attempt to take some of the pressure off her parents. Gilly just loved, cher finds the time when her Circle meets the best. She is relaxed, cheerful, sometimes noisy and sometimes nods off but she absolutely knows that it's her time with people around her that care deeply.



Gilly's mum says about Circles of Support - "The advocacy element is a good, neutral sounding board and we can bounce off people that are not judgemental and don't have an axe to grind. Social services and other professionals have an agenda, her circle members and her circle facilitator dont. An independent facilitator is essential for us. They are objective, manage the dynamics of the group without upsetting anyone and guide the planning process".

Stella a member of Gilly's Circle of Support says -" The Circle helps to prevent Gilly becoming isolated and promotes inclusion. Without groups like this we would become insular. We wouldn't know where to go or what to do, all we would do is attend appointments. My daughter has just turned 18 years old and has PMLD. I have learnt a lot from being a member of Gillys Circle and I would like to develop one around my daughter.

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M's story

Frances Pett

I first meet M back in 1983 when I first started working in this borough. She was the person that came in and sat in her chair in the living room where she had her dinner till it was time to have a bath and go to bed. I remember her sleeping from the moment she came in to when she went home. I can't say she ever really engaged with those around her and staff including my self didn't pay much attention as others often called for attention and we were left insuring her basic needs were meet and that was enough.

M's mother who not only was a wonderful advocate for her daughter but also a really kind person would come to collect her daughter go up to her and give her a big hug and kiss as any mum would do, I remember being there on one of these occasions when the staff member I was on duty with couldn't understand how the mum could do this as M always had a smell from being dehydrated. I was shocked and although I new this was not the way to support there was no time or space to work in another way. I should say these were not

uncaring badly trained staff they just didn't have time or the training to know how best to support M.

I meet M again when I came to work in the services I am currently working in. Again she was the lady sitting on the side of the room not engaged or involved with the wider group. There was however a difference, one of the staff working with her she was young energetic not bothered by smells and liked M. Over time I noticed that M was responding to this member of staff she would

stare into her eyes I think trying to figure out who this thing was and what she wanted. The member of staff would approach her with lots of energy happy and engaged with her, she would always take her lead from M, waiting for her to respond, even if this took some time and staying engaged until M had finished with her.

Over time the staff member learnt that at first she would respond to her, then due to her approach other customers she spent time with also responded differently. Over time this staff member passed her knowledge to other staff so they could interact with M which built her confidence. This communitive approach is now embedded into the service we deliver to all our customers, and forms the foundation from which our service is built.

Some thoughts and comments from others:

From Ella Tarratt – Senior Service Coordinator Skills Development

When I first started to work with M I didn't have much experience of working with people with PMLD but I felt like M had the most inspiring energy, and she was so gentle and patient with my lack of understanding (Question yourself and your practise. Am I getting it right maybe she means something else? Ask anyone who cares enough to listen. Research. Reflect. Apply).

I could see that there were barriers there for her relating to people and life had become boring. M has Retts syndrome which I researched and learnt is characterised by involuntary body movements and I thought at the time, she would try to steady her head by biting her hands so they were often soggy and wrinkled. I got more involved in M's life spending time developing a person centred plan and communication profile. I spent time with her at home, asking questions, watching how she communicated with her mum, looking at photos and talking about her younger years. This helped develop a clearer understanding of what she was experiencing and how her health needs affected her day to day functioning. I learned how to tell how she is or had been feeling, how much she had been sleeping, drinking, how her belly was by the sogginess of her hands, the bite marks on her skin, her facial expressions when she was biting them. All these signs help to open up conversation with M so we would be talking about real things, catching up on how we were feeling, me twittering away asking questions and her eyes telling me if I was right or wrong. (Practise daily to make a difference to your life, to imbed it in your muscle memory).

There were some health concerns that could be eased by supporting M to get more physical. I found that by ensuring she had time to spend on the standing frame

every morning instead of once a week in a 'physio session', it should be real, functional and it would help ease trapped wind that would otherwise make her day very uncomfortable. At home M would spend most of her time out of her wheel chair, sitting on the edge of the sofa and lowering herself onto the floor to then walk around on her knees. This led me to become insistent that at every opportunity whether it be in the centre, at a café, at the cinema, in meetings, sometimes on the bus that she should be supported to stand up out of her wheel chair and sit on any available chair. This lessened the risk of her getting cosy in her wheel chair and sleeping. At times people would comment that I took too many risks but none felt as risky as losing her for a whole day to slumber. (There are no risks that are as great as the risk of nothing happening).

When I was working for M nothing could distract me and take me out of our own little world. We started swimming and trampolining, body awareness sessions and spent time in the sensory room and developed a simple way of standing up on our feet together from the floor without any equipment, holding hands and waiting for each others body tension to be ready. M would place a foot flat on the ground and use me to pull herself up onto her feet and we would rise together to stand. It was always about being ready and listening to her being aware of her signals. This became very easy the more we practised and the stronger she became we got to a point where physical transitions happened smoothly and effortlessly. (If you can breath, you can communicate).

If someone attempts to communicate, respond; in fear that if you don't she may never try again. I would try and use any sign that she gave me as communication, her mum had taught her to blink once for no and twice (or more) for yes and the more we used it the more gestures she adopted, she would raise her eyebrows and lean into me she would rock forwards in her wheelchair to say 'let's go!' We started to play a game with each other when we were out and about, I would say to her, if you want to go fast tell me and she would rock forward and on that cue I would start running whilst pushing her wheelchair and she would giggle and as we slowed down she would say 'again again' by rocking forward and off we would go again.

(Try new things, ask questions and try them again if you're not sure, observe and reflect and then try one more time to make sure. Share what you have learnt).

I have always considered M is my teacher and my hero! With her permission I would explain to people exactly how much she can see and do for herself. We had endless circle meetings and guideline meetings, training other people in her life to support her more fully, to see and value her as she deserved. To help her see that if she



documentation about how people communicate must be kept up to date and used by all involved. Great support workers can be prevented from supporting an individual by poor and frightened management. It is important to support staff to listen to the individual and to take the risk to help them live their life.

In finishing we would like to say in supporting M everybody has contributed not one person has all answers or should not be heard we are all part of a circle and or governed by it

reached out to people they will like her as I do too. And they did, she formed an army of people around her who could help her speak up for herself, when her life went into crisis she had developed a network of people around her who understood her and this helped prepare her for the hardest transition of her life time.

From Frances Pett and M's Sister

M was lucky as she had her own personal facilitator/worker who spent a solid five years consistently gathering the support needs and putting the pieces of the puzzle together. Not focusing only on support needs but on the whole person. Inspiring family, health workers, other carers and the wider public to see the individual in a different light.

None of this work was or could have been done in isolation by one person alone and needs to be valued by those in control of budgets' and management. One person coordinating checking information and passing this on to others none of this work was or could have been done in isolation by one person alone. And needs to be valued be those in control of budgets' and management

Every day a piece of the puzzle can be lost, as every time a new member of staff, manager or policy arrived. In fact every single day the whole process can collapse. One dominant person can decide to change the approach and M feels rushed, ignored and withdrawn again. The key elements must be captured in a way that everyone can understand especially support staff), be inspired and put into practice. Thorough detailed

From Fran Pett – PMLD/Autism Service Co-Coordinator

We always try to expand a person's world and key to this is communication with this tool all other needs wants and desires can be explored for me this should always be the focus of our work to support us to see the whole you as Ella did with M.

M has had many changes in her life. She will have many more; but for me, the most important was the one that said to her – we can hear you – and you can tell us what you want.

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A 'NICER' Way to Cope with Transition from Children's to Adult Services

Felicity Court

Those of us either caring for or working with a young person with PMLD know about the challenges faced at every new 'transition': Dealing with new environments and new people can be tough for all concerned. When someone has more than one complex health condition and requires large amounts of care, the anxiety is compounded as these steps into 'the unknown' are taken: from leaving a young child with a childminder for the first time, to 'letting go' on the first day at school; perhaps spending a night away from home with friends or family or going to a short breaks unit for the first time; these 'transitions' can be nail-biting times, and yet we all recognise that 'change has to happen'.

A particularly difficult transition to make is the one that occurs when someone moves from Children's to Adult Health and Social Care services. This usually coincides with leaving school – just to add to everyone's stress levels! Typical concerns include trying to understand and 'navigate' whole new systems and ways of working; leaving the care of professionals who have known a young person for many years – often from babyhood - and 'starting again' with new doctors/therapists etc. There is often a fear that the health and social care that is needed will not be forthcoming.

The National Institute for Health and Care Excellence (NICE) is an independent organisation that has a range of responsibilities. One is to produce guidance that supports health, public health and social care practitioners to provide the best possible quality care and the best value for money. In 2012 The Health and Social Care Act set out a new responsibility for NICE to develop quality standards and guidance for social care in England from April 2013.

A new NICE 'social care guidance document 'Transition from children's to adult services for young people using health or social care services' will be published in February 2016. This should be good news for all of us working or caring in the PMLD field.

Numerous interested 'stakeholders' have recently been consulted on the scope of the draft guidance document and it has been modified in the light of comments received. It should be available on the NICE website anytime soon.

The next step is that a panel of practitioners, service users and carers will meet regularly over the next 18

months to 'thrash out' the details. The resulting guidance, although not mandatory, will provide practical support to help drive up the quality of adult and children's care.

Likely benefits will be:

- A more consistent approach to social care provision across the country - any move away from a 'post code lottery' for the care of people with PMLD is to be welcomed.
- 'Joined-up' working between agencies and professionals
- Easy access to the new guidance for all practitioners, service users and parents/carers
- A clear 'pathway' that will support all concerned in planning ahead so that every young person's transition between services is anticipated and well managed.

No one is suggesting that the transition between children's and adult services is an easy one to make. However, with the right help and support – and from February 2016 clear guidance from NICE - the hope is that ultimately we will look back and think 'it wasn't that bad after all.....' - just like that first day at school!

For more information visit the NICE website: <http://www.nice.org.uk/>

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Top websites for this issue

www.lukeclements.co.uk

Packed with information on social care law

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

Disabled children: a legal handbook is an authoritative yet accessible guide to the legal rights of disabled children and their families in England and Wales. Currently being updated but chapters can be downloaded from

<http://www.councilfordisabledchildren.org.uk/resources/cdcs-resources/disabled-children-a-legal-handbook>

www.learningdisabilities.org.uk

The Foundation for People with Learning Disabilities website is packed full of useful information and links to initiatives. In particular take a look at **Moving onto secondary school, Transition Innovations Project** and the **Thinking Ahead Guide** – a planning guide for families covering many aspects of transitions including how to plan when you are gone or no longer able to help your loved one

www.peoplehub.org.uk

It is really worth looking up Mitchell's story a young man with complex health needs who has piloted a personal health budget

<http://www.pcpld.org/>

A website with more information on the sensitive topic of the transitions involved in end of life care

<http://www.ndti.org.uk/who-were-concerned-with/learning-disability/best-practice-in-transition-planning/>

Reports on a project from 2010 on best planning in transition – worth a look (even if not specifically focussed on people with profound and multiple learning disabilities)

www.mencap.org.uk anyone wanting information specifically for people with pmlD should go to the mencap website and search for Raising Our Sights – where you can find a series of guides based on a report written by Jim Mansell

www.gov.uk for direct information about the new Children and Families Act 2014 and the new Health and Social Act 2014

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

PAMIS provides support for people with profound and multiple learning disabilities (PMLD), their family and carers and interested professionals. Their newsletter is available at:

<http://www.pamis.org.uk/email.view.php?id=14>

http://www.pamis.org.uk/cms/files/pamis_spring_e-news_2014.pdf

FUTURE FOCUS

Innovations

In the next issue of PMLD Link, we will be looking for articles on innovations – something new or unusual that has the potential to make a difference or to have an impact on any aspect of the lives of people with PMLD. Now, these do NOT need to be innovations to the world, they can also be innovations to you and your family member, service user or learner with PMLD. Of course, they certainly can be innovations to the world and we will be delighted to hear about them.

Innovations can sometimes sound wonderful but when you try them out in the real world, they don't work. We'd like to hear about these too. One of our colleagues (Beryl Smith) used to say that it would be great to have a journal full of articles about interventions that had failed. She felt it would be just as helpful as interventions that worked!

It is likely that some of the innovations will be about technology, and those will be particularly welcome as technology does have the potential to change people's lives. However, we do need a bit of caution with any technology [especially 'educational 'items] as a whizzo piece of kit is of no use to someone who doesn't have the intellectual ability to make sense of it. We have lots of examples of technology for teaching cause and effect, but you might find that the person you are working or playing with is much more likely to understand cause and effect when it involves people. People can be flexible and respond even when the person with PMLD doesn't quite get it right. If s/he is using a switch and is struggling to hit it correctly, it stubbornly won't work. We are really interested in the potential of eye gaze technology, so any examples of that with people with PMLD would be great. It is not often that people with PMLD are even assessed to see if they could make use of eye gaze, let alone given the technology. But we know there are some and it would be so good to hear what has transpired. Low tech equipment can be really innovative too! Maybe you've recently discovered adapted bikes at a local park- this might mean for the first time, you can go out together as a family and enjoy something that involves every one of you?

Of course there are lots of other potential innovations. Maybe your service has been reorganised? Tell us about some of the innovative and inspiring activities you offer, the creative ways you deliver these or even the unique venues for these opportunities. Perhaps you are preparing to support the new Education, Health and Care Plans; or you have set up a new parent partnership

activity; or you have trialled a new training programme for practitioners. Maybe you have just completed the first School Direct training or are experimenting with how to use direct payments for leisure activities in adult services. Perhaps you have tried out a new way of indicating progress in learning in your pupils or students or taken a group of people with PMLD abseiling for the first time.

There is no limit to what your innovation could be about. The next issue of PMLD Link is still a few months away – so you've got time to deliberately try out something new and write up what happens! Students on the University of Birmingham programme 'Severe, Profound and Multiple Learning Difficulties', are asked to do just that. They try out something new in their context and then collect research data to help them evaluate its success. Hopefully a few of them will write short articles explaining what they did. It's worth asking!

Penny Lacey and Annie Fergusson

Please send any contributions by 24th October to us at:

p.j.lacey@bham.ac.uk

Or

ann.fergusson@northampton.ac.uk

Let us know if we can help you with sharing your stories – we are happy to help!

PMLD Network Forum A Digest of Discussions



The PMLD Network forum is an open email discussion group which focuses on issues relating to PMLD. Here is a summary of the key themes that have come up on the forum over the last few months.

Campaigns

Justice for LB campaign

There is a 107 days campaign to gain justice for Connor Sparrowhawk, an 18 year-old man who died a preventable death in a specialist assessment and treatment unit for people with learning disabilities: <http://107daysofaction.wordpress.com/> Nico, a young man with PMLD, also died in a service. Connor's mum says in her blog that Nico's family have been fighting their fight for Justice for Nico for 317 days longer than LB's family and friends and are still no closer to answers. She said in her blog, 'Our campaign is inspired by LB, but one thing is for sure #JusticeforLB has always been about Justice for all Dudes'. Read about Justice for Nico: <http://abitmissing.wordpress.com/2014/06/07/the-dust-in-the-corner-justice-for-nico/>

- **Legal web-chat**

As part of the Justice for LB campaign, Steve Broach, a barrister at Doughty Street Chambers held a free web Q&A on the law in relation to education, health and care services for disabled young people in England. He discussed both the current law and the changes coming soon under the Children and Families Act 2014 and the Care Act 2014. He also covered what the Human Rights Act 1998 should mean for the standard and quality of care disabled young people receive:

<https://107daysofaction.wordpress.com/legal-web-chat-justiceforlbaw/>

- **Guardian letter**

The Justice for LB campaign asked people to sign a short letter for Guardian in support of the #justiceforLB campaign. This was published: <http://www.theguardian.com/society/2014/jun/11/justice-people-learning-disabilities>

Death by Indifference - Debate on the Confidential Inquiry into premature deaths of people with a learning disability

'The government must do more to prevent those with learning disabilities dying younger and having poorer health' Baroness Hollins said. She criticised the government's inactivity since the 2013 University of Bristol Confidential Inquiry report found that over 1,200 people with a learning disability die needlessly every year in NHS as a result of discrimination in the health service.

Watch the debate at: <http://www.bbc.co.uk/democracylive/house-of-lords-27821358>

Winterbourne View: The Scandal Continues

A new report and a petition from Mencap and the Challenging Behaviour Foundation calling on the Prime Minister to ensure NHS England, local and national Government take action to ensure people with a learning disability are moved out of places like Winterbourne View and get the right support and services in their local areas: <http://www.challengingbehaviour.org.uk/cbf-articles/latest-news/the-scandal-continues.html>

Resources

Going into hospital with a learning disability

'If you care for someone who has a significant learning disability and needs to go into hospital, it can be a worrying time for them and you. But there are steps you can take to help make their time in hospital a success'. Read the NHS Choices 10 step guide: <http://www.nhs.uk/Livewell/Childrenwithlearningdisability/Pages/Going-into-hospital-with-learning-disability.aspx>

Feeling Down: Improving the mental health of people with learning disabilities

This report by the Foundation for People with Learning Disabilities (FPLD) is designed to help promote positive mental health by offering information, case studies and real-life experiences of people with learning disabilities and their carers and their strategies for enhancing their mental wellbeing. Standard and easy read versions of the report are available: <http://www.learningdisabilities.org.uk/publications/feeling-down-improving-the-mental-health-of-people-with-learning-disabilities-report/>

Ordinary Life - package of new support materials

The Foundation for People with Learning Disabilities (FPLD) has launched a package of new support materials to raise awareness of the aspirations of children with complex health needs and their families, and to highlight the opportunities available to improve their lives. The materials are the result of the charity's three year project "An Ordinary Life". The resources are aimed at practitioners, children's health and social care commissioners, schools and colleges and families. They include:

- A one stop booklet for parents: Children and young people with complex health needs
 - An easy read person centred planning template: My Health and Person Centred Plan
 - Three factsheets: Leisure, Flying and Financial Benefits
 - One page profile template for children with complex needs: A book about me
- <http://www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life/>

Webinar for professionals who are introducing personal health budgets to people with learning disabilities

Think Local Act Personal (TLAP) commissioned the guide 'Personal Health Budgets - Including People with Learning Disabilities'. A webinar took place in June to introduce the guide to people responsible for implementing, or supporting implementation of Personal Health Budgets (PHB) to people with learning disabilities. From October 2014 people eligible for NHS Continuing Healthcare (NHS CHC) will have the 'right to ask' for a personal health budget. Read the guide at: http://www.thinklocalactpersonal.org.uk/_library/Reports/TLAPIncludingLD.pdf

Adult safeguarding

- **Adult safeguarding and housing staff**
This online guide from SCIE raises awareness about safeguarding in key areas relevant for housing staff: <http://www.housinglin.org.uk/Topics/type/resource/?cid=9179&msg=0>
- **CQC, together with other partners, has produced a document** 'Safeguarding Adults – Roles and Responsibilities in Health and Care Services' sets out how individuals and organisations should work together to prevent abuse and neglect from happening and ensure the safety and well-being of anyone who has been affected: <http://www.cqc.org.uk/content/cqc-joins-forces-partners-strengthen-roles-and-responsibilities-adult-safeguarding>

Care and Support Jargon Buster

Think Local Act Personal (TLAP) has produced an online Jargon Buster. It is a plain English guide to the most commonly used social care words and phrases and what they mean: <http://www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=9555>

SEN Facts & Figures Infogram

Special Needs Jungle have produced an Infogram using figures taken from the Department for Education guidance document aimed at helping local authorities prepare for the coming changes to the SEN system.

Infogram: <http://www.specialneedsjungle.com/sen-facts-figures-infogram/>

DfE guidance: Implementing the 0 – 25 special needs system <https://www.gov.uk/government/publications/implementing-the-0-to-25-special-needs-system>
The DfE also answered some practical questions on the Special Needs Jungle website: <http://www.specialneedsjungle.com/department-education-answers-practical-questions-sen-reform/>

Holiday guide

Contact a Family's guide to holidays, play and leisure for families of disabled children has been updated. Parents can get a free copy by calling their helpline on 0808 808 3555. They can also download the guide at: <http://www.cafamily.org.uk/news-and-media/free-copy-of-holiday-play-and-leisure-guide-available-from-0808-888-3555/>

Rough Guide to Accessible Britain

The Fifth Edition of the Rough Guide to Accessible Britain is now available online for free. It has reviews, hints and tips on some of the UK's best attractions written by and for disabled people: <http://www.accessibleguide.co.uk/the-guide.html>

Reports

Supporting health checks

Improving Health and Lives (IHAL) says there is clear evidence that health checks detect unmet health need and lead to actions to address these needs, but half of all people with learning disabilities eligible for a health check are still not getting them.

Their new report signposts people to a number of resources that can help improve the uptake and quality of health checks by making reasonable adjustments. Read the report: http://www.improvinghealthandlives.org.uk/publications/1224/Making_reasonable_adjustments_to_primary_care_services_supporting_the_implementation_of_annual_health_checks_for_people_with_learning_disabilities
Read IHAL factsheets: what helps health checks work better, are health checks helpful, and can health checks help people with behaviour that challenges. <http://www.improvinghealthandlives.org.uk/projects/annualhealthchecks/detail>

Teenagers with complex health needs lack support as they approach adulthood

CQC says the findings from its recent review show that young people with complex health needs do not always receive the necessary care and support when they move on to adult care services. Read their report, 'From the pond into the sea' at <http://www.cqc.org.uk/content/teenagers-complex-health-needs-lack-support-they-approach-adulthood>

Progress on improving nursing for people with learning disabilities

Strengthening the commitment: 1 year on – a Department of Health report looking at how learning disability nursing is improving:
<https://www.gov.uk/government/publications/progress-on-improving-nursing-for-people-with-learning-disabilities>

3 Lives report

CQC published a report with the Challenging Behaviour Foundation (CBF), called '3 Lives'. It looked at the experiences of three young people with learning disabilities who were in assessment and treatment units. CQC and CBF say the main message from these stories is that the care they received was not based on their individual needs and did not put them and their families at the heart of their care. Read the full report below
<http://www.cqc.org.uk/content/3-lives-report>

Improving wheelchair services

Sir David Nicholson made it his pledge for NHS Change Day 2014 to bring wheelchair users together with NHS clinicians and managers, and with third sector organisations, to improve wheelchair services across England. NHS England held a wheelchair summit in February. The key comments made at the summit and the draft action plan proposed can be read here: <http://www.england.nhs.uk/2014/03/28/wheelchair-services/>

How local learning disability communities rate themselves

The Learning Disabilities Observatory, part of Public Health England, has published the first detailed report of the Joint Health and Social Care Learning Disability Self-Assessment Framework (JHSCSAF) that aims to provide accurate data about how local services are working together to meet the needs of people with learning disabilities.

Local areas rated themselves against 27 indicators, with 9 indicators each in three domains: Staying healthy, Being safe, Living well.

For the first time this year, the learning disabilities self-assessment framework exercise contained an opportunity for local authorities to share stories of people with a learning disability, carers and advocates. Read the report: <https://www.improvinghealthandlives.org.uk/projects/hscldsaf>

Mental Capacity Act: government response to the House of Lords Select Committee report

The Government has published its response to the House of Lords Select Committee's report into how the Mental Capacity Act is working in practice - 'Valuing every voice, respecting every right: making the case for the Mental Capacity Act': <https://www.gov.uk/government/>

[publications/mental-capacity-act-government-response-to-the-house-of-lords-select-committee-report](#)

Consultations

Care Act 2014: launch of care and support consultation

The Department of Health is asking for views on the draft regulations and guidance for Part 1 of the 2014 Care Act. Find out more and have your say: <http://careandsupportregs.dh.gov.uk/>. Closing date: 15th August 2014

Personal Independence Payment (PIP) assessment: first independent review

Individuals and organisations are invited to submit evidence to an independent review, commissioned by the DWP, of how the Personal Independence Payment (PIP) assessment is working. Closing date: 5 September 2014.
<https://www.gov.uk/government/publications/personal-independence-payment-official-statistics-june-2014>. Mencap is also collecting evidence about how PIP is working. To share your experiences, please contact james.bolton@mencap.org.uk

Other

Matthew's book

Matthew's parents shared an interactive e-book about their son Matthew and his care needs, which they put together with key professionals working with Matthew. They thought it could be of interest to other families and to professional staff working with people with learning disabilities.
More information at: <http://designforcare.wordpress.com/projects/matthews-book-2/>

Take a Break grant fund for families with a disabled child is now open

'Take a Break' is grant funding for families living in Scotland. The aim of the fund is to support carers, including kinship carers and their families to take a break improving their physical and emotional well being, enabling them to enjoy life and opportunities outside. It can be used towards a break, holiday, outing, sport activity or other activity in the UK or overseas. To find out more visit: <http://www.takeabreakscotland.org.uk/>

To take part in discussions please join the PMLD Network Forum at http://www.pmldnetwork.org/about_us/join.htm

Visit the PMLD Network website at www.pmldnetwork.org

REVIEWS

Title: Dignity & Inclusion: making it work for children with complex health care needs

Author: Edited by Amanda Allard, Jeanne Carlin and Jan Delamore with Ian Townsend

Publisher: National Children's Bureau

Date: April 2014

ISBN: 9781907969539

Pages: 201

Price: £24.99 (Members Price: £19.99.)

In 2004, the Council for Disabled published 'Including Me - Managing complex health needs in schools and early years settings' written by Jeanne Carlin. This was an immensely informative and practical work demonstrating how health and education professionals could work together to find solutions to the day-to-day difficulties of providing access to the educational opportunities to which pupils with challenging health needs are entitled. This was an expert guide and reference text and, as a Head Teacher at that time, I felt that it was of inestimable value for any school with concerns about how to respond to the needs of pupils with complex health issues.

Ten years on, in April 2014, the National Children's Bureau launched this new publication which successfully builds on Jeanne Carlin's original book. It is targeted at all service providers, focusing on children who require clinical procedures, children who require moving and handling and children who need intimate care as part of their personal support. The focus may be on children from birth to 18 years but it also has relevance for young people up to the age of 25 years. The new book rightly addresses the challenges of the new partnership arrangements required between all services working with disabled children and their families and in the early chapters provides a survey and explanation of developments in practice and legislation over the past ten or more years.

Officers of local authority services and NHS services will find a renewed insistence on comprehensive and integrated local agreed arrangements. Schools and other education providers will find that their perspectives and needs are still given full consideration with due attention to their duties, risk management and assessment, health care plans, training of staff and support arrangements, again with practical models and vignettes.



The original chapter on partnerships with parents and children has now been divided into two chapters and these have been given due prominence. Good communication with families is still to the fore because it is essential to building a genuine partnership and there is a particular focus on sharing information. The chapter on partnership with children promotes the development of independence and self-reliance, communication and maintaining the dignity of the individual.

The book contains a wealth of case studies, examples of good practice and realistic models for written plans and records. The final chapter presents a checklist to assist readers in determining whether they have given sufficient attention to all of the issues addressed in the preceding chapters. Comprehensive references provide a good guide for further reading if wished.

The aim of the book is to enable all services to be inclusive of children and young people with complex health care needs. It surely succeeds in giving services the information and guidance that they require. The ball is firmly in their court! Its publication is timely given the current and impending special educational needs and disability reforms and the introduction of new statutory guidance for supporting pupils in schools with medical conditions. Also, as pointed out in an early chapter there has been a significant growth in the number of children with high support needs in the past ten years. If a school does not have a pupil with complex health needs on roll yet, they surely will have one some day.

As a former Headteacher I would strongly recommend this as a book to be studied by the leadership team of

every school and college. Indeed, it should be widely read by all lead professionals concerned with developing effective services, not just school leaders, and many parents and support groups for families will be interested in what it has to say. Of course, it will remain for these individuals to develop their own local approaches that fit their context but they will find much inspiration and guidance for their work here.

All customers purchasing this book will receive a 50% discount if they also buy the companion volume 'Making it work for children with behaviour that challenges' at the same time via the NCB web shop (shop.ncb.org.uk).

Rob Ashdown



Frozen Light

A number of PAMIS staff had the wonderful opportunity to go along and experience the new show *Tunnels* put on by the theatre company *Frozen Light*, at the Bonar Hall, Dundee at the end of May. This new piece of theatre has been designed especially for teenagers with profound and multiple learning disabilities (PMLD) and gives them the opportunity to enjoy the whole theatre experience.

When we arrived the teenagers, with their teachers and support staff, were all tucking into their lunch in the foyer and the atmosphere was very relaxed. When the doors opened you were personally led through the tunnel of light to your seat; the performer's faces were full of expression and the use of non-conventional sounds, immediately engaged each person from the outset. The multi-sensory show included the diverse use of carefully chosen props which included; glowing UV chains, heated bowls of grains, aroma sprays and even a giant white vibrating pillow was handed around! The body language, visual expression along with vocal squeals of delight from the teenagers emphasised the positive effect of this theatrical experience. It was a full hour of multi-sensory delights adapted to each individual's needs.

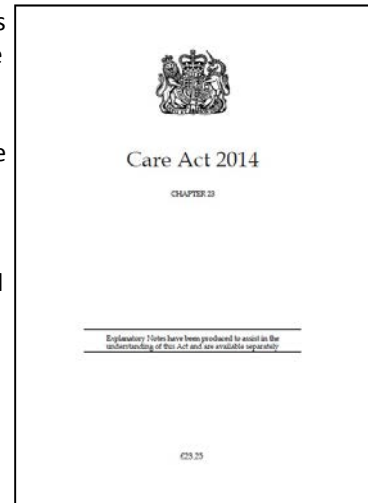
Care Act 2014 and Transitions – an introduction to Luke Clements and his overview of the Act

The Care Act 2014 is the biggest change in social care law for 60 years. Once someone is 18 the Care Act will shape their care and support package. Luke Clements has prepared a very useful briefing on the Act. Luke is a Professor of Law at Cardiff University and is a solicitor with Scott-Moncrieff & Associates

Ltd. He also has a website packed with useful information regarding Social Care Law. His website can be found at www.lukeclements.co.uk. Anyone involved in the transition of people with PmlD from children's services to adult services would be well advised to take a look at this website.

Luke will issue a further briefing that will look at, in his words ...'the wicked detail within the draft Guidance and Regulations'. The draft guidance has been published and the consultation is open until the 15th of August. Luke's full overview for the Care Act can be found on his website. For the purpose of this Transitions Issue, and in the hopes that it will encourage people to look at the whole briefing, we are printing extracts from Luke's overview that refer to transitions and the underpinning principles of the Act - Well-being. However to get the full context of the briefing we urge readers to look at the full document.

Among the other resources available on the website is a very accessible 'Lecture Series'. Currently there are 3 films/lectures: *Assessing Social Care Needs*, *Care and Support Planning*, and *NHS Continuing Care and the Law*. The care and Support Planning lecture is particularly useful for anyone wanting to understand exactly what is needed and the detail required to achieve a comprehensive Care and Support plan.



What follows are extracts from: Care Act Overview 2014
by Luke Clements

Underpinning principles (section 1)

Well-being

The consultation process leading to the drafting of the legislation resulted in demands that the Act be underpinned by a coherent set of guiding principles (rather like those that apply in relation to the Mental Capacity Act 2005, s1). Many consultees argued that these principles should include (for example) ‘dignity’ and ‘independent living’ (ie that the care planning process should aim to promote independent living and should not subject anyone to indignity). The Act does not have such a set of principles – it merely has general duty to promote the well-being of individuals (ie adults and carers). The duty applies to local authorities and their staff / members when exercising ‘any function under Part 1 of the Act (ie sections 1-80).

“Well-being”

Well-being is so widely defined that it is quite possible that it will be of little practical application. It includes personal dignity, physical and mental health and emotional well-being; protection from abuse and neglect; control over day-to-day life; participation in work, education, training or recreation; social and economic well-being; domestic, family and personal relationships; suitability of living accommodation; and ‘the individual’s contribution to society’.

When discharging any obligation under the Act, the local authority must ‘have regard to’—

- the individual’s views, wishes, feelings and beliefs;
- the need to prevent/ delay the development of needs for care and support;
- the need to make decisions that are not based on stereotyping individuals;
- the importance of individual’s participating as fully as possible in relevant decisions (including provision to them of necessary information and support);
- the importance of achieving a ‘balance between the individual’s wellbeing and that of any friends or relatives who are involved in caring for the individual’;
- the need to protect people from abuse and neglect;
- the need to ensure that restrictions on individual rights /freedoms be kept to the minimum necessary.

Provisions relating to disabled children, young carers and ‘parent carers’

Disabled children in transition (sections 59 – 60 Care Act 2014)

Although the primary purpose of Part 1 of the Care Act 2014 is to reform adult social care law, the Act also contains provisions relating to disabled children and carers

‘in transition’ to adulthood. These are overly complicated – as the Act contains considerable detail on the issue of consent / capacity to consent and what must be included in the assessment.⁴⁰ Put simply however: a local authority must undertake a needs assessment of a disabled child if it considers that the child is likely to have needs for care and support after becoming 18 and that the assessment would be of significant benefit to the child. Such an assessment is referred to as a ‘child’s needs assessment’. If a local authority decides not to undertake such an assessment it must give reasons for its refusal.

Parent carers in transition (sections 61-62 Care Act 2014)

In very similar terms, ss61 – 62 of the Act places obligations on local authorities to assess the disabled child’s parents during this transition process. In simple terms⁴¹ the Act provides that a local authority must undertake a needs assessment of the carer of a disabled child if it considers that the carer is likely to have needs for support after the child becomes 18 and that the assessment would be of significant benefit to the carer. Such an assessment is referred to as a ‘child’s carer’s assessment’. If a local authority decides not to undertake such an assessment it must give reasons for its refusal.

Parent carers in general (section 90 Children & Families Act 2014)

The Children & Families Act 2014, s90 amends the Children Act 1989 (by adding s17ZD and s17ZE) to oblige local authorities to assess parent carers (referred to in the Act as ‘child’s carers’) on the ‘appearance of need’ – ie if it appears to a local authority that a parent carer may have needs for support (or is requested by the parent) then it must assess whether that parent has needs for support and, if so, what those needs are. Such an assessment must include an assessment of whether it is appropriate for the parent to provide, or continue to provide, care for the disabled child, in the light of the parent’s needs for support, other needs and wishes.

The assessment must also have regard to.

- the well-being of the parent carer (‘well-being’ has the same meaning as s1 Care Act 2014), and
- the need to safeguard / promote the welfare of the disabled child and any other child for whom the parent carer has parental responsibility.

Having undertaken such an assessment the local authority must then decide whether the parent has needs for support; whether the disabled child for has needs for support; and if so whether those needs could be satisfied (wholly or partly) by services under Children Act 1989, s17.

There is in addition a strategic duty on the local authorities to take reasonable steps to identify the extent to which there are parent carers within their area who have needs for support.

Young carers

At the moment, 'young carers' is not a term that appears in any legislation. For a local authority to have an obligation to a young carer (ie someone aged under 18 who provides care on an unpaid basis for another person), she or he has to be labeled a 'child in need' – for the purposes of Children Act 1989, s17. This has now changed, as both the Care Act 2014 and the Children and Families Act 2014 address the needs of 'young carers' directly.

Young carers in transition (sections 63 – 64 Care Act 2014)

The Care Act 2014, ss 63 – 64 concern young carers 'in transition'. The Act (in simple terms) requires a local authority to undertake a needs assessment of a young carer if it considers that she/ he is likely to have needs for support after becoming 18 and that the assessment would be of significant benefit to him / her. Such an assessment is referred to as a 'young carer's assessment'. If a local authority decides not to undertake such an assessment it must give reasons for its refusal.

Young carers in general (section 96 Children & Families Act 2014)

The Children & Families Act 2014, s96 inserts a new s17ZA into the Children Act 1989 to address the needs of young carers. This creates detailed obligations (many of which will be fleshed out in regulations) including a duty to assess a 'on the appearance of need' (ie without a 'request' having to be made (s17ZA (1)) and a strategic duty on the local authorities to take reasonable steps to identify the extent to which there are young carers within their area who have needs for support (s17ZA (12)). The provisions will come into force in April 2015 to coincide with Care Act implementation. It is expected that where eligible needs are identified in relation to young carers, local authorities will have to either provide support under s17 CA 1989 to the young carer or demonstrate that the 'cared for person's' assessment has provided adequate care and support to prevent inappropriate care being required from the young carer.

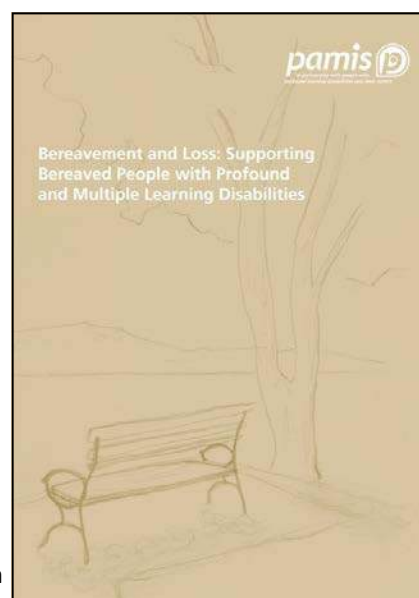
Continuity of support for disabled children / young carers in transition (section 67)

The Care Act 2014, s67 creates a complex set of provisions, the effect of which is (in essence) that the assessments of disabled children / young carers that take place before the young people become 18, will either continue to apply when they become 18 until reviewed⁴⁴ or if the local authority do not treat the assessments as a continuing obligation – then they must reassess.

RESOURCES

PAMIS' Bereavement and Loss Learning Resource Pack

PAMIS' Bereavement and Loss Pack is a long awaited resource around the taboo subjects of death and grief, in relation to people with profound and multiple learning disabilities and their parents and carers. The pack also includes a DVD of two 20 minute films of conversations with



parents and carers which is a great training tool. These brief films help us to understand the experience of bereavement for people with profound learning disabilities and those caring for them.

The resource explores the bereavement and loss experiences of people with profound and multiple learning disabilities, their reactions to bereavement and how to provide support by considering the circumstances that may further exacerbate grief. Providing suggestions of support, it shows us ways of engaging people with profound learning disabilities in the sensitive issues around bereavement and loss.

The resource also shares with us experiences of bereaved parents and carers whom have cared for someone with profound learning disabilities and complex healthcare needs. It goes on to show how in order to understand the specific issues related to bereaved families, it is necessary to gain a better understanding of their life experience. Families' experiences demonstrate that the extent to which the palliative care needs of people with such complex disabilities are met will shape the experience of bereavement for families. In essence, "bad deaths" have been those which have prevented families from meeting the palliative care needs of their son or daughter.

The authors of this material demonstrate that the journey of grief can be supported sensitively by listening to, nurturing and cultivating stories of relationships. It also becomes clear that through this approach, relationships can be formed, maintained and developed. The range of additional reading and resources cited strongly supports the material in both understanding the experience of bereavement and suggestions for how we can sensitively support bereaved people. Beautiful illustrations and photographs complement the shared experiences of those involved in PAMIS' Bereavement and Loss Project.

Dr Donald MacAskill, Learning Disability Social Care Consultant, who also served on the Advisory Committee for the project said, "There is a lot of silence around death and bereavement. People are uncomfortable and avoid the issues. The silence is deafening for people with profound and multiple disabilities and for a long time their experience of loss has gone unheard and unmet. This brilliant resource speaks for them, their families and carers. In creative and respectful ways it tells their story and will undeniably serve to support hundreds who have grieved and are grieving. It should become a must read for workers, advocates and families alike."

A reception was held at the Scottish Parliament on the 28th May to celebrate this piece of work and it was a successful evening. Pat Graham, parent, who spoke at the event said, "I believe PAMIS has given us a great gift. It's one of the best things we have ever done. We were never going to find a way to explain to Lauren [my daughter] that her Gran had died but we had at last found a way to keep a little bit of Gran alive in Lauren's memory. And as for me, by thinking about my mum and talking about her most days to Lauren, I at last got to do my own grieving. I can't think of a better way to thank PAMIS for what they did for our family than to do so in this place and in this company. Thank you."

This is a resource pack which will be sure to make positive changes in the lives of people with profound and multiple learning disabilities and those who care for them.

This work has been funded by the Esmée Fairbairn Foundation, Scottish Government, True Colours Trust, Rix, Thompson, Rothenberg Foundation and Alexander Moncur Trust

PAMIS is a registered charity that supports people with profound and multiple learning disabilities and their families across Scotland. It provides a range of services and campaign for equity in services for people with profound and complex disabilities.

To order your copy of the Bereavement and Loss

Learning Resource Pack, please visit www.pamis.org.uk or order a copy by telephone: 01382 385154.

Elizabeth McBride: Future Choices Manager, Pamis, Email: elizabeth.pamis@btconnect.com

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.

IN THE NEWS

A Development and Subscriptions Manager for PMLD LINK

The Trustees are pleased to announce that they have contracted the services of Rebecca Jones, a freelance worker, as a development and subscriptions manager for PMLD LINK. Rebecca will focus mainly in the coming year on raising awareness of the benefits of the journal among professionals working in



schools and adult services and other organisations that support children and adults with PMLD and their families. It is hoped that the journal will be more widely read as a result and that the information will help to improve services for people with PMLD. Of course, this is not the only activity that Rebecca will be engaged in: she will be making other contributions to the development of PMLD LINK as an organisation and improvement of its own services wherever possible.

Since she is new to PMLD LINK, it seems appropriate to ask Rebecca to say a little about herself as follows in her own words:

"I live in Leicester with my partner and children. I have four children, the eldest is training to be a dancer and the younger three children who are 14, 13 and 8 are home-educated. With my spare time I enjoy reading, attempting success on my allotment, socialising and eating out, watching films and eating cake!"

Alongside being a mum I have spent many years campaigning and volunteering for small charities and

community groups, which are diverse in topic but all close to my heart. In the past I have chaired a large branch of a national charity relating to parenting, been the parent contact for another national charity, and fundraised and supported community projects. Currently I am the treasurer for our Home Education group, I run a social media page raising awareness of Domestic Violence, and run a support group. I organise and administrate educational trips for home educating families locally and nationally. I very much enjoy spending my time helping and supporting people in any way that I am able.

As my children are getting older, I am able to take on a role which can utilise my strengths and experience. I feel very passionately about PMLD LINK. I feel the publication is invaluable and I hope to be able to contribute positively toward the growth and reach of the journal. I look forward to working with PMLD LINK over the coming years."

Holidays, Play and Leisure

Our guide to holidays, play and leisure for families of disabled children has been updated with a smart new listings format.

Holiday Guide <http://bit.ly/1rf1B1e>

Parents can get a free copy by calling our helpline on 0808 808 3555. Packed full of useful information to help you plan to keep the kids occupied this summer holiday, the guide covers:

- where to find suitable play and leisure facilities
- ideas for days out
- your child's rights to play and leisure
- financial help with leisure, and with holidays in the UK or abroad
- finding holiday and travel insurance
- short breaks for carers.

Other printed guides for parents available from the helpline are:

- Money Matters checklist - when your child has additional needs
- Relationships and caring for a disabled child
- Siblings
- Grandparents
- Aids, equipment and adaptations

Special Educational Needs (SEN) Code of Practice: for 0 to 25 years

In March the measures outlined in the Children and Families Bill were made law and it became the Children and Families Act 2014. The Act includes changes to the support and services children and young people with special educational needs and disabilities (SEND) will receive. These changes will come into force on 1 September 2014.

For those with the most complex needs, which must surely include children and young adults with PMLD, the government is introducing a single birth-to-25 education, health and care (EHC) plan which will replace the current statements of special educational needs and learning difficulty assessments in post-16 education. The creation and delivery of these EHC plans will be led by the local authority but the expectation is that schools and other services will be involved in developing, delivering and reviewing these plans working closely with parents. The changeover to the new EHC plans for all will take place over the course of the next three years, probably at times of transition points in each child or young adult's education, such on entry to the education system and when they move from one phase of education to another.

The government launched a public consultation on a new 'Special educational needs and disability (SEND) code of practice: 0 to 25 years' in Autumn 2013. This closed on 9 December 2013 and over 700 responses were received. In April 2014, the government consulted again on the revised draft of the code. Edward Timpson, the Minister for Children and Families, wrote an open letter to all teachers, parents and local authorities explaining that the final code would be issued as soon as possible but that the draft code could be used as a planning tool.

The government has involved nasen (the UK charity which aims to promote the education, training, advancement and development of all those with special and additional support needs) in setting up an online resource for teachers. The online document, 'Everybody Included: The SEND Code of Practice Explained' is available on the nasen website (<http://www.nasen.org.uk>).

There have been concerns expressed about the new code. The IPSEA (Independent Parental Special Education Advice) charity has expressed concerns about what it

perceived to be inadequate periods of consultation for such a complex and important code – the first time it was 9 weeks instead of the usual 12 weeks and the second one lasted a mere 12 days and largely coincided with school holidays. IPSEA has published its response to the second consultation on its website (<http://www.ipsea.org.uk/news/changes-to-sen-law/ipsea-responds-to-the-revised-draft-sen-code-of-practice-may-2014.aspx>). IPSEA's concern is that the draft code does not provide clear and accurate guidance for the people who will be implementing it. They fear that a September 2014 implementation date will not allow sufficient time for preparation for a smooth transition to the new system.

The final code should be published by the time this issue of the PMLD LINK journal reaches you.

Independent Parliamentary Inquiry on Childcare for Disabled Children

An independent Parliamentary Inquiry was launched in May to report on the problems faced by disabled children and their families in accessing childcare. The inquiry committee held evidence sessions in Parliament in June. The inquiry sought evidence from families, professionals and a range of stakeholders and should report by the end of July.

The inquiry is co-chaired by Conservative MP Robert Buckland and Labour MP Pat Glass and is being supported by Every Disabled Child Matters (EDCM), the Family and Childcare Trust, Contact a Family and Working Families.

The inquiry aims to 'shine a spotlight on the long-standing problems concerning access to childcare that affects many families with disabled children': for example, having to pay more for childcare for disabled children than for non-disabled children; insufficient childcare for disabled children in many local authorities; and a lack of confidence among parents of disabled children believed that childcare providers can cater for their child's condition.

Robert Buckland MP said "Despite the growing political and public attention childcare has received, the issue of childcare for disabled children, has received comparatively little attention. We have launched this inquiry to ensure that disabled children are part of the ongoing childcare debate." The terms of reference for

the inquiry are:

1. Assess the extent to which disabled children and their families face affordability, quality and access barriers to childcare.
2. Identify good practice and examples of quality childcare provision that promotes the inclusion of disabled children and young people.
3. Examine potential policy measures to address these barriers.
4. Make recommendations as appropriate.

The focus is on children aged 0 to 18 with a disability and the whole range of childcare from formal arrangements (including out of school and holiday clubs) to domestic informal childcare provided in exchange for remuneration.

The government funded Disabled Children Access to Childcare (DCATCH) pilot programme ran from 2009 to 2011 and tested a series of models for extending access to affordable, high quality childcare for disabled children. The programme successfully identified a range of approaches but funding for the pilots ended in 2011. The inquiry will aim in part to explore the most effective next steps to build on the DCATCH programme.

Information about outcomes from the inquiry should become available from the websites of the supporting organisations:

Every Disabled Child Matters

Every Disabled Child Matters (EDCM) is a national campaign to get rights and justice for every disabled child. It is run by four leading organisations working with disabled children and their families: Contact a Family, Council for Disabled Children, Mencap and the Special Educational Consortium. Find out more at <http://www.edcm.org.uk/>

The Family and Childcare Trust

The Family and Childcare Trust works to make the UK a place where government, business and communities do all they can to support every family to thrive. For more information, go to <http://www.familyandchildcaretrust.org/>

Contact a Family

Contact a Family is a UK charity that provides information, advice and support to families with disabled children whatever their condition or disability. Visit <http://www.cafamily.org.uk/>

Working Families

Working Families is a charity helps working parents and carers and their employers find a better balance between responsibilities at home and work. Visit <http://www.workingfamilies.org.uk/>

Supporting Pupils at School with Medical Conditions

The government has made available the proposed text for guidance that will be issued in accordance with the duty, specified by the Children and Families Act 2014, to make arrangements for pupils with medical conditions. This duty comes into force on 1 September 2014. The guidance was updated in May 2014. The text is being published in advance to enable local, authorities, schools and others to prepare for implementation and fully understand the requirements. The text is available online along with templates for individual healthcare plans, records of administration of medicine, staff training records and parental agreement records plus links to other resources and guidance.

The guidance states that the government's aim is 'to ensure that all children with medical conditions, in terms of both physical and mental health, are properly supported in school so that they can play a full and active role in school life, remain healthy and achieve their academic potential' (para 1). This guidance should be read in conjunction with the SEN code of practice. All schools (including academies, free schools, etc.) must develop a policy for supporting pupils with medical conditions that is reviewed regularly and is readily accessible. This should set out the procedures to be followed whenever a school is notified that a pupil has a medical condition. It should make plain the need to draw up and maintain individual healthcare plans and state who is responsible for their development and review (at least annually). It emphasises that governing bodies and school managers should ensure that sufficient staff have received suitable training and are competent before they take on responsibility to support children with medical conditions. The guidance states that it is important that the school policy sets out the details of the school's insurance arrangements which cover staff providing support to pupils with medical conditions.

Although relevant, this guidance does not specifically address complex health care needs, such as the need for some clinical care procedures. Readers may be forgiven for thinking that there is focus on medicines and their administration alone. But this guidance does provide details about what should be in place to support all pupils with medical conditions. For further guidance on support for pupils with complex health care needs see 'Dignity and Inclusion: making it work for children with complex health care needs' which is reviewed elsewhere in this issue of PMLD LINK journal.

To access the statutory guidance and templates go to: <https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions>

Disabled movement programme first for Dorset

Wyvern Academy in Weymouth has become the first school in the South West to receive accreditation for a teaching programme that helps physically disabled children gain more freedom of movement. The school has become a MOVE Centre of Excellence for the MOVE Programme, a unique activity-based programme that focuses on skills essential to independence in class and at home. MOVE teaches children with severe physical disabilities actions such as sitting in an upright position, standing, walking and transferring, through learning new skills in often, tiny incremental, steps. The accreditation also means Wyvern will now be able to provide MOVE training for local health workers, carers and parents of physically disabled youngsters and adults throughout the region.

“We are absolutely delighted to have received MOVE Centre of Excellence status. “It’s a marvellous achievement and will make real a difference to many young lives,” says Sue Marshall, Wyvern’s MOVE co-ordinator.

“The heart of this programme is that movement is a prerequisite for learning. A child restricted to a wheelchair lacks the same learning opportunities as an able-bodied youngster to explore their environment.

“The more they are able to interact with the world around them, the more their interest and motivation grows and the more they can learn.”

Sue says the most basic of actions – giving a hug, going to the toilet, or raising your head to look out of the window – can often present a huge challenge for many of the UK’s 110,000 children with severe physical disabilities.

“A young person who is unable to control their head for instance, might only be able to stare into their lap or else look up at the ceiling, which effectively shuts them off from the rest of the world.

“Gaining movement and strength can make a huge impact on their lives and make a whole world of difference to a child’s ability to receive an education and to their general happiness.

“If you can control your head, you can make eye contact with other people. It also means you can look at a screen with the freedom to make your own choices about what you want to explore, just like any other child.”

Developing head control also means the child is less likely to choke while eating or drinking, and can improve the position of the spine and internal organs and helps prevent skeletal deformity.

There are currently 22 children on the MOVE Programme at Wyvern Academy which has 81 pupils aged between 3 and 19, all of whom benefit from regular access to the programme and specialist equipment. Thirteen-year-old Mitchell, who has cerebral palsy, was unable to stand when he started the programme 18 months ago and would spend the majority of his time sat in his powered wheelchair. Mitchell was provided with a walking frame, and the opportunity to use it was built into his daily routine – for example, taking the register to the office in the morning or walking down to the kitchen to see what was for lunch. The range of movement in his legs and feet has now improved to the extent he now uses his walker throughout the school day and to go out into the school playground at break times. His mum Tina, says her son’s legs have grown stronger and his digestion has also improved through being more active, along with his confidence levels and self-esteem. He now wants to learn how to ride a bike.

“We have made our home and garden more accessible. Mitchell is happy he has choices now rather than just sitting in his chair.”

The UK-based charity The MOVE Partnership also has a presence across the world in more than 10 different countries including Spain, Japan and New Zealand. For further information visit:
www.themovepartnership.org.uk

Issued by Empica Ltd on behalf of Wyvern School. For further information contact Judith Skorupski on 020 8983 0779 or Nicki Sampson on 01275 394400.

Moving on to secondary school

The move from primary to secondary school can unnerve the most confident of pupils, however with over half of pupils with statements of Special Educational Needs (SEN) being placed in mainstream schools (DFE 2012), including pupils with profound and multiple learning disabilities and those with complex health needs the transition can altogether be much more challenging for this group. Not only do they have to cope with a change of school which is much bigger, they have to adapt to having a new set of teachers, moving between the school for each class, new rules and new pupils.

A team of researchers including Ann Fergusson from the University of Northampton, Richard Byers from the Faculty of Education, University of Cambridge, and Jill Davies from the Foundation for People with Learning Disabilities gathered the views of pupils with SEN who remembered the move to develop guides to improve the move.

From the information and advice gained from talking to the pupils, along with discussions with the year 7 heads, SENCOS and primary school staff, the team developed three sets of guidelines designed to provide practical suggestions, additional approaches and broader strategic ideas to better plan for the transition. The guidelines are relevant not just for pupils with a statement of SEN, but for all year 6 pupils entering the transition stage. They are:

- **Top tips for pupils**
This is an easy-read guide that includes a checklist and poster, to give young people simple ideas of how to prepare for the move to make it less stressful. The emphasis is on encouraging pupils to

take more responsibility for themselves and be prepared for the move. For example, start thinking about getting organised when at primary school - pack your own bag for school, or start using a diary or timetable. Other ideas to increase independence include ordering food yourself when you are in cafes or joining your local library. During the summer holiday study the school map and have practice runs on public transport to the school before the start of term

- **Advice for busy parents**
This includes practical ideas for families to help support their child to feel more prepared and able to cope with the move to secondary school. For example, contact the primary school SENCO to draw up an action plan for the transition, or keep a timetable at home to make sure your child is packing the correct books and equipment for each day.
- **Guidelines for busy teachers.**
These guidelines includes advice for those working in primary and secondary schools and is divided into three levels – small changes that can be achieved quickly; those which require a little more effort; and those which require strategic change within the school. Suggestions for primary staff include running a regular circle time to talk about the transition to secondary school and identifying those who may need several visits or a phased transition to secondary school. Ideas for secondary school staff include assigning buddies for pupils with SEN, and send out packs to feeder primaries to introduce secondary school staff, campus map and timetables.

The guides and posters can be downloaded online at:
<http://www.learningdisabilities.org.uk/our-work/employment-education/moving-on-to-secondary-school/>

Jill Davies and Ann Fergusson

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The SLD Experience

The British Institute of Learning Disabilities (BILD) regularly publishes a journal called 'The SLD Experience' which is aimed at parents and practitioners working with and caring for children and young people with severe learning difficulties (SLD) in mainstream and special schools. To find out more about the journal go to the BILD website (<http://www.bild.org.uk/our-services/journals/sld-experience>).

The SLD Experience – some reviews of recent articles by Rob Ashdown Spring 2014, (Volume 68)

'Special educational needs and disabilities (SEND) legislative change: the impact for schools, children, young people and their families'

This article by Lorraine Petersen, the former chief executive officer of *nasen*, about the new SEND Code of Practice was published before the enactment of the Children and Families Act 2014. Nevertheless, it contains some useful background information and Lorraine makes some interesting points and dispels one or two myths.

Petersen describes the new assessment processes and the intended transition from statements and learning disability assessments to the new system of education, health and care plans (EHC plans or EHCPs). She reiterates that there have been assurances by the government that no one will miss out on provision on transfer from statement to EHC plan, but seems to feel that this remains to be seen.

The article also presents details about (a) personal budgets as a critical element of a personalised approach to supporting children and young people with SEN; and (b) the obligation on local authorities to publish a 'local offer' that provides clear, comprehensive and accessible information about the provision available. As regards the local offer, she suggests that this could make provision more responsive to local needs and aspirations.

Petersen argues that children, young people and their families are at the heart of the SEN reforms and their successful implementation will depend upon the engagement of these key stakeholders. All of the new systems should be informed by the experiences of Pathfinder authorities, working with relatively small numbers of children, young people and their families. Despite their success, Petersen reminds us that there are 1.5 million children identified with SEN as well as all those who will be new to the system from September 2014. She questions whether every local authority has the capacity to engage with all of these stakeholders as successfully.

Petersen expresses concerns that all these new systems could result in a 'huge implosion as local authorities do not have the capacity to deliver' (p.15). She notes that the last three years have seen a huge reduction in local authority personnel who had the necessary knowledge, skills and understanding and she doubts that the implementation process can be as smooth as the government suggests it will be'

'Recent Research'

Dawn Male reports a case study of the difficulties experienced by the family of a nine year old boy with SLD and autism in accessing a simple medical procedure: a blood test. It took seven appointments and 15 weeks to take a blood sample and caused significant distress to the child and to his family. The authors of the report note that similar issues have previously been identified for people with learning difficulties and disabilities accessing health-care services and their recommendations will be very familiar. In their conclusion they state: 'There is no single process or system that will work for everyone. Rather, professionals need to ensure they consider the individual needs and adapt existing systems to meet them. In particular, professionals need to take time to plan and prepare how to do this.' (Jackson Brown, Cooper and Diebel, 2012, p.131). As Dawn Male notes, people will agree with the principles but the challenge lies in finding the time to plan and prepare.

The article reviewed was:

Jackson Brown, F, Cooper, K and Diebel, T (2012) 'Access to mainstream health services: a case study of the difficulties faced by a child with learning disabilities', *British Journal of Learning Disabilities* 41, 128–132



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

Flo Longhorn training

Email: FPLcourses@aol.com
Website: www.flolonghorn.com

July 2014

Title: **Conference: Children and Youth with Disorders of Consciousness: Linking practice with research**
Date: **OCTOBER 9th** (*book by August 1st*)
Location: Tadworth, Surrey
Provider: The Children's Trust
Contact: www.thechildrenstrust.org.uk/doc14

Title: **Fast Track Summer School Training to become a Registered Certified Practitioner in Therapeutic Play Skills**
Date: 26th for 15 days
Location: South of France
Contact: Email: mokijep@aol.com
Web: <http://www.playtherapy.org.uk/TrainingCourses/TrainCrseSSVenue.htm>

September	
Title:	The 9th International Short Break Conference 2014: Inclusion worldwide – supporting People with Disabilities and their families
Date:	9th-11 th
Location:	Wolfenbüttel, Germany
Provider:	ISBA
Contact:	www.isba.me/index.php?id=31
Title:	Kidz Scotland
Date:	11 th
Location:	Edinburgh
Provider:	Disabled Living
Contact:	Tel: 0161 607 8200
Title:	Practical and Effective Ways of Using Multi Sensory Equipment
Dates:	<u>September 12th</u> Glasgow, <u>16th</u> Dublin, <u>18th</u> Belfast, <u>30th</u> London, <u>October 7th</u> Birmingham, <u>November 13th</u> Manchester, <u>27th</u> London, <u>December 8th</u> Glasgow
Provider:	Concept Training
Contact:	See provider details
Title:	Intensive interaction: Sensory Issues And Communication Using Body Language
Dates:	<u>September 15th</u> Glasgow, <u>November 12th</u> Chorley
Provider:	Concept Training
Contact:	See provider details
Title:	Learning Outside the Classroom – Taking the Curriculum Outside
Dates:	<u>September 16th</u> Glasgow, <u>October 13th</u> Birmingham, <u>November 10th</u> London, <u>17th</u> Chorley
Provider:	Concept Training
Contact:	See provider details

Title: Dates: Provider: Contact:	Intensive Interaction Co-ordinator Course September 16 th 2014 to November 2015, in 7 blocks of 3 days Intensive Interaction www.intensiveinteraction.co.uk/	Title: Dates: Provider: Contact:	PMLD: Profound and Multiple Learning Disability – engaging children in learning October 9 th London and Birmingham, 16 th Chorley, November 14 th Glasgow Concept Training See provider details
Title: Date: Location: Provider: Contact:	Rebound Therapy for SEN, Open College Network, Level 2 23 rd and 24 th Newcastle upon Tyne EQUALS See provider details	Title: Dates: Provider: Contact:	Conference: Children and Youth with Disorders of Consciousness: Linking practice with research 9 th (book by August 1st) Tadworth, Surrey The Children's Trust www.thechildrenstrust.org.uk/doc14
Title: Date: Location: Provider: Contact:	Advanced Pain and Symptom Management – master class 21st- 26 th Minneapolis Children's Department of Pain Medicine, Palliative Care and Integrative Medicine http://www.childrensmn.org/health-professionals/education/conferences	Title: Dates: Provider: Contact:	Intensive Interaction: Building relationships with people who have profound learning disabilities and complex needs Jane Gurney October 10 th London, November 19 th Birmingham, December 4 th London Concept Training See provider details
October			
Title: Date: Location: Provider: Contact:	Professional Training Opportunity with Oily Carte, creators of theatre for young people with PMLD and ASD, and Rose Bruford College of Theatre and Performance 6 th -11 th Ashford, Kent Oily Carte Email: oilies@oilycart.org.uk Tel: +44 (0) 20 8672 6329	Title: Date: Location: Provider: Contact:	Global Symposium for Ketogenic Dietary Therapies for Epilepsy and Other Neurological Disorders 11 th Liverpool The Matthew's Friends Ketogenic Dietary Therapies Charity liverpool2014@matthewsfriends.org Tel: 01342 836571
Title: Date: Location: Provider: Contact:	How to do Positive Behaviour Support 6 th Birmingham BILD Tel: 0121 415 6960 Email: enquiries@bild.org.uk	Title: Date: Location: Provider: Contact:	Sleep Practitioner Training for people working with families of disabled children 14 th and 15 th London Handsel Project peter@handselproject.org.uk http://www.handselproject.org.uk/sleep1.html

<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>A day with Jo Grace / Sensory Stories 14th Dudley, 15th Manchester, 16th Cardiff Learning Enhanced Tel: 01384 459 117 http://www.learningenhanced.com</p>	<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Sensory solutions for autism and challenging behaviour 17th London, 19th Bristol, 21st Birmingham Hirstwood Training See provider details</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Introduction to Independent Advocacy 15th Birmingham BILD Tel: 0121 415 6960 Email: enquiries@bild.org.uk</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Interactive and Multi-Sensory Storytelling 20th London Concept Training See provider details</p>
<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Learning and progression in the Multi-Sensory Classroom 15th London, 17th Chorley Concept Training See provider details</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Assessing Pupil Progress and Target Setting for Pupils and Students working at or below Level 1 20th Manchester EQUALS See provider details</p>
<p>November</p>		<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Sensory Play for All <u>November</u> 27th Birmingham, <u>December</u> 4th London Concept Training See provider details</p>
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Sensory processing in the Classroom 7th Newcastle upon Tyne EQUALS See provider details</p>	<p>December</p>	
<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>The 2014 Good Autism Practice Conference 14th Birmingham BILD Tel: 0121 415 6960 Email: enquiries@bild.org.uk</p>	<p>Title:</p> <p>Date:</p> <p>Provider:</p> <p>Contact:</p>	<p>Behaviour: Positive Ways of Changing Behaviour 4th London Concept Training See provider details</p>
<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Sensory Communication: developing engagement and interaction 17th Manchester, 18th Birmingham, 21st London Hirstwood Training See provider details</p>	<p>Title:</p> <p>Date:</p> <p>Location:</p> <p>Provider:</p> <p>Contact:</p>	<p>Maths for Pupils with Very Special Needs 4th London EQUALS See provider details</p>
<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Sensory Communication: developing engagement and interaction 17th Manchester, 18th Birmingham, 21st London Hirstwood Training See provider details</p>	<p>Title:</p> <p>Dates:</p> <p>Provider:</p> <p>Contact:</p>	<p>Intensive Interaction Co-ordinator Course December 11th 2014 to April 2nd 2015, in 7 blocks of 3 days Intensive Interaction www.intensiveinteraction.co.uk/</p>

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.

Severe, Profound and Multiple Learning Difficulties

Blended Learning (a combination of online and occasional weekend study on campus)

The Severe, Profound and Multiple Learning Difficulties blended learning programme has been developed for a range of professionals/practitioners who work with children and adults with learning difficulties in educational settings across the severe and profound range (SLD/ PMLD). The programme covers issues for staff who work in any education and learning services and has particular emphasis on working together to meet needs. The programme aims to help participants to study systematically, critically and in-depth, aspects of educating children and adults with severe, profound and multiple learning difficulties. Participants are encouraged to research and reflect on their own practice, carrying out small-scale research leading to developments and innovation.

For further details: University of Birmingham, Dr Penny Lacey (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

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

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

For further details: Whitefield Schools and Centre, Louise Langworthy l.langworthy@whitefield.waltham.sch.uk

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

The Postgraduate Certificate, Diploma and Masters programmes are delivered at Whitefield Schools and Centre in partnership with Kingston University, London. The Certificate course runs for one year and the Diploma runs for two years. Both years carry 60 "M" level credits, allowing access to the third year Masters Degree that takes the form of an educational action research project.

The *Diploma and Certificate* courses are practitioner based and there is a requirement that students are working, either as a paid member of staff, or in a voluntary capacity for at least two days a week with children or young people with special educational needs.

The *Masters programme* is also practitioner based but there is no requirement for work to be but students can be accepted straight on to this programme (subject to an official transfer request and University approval) if they already have the appropriate number of credits at "M" level.

Whitefield can also offer the mandatory qualification for teachers of pupils with [Multi-Sensory Impairment \(MSI\)](#). Teachers undertaking this course complete two years of study as above, addressing the mandatory standards for this course, followed by a four week assessed teaching placement working with MSI pupils in a recognised centre of excellence.

Course start date: September 2014

For further details: Whitefield Schools and Centre, Louise Langworthy l.langworthy@whitefield.waltham.sch.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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