PMLD LINK
sharing ideas and information

Family and Friends

Summer 2012

Vol 24 No 2. Issue 72
ISSN 2042-5619

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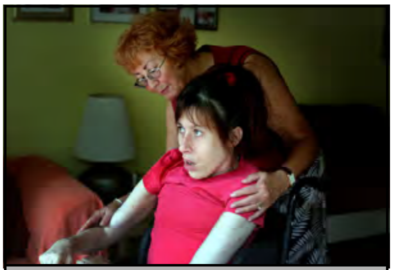
SUMMER 2012 contents



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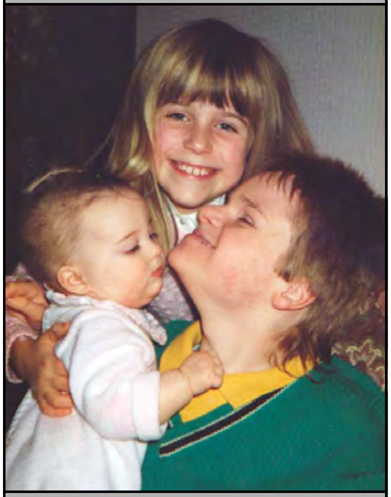

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PMLD Link is a journal for everyone supporting people with Profound and Multiple Learning Difficulties

Vol. 24 No. 2 Issue 72

GUEST EDITORIAL

Family and Friends

Welcome to the Summer edition of PMLD Link, featuring articles and information about Family & Friends for you *& by you*! Thanks to all who have sent us contributions.

This issue is brimming with articles that we know you will find both compelling and informative. Our articles, the wonderful collection of photos and even poems we hope reflect our wide ranging readership – families [parents, siblings, grandparents, nephews, and cousins we know are featured this time], people with disabilities, researchers and a number of professional perspectives. Contributors have so generously shared personal and professional insights and reflections into often intimate aspects of their own lives or those of people with PMLD that they love, care for and support. However emotive [and some are!] they each have a very positive and inspiring perspective.

We begin with a focus on Family issues. Our first article from Jean Willson offers us hope and a positive view of preparing for the end of life. Jean shares difficult dilemmas with us as well as some very valuable practical information, as she describes her family's journey to ensure her daughter Victoria lives her life to the full, enjoying its entirety in comfort with family and friends around her. We hear Linzi Lee's reflections on the life of her brother Lee and her memories as she looks back and considers them growing up together. We have two articles that offer some quite different experiences of family life from a perspective of taking on the 'parenting' role [from 'Janet' and 'Peter & Pat'].

Jill Davies describes some new resources developed as part of an on-going project to support families with children who have complex health needs – these may well be of help to other families too. Jo Roach through poetry highlights a lifelong concern for families, over the safeguarding of their vulnerable relatives when they are not around. To address such concerns or 'when things go wrong' we have information about two valuable new resources for families about safeguarding produced by Hft & the National Family Carers Network.

Our collection of articles around Friends and friendship offers an interesting mix. Antonia tells us herself about her personal experiences of spending time with her two friends. Wendy Newby talks about her role in enabling friendships to develop in the classroom and her positive steps to providing opportunities for her students to make such meaningful connections. Nicola Grove and colleagues from Openstorytellers continue the theme of enabling through their descriptions of three exciting projects to promote friendship and meaningful participation. Rachel Parry Hughes takes a different perspective on concepts of friendship by offering some insights gained through her research into friendship for people with PMLD.

Beyond these Rob Ashdown writes about the Family Fund and in another piece offers an update on government plans for education. Don't miss information about Hft's latest Holiday Guide either!

In keeping with the theme Helen & I have included a couple of family snaps to set the scene. Happy reading!

Ann Fergusson and Helen Daley

Life Transitions: Victoria’s Journey

Jean Willson

For Victoria, every life transition from baby to childhood, finding a school, leaving school, leaving home – all have been full of difficulties and pain, and very occasionally, unexpected joy.

Born in 1970 with the whole range of Tuberous Sclerosis Complex, so bad that the doctors would not even give a life expectancy, now aged 42 with her kidneys failing; major seizures, infections, and very poor health her tiny body worn out, and now, it seems, she is nearer her final transition, death.

However, her family, her friends and her staff team want to share with you what we have planned so that we will give our remarkable and lovely woman Victoria her final transition without pain, with dignity and peace and lots of love in the most positive way we can for a much loved woman.

As a family, it was very difficult to face the facts that late last year, Victoria was becoming increasingly frail, and taking longer to rally after set backs in her health. As her mum, I went to a conference on Palliative Care for People with Learning Disabilities, and this set me thinking. I talked through where Victoria was at with Irene Turffey-Wijne afterwards about when would be the best time to call in the Palliative Care Team? She was very clear and said “do it tomorrow, often family carers have said to me: I wish I had done this earlier.” Victoria had an appointment with her consultant in the Renal Unit the next day and he immediately set the ball rolling.

The very word ‘Palliative’ has dire overtones and something that I had been blocking, I think for sometime. When her consultant reacted as if he had been waiting for us to come to this conclusion, doubly re-affirmed that this whole business *was real* and Victoria could indeed, not be here! Then we had to go back to our family of just one – her elder sister, and her Circle of Friends and tell them of this future HUGE life transition stage.

Words cannot describe how we felt, but our overriding passion, determination and focus, *then* and *now* is that the quality of life for Victoria must be of the very best. After all, this is such an exceptional woman who has achieved so much throughout her life as a role model, activist, campaigner and trail blazer, as well as a much loved daughter, sister and close friend, that she deserves the very best we can get for her. Expecting the usual battles, blocks and barriers when facing another life transition for Victoria, imagine then our complete surprise when we had our first meeting with Barbara her first Palliative Team nurse, just four days after the hospital referred her. Barbara came to the house, went straight to Victoria touched her arm said hello etc. and said to her that she was here to make sure she was going to be comfortable and without pain. She was like a breath of fresh air, and so refreshing liberating, it was a huge relief to know that Victoria was going to be in safe hands. She checked out about talking things through in front of Victoria, and with that set the whole tone for the next few months of planning.

Victoria has lived safely and happily in her own home, with 24 hour support, for the last 21 years. It was, and is, essential that all the team, which includes the family and friends, work together, so it was at this stage with Barbara that we shared our plans for Victoria not to go to hospital and not be resuscitated. (We had gone through this with various medical emergencies over the years, and it had taken us a long time to come to this decision)

Barbara was amazed at how far we had planned things, and it was so re-assuring that she could now take the plans, give them medical authority and really make things happen. For example ensuring that ambulance people know that Victoria will not be admitted to hospital; that the emergency doctors know there is an End of Life Plan. And this was put into place immediately. I can't express her staff team's and the family's relief at this!

Over the months now, the Palliative team has helped Victoria's team with anything we present to them i.e. responding to Victoria's ever changing needs, like ensuring that pain killers are now given on a daily basis and anti-sickness mediation is in the house. Problem solving with some medics who fail to believe her End of Life plans. Re-assuring us and explaining to us all the stages that Victoria might go through, and how she must feel. We, in turn, are able to explain to Caitlin (her new nurse) how Victoria might react. Caitlin is also cascading out through Islington and Camden, information about supporting someone with PMLD's.

Over the months, Victoria is getting even more tired; and the episodes of nausea/ diarrhea are increasing. The frequency and strength of her seizures are also increasing. But an unidentified infection which led to her refusing food was treated, and she has slowly come back, a little bit like her old self. Encouraging Victoria to eat and drink takes lots of imagination and patience. Pacing her moods and ability to do things takes an enormous amount of skill and attention to detail. Ensuring her flat mate is aware of what's going on, but making sure she still does what she loves to do. All of these things her staff do exceptionally well and positively.

We, her family have been making sure the bungalow is bright and looking good. Arranging and bringing Victoria visitors who have known her for years for brief visits. She seems to enjoy these visits, as we sit round her chatting and talking about her music.

Victoria has always struggled to make herself understood, and we often wonder what she would be saying to us now at this time. All we know is that we have done the very best we can to make sure our lovely daughter is without pain, supported by a terrific staff team who know what she wants and when. That her family and friends are going to be there with her.

Jean Willson

For any information on the work of the:
Tuberous Sclerosis Association
Telephone: 0121 445 6970
http://www.tuberous-sclerosis.org

Palliative Care for People with Learning Disabilities
PCPLD Network www.pcpld.org

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ISSN 2042-5619

He Ain’t Heavy he’s my Big Brother

Linzi Ellison

He Ain't Heavy…. being Lee’s sister, Lee was my big brother, so I never knew any different. He was older than me by 7 years. I didn't know my family was "*different*" until I got to school.

My Gran had bought me and Lee these incredible cups- mine was an elephant whose trunk made the handle and Lee's was a monkey whose tail made the handle. Lee's was by far the coolest!

When friends came to play and I would offer them the choice of which cup they wanted, they would ask which was mine and choose that one. I was completely baffled! I'm not sure when I realised that they thought they could ‘catch it’!

I remember in town, kids would often point and stare saying "mummy what's the matter with him?" "He's dribbling is he a baby?" Mummy, mortified would drag them away saying "come away, it's rude to point." But Mummy would offer no explanation; maybe that's why they thought you could catch it.

But you can't catch Cerebral Palsy. The only thing that Lee had that was highly contagious was his chuckle! He was famous for his dirty laugh and his red hair! That and his love of chocolate cake!

Lee was profoundly disabled. He had little control over his body, he couldn't see very well at all, he couldn't walk or talk or sign. We learnt to communicate in other ways, from such seemingly small signals, that it must have looked as if we were all telepathic or making it up!
When I was little Lee had epilepsy and would have several fits a day. He would fit, be unconscious, wake up and cry- it was perfectly normal to me, before I learnt we were "*different.*"

People have said that as a sibling of a disabled child I might feel jealous that Lee got all the attention, or neglected or ignored or lonely and I guess it is possible that other children in other families do feel those things all I know is that we just understood that Lee needed more help.

Let me assure you I was never ignored or neglected or lonely or jealous! My mum was very good at including and involving me and my little sister Cheryl, who came along 7 years after me. We always seemed to get everything we wanted without being "bought" or spoilt. It wasn't just material things either, all the knowledge my Mum had gained about child development benefited us.

In fact using the "flash cards" she had created to help stimulate Lee's vision my sister and I were both taught to read before we even got to school! This was the start of my life long love of words!

I am sorry I can't give you a wider perspective of what it is like to have a disabled sibling. I cannot offer you statistics and will not give you generalised information. I can only tell you what it was like for me, being part of my family. Every individual is different and every family is different; in fact Our family motto has become "Not better, not worse, just different!"

Being part of any family has its pros and cons! Here are a few of our pros and cons!

All of us being ready to leave the house for 9 o'clock was practically impossible! But half day entry to Alton Towers is cheaper which meant we could go more often! And we didn't have to queue for any of the rides if Lee went on with us! Thankfully he was an adrenalin junky and loved the runaway train! I think the record stands at four times in a row, before we bailed- I'm sure Lee would have stayed on!

Lee had to have a lot of equipment to help him and the giant "potty type thing" over the downstairs toilet was a bit annoying, but the monkey bars, adapted roundabout and giant soft play tube we could roll down the hill in were great. When I was really little I also loved sneaking into Lee's room to sleep, as the sound of his respirator was like a lullaby to me and I loved to fall asleep twiddling his hair round my fingers! I must have felt most comfortable in Lee's room, as quite often I would sleep walk there, slightly baffled when I woke up.

Mornings were always chaotic; with myself, Cheryl, Lee, Mum and Lee's carers trying to get ready! Even though I lived across the road from school I was always late. This however was only ever due to my lack of organisation! The teachers though seemed to think it was something to do with having a disabled brother? I never got told off! For the first 7 years or so of my life, Lee needed a lot of physical exercises carrying out, which took a lot of time and effort from my mum and the small army of volunteers she recruited for this purpose! It was great there was always someone to talk to or play with and I had loads of friends!

When we went on holiday a lot of places were inaccessible and too hot for Lee, so eventually Lee would go on his own "respite" holiday and we would go without him, but we also *had* to go to Disney World TWICE with him because it was so accessible!

Because Lee couldn't tease me like a "normal" big brother I never learnt to stand up for myself and felt bullied when I got to senior school. Although on one occasion when I was about 16, I was extremely upset because "Andrew" (name has been changed to protect the innocent!) didn't love me back! I decided to confide in Lee and just like any other "normal" big brother he laughed in my face!

Lee had a knack of forcing people to show their true colours. I remember once being asked to leave a restaurant, because Lee was a fire hazard. I also remember a lady coming up, taking Lee's hand and saying God bless you! She disappeared and came back with a big bag of chocolate mint fudge, which turned out to be Lee's favourite thing to eat. (Second only to chocolate cake!)

The biggest con of being a sibling to a disabled child for me, was watching him suffer. As he got older his fits all but stopped, but the rare few he had were terrifying. Watching him choke on a fish bone and the time he ended up in hospital on his 18th birthday, because he hurt his knee. (He made it out and back home to drink champagne in the evening thank goodness.) The crippling stomach aches he experienced and when he was vomiting blood. This has been almost the hardest thing about being Lee's sister.

The biggest pro was what a great person he was. He taught me so many things! I learnt to be patient and wait my turn, I learnt the importance of not judging people, I learnt to accept people for who they are, I learnt "it's not better or worse just different", I learnt to respect individuality, I learnt that people communicate in so many ways other than just words and I learnt to truly listen, I learnt to always try my best, as I could do so many things that Lee couldn't, I learnt to be glad for all the good things in my life, I learnt not to waste my potential and to always try to be kind and the best person I could be.

I do not mean to be patronising, I am not suggesting that Lee was only a good person because he was disabled. Lee was disabled and a good person.

Lee died March 23rd 1997, when he was 23 years old. This is the hardest thing about being Lee's sister!
Since then I have learnt just how much I loved him and how much he was loved by others. He touched so many people's lives by just being.

I have also learnt to be happy again, because I would never want to change a thing about having had Lee as my big brother! After all, the depth of our grief is due to the depth of our love.

I still miss him and now that I am a mother myself, I worry about how I will teach my son all these wonderful things, without Uncle Lee to help me. But Lee is always with me, he is in everything I do and everything I have become.

I guess I will have to teach as Lee did; by example. Even if it wasn't a financial necessity I would still work. I am a project facilitator for Circles Network and facilitate the Peer Mentorship Project where "mainstream" students and students from "special educational schools" come together to share time, space and activities; to make friends and have fun. I hope this will teach my son the importance of inclusion and the importance of doing something you believe in.

The impact of having a profoundly disabled brother is huge; the impact of having had Lee as a brother is magnificent.

Linzi Ellison sister to Lee and Eastern Regional Coordinator for Mencap's Inspire Me Project

Joint training for parents - by parents

Jo Hough

I first found out about the Challenging Behaviour Foundation while I was on the Partners in Policymaking course, an inclusive family leadership development programme for disabled adults and parents of disabled children. In a room full of people who I barely knew but who had disability as a common theme in their lives, the realisation that other parents were also struggling with their children's behaviour was both a revelation and a huge relief to me.

It was the perfect time for me to have found an organisation that didn't judge me as a parent, but which had all kinds of information, tried and tested by people in similar circumstances, to help me and my family to cope. My sons were only 5 and 8 years old back then, and I realise now how lucky I was to have had this information so early on. Just knowing that despite what some people had suggested under their breath at supermarkets and play-groups, this wasn't about me and my partner being useless parents; no, the real cause of the strange and often dangerous behaviour we were experiencing was the degree of our sons' disabilities, and particularly their language and communication impairments. What eventually made the biggest difference for us as parents was recognising the triggers and reasons for behaviour, and changing how we interpreted and reacted to these alternative methods of communication. The journey out of a long, dark tunnel had begun, and although we are still learning more each day about how to communicate effectively with our younger son, we now have sufficient understanding about his needs, and the triggers to avoid, for us all to be living reasonably included lives within our local community.

Against this backdrop, it should be obvious that when I heard that the CBF was delivering joint training by parents and professionals, I was immediately interested. I have always believed that the earlier people get the information they need, the more likely it is that there will be a better outcome and a broader and deeper reach for that information – families in similar circumstances do talk to each other!

So when I heard they were looking for more trainers specifically to deliver training in schools, to parents and staff, I was even more keen to get involved. I applied at once but couldn't do the training dates due to family and work commitments, and then about 6 months later, another course was announced, and I was really pleased to be offered a place.

Arriving for the first 2-day training session, I wasn't sure what to expect, but I'd been reassured by the emails and conversations that I'd had with the CBF training staff prior to the actual training day. I had been sent a programme for the first 2 days and it was good to see that plenty of time had been allowed for people to find the venue, arrive, and settle in. The venue, a central London hotel, was pleasant, fairly easy to locate, and reception staff were welcoming and helpful. I was introduced to my fellow participants, and we made an interesting mix of family carers, professional workers, and CBF staff members.

The content of the first session focused on the background history and the ethos of the organisation, and understanding the basic principles behind the training. The initial introduction to the day was delivered by the Chief Executive of the CBF, Viv Cooper, who talked at a very personal level about her own experiences as a family carer, and the effects upon her family life. There followed a series of “train the trainer” workshop sessions, during which a pair of very experienced co-trainers demonstrated how to run the main workshop sessions. This format had the added benefits of ensuring that everyone re-visited the basic training in its most up-to-date version, and of giving everyone time to think about and discuss the content from our different perspectives. We were also given copies of the four CBF DVDs to use for further familiarisation, and we received advance warning of the homework assignment, which was to personalise and prepare a presentation on a pre-defined topic with an allocated training partner, and be ready to deliver it at the second session.

By the end of those first two days, I felt quite comfortable about discussing personal experiences with people in the classroom. Generally, I don't mind giving details about myself if asked, but sharing information about my boys with relative strangers has always felt very difficult, especially when they are not present. However throughout the training sessions, it was made clear that, as for all CBF training, the specifics of any information given by anyone during training would not be shared outside the classroom, aside from any potential safeguarding issue being disclosed.

I think I was surprised by how tired I was when I got home, but I really shouldn't have been - it was an intense couple of days, and having had good food and stimulating conversations with highly motivated people, my mind had been busily processing all manner of thoughts about the past, and ideas about the present and the future.

In between the training sessions, we were put in touch with our co-trainee/trainers and given the outlines of our presentations. It was really interesting to prepare some work with someone new, in quite an intensive way, and to do this via email and telephone! It was also incredibly useful though, in the sense that, certainly for me and my particular co-trainee, it required some very open and in-depth discussion, and I thought we quite quickly developed a trust and respect for each others' experiences and viewpoints. We had to decide how best to share the delivery of the information, who it might sound better from, and whether we needed to actively drive the discussions of the two case studies, or simply let the audience develop them naturally. It was a relief to get through the presentation, but also it felt like quite an achievement, given the limited time that was available to us for the preparation!

A month later, we gathered for the second session at the same venue, and there were a couple of additional trainees attending from a previous core training cohort. As before, we had been given a detailed schedule in advance, so we knew that for the first day, we would be taking turns to deliver our homework presentations in our parent-professional pairs. We had already asked the experienced trainers we'd met at the first session about how they approach working together, and our presentations illustrated that there is a lot of scope for different delivery styles and plenty of room for the nuances that can be used to suit different audiences.

On the final day, we had a workshop and discussion about reducing the use of physical interventions and medication, whilst recognising that occasionally, they may still be appropriate as a very last resort. We also covered safeguarding issues and responsibilities that may be encountered by trainers during training sessions, and how we should deal with them. There was a fairly brief presentation about how to deal with difficult or emotional conversations, how to offer support, and what effect group dynamics might have - understanding that every group is likely to be different. We heard about how trainers are supported by the CBF to prepare their personalised training materials, to practice with a co-trainer, and to deliver the first workshops and training days. We were also told about how the quality of our training sessions will be monitored to ensure that the training is being delivered consistently.

Finally, we discussed our options as trainers. The CBF offers all trainers the choice of working as volunteers, or on a seconded, casually-employed, or freelance basis. They also arrange Enhanced CRB checks, and provide an excellent handbook which covers all the essential aspects of working with the CBF.

In summary, I was impressed by the structure, content and quality of the training. On paper, it could possibly appear to be rather dry and serious, but thanks to the efforts of the CBF staff, and the very good humour of my fellow trainees, I thoroughly enjoyed each of the four days, and I came away feeling empowered and valued as a family carer and co-trainer.

Training Organiser: Challenging Behaviour Foundation

Jo Hough

Website: www.chanllengingbehaviour.org.uk
Email: info@thecbf.or.uk
Telephone: 01634838739

In conversation with Janet … about Kinship Care

There are somewhere between 200,000 - 300,000 kinship carers. A kinship carer may be any family member or close friend. The majority of Kinship Carers for children are Grandparents. People become a Kinship carer for many reasons.

PMLD Link interviewed Janet, Daniel's Grandmother and kinship carer.

To protect those involved names and some details in this interview have been changed.

Tell us about Daniel?

Daniel is an amazing kid - he is full of energy and life - in some ways too much. We call him the Kamikaze Kid. He loves moving around and reaching for things, pulling them down, putting things in his mouth - at nursery all the pictures are now mounted in the 'post Daniel position' - ie higher than Dan can reach! Although he whizzes around - his medical condition and profound learning disability mean he is in constant danger of dropping to the floor; he has severe epilepsy, no sense of danger, no spatial awareness and doesn't learn from his experiences. So we have to be constantly watchful.

He loves riding his special bike - he has this thanks to fundraising by my great friends and support network.

In many ways he is a great little boy, full of character, playfulness and a cheeky grin - we love him to bits - but he is also challenging.

How did you become a full-time kinship carer?

Phew that's a long story. WHERE TO BEGIN? His Mum, my daughter was a great child, never in trouble - always hard working, but she has a very rare genetic condition - phenylketonuria (PKU). It's a complex condition - that has to be strictly managed and monitored. People with PKU have to be on a strict diet - almost like a vegan diet - the body cannot cope with a lot of protein - if they have too much the brain takes a battering. In her late teens - it was harder for her to control, she wanted to do what everyone else did and she became a bit rebellious - we couldn't keep her in at 17,18. When she was 19 she fell pregnant and didn't tell anyone until she was 24 weeks. This is very dangerous for the unborn baby of someone with PKU.

She tried to look after Dan - but it was tough for her - maybe what she had already done in those couple of years had taken it's toll on her own health - it became increasingly difficult
To cut a long story short there was a string of broken promises, her not turning up to appointments for Dan– she was more and more unreliable. Things came to a head when Dan needed an operation.

That must have been tricky - how did you overcome the legal need for next of kin to give permission?

Technically in law we should have done something sooner because Dan was seeing doctors and we were making decisions - but I didn't know that. It was all very difficult and nobody really wanted to help. We weren't getting any good help or information - everybody wanted Beth, his Mum, to be involved - but really, given her needs, and the place she was in, unreliable, disappearing - it was so clear she wasn't able to support Dan and his very, very complex needs. That's what I feel angry about - leaving us and more importantly Dan in limbo. It wasn't what was best for Dan - it wasn't about Dan - it was about Beth and that's wrong. The operation meant they had to do something for Dan

How did you get legal responsibility for Dan?

With the support of my solicitor and later Kinship Carers we were fast tracked through the court to get a 'residents order' - so Dan could get his operation. Their website tells you all about the legal options - www.kinshipcarers.co.uk We cannot give anyone detailed legal advice - but we can point them in the right direction.

Tell me more about Kinship Carers
www.kinshipcarers.co.uk

Kinship Carers has saved my life. It is a group for kinship carers run by kinship carers. When you have someone like Dan, with such complex disabilities in your life it is easy to become isolated. I couldn't go to work and my husband had to reduce his working hours to help. It's not just that you miss work friendships, but you also don't have the money to do what everyone else does. My grandson can be difficult - not everyone welcomes him, even family, they don't always understand.

With our Kinship network, we can have a great time together - we try and find small pockets of money so we can have days out or go on holiday. It is fantastic for all the members of the family. Other children like brothers and sisters - or in my case my own child, who is only 11 herself, she can talk to other young people - she is not alone. At the same time we are doing normal things that keep you sane.

We have an annual 'Kinfest' and 'minifests'. Kinship Carers are a very tight, very supportive group, they are safe.

There are 8 administrators. We are all kinship carers and it is voluntary - we are 'the big society'! We have our website, anyone can assess it except the members bit.

Kinship Carers are a very tight, very supportive group, they are safe.

You emphasised the word 'safe' - can you tell us more about that?

We only want Kinship carers joining the members group - you can look and take part in all the other spaces on the site - but we wanted a safe bit where we could talk to each other without fear. Sometimes people are in very vulnerable places. Also we want to be in charge of our destiny; sometimes local authorities tell us how to run things, what we can campaign about. We are going to 'bug' lobby, our MP's next week - we don't want people telling us we don't need to do that - they will sort it out - they wont.

How do you fit in with other kinship groups?

We think it is really important to all pull together and we are working closely with other people such as Grandparents Plus and Family Rights Group. Both are really good at giving advice. We all want better things for Kinship Carers.

For more information:

Grandparents Plus
Grandparents Plus is the national charity which champions the vital role of grandparents and the wider family in children's lives. The charity estimates that 200,000 grandparents and other family members in the UK are raising a child full-time because of a range of difficult family circumstances, including parental death, disability, drug or alcohol abuse, imprisonment and domestic violence.

With the support of the Big Lottery Fund, the charity supports these family and friends carers through their Grandparents Raising Grandchildren Network. The Network puts members in touch with each other so they feel less isolated. They hold events around the country to provide advice and support and to give members a voice. They also produce a quarterly newsletter full of advice, information and personal stories.

To join the network, email Grandparents Plus info@grandparentsplus.org.uk.
They provide information and advice on a range of issues including welfare benefits and financial support, employment rights, legal orders and education. The telephone number is 0300 123 7015 and lines are open from 10am – 3pm Mon to Fri, or you can email advice@grandparentsplus.org.uk.

More information about :

PKU www.pku.com or www.nhschoicespku There is now a drug available in most European countries and some English Health Services - Kuvan –

Solicitor Oliver Wright - who specialises in judicial review has challenged Derbyshire PCT to provide the drug to a young person. The PCT agreed to give the drug to this person before the case went to court. Oliver Wright works for Lewis Hymanson and Small LLP.

Fostering Emily … 'Peter' and 'Pat' look back on 30 years of family life with Emily

[All names have been changed in this article]

Emily was born to an unmarried teenage mother 46 years ago. Her birth was natural and apparently uncomplicated but at 2 days old Emily contracted meningitis. This left her brain damaged and epileptic. She has never spoken, has the ability of a 2 year old and is also physically handicapped.

46 years ago the stigma of an illegitimate child born to a young mother was very difficult but to this mother the acute awareness of having a child that was physically and mentally handicapped was perhaps just too much to handle, so much so that Emily came under the care of the local authority.

The first 14 years of her life were spent in a local hospital. She was not visited by her mother in that time. At the age of 14 Emily's plight at having been in hospital so long was recognised by an astute employee of the local authority who fought tirelessly to bring Emily, and likeminded children, out of an ''institution'' and into a more caring environment, a children's home.

Emily came out of hospital with what one employee described as having ''prison pallor''. For 2 years she was gradually introduced to having some of life's basics , such as a holiday, listening to music, having an ice cream, being surrounded by people who wanted to improve the quality of her life. This was not an easy transition for Emily. The local authority wanted to integrate Emily and her peers into the community through fostering but sadly Emily was classed as being ''ugly and unfosterable'' due to her mental and physical handicaps. Was this child destined to live in a children's home for the rest of her life?

Peter and Pat had 2 children of their own, Jack 6 and Oliver 4. Peter was a teacher and Pat a housewife. They belonged to their local church and had thought for some time about wanting to foster, but to foster a child with a handicap. They had seen an advertisement regarding fostering in their local paper and this gave them the push to put themselves and their family into applying to foster. After several weeks of form filling, phone calls and letters they came face to face with the local authority employee who would over the next 12 months assess the whole family as to their suitability for this demanding role. The questions were never ending as to the life style of the family, what rules and disciplines were in place? What qualities did they have to be foster parents? Were they taking too much on? These were reasonable questions to ask. If any of their own children had to be fostered for any reason, Pat and Peter would have wanted the foster carers to have been fully vetted.

After 6 months Pat went to a meeting at the children's home where Emily lived. Pat saw this 15 year old physically and mentally handicapped teenager for the first time, and they were introduced to one another (the local authority had ear-marked Emily to be fostered by Pat and Peter and their boys). Emily had no "social skills" but did know how to remove Pat's cup of tea from her hand and drink it! This was a trait she would continue to the present day.

Finally the day came when all the family went to meet Emily, instantly they knew Emily was the one they wanted to foster and from that day their lives changed. Emily began visits to the family home. Initially short visits followed by longer stays increasing to weekends until the day came when they were told "We feel the time has come for Emily to live with you permanently" It had been a full 12months from their initial enquiry to them going "live."

With anxiety and trepidation the journey had begun. Many human emotions were to be experienced over the next 30 years.   Emily was expected to have a life span of about 25 years. She is now 46! She came to the family very institutionalised, and had never been upstairs in a house. Pat and Peter had been told that any behaviour could be expected from Emily! This was to be born out in Emily tearing wallpaper off her bedroom wall on a frequent basis, tearing up homework the boys had done, tearing up the odd £20 note left unattended and blocking the toilet up by putting the loo roll down it! Eating habits included eating well one day and abstaining from food the next! She could have a “Sunday roast” put in front of her, only for her to push it away, but on being offered some chocolate, she would devour it RAPIDLY. These traits are still going strong to the present day.

In the 30 years, she has, on the plus side, developed her own identity. She doesn’t do anything she doesn’t want to do! She has a mind of her own. Emily is treated exactly as one of the family. The boys love her as much today as they did 30 years ago! Whenever they ring the family home Emily is the one they want to know about. The parents are an after thought! As a family they have shared many joys, seeing Emily open Christmas presents, going swimming, horse riding and listening to music - Widor being a favourite. But they have also shared in the sorrows, such as waiting around a hospital bed for Emily to awake from an epileptic seizure, which always left her without sight for a few days. The worst was 4 weeks before her sight returned.

Emily will always have the ability of a 2 year old, enjoying all that a 2 year old enjoys, but never progressing. Emily puts very little effort into anything she does and only has a very brief concentration span. Despite this, she does have certificates of achievement in Horticulture, Cookery and Independence.

Emily is a very special member of the family. It is a huge commitment to take on a “handicapped child/adult” and is not always easy. There are many sacrifices to be made when you are a foster parent. You can’t phone in “sick” and say ‘I can’t come in today I don’t feel well’, you just have to get on with it. Fortunately Emily does go to a Day Centre for a few hours 5 days a week, which helps. By being part of a family Emily has had a better quality of life and has enriched Pat, Peter, Jack and Oliver beyond their wildest dreams.

For information purposes, fostering ceases at the age of 18. The terminology for above 18 is now called ‘Shared Lives’.

New resources to help children with complex health needs live *"An Ordinary Life"*

Jill Davies

As part of the charity's *An Ordinary Life** project, the Foundation for People with Learning Disabilities (FPLD) recently launched a free interactive booklet and communication passport to help families transform the quality of life for their child with complex health needs or who is dependent on medical technology to survive.

This is about children and young people who are like Mitchell. Mitchell has brain abnormalities, epilepsy, visual impairment and he also hypo-ventilates which means that he under-breathes. To support his complex health needs, he needs oxygen 24-hours a day to help with his breathing and he has a gastrostomy to feed him because he has trouble with his swallowing. **Mitchell's mother Jo Fitzgerald, says**: *"I became frustrated by the bureaucracy and lack of flexibility in the support that Mitchell was receiving. To me, it made sense for Mitchell to be central to the decision-making, so I realised something had to change."*

It is estimated that over 6,000 children in the UK** have complex health needs; these are children who are disabled, may have special educational needs and/or life-limiting conditions. While their medical needs are often well attended to, their social, emotional and developmental needs are not prioritised. This group of children is growing as increasing numbers are surviving in to adulthood thanks to improved healthcare and the use of medical technology. There is now a group of children and young people who require very individual and family-centred support to ensure that they can make the most out of life – even the simple things so many of us take for granted.

The FPLD's booklet, *An Ordinary Life*, has been designed to help families make sure their child is at the heart of their own care. Thirteen families with children who have complex health care needs were interviewed, in addition to health and social care professionals, to identify the barriers that families face when trying to get the right support for their child. The booklet addresses these issues, which include education, transition, emergency planning and knowing your rights, and signposts families to more information and helpful services.

The charity also launches an interactive communication passport, *A Book About Me*, which can be completed to contain personal information about the child's needs, medical conditions, likes and dislikes, in order to help new people, such as health professionals, better understand the child's needs. We know how essential communication passports can be, as illustrated by the tragic death of Martin Ryan, who had Down's syndrome and epilepsy and died as a result of hospital staff not feeding him for 26 days as they didn't know how to***.

Mitchell was one of the first people in the UK to have a personal health budget. Jo Fitzgerald, Mitchell's mother, talks about how it's changed their lives:

"The first hurdle we faced was getting the confidence to challenge the system – I was very scared of rocking the boat, worried that by drawing attention to ourselves that we would actually end up worse off.

We'd been managing a small direct payment over a period of time and realised what could actually be possible – that we could organise the staff, train them, and expand that experience in to a wider, more tailored package for Mitchell. It was clear that this had never been done before, but our PCT was committed to making it work. Things have changed dramatically for Mitchell. We're trying to give him a good life and keep him well. His personal health budget has given us a lot more freedom as a family and we can do things that we couldn't do before."

Children with complex and severe health needs still have the same 'ordinary' wishes and needs as other children – what matters most to them is being able to live at home, go to school, spend time with friends and take part in leisure activities with their family and peers. And this is also important for their families.

To try and achieve as ordinary a life as possible, families constantly fight for the best care for their child, and this is where we hope our resources can make a difference. The parents we have spoken to say that they had to break down many barriers to achieve better outcomes for their child, including getting their house adapted to suit the child's needs, getting better information about what individualised funding for health and social care can be used for, managing the transition from children to adult services and finding out about the benefits of employing your own team of support workers.

Our resources hope to support the family as a whole by providing them with more information to develop a personalised, holistic package of support which will ultimately improve their quality of life.

The FPLD's *An Ordinary Life* project aims to improve the quality of services to children who need long-term care and their families through supporting families to develop individual, personalised, and person-centred planning solutions. This is a three-year project funded by the Department of Health. The next stage of the project will see ideas for practical action from the *An Ordinary Life* booklet piloted in five areas of England with the aim to produce good practice guidance at the conclusion of the project in March 2014.

Information about:
The booklet *An Ordinary Life* and the communication passport *A Book About Me* are on page 42.

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*** About *An Ordinary Life***
An Ordinary Life is a three year project funded by the Department of Health and run by the Foundation for People with Learning Disabilities. Its aim is to inform families who have a child with complex health needs or who is dependent on medical technology about the ways they can seek support to lead as ordinary a life as possible.
www.learningdisabilities.org.uk/our-work/changing-service-delivery/an-ordinary-life/

**** 6,000 children in the UK have complex health needs**
The prevalence of this group of children is unknown in the UK, however research by Sue Kirk (1999) cited approximately 6,000 children, most of whom are under two years of age.

***** Martin Ryan**
More information on Martin Ryan's death can be accessed here: www.guardian.co.uk/society/2009/mar/24/neglect-nhs-learning-disabilities

For my Daughter

And you Suzie, what should I leave you?
Not the pewter statue of the boy
his right hand missing,
let him stay on the mantelpiece
for the second hand dealers.
Not photos of my mother who died
before you were born into that grieving time.
Not money, to be banked for you
by someone else.
Not my poems, you'll never read them.
But the very fiercest of watchdogs
who wouldn't sleep for a hundred years.

Jo Roach

Constantine D & O'Donoghue [2007] Oxford Poets: An Anthology 2007 Carcanet Press

To read more of my work http://www.poetrypf.co.uk/joroachpage.html

Making Sure Your Relative is Safe

The National Family Carer Network (NFCN) and Hft (a national charity creatively supporting people with learning disabilities) launched Safeguarding resources for family carers on their websites www.familycarers.org.uk/safeguarding and www.hft.org.uk/safeguarding during Carers' Week and Learning Disability Week (18 – 24 June).

The National Family Carer Network's Making Sure Your Relative is Safe resources respond to an urgent need for information about safeguarding that address the concerns of family carers of adults with learning disabilities. The two publications launched this week were produced by the NFCN in collaboration with a number of organisations working in learning disabilities or with family carers; they are funded by Hft.

- The 'Top Tips' is a 4 page briefing, based on the views of family carers, that provides suggestions about preventing harm from happening in the first place and what you can do if things go wrong.

- The 'Essential Guide' is a 16 page booklet covering some of the key terms you may come across in relation to safeguarding and suggests what you can do to keep your relative safe and how to act if they have been harmed.

A Resource Pack (including useful examples of good practice around safeguarding, supported by film clips featuring people's stories), produced by Hft, will follow in the Autumn.

The current wealth of information about safeguarding is often complex and technical, written to meet the needs of health and social care professionals. It can take a partial view of the role of family carers, with an emphasis upon families as perpetrators of abuse, while very little is written about the wider context of prevention and awareness-raising.

Since the revelations of abuse at Winterbourne View, more attention has been drawn to the active involvement of family carers in planning and decision-making and, more formally, through inspections and quality checking. Families also have a key role to play in positive risk management to enable their disabled relatives to benefit from developments in self-directed support and personalisation.

The availability of clear and accessible information about the services that exist and what they can offer has been found to reduce stress and isolation, two key factors associated with abuse by family carers. Moreover, family carers should be offered support when suspected or alleged abuse is reported in good faith and their views and opinions taken into consideration. They also have the right to be kept informed of the processes and outcomes where it does not conflict with the proper investigation of incidents or the best interests of the alleged victim.

For more information contact:

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email: info@familycarers.org.uk or t: 07747 460727

Robina Mallett at the Family Carer Support Service, Hft:
email: Robina.mallett@hft.org.uk
tel: 0117 9061700

To sign up for the NFCN Weekly Bulletin: e-mail info@familycarers.org.uk

The National Family Carer Network links groups and organisations that support families which include an adult with a learning disability. The Network was registered as a charity in 2008, after being set up and run by Hft's Family Carer Support Service as a 3 year Department of Health funded project (2004 – 2007).

National Family Carer Network

Linking groups and organisations that support families that include an adult with a learning disability

Friday is my favourite day

Antonia Martinez

My name is Antonia and I go to Marlborough Park Special School in Sidcup. Because I will be leaving soon my week is very different to my friends. On Monday I have a carer. Tuesday and Wednesday I go to school. I like Wednesdays the best because I help a teacher called Corrinia and then in the afternoon I help in Reception. I even broke the shredder! I like pressing the button to open the gate to let my Mum or Nan in at home time.

Friday is my favourite day when I go to see my friends Donna and Kelly. They live in a home and are always in their wheelchairs. Donna can't eat but Kelly can. When I get there, one of the residents will come to open the door with staff. I try to guess who it will be. The first person I look for is Kelly to give her a hug. Kelly will blink her eyes when she sees me and smiles and I know she is happy.

When I am there I do lots of different things. I talk to Kelly, help them if they are making cakes. The other week it was really sunny and hot so we went into the garden. Kelly let me put sun cream on her legs and arms. Donna is usually last to come downstairs. She wears very pretty necklaces and earrings and I bought her one for her birthday. Donna invited me to her birthday party and we all had to wear tiaras. I was in charge of the music because I like doing things like that. Every time I go there we have a singing session which makes them all really happy.

I like helping to feed Kelly but she eats very quick so I need staff to help me. At Christmas the manager asked me to sort all the music for the Christmas party. My mum helped me at home on the computer and every person had a line of Twelve Days of Christmas to do with their families.

I am really pleased my mum lets me visit there every week because they are my friends and I miss it if I don't go. I think they miss me as well.

Using storytelling to develop friendship and participation

Nicola Grove, Cindy Moxham, Katy Gunning & Jane Harwood

'I can't remember other occasions when service users have willingly sat together – so unusual. It's really exciting! I wouldn't have believed it! It surprised me.' (Staff Member on the Storysharing in Somerset programme)

Openstorytellers is a charity which seeks to promote a strong sense of identity, secure relationships and social participation through the use of story.

We do this through the telling of legends and traditional tales which we link to the lives of the audience and the narrators – who have learning disabilities themselves – but we also focus on the ways in which we develop friendship through the sharing of experience in personal anecdotes. This conversational type of storytelling is often overlooked and tends to emerge fortuitously and fleetingly in interactions: however, we have found that it is possible to teach strategies of collaborative telling to people with severe and profound disabilities, and to their families and the professionals who work with them. The technique, StorysharingTM, involves a simple process of supported narrative, whereby the communication partner takes responsibility for recalling the events, and makes space for the person with a disability to contribute in whatever way they are able, often through a basic voice output communication aid, or showing key objects. Through telling, a sense of community develops, and people are enabled to take ownership of their personal histories. In this short article, we describe some of the projects undertaken by the charity, which is based in Frome in Somerset.

Storysharing projects

We have now come to the end of two 3 year programmes With Mencap's Involve Me nationwide project, in Salisbury in Wiltshire, we worked in three homes with around 10 people with profound disabilities, and a wider group of fellow tenants. We focused on building up the ability of tenants to share stories about their own lives, and towards the end using their experiences to lobby their local MP against the proposed removal of mobility allowance. The group used storysharing, with the aid of a VOCA, to tell the MP where they went with the money and what it meant to them. He supported their case, and as we know, this sustained campaigning won a reprieve

In Somerset, we worked in nine homes with a core of 65 individuals and around 40 staff, to set up weekly sessions for sharing experiences. The projects developed in ways we had never imagined, into tenants meetings and the use of traditional stories to solve social problems between tenants.

Storysharing in school

This new three year project involves children with a range of complex needs, including those with PMLDs, who come together once a week to review what has been happening in school and at home, and share it with their friends. A new focus for us has been on stories to take to transition meetings, which reflect the achievements, hopes and dreams of the young people. After a slow start, stories are pouring in from home, and the class are having to create a much larger book than they started with. We are developing a group of peer mentors who will work with younger children to support them in storytelling; our leavers group will be looking towards taking their skills out into the community to make their ideas heard in local decision making fora.

Friends Meet Up is a monthly creative arts group for 15-25 year olds, which offers a safe place to meet in a community venue. Around 35 young people, about seven of whom have profound disabilitites, use the service, with a core of around 20 who come regularly. FMU Live grew out of a friendship course that Openstorytellers ran in Mendip for young people called How 2B Friends. This was targeted at vulnerable young people who found it difficult to negotiate social relationships – at the end of the course they wanted to carry on meeting and extend the group.

Friendship Skittles group

Within Frome itself, we have a large population of people with learning disabilities, who remain very isolated in the community. The Friendship skittles group is run co-operatively, involving around 30 people, some of whom do not have learning disabilities, but are isolated for other reasons. The project started by trying to integrate people with learning disabilities into existing groups, but they quickly let us know that they wanted something of their own. Their reasoning is of interest, we think, to anyone trying to develop inclusive approaches. The group, about five of whom have profound disabilities, like the early start (5-7.30), the fact that they can get home before its too late, the meal is included in the price, and the venue stays the same. Those who tried the existing pub skittles group found it hard to commit, did not really want to travel to other venues, and also, it felt like a pressure to conform. Now we have confident people who are wanting to start a craft group, and a film club!

What have we learned?

- Transport is a huge issue, just getting to have a cup of tea with someone can be very hard.
- People don't have the facility to pop in to each other's homes, they tend to meet in public places. Residential homes don't have spare rooms, so you can't have your friends to stay
- We had started with wanting to enable people to join existing groups – but that was our agenda, and people had their own views about what they needed
- It's important to make the group open to everyone – we've now got a wide range of people attending
- It takes time and confidence to develop a sense of ownership, the group still need support in the background.
- When working with people who have PMLDs, having others in the group who are verbal makes it easier to involve and engage them – they see their peers interacting and listening to them, the peers often voice in response or for their friends who are nonverbal, and it creates a lively dynamic.
- In schools, it can be hard for staff to move away from a curriculum focus where the emphasis is on eliciting facts rather than experiences, but when they have the permission to do so, they are hugely creative. The kids seem to get the idea straightaway!

We are really grateful to all the funders for our different friendship projects:

The Renton Foundation, via National Mencap; Somerset Partnership Board; Paul Hamlyn Foundation; the Rayne Foundation; Arts Council England; Youth Music; Frome Lions, Frome Carnival, Frome Mencap; the Woodlanders and many other local funders who have supported our work in the past.

Cindy Moxham is the Director of Openstorytellers, Katy Gunning is Friendship Co-ordinator, Jane Harwood runs Storysharing projects, and Nicola Grove is Chair of Trustees

Reports on projects can be found at:
http://www.openstorytellers.org.uk/pages/storysharing_final_report.pdf
and www.mencap.org.uk/involveme

Openstorytellers is running a course in StorysharingTM on September 20th 2012, which will be co-tutored by people with severe and profound disabilities.
For details please see our website:
www.openstorytellers.org.uk

Using Storytelling to Support Children and Adults with Special Needs: Transforming lives through telling tales - a new book edited by Nicola Grove will be published by Taylor and Francis in November 2012.

This is the first publication to provide a comprehensive overview of the wide range of approaches to storytelling in the field of special needs and disability. It consists of contributions by established practitioners who outline their approach, their rationale, and the evidence they use to develop their work, and is designed to be readable for both professionals and families.

Contact Details

www.openstorytellers.org.uk

Alice’s Friends

Wendy Newby

As a teacher of a class of pupils with PMLD, I have long since realised how important friendships, relationships and interactions are for my pupils. This is not always easy when they have PMLD, which involves complex physical needs and in some cases, sensory impairments. This article is a collection of my musings about how I strive to encourage these friendships from the perspective of one of my pupils.

The hustle and bustle of the classroom is at its greatest within the first half hour of the school day with pupils arriving, coats being taken off, postural management positioning being catered for, the register being done and ‘good mornings’ being said. In the middle of this Alice is clapping her hands and shouting her usual greeting ‘hey! …. hey! …hey!’.

My teaching assistants and I truly believe in a responsive environment and feel it is essential to respond to this, allowing Alice confirmation and recognition of those around her. Our responses to her vary from “good morning Alice” to an imitation of her sound. It also includes the use of touch. We touch her hand and she takes it, turns it over and claps our hands in the same rhythm as hers. This touch and auditory feedback to her greeting is essential as Alice is blind. You might think this is all very well, but is this friendship as it is with an adult? We perceive there is mutual pleasure, trust, and acceptance and it is an interaction that is sought after by both parties. It is one of the highlights of my day! So, to me, it is friendship.

Alice uses a variety of vocalization that has developed and been encouraged using intensive interaction techniques over many years. This has led to Alice being able to turn take. This is significant within the class as Alice has a friend called Emma, another pupil in our class. From September I have noticed that when Alice vocalizes Emma very often smiles and looks towards her. Throughout the year this has been nurtured by making sure they are have the chance to sit next to each other and join in paired, grouped and class activities. Emma will occasionally join in with Alice and they have begun to independently take turns vocally. They are, in fact, beginning to become the ‘class chatterboxes’. Enabling this is really important and has resulted in social activities being an integral part of my curriculum design. Every opportunity is taken to develop these skills in a wide range of mutually enjoyable experiences. Both Alice and Emma enjoy the resonance board, or what we call ‘Clonker’ board activities. While sitting together around the board, we sing and take in turns to experience rhythmic touch. The girls get very chatty during these sessions and Alice quite often will reach for the hand of the person sat next to her. So if Emma is within distance they are able to experience the feel of each other’s hand. Music is a fantastic medium for Alice as she loves to join in with Tim, another pupil, to bang beats on a drum, shake bells and maracas. They often create a cacophony of noise between them. The pleasure of this is always evident on their faces.

Quite incredibly, even considering her physical disabilities, Alice can swim independently. Her aquatic therapy session is an incredibly social time. She loves to splash, to swim with her support worker and especially loves the Jacuzzi! Her ability to turn-take has led to this being great fun for all. She giggles, laughs and shouts whilst splashing and will pause to be splashed back and responded to. The fact that this is such a special time is evident from the expression on the face of the teaching assistant that supports Alice within this session. “We have had great fun!" is often her response. Alice is very motivated by water. These are just a few experiences where I feel Alice really does have friends.

To be able to provide experiences such as these, I believe it is of great importance that we start with the unique likes of individuals: what they show enjoyment from and let them take the lead. We have a great sense of fun in our class and both the teaching assistants and I have immense enjoyment from the responses and feedback the pupils give us and to each other. We are quite often seen doing the silliest of things! I am very fortunate because the teaching assistants within my class, have a wealth of experience and are both creative and imaginative. This really helps when faced with finding ways for the pupils to have the close proximity to be able to respond to each other. Being close together builds up the familiarity such as that between Alice and Emma. I have developed a curriculum that allows a flexibility to enable us to be reactive to responses as they occur. It is a developmental curriculum where leisure and social time are of paramount importance. It requires time, the bravery to be patient and the ability sometimes to stand back and give the pupils time to respond to each other. This requires flexibility within the class and I quite often have to throw my planning in the air! This is not possible in a 'traditional' lesson structure, so I have stepped away from that, as I have the conviction that what I am doing is a positive move.

To help Alice develop relationships and friendships is a challenge. I do not think there is a one method fits all, a how-to guide or even a solution because everyone is very different. We are all idiosyncratic. However, that does not mean I will stop trying because every minute is worth it when you get responses like those of Alice!

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Vol. 24 No. 2 Issue 72

PMLD LINK
sharing ideas and information

Analysing Stories of Friendship and Adults with PMLD

Rachel Parry Hughes

This issue of PMLD Link is full of compelling stories of people with PMLD and their friends. In this article, I take a step back and ask what do stories like these do?

In the Spring 2011 issue of PMLD Link I explained the background to my PhD research project, the Friendship Matters Study, and outlined the data collection work which was then in progress. This work resulted in a rich trove of stories of adults with PMLD and their friends; stories much like those which feature in this issue of PMLD Link. As part of my analysis of these stories, I have looked at them and asked what do these stories do?

The Power of Stories

The idea that stories do things is perhaps not a common idea. If we think of stories as doing anything, it is a neutral act: the act of transmitting reality. Indeed, stories like those I collected and those in this issue of PMLD Link are sometimes called 'real life stories'. I would argue that these stories are far from neutral. No story can capture experiential reality. Stories are inevitably selective. Rather than simply transmitting reality, they shape it.

Stories told to a researcher asking about people with PMLD or written for a PMLD journal shape the category 'people with PMLD'. This category is a comparative one. One version of it divides us from people with PMLD while another binds us.

What stories do often has little to do with the intentions of the people who tell them. The stories we tell are never entirely or even mostly our own, although this is how we experience them. But we may be able to make them more our own by becoming aware of what they do, why they do what they do and what other possible stories we might tell.

Social participation stories

In the rest of this article, I am going to discuss two kinds of stories of adults with PMLD and their friends and how they shape the category of 'people with PMLD': social participation stories and connectedness stories. In social participation stories, adults with PMLD and their friends share socially-valued identities, participate together in socially-valued activities, and communicate using conventional means. For example, they are described as: old schoolmates, girly girls or techie lads; as going to the pub; and as talking on the phone and engaging in online social networking. Social participation stories are stories of ordinary people doing ordinary things together or sometimes, as the extract below illustrates, of extraordinary people doing extraordinary things together but never of odd people doing odd things together. The extract below comes from my correspondence with Christine, mother of Ed, who has PMLD, and tells the story of his friendship with Jonathan, another man with learning disabilities.

It's Ed's birthday today Rachel where do the years go?! Celebrating from today through the weekend with friends and then off to _shire […] to meet up with a newly rediscovered friend who is a registered clown so we are all going to the clown convention! […] Ed has just been to Jonathan's birthday party with a clown theme! He has met up with other ex-school friends that Jonathan, through Karen his mum, has maintained contact with. [...] [Karen] really is a kindred soul who I look forward to sharing time with. We both think the guys have things to offer each other – also from their shared interests -- both love clowns circus […], tools and swimming and music and eating etc!

The extract also illustrates another characteristic feature of social participation stories: the inclusion of third parties as characters in the stories. In this case, the third parties are Karen and Christine, the men's mothers. But having mothers around may be seen to be at odds with being 'ordinary people doing ordinary things together'. Are people with PMLD really ordinary? Are they really doing ordinary things or is it actually mother (or father or care worker)? These were questions raised by some of the professional participants in my study.

Connectedness stories

In connectedness stories, one element in the plot of social participation stories serves as the whole plot. That element is connectedness or *"that feeling...that we* *feel the same".* Moments of connectedness constitute the beginning, ending and high-point of these stories. The story which Nina, a day centre worker, told me about the friendship between two men with PMLD, Mark and Ashok, illustrates this.

Mark and Ashok, they're definitely friends – they swap spit.

What Nina's brief story refers to is a habitual sequence of interaction between Mark and Ashok centred on the silvery strings of saliva which frequently dangle from Mark's chin. What goes on between Mark and Ashok is something very intimate. However, friendship-as-spit-swapping is not, I suggest, friendship as we know it in our modern Western culture. When I have shared this story with people who do not know adults with PMLD, they have reacted to it as a case of 'odd people doing odd things together'. This is friendship stripped of the social practices which usually signal 'friendship' to onlookers - the social practices which are so prominent in social participation stories.

The strangeness of connectedness stories may make it harder for outsiders to the world of PMLD to hear connectedness stories as stories of friendship. Indeed some 'insiders' seemed to struggle with this. The extract below comes from an interview I did with Kerry, the leader of a social club for adults with learning disabilities. It is a story about two adults with PMLD which she told when I asked her about friendships between club members.

He's a noisy sod but he does like a bit of a sing and that, so, um, between him and Clarrie making their noises you often got sort of the odd interact- they were just sort of looking at each other and you're thinking 'what are they doing?' Cos both of them are non-verbal so neither of them spoke and you thought, oh what's going on here then? You know, it's a bit of a blossoming relationship or something […] you know, he knows that she's there because her wheelchair's there or she knows that he's there because she can hear him and his noise. She might be thinking, 'oh Christ please shut up!' But they, they seem to, you know, react to each other, even if it's just for an instant.

Kerry feels that there is something significant going on between Clarrie and the unnamed man but she isn't sure how to categorise it. She breaks off from calling it an interaction and she qualifies her claim that it's a "blossoming relationship" with "or something". What she does know is that there is an "instant" when Clarrie and the man react to each other – a moment of connectedness.

A significant difference between connectedness stories and social participation stories is that connectedness stories show adults with PMLD connecting with their friends without third party involvement. Connectedness stories thus posit an idea of 'people with PMLD' as people as equally able to connect with others as the rest of us, even while they may be incapable of doing many of the things which we traditionally think friends do. They may be stories of stripped-down friendship but for some they are *"friendship stripped-to-its-essentials".*

An everyday epiphany

So far I have discussed two kinds of stories of people with PMLD and their friends, both equally compelling in my view. They each shape the category of 'people with PMLD' in particular ways and consequently they have their own particular strengths and limitations when set in the context of outsiders' expectations of what it means to be a person and a friend.

I want to finish by discussing a story which is a hybrid of these two kinds. This story draws upon the strengths of both connectedness stories and social participation stories while avoiding their limitations. In the plot of this story, a moment of connectedness arises in the context of a socially-valued activity. It is an epiphany of an everyday sort. I reproduce an extract from the story below, as it was told to me by Matt, friend of Sonia, a woman with PMLD.

Rachel: You mentioned about some things that are similar about your relationship with Sonia compared with other friendships. I think you said mutual…um, what did you say? About cooking or was it mutual interests or…
Matt: Enjoyment.
Rachel: Yeah, mutual enjoyment, that's right [...]
Matt: Well, yeah, for example, I remember one visit, particularly one time I was making food but it was a little bit late so I was hungry and I just had a little nibble of some cheese that was in the fridge and that was some gorgonzola, some blue cheese and I just gave her a little taste as well and she did- like, her face just lit up and…
Rachel: Oh wow (laughs).
Matt: …to see her reaction to this new flavour and I guess it's not the sort of thing she has regularly.
Rachel: No.
Matt: She really enjoyed it, so little moments like that I think are really, you know, that's what I really enjoy about our relationship.

In this story, a moment of connectedness occurs during the everyday activity of cooking. Matt spontaneously gives Sonia a taste of blue cheese and sees her face light up. At this point, both Matt and Sonia feel pleasure. For Matt, the pleasure is at several levels. It is pleasure in blue cheese, pleasure in Sonia and pleasure in mutuality *("that feeling…that we feel the same").* For Sonia, the pleasure is in the new sensation on her tongue. Nothing more is claimed of Sonia in this story. The power of the story does not lie in a demonstration of Sonia's abilities. Rather, it is powerful because this 'everyday epiphany' is one that most people could imagine experiencing themselves.

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Acknowledgments

Many thanks to the adults with PMLD, family members, friends, care workers, professionals and other who have helped me with the research. My PhD study is supervised by Dr Marcus Redley and Dr Howard Ring of the Cambridge Intellectual and Developmental Disabilities Research Group and funded by the SHI Foundation, the Health Foundation and the NIHR CLAHRC for Cambridgeshire and Peterborough. Thanks to all these individuals and organisations for their help.

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The Family Fund

Rob Ashdown

In this period when everybody appears to be cash-strapped, it is important to remember that there are people and organisations out there who do a lot to make people's lives more bearable. One such organisation is the Family Fund which is a registered charity covering the whole of the UK and mainly funded by the national governments of England, Northern Ireland, Scotland and Wales. It provides practical help to families with severely disabled children under the age of 16. The information that follows here is taken from the charity's website http://www.familyfund.org.uk. Do go online to view it.

The Family Fund supports families by providing grants that help to meet the need of their disabled child. In 2011-12, the Fund distributed over £33 million to over 59,000 families. You too can apply to the Family Fund if you live in England, Northern Ireland, Scotland or Wales and you have evidence of your entitlement to one the following: Child Tax Credit, Working Tax Credit, Income based Job Seekers Allowance, Income Support, Incapacity Benefit, Employment Support Allowance, Housing Benefit and Pension Credit. If you do not receive any of the above, further information may be needed to complete your application.

Help from the Family Fund is discretionary and subject to available funding. The Fund is unable to help children in local authority care, including those living with foster carers. Where a statutory agency has a responsibility to pay for the item needed, the Fund cannot help.

Most parents and carers of children with PMLD are likely to be eligible for support from the Family Fund. There must be evidence that their additional needs impact on a family's choices and their opportunity to enjoy ordinary life. If you think your child or young person may meet the Fund's criteria, do consider making an application. Even if you are in doubt as to whether your child is eligible, still apply.

The Family Fund website contains vignettes about how support has been made available to a range of children who are severely disabled. For instance, Alex's grandmother, who is his special guardian, received a grant for sensory stimulation equipment and a fridge-freezer with space for the special food Alex needs. As Alex's grandmother says, *"All of these are not luxuries but necessities for us. We couldn't manage without them."*

Contact details:
Family Fund
4 Alpha Court
Monks Cross Drive
York
YO32 9WN

Email info@familyfund.org.uk
Tel 08449 744 099
Textphone 01904 658085
Fax 01904 652625

The 2012 Holiday Information Guide from the Hft's Family Carer Support Services is here!

This free guide is designed for people with learning disabilities and their families, but many support staff also request copies.

This year's edition has 48 pages and includes sections on:

- Useful advice
- General Guides
- Tour Operators
- Places to stay – UK
- Meeting specialist health needs
- Places to stay – abroad
- Special interest holidays
- Benefits and help
- Insurance
- The Family Carer Support Service

The guide can be downloaded at:

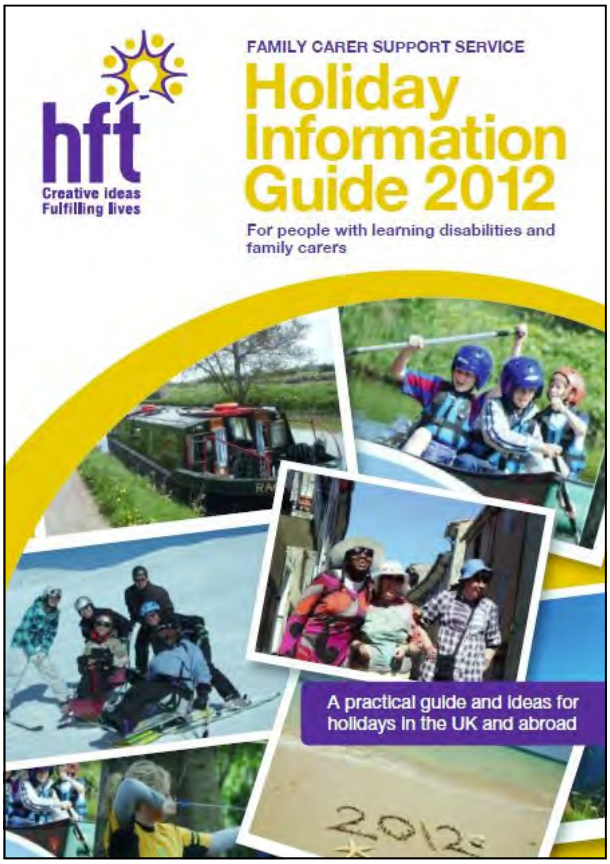
www.hft.org.uk/holidayinformationguide

Or to request a paper copy:
Hft/ FCSS,
5/6 Brook Office Park,
Folly Brook Road,
Emersons Green,
Bristol,
BS16 7FL

Please send an A4 self-addressed envelope, with appropriate postage to the address below. [Each guide weighs 158 grams. 1 x guide = £1.20 first class / £1.10 second class.]

If you would like multiple copies please calculate the postage cost by the number of requested guides and their combined weight. Please contact us if you would like more than 4 guides at:

Telephone: 0117 907 1751
Email: familycarersupport@hft.org.uk



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FAMILY CARER SUPPORT SERVICE

Holiday Information Guide 2012

For people with learning disabilities and family carers

A practical guide and ideas for holidays in the UK and abroad

PMLD LINK
sharing ideas and information

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The Government’s Green Paper on Special Educational Needs and Disability - Progress and Next Steps

Rob Ashdown

On 15th May, Sarah Teather, the minister for children and families, presented the government's formal response to the outcomes of a public consultation on its 2011 green paper Support and Aspiration: A New Approach to Special Educational Needs and Disability. This green paper had set out proposals for radically reforming the current system for identifying, assessing and supporting children and young people who are disabled or have special educational needs (SEN) and their families.

The latest document confirms the government intention to introduce new measures that would force education, health and social care services to plan provision for children together and involve the parents and children wherever possible. Sarah Teather describes this as the biggest reform of SEN provision for 30 years. The claim appears justified when you read parallel proposals on reforms of funding for ‘high needs pupils’, who will certainly include children and young people with PMLD. These reforms will hugely change the way that local authorities and education providers (special schools and other specialist settings) are funded. Moreover, parents in England are to be given by 2014 the option of exercising control over their child’s education, health and social care budgets and this could well give them the power to select provision of their own choice.

The proposed legislation was announced in the Queen's speech to the House of Parliament in May and a children and families bill to enact this will be introduced in the Autumn. Significantly, statements of SEN and separate learning difficulty assessments for young people over 16 years are to be replaced with a single, 0-25 years assessment process and a single education, health and care plan (EHCP) from 2014. At the moment, children with PMLD and other children with SEN receive a statement of SEN from their local authority. This covers only the services that schools are expected to give, rather than those they need from the health services or social services. The government aims to introduce a single care plan which would mean a child's educational, social and health needs must be considered and addressed together. The plan would also reflect the needs of the pupil’s family and would be continually reviewed.

The parallel funding reforms are intended to fit with and support the reforms of the SEN and disability framework and to ensure that funding for high needs provision is arranged on an equivalent basis across different types of providers. The government is working towards the introduction of these funding reforms from financial year 2013-14. It is worth noting that the introduction of these reforms will not create changes to the current levels of spending power for education providers and will not affect the total budget made available for high needs pupils or students. In the foreword to this latest document on the next steps, Sarah Teather herself states that:

> *The difficult financial situation we face makes it vital for us to make the best possible use of resources. The Green Paper proposals and the Government’s wider reforms in education and health will support this through better planning, streamlining assessment processes, making the system less adversarial and focusing on achieving better outcomes.*
>
> (DfE, 2012, p.3)

Sarah Teather recognises that we are in a time of fiscal retrenchment but has the view that a lot of money could be better spent if the education, health and social care services worked more closely on assessment and need from the earliest possible stage. At same time families would get the services they need for their children without feeling that they had to battle against the ‘system’. Where high needs pupils or students have health and social care needs, the Government expects that education providers will work closely with partners in local social care and health services, such as NHS Clinical Commissioning Groups, in order to pioneer innovative and effective provision and support. In these instances, it is stated that the appropriate forms of support to meet a child’s health and social care needs would be funded by the appropriate agencies.

In essence, the government will provide a base level of funding to specialist settings and special schools that is broadly equivalent to £10,000 for each high needs pupil. This base funding will be paid to education providers on the basis of an agreed number of planned places. £10,000 is not enough to meet the needs of many and additional funding will come in the form of a top-up directly from the local authority based on the assessed needs of each individual pupil or student. It is expected that some form of banding framework will be developed to ensure that appropriate levels of top-up funding are provided.

According to this approach, the education providers would be responsible for:

a. delivering the provision for which they have been commissioned for the individual pupils, using their professional expertise and judgement;
b. engaging in dialogue with commissioners (usually local authorities) in relation to individual pupils and students and being accountable for their progress and achievements, for example through annual reviews of progress;
c. contributing to clear and transparent information about the provision they offer for high needs pupils and students.

Further guidance on funding is due in June. If a revised funding formula needs to be properly approved by local authorities, most of the modeling and consultation with schools, other education settings and various agencies and decision-making bodies may need to take place in just a few months in the summer and the early Autumn. If this is a correct analysis, there is not much time left in which to sort out a considerable amount of detail and get things right for April 2013.

Parents of pupils and students with combined EHCPs would have the right to a personal budget for their child's support, and local authorities and health services would be required to ensure services for disabled children and young people were jointly planned and commissioned. Managing the budgets will be optional for parents, and the government will try out a number of different approaches, either giving money to parents directly or leaving the budgets with the local authority. The government has appointed 20 pathfinders representing 31 local authorities and NHS Primary Care Trust partners to develop the new 0-25 years assessment process and single plan and to ensure the fullest engagement possible of children, young people, and their parents and families. Learning is beginning to be shared, including through the pathfinder website: www.sendpathfinder.co.uk. By the autumn a significant number of children and young people in all pathfinder areas are supposed to have EHCPs agreed after having been through a single assessment process.

The Pathfinders are expected to test the scope for personal budgets, mechanisms to give families control and the impact and consequences of a personal budget. Many professionals have expressed worries about the impact on forward planning and co-ordination of services when budgets are put in the hands of so many individuals and families. Also, they doubt whether all parents are equipped to be the best advocates for their children's needs and whether they have the knowledge and ability to decide on the best type of expert assistance for their children. Indeed, many parents may not wish to take on this responsibility. Nevertheless, one of the undoubted benefits of parents gaining a personal budget to spend on services is that this will create an entitlement for children and young people and their families. It must be a good thing if this can, say, reduce the long waits for a wheelchair due to budgetary constraints or the apparent postcode lottery to get basic equipment. In this sense the Government proposals could well improve life for children and young people with special needs and disabilities and their families if sufficient funding and a range of genuine choices are available. These are somewhat scary and challenging changes that have the potential to revitalise services for children and young people and their families.

References

Department for Education (2011) Support and aspiration: A new approach to special educational needs and disability

Department for Education (2012) Support and aspiration: A new approach to special educational needs and disability - Progress and next steps

These documents are available from the government website at http://www.education.gov.uk

Annie and Helen’s top 10

Some useful websites for families and friends

www.pmldnetwork.org
pmld network Is a collection of people and organisations who champion improving lives for people with pmld. The site links to: good resources from many organisations, the PMLD Network forum see below. It responds to consultations. The organisations of the Network Lobby Government and politicians.

www.mencap.org.uk
mencap has a specific team working in partnership with people with PMLD and their families. Once on the mencap website search for pmld and a whole range of information will appear. Mencap also continue to successfully campaign in partnership with people and families to improve life for people with learning disabilities.

www.learningdisabilities.org.uk
‘foundation for people with learning disabilities’ site hosts 4 very useful forums including The PMLD Network forum. At the time of writing discussions included social and emotional experiences of people with pmld, use of hoists and changing beds and detecting seizures. They involve people and families in their work to inform Government, creating resources and improving services.

www.kithandkids.org.uk
Kith and Kids - this organisation is families at the coal-face. They run programmes and training - although generally London based they provide support for everyone by phone or email - conferences and training. The network of families is very active and all are welcome to share their learning and development experience.

www.cafamily.org.uk
Contact a Family - provides some excellent medical information and is involved in practical campaigning work. It also has a regional network.

www.openstorytellers.org.uk
Grounded in practice - they use storytelling and narrative to help people be heard. Excellent for those looking to include people with pmld using imaginative and meaningful techniques.

www.lukeclements.co.uk
Luke is a Professor at Cardiff Law School and a solicitor with Scott-Moncrieff & Associates LLP solicitors. His website has a range of extremely useful legal resources and up-to-date news. The area of social care law and human rights is very complex and the information does not shy away from this.

www.dls.org.uk/
Disability Law service, is a charity which provide advice and information specialising in areas of law that most affect people with disabilities. If you want to contact them they ask that you read their advice booklets first to get the most out of the call.

www.familycarers.org.uk
This will link families to strategic networks - National Family Carers Network. The NFCN networks with groups and organisations that support families which include an adult with a learning disability.

www.pamis.org.uk/
PAMIS an organisation in Scotland working with people with PMLD, their family carers and professionals who support them

and don’t forget…PMLD Link **www.pmldlink.org.uk**

FUTURE FOCUS: Technology

We live in an age where technology influences all aspects of our lives. It allows us to communicate and develop relationships and friendships. We entertain ourselves through a wide variety of media. Technology keeps us safe and healthy. It is an integral part of our daily lives from the minute the alarm wakes us up in the morning continuing right through until we read our e-book in bed at night. We rely on, and take advantage of the innovations that have been developed over the last generation. Technology has widened our experiences and opportunities and allows us to interact with people, events and developments all over the world at the click of a mouse.

So how does technology influence the lives of people who have profound and multiple learning difficulties? How does it encourage them to interact, communicate and develop relationships with people within their world? The development of ipads, has resulted in a revolution of apps (applications) that can be used with people with PMLD. Has the development of such technologies led to greater access with the use of a touch screen, its compactness and diversity? Plasma screens are used as touch screens with switch software and have the advantage to allow for large images. Sensory trolleys and sensory rooms are being designed to stimulate and motivate those with PMLD. There are many people who are enthusiastic about such innovations, if you are one of them please share it as it really can inspire others. Or, conversely, have you had difficulties or bad experiences in using technology – or in maintaining it once it has been set up? If so, sharing your problems with other readers may help.

Music is important to the lives of a lot of people with PMLD. Only the other day Thomas, a young man with PMLD in my class was using independent movement of his fingers to activate a sound beam. There was real joy on his face, he smiled and there was a connection. He understood that it was his actions that had created the musical sound. Is there greater scope to use technology to create motivating experiences such as this? Have you got any stories of how technology has opened up such realisations and early cognitive development? If so we would value your contribution.

With the advancement of medical science, how is it affecting the health and well-being for people with complex medical needs? With the development of technologies such as Vagal Nerve Stimulators (VNS), electrical activity and seizures can be controlled and reduced. This has a significant effect on the lives of such vulnerable people. Sharing your experiences and knowledge can really help. If you have experiences, ideas or comments to share we would love to hear from you. We welcome articles from all perspectives.

Wendy Newby and Carol Ouvry
wennewby@aol.com

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Vol. 24 No. 2 Issue 72

PMLD Network Forum
A Digest of Discussions
April 2012 to June 2012

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.

Assessing pain in adults with PMLD

The parents of an adult woman with PMLD got in touch. They said that their daughter uses body language to communicate that she is in pain. She lives independently with 24hour support. They said that despite them, her parents, writing and re-writing care plans, her support workers are struggling to identify when she is in pain or whether she is telling them she does not want to do something. They said that some of them 'get it' but others struggle to. In the meantime their daughter struggles through, which she should not have to do. They asked if anyone knew of an assessment tool that they could use to help their daughter?

Responses included:

- Several people said that the DisDAT (Disability Distress Assessment Tool) could be useful: www.disdat.co.uk
- Someone from Australia said that although the DisDAT tool was not developed for people with PMLD specifically, they have completed a trial with a group of adults with PMLD. They said they have found it really useful and have had great feedback from families and support workers.
- A couple of people mentioned the Affective Communication Assessment. They said it is a useful way to get a picture of how a person shows their likes, dislikes and other emotional responses. The descriptions or video clips can be incorporated into a format, either paper or electronic, that can be shared with other people. It is available from Melland High School: www.melland.manchester.sch.uk
- A parent of an adult with who communicates without words, who is also a speech therapist, said, ‘I have decided that what is needed is a very clear description of my daughter when she is in pain. A written description can help, as in the form of the charts currently used by some workers. As can the use of photographs, and video of the person in pain. It also helps if those who get it, double up on shifts with those who don't get it. Then as and when the person is in pain, the good interpreter can help the less proficient interpreter. It can take up to a year for a new carer to learn to understand my daughter's communication. Some people never actually get it, yet from my perspective my daughter is using a few clear signals. Pain is one of her clearest signals.’

- Someone else said that they have taken photos and videos of their daughter. They said that she has the photos in a book on her wheelchair and the videos have been emailed to her school and are there for reference but obviously not as easily accessible. They said, ‘the photos vary but at the moment she has one of a ‘yes’ face, one of her ‘no’ face, one of her bright and alert and one of her with her eyes wide open having a seizure - people mistake seizure activity for her being really interested in something all the time!’. They said that their eldest child had seizures which just manifested as a lip and thumb twitch and whilst you couldn't catch the twitch in a photo, you could photograph and highlight the area they needed to be looked at. They suggested this approach could be used.
- The same person said ‘We do still have problems with staff not being able to differentiate a happy singing coo from a bored/frustrated coo and both of those from a painful one. I get calls saying she's crying and when I get there, it’s very obvious (to me) that she is singing away happily enjoying all the attention she's getting. I have considered recording them but I suppose the differences are probably subtle if you don't know them.’
- The same person also said that something they have found helpful for people who really can’t get it at all is to provide a checklist of how everything should be so they aren't relying on her daughter's reactions to tell them if they have it right. She said this includes ‘a run through of proper positioning in the wheelchair including a check that the hips are aligned (even half an inch wrong causes her a lot of discomfort), checking toes aren't rucked up in socks (she can't wear shoes), hair isn't caught in headrest. Plus we have a few things which will nearly always make her smile, for example, whistling, running over cobblestones. So if she doesn't smile in response to a whistle or a bumpy ride, they can

assume something is wrong even if they don't quite know what.’
- Someone suggested that to make videos easily accessible they could be on an iPad in someone’s bag, perhaps as part of an electronic communication passport.

Help sought re: music/lights for gift

Someone said that their friend’s daughter, who has severe disabilities, is having her 16th birthday next month. They said she loves music and lights and they wanted to know of any websites where they might be able to buy a suitable gift.

Responses included:

- A number of people suggested websites:
    - ◊ www.rompa.com/catalogsearch/result/?q=lighting
    - ◊ www.soundbeam.co.uk/products/sb5-intro.html
    - ◊ www.lightinthebox.com/c/led-lights_4001
    - ◊ www.snoezeleninfo.com
    - ◊ www.mikeayresdesign.co.uk
    - ◊ www.specialneedstoys.com/uk
    - ◊ www.spacekraft.co.uk

- A couple of people said that high street shops can be much cheaper than specialist companies. For example, Maplins has lazers and sound activated disco lights.
- Someone mentioned that national and local disability events, such as Naidex www.naidex.co.uk, might include companies which provide sensory equipment. h
- Someone suggested contacting local special schools, as they may have information about catalogues or even be able to show examples of sensory equipment.
- Someone mentioned Optimusic www.optimusic.com. They said this has computer equipment combined with lights, so that when the light beam is passed through with a hand or a paddle this creates sounds or music or whatever noise is set on the computer.
- Someone said that their daughter has similar needs and of all the many lights they have purchased for her over the years, the one that stands out in terms of never failing to keep her interest is the Mathmos projector with oil wheel and/or graphics wheel. They said it was a very reasonable price www.mathmos.com. They said they use it with a lightweight pop-up circular projection screen that can be placed within her field of vision www.spacekraft.co.uk. They said that another favourite of their daughter’s is a large sturdy bubble tube. The one they have has a choice of sound effects and you can also play music through it via an MP3 player. They found it on ebay for about £50.

Creative FE opportunities for students with complex needs

The Norah Fry Research Centre asked if anyone knew of a Further Education college which is making efforts to include students with more complex needs, including young people with PMLD or behaviour that challenges. They said they are carrying out some research about FE for students with complex needs in Wales, but want to find examples across the UK of creative and innovative practice, which they can feed in to stakeholder groups in Wales.

Responses included:

- Reaseheath Agriculture College, Nantwich and Newcastle (Under Lyme) College www.reaseheath.ac.uk
- Someone said that Chelmsford College in Essex has a wonderful new 'Special Provision' programme for PMLD students: www.chelmsford.ac.uk
- Someone said that Lancashire Adult Learning have a programme. But they said, ‘We struggle generally for good FE courses for people with PIMD/PMLD and often our day services provide the best day time supports. Look up 'Involve Me' project at Ellesmere Port Day Service, it did an excellent project on this in 2011 www.mencap.org.uk/involveme
- Someone said that they run a provision for young people with complex needs, including life limiting illnesses and for those whose needs fall within the Autistic Spectrum and who may present with behaviours that challenge. They said this provision is based within an FE College in Hertfordshire. They said they are able to offer individual programmes, funded through the regional placement budget. They do not follow any accreditation. They said that this enables them to provide physiotherapy, osteotherapy, 2 Nurses and Speech and language therapy. They said that 95% of the young people receive 1-1 or in some cases, 2-1 support.
- Someone said that they were part of a project looking to develop the inclusive provision in local colleges. At the time, the only example they could find of an FE college who was truly doing this was Blackburn College in Lancashire. They gave a link to a case study of the College that was written up as part of the Transition Support Programme http://www.choiceforum.org/docs/bburn.pdf

- Someone said that the Hollybank Trust in Mirfield in West Yorkshire www.hollybanktrust.com run a personalised post 19 provision. They said they had also heard that Stockport College is doing some good work in this area.
- A family carer said they hoped that the Norah Fry Research Centre would share all the information they find out about supporting young people with a learning disability or complex needs as this is much needed by so many parents & carers. She said, ‘as carers we need to know about what is possible with our children. We need information like yours to show our own local colleges etc exactly what they could do instead of them insisting that it isn't possible or it can't be done or it would take funding.’

Use of touch guidelines

Someone from a school asked if anyone had guidelines or policies that they could share which address the use of touch/ appropriateness of physical proximity when working with people with PMLD. They said they would like to give their staff sensible training that allows for the physical connection in relationships that all children and young people with PMLD need, and yet will at the same time address appropriateness and safeguard both staff and young people.

Responses included:

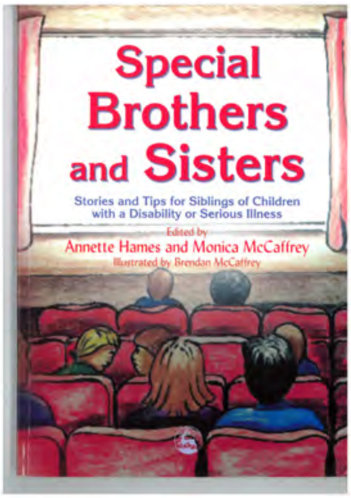
- Someone said to look at a discussion paper from the school they used to work at. They said, ‘we all know touch is very important when working with students with PMLD and this paper looks at some of the issues surrounding it.
- www.riversideschool.org.uk/page_viewer.asp?page=Discussion+Papers&pid=138
- ‘At Us in a Bus we work mainly with adults with PMLD – but some of the issues will be the same as for your team supporting children and young people. Please find attached the guidelines that we are currently using (I say ‘currently’, as they are in a state of fairly constant reflection and alteration). www.choiceforum.org/docs/glinetouch.doc. Our guidelines are influenced by Dave Hewett’s work on this issue, and if you visit www.intensiveinteraction.co.uk you will find more helpful information there.’

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: Special Brothers and Sisters.
Stories and tips for siblings of children with a disability or serious illness.
Author: Annette Hames and Monica McCaffrey(
Publisher: Jessica Kingsley
Year: 2005
ISBN: 1843103834



This is a very useful little book, tackling some of the feelings and experiences of living and growing up with a sibling who has a disability, through 40 illustrative, real life stories.

The diverse stories are told through the eyes of the siblings themselves and share the pleasures and challenges they have personally experienced. These siblings are aged between 3 ½ and 18 years and talk about their brothers and sisters who between them have a wide range or disabilities and/or serious health issues. The stories are arranged by age of the sibling story-teller; stories about particular conditions can be found through the index at the back.

Through the stories, this book acknowledges the many real issues that impact on everyday life for families, seen from the unique perspective of siblings. The book does not shy away from very real examples – from practicalities like ‘she poos loads and runs around’, to worries such as, ‘I get scared when he has a fit and has to go to hospital’; accepting medical interventions like gastrostomies and suction machines as part of their family life. Emotions are also part of the focus of this book- including quite understandable feelings such as impatience, embarrassment, jealousy and worry about the future.

What the book does so valuably is to draw out and explain what makes their family life feel different from others. It highlights some useful terminology and medical descriptions that are common to the stories and gives an easy-read clarification [*Keywords explained and Find out more sections*]. Alongside each ‘story’ is a box giving tips and more information about a number of topics. In these, the editors very valuably explore the issues brought up in each personal account – asking about the reader’s own experiences and offering some simple practical steps to deal with their feelings and to the responses of other people. A list of organisations is included as a useful source of further information and support.

This book is primarily text-based and the authors suggest parents may read the stories to their sons and daughters or explain some of the issues before letting them read the book alone. Other family members [extended family and friends] might also find this book helpful in adjusting and understanding more about their relative with the disability and the possible impact on the whole family. Although aimed directly at families, professionals may find the personal insights useful - selecting individual stories relating to specific situations/conditions to aid their support to families.

A great little resource that reflects some of the excellent work developed by SIBS, the UK organisation for siblings. For other resources see SIBS website http://www.sibs.org.uk/parents/books-for-siblings

Annie Fergusson
Sister and member of the PMLD Link Editorial Group

PUBLICATION

A Better Life

A publication to celebrate the 20th birthday of PAMIS. PAMIS is a registered charity working with people with profound and multiple learning disabilities and complex health care needs, their parents and carers and interested professionals in Scotland. The booklet showcases the services, projects, campaigning work and research that PAMIS has carried out over the last 2 decades and continues to do so. The booklet highlights through the many colourful images and accompanying text how people with complex needs are valued as both individuals and the contribution they make to the community.

The publication is available to download from the PAMIS website at www.pamis.org.uk

IN THE NEWS

Hampshire's Furzey Gardens Wins Gold at the RHS Chelsea Flower Show

Furzey Gardens in Minstead, one of the New Forest's best kept secrets, is centre stage today as it wins a coveted Gold Medal at the RHS Chelsea Flower Show. The Furzey Team, led by designer Chris Beardshaw, has bucked recent trends at Chelsea by celebrating the beauty of ericaceous plants and shrubs and evoking the unique spirit of Furzey Gardens.

Emotional celebrations were the order of the morning as even experienced and multi Gold medal winning Chris could not hold back the tears. Chris commented *"I am absolutely thrilled for everyone and I am genuinely surprised. I really didn't think it was the sort of garden the judges would like - but delighted they did! This project has brought people and plants that are often considered on the fringes of society to Chelsea and has shown just what they can achieve.*
This is a wonderful result for the literally 100s of people who have helped Furzey Gardens make this garden a reality through their kind donations and volunteering and it's a great testament to all the hard work given by everyone who has worked so hard on the project."

Independent charities Furzey Gardens and The Minstead Training Project work together to provide training for people with learning disabilities to enable them to lead fulfilled lives. Although Furzey Gardens welcomes twenty five thousand visitors a year, its main purpose is to provide work experience opportunities for people with learning disabilities. The training is not aimed necessarily at producing horticultural workers but rather to provide a sympathetic environment in which to learn the type of work skills that are required for a range of employments. The students have been intimately involved with every stage of the Chelsea garden in a variety of different ways including planning, propagation of plants and the building of the show garden. They will be involved with recreating the garden back in Furzey Gardens when everyone has got their breath back.

Trust Chairman, Rev. Tim Selwood commented from the crowds of RHS members at the show this morning, *"We are so grateful to the RHS and so many well-wishers and supporters who have enabled us to present this magnificent Show Garden on our very limited funds. Our Gold Medal is a great honour for our whole team who have worked so hard to show what can be achieved by people with learning disabilities provided they have proper support and funding".*

New guide launched to help people with learning disabilities get the best from the NHS

Good health care for all

What can I expect from the NHS?

Alison Giraud-Saunders
February 2012

foundation for people with learning disabilities

Foundation for People with Learning Disabilities in April launched a new easier-read resource about what to expect from the NHS.

The booklet provides practical hints and tips for people with learning disabilities, family carers and anyone who supports a person with learning disabilities on how best to use the NHS, what to expect, real life examples of challenges and how they can be overcome as well as advice about how to get help and useful contacts to get more information. Drawing on the Foundation's extensive work on access to health care for people with learning disabilities, the booklet was funded by the Valuing People Now programme.

Alison Giraud-Saunders, Consultant at the Foundation for People with Learning Disabilities, says:

"Through our many years of work to improve health outcomes for people with learning disabilities, we know that people with learning disabilities and family carers often lack information about how to get the best care from the NHS. Health care systems can be confusing and stressful for anyone and it is difficult to know what extra help you can get if you are disabled.

"The resource is organised into sections including: what the NHS is; tips about looking after and making decisions about your health, and how to go about using the NHS, as well as practical tips about what it's like to go to the doctor or nurse or to go to hospital for an appointment. Each section draws on the real experiences of people with learning disabilities and is illustrated by stories to show what a 'good' service from the NHS looks like.

"We hope that this new resource will prove a real help to people with learning disabilities, their families and supporters and make a significant difference to their experiences of the NHS."

To download the booklet please visit: http://www.learningdisabilities.org.uk/publications/176171/

Partners in Policymaking [PIP]: Altogether Better

Take a few minutes to watch this and pass the link onto families and people with learning disabilities.

http://www.youtube.com/watch?v=V9rbdbuCrgI

Overview of the PIP suite of leadership training courses for disabled adults, parents and carers of disabled children, professionals and other service providers working in education, health and leisure. http://www.in-control.org.uk

Reports expose failings in learning disability services

Reports published on 25th June have revealed shortcomings in care services for people with a learning disability and continued failings to protect people from abuse.

The Care Quality Commission (CQC) has published its review of 145 services for people with a learning disability and behaviour that challenges. The review was commissioned as as part of the government's response to the abuse that was uncovered at the privately-run Winterbourne View care and assessment centre by last May's BBC Panorama programme.


CareQuality Commission

Learning disability services
inspection programme

National overview

June 2012

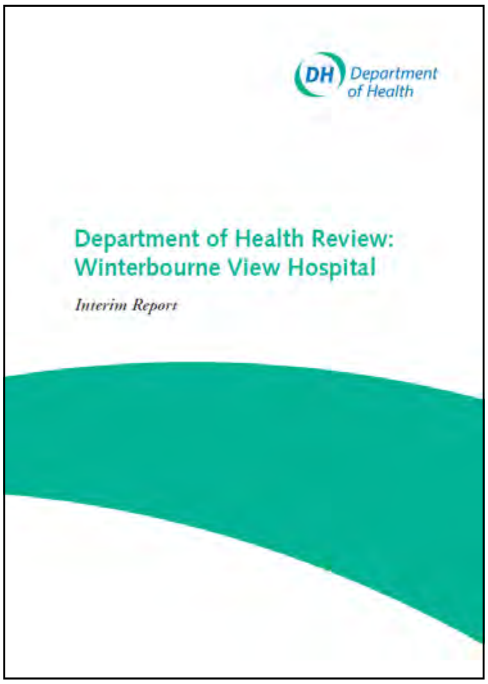
The unannounced inspections took place between September 2011 and February 2012. They investigated the level of care provided at care and assessment units similar to Winterbourne View, run by the NHS, private care providers and adult social services.

The report, 'Learning disability services inspection programme: National overview', finds nearly half of the services inspected failed to meet CQC essential standards of quality and safety of care that people should expect.

Among its findings, the CQC identified specific safeguarding concerns at 27 locations, which needed to be referred to local authority safeguarding adult teams. It also found that length of stay at NHS and privately-run care and assessment centres ranged from six weeks to 17 years. 'Generally, these were unacceptably long, and inconsistent with the descriptions of assessment and treatment,' states the report.

National actions

The Department of Health responded to the CQC's inspections by publishing its interim Winterbourne View report into how the health and social care system supports vulnerable people with a learning disability and autism.


DH Department of Health

Department of Health Review:
Winterbourne View Hospital

Interim Report

The review sets out 14 national actions to address the issue of bad care or potential abuse. The actions include the promotion of open access to services for family members, advocates and visiting professionals, along with more unannounced CQC inspections.

"This report is not our last word on the shocking events at Winterbourne View," said care services minister Paul Burstow. "However, there is compelling evidence that some people with learning disabilities are being failed by health and care services… Our national actions will mean that people have access to good care, closer to home. They will make sure those who provide care, commission care and care staff – know exactly what part they must play and what standards are expected of them."

But Mencap and the Challenging Behaviour Foundation are concerned that the national actions do not go far enough. The charities have called for the phased closure of large, institutional-style services for people with a learning disability, and their replacement by appropriate local services.

Continued from last page

In a joint statement, Mencap's chief executive Mark Goldring and Challenging Behaviour Foundation chief executive Viv Cooper, said: "One year on from Panorama's undercover investigation into a private hospital for people with a learning disability, people continue to remain in large, out-of-town units for long periods of time, isolated and at risk of abuse and neglect.

"Action is needed to stop people with a learning disability and behaviour that challenges being sent away to these services. The government's proposals on local action will not be enough to create the systemic change needed. We are looking for a direct commitment from government to put in place a strong, practical action plan with clear targets when it publishes its final review".

The government's final report is expected later this year, once criminal proceedings involving former Winterbourne View staff members have been concluded.

Read the CQC's review of learning disability services: http://www.cqc.org.uk/public/news/half-learning-disability-services-did-not-meet-government-standards

Read the Department of Health's interim Winterbourne View report into services for people with a learning disability: http://www.dh.gov.uk/health/2012/06/interimwinterbourne/

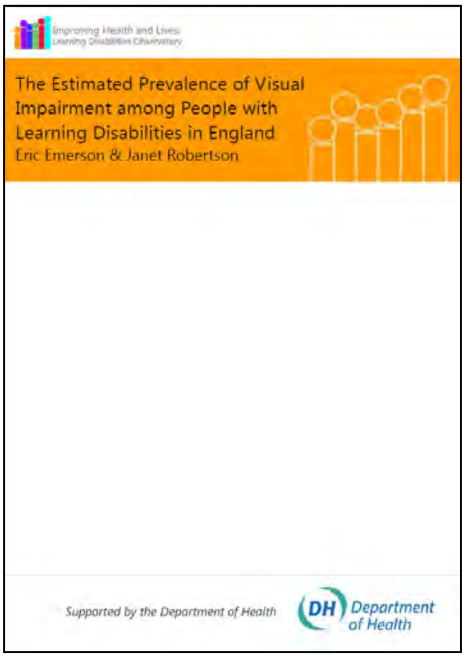
Email your MP: take action to stop the abuse and neglect of people with a learning disability: http://e-activist.com/ea-action/action?ea.client.id=78&ea.campaign.id=15541

The estimated prevalence of visual impairment among people with learning disabilities in the UK

The aim of this report is to estimate how many people with learning disabilities in the UK are likely to have visual impairments. It has been known for some time that visual impairments are more common among people with learning disabilities, especially people with more severe learning disabilities, and that the presence of visual impairments can significantly impair the independence and quality of life of people with learning disabilities. There is, however, no national monitoring of the number of people with learning disabilities who have visual impairments. Neither does there exist robust epidemiological data on the prevalence of visual impairments among people with learning disabilities in the UK. As a result, this report uses epidemiological data from the Netherlands and Denmark to answer two questions: 1. How many people with learning disabilities in the UK are likely to have visual impairments? 2. How will this number change over the coming decades?

The research described in this report was funded by RNIB and SeeAbility.

http://www.improvinghealthandlives.org.uk/publications/956/



Improving Health and Lives:
Learning Disabilities Observatory

The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in England
Eric Emerson & Janet Robertson

Supported by the Department of Health

DH Department of Health

Prevalence of Visual Impairments Among People with Learning Disabilities

Alternatively try: http://snipurl.com/23usk55

Stuck at home

Mencap report reveals that 1 in 4 adults with a learning disability are stuck at home due to cuts to day services. Nearly a third of local authorities have closed day services in the last three years, leaving 1 in 4 adults with a learning disability stuck at home.

These findings were revealed in Mencap's report 'Stuck at home: the impact of day service cuts on people with a learning disability', which was published in May. The report exposes the heavy impact of cuts and increased charging for services on disabled people – leaving them feeling isolated, lonely and cut off from their communities.

The report brings together data gathered from a freedom of information request made to 151 local authorities in England, along with a survey of 280 people with a learning disability and their families, and nearly 200 professionals who work in the learning disability field.

'Stuck at home' shows:

- In the last three years, almost 1 in 3 local authorities have closed day services.
- Of these, 1 in 5 are not offering any form of alternative service.
- 57% of people with a learning disability known to social services do not receive any day service, compared to 48% in 2009/10.
- 3 in 5 local authorities have increased charges for going to day services, by an average of 70%.

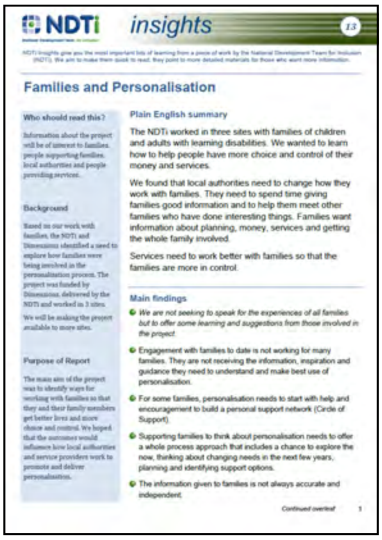
In addition, nearly 9 in 10 respondents with a learning disability felt that they were not adequately consulted about the changes made to their day service, with 64% not having been asked for their views at all, despite local authorities having a legal duty to do so.

“Our social care system is letting down this country’s most marginalised adults,” said Mark Goldring, Mencap's chief executive. “It is deeply worrying that progress towards greater participation of disabled people in the community and mainstream society risks being undone by a failing system that has long been ignored and is now creaking under the pressure of increased demand and budget cuts.”

Read the report, 'Stuck at home: the impact of day service cuts on people with a learning disability':
www.mencap.org.uk/sites/default/files/documents/Stuck_at_home.pdf

Outcomes from their Families and Personalisation

As part of learning disabilities and carers week the NDTi and Dimensions are publishing the first wave of outcomes from our Families & Personalisation programme. This calls for better information and support for families if we are to move beyond budgets to real change, choice and control.



NDTi insights 13

NDTi Insights give you the most important bits of learning from a piece of work by the National Development Team for Inclusion (NDTi). We aim to make them quick to read; they point to more detailed materials for those who want more information.

Families and Personalisation

Who should read this?

Information about the project will be of interest to families, people supporting families, local authorities and people providing services.

Background

Based on our work with families, the NDTi and Dimensions identified a need to explore how families were being involved in the personalisation process. The project was funded by Dimensions, delivered by the NDTi and worked in 3 sites.

We will be making the project available to more sites.

Purpose of Report

The main aim of the project was to identify ways for working with families so that they and their family members get better lives and more choice and control. We hoped that the outcomes would influence how local authorities and service providers work to promote and deliver personalisation.

Plain English summary

The NDTi worked in three sites with families of children and adults with learning disabilities. We wanted to learn how to help people have more choice and control of their money and services.

We found that local authorities need to change how they work with families. They need to spend time giving families good information and to help them meet other families who have done interesting things. Families want information about planning, money, services and getting the whole family involved.

Services need to work better with families so that the families are more in control.

Main findings

- *We are not seeking to speak for the experiences of all families but to offer some learning and suggestions from those involved in the project.*
- Engagement with families to date is not working for many families. They are not receiving the information, inspiration and guidance they need to understand and make best use of personalisation.
- For some families, personalisation needs to start with help and encouragement to build a personal support network (Circle of Support).
- Supporting families to think about personalisation needs to offer a whole process approach that includes a chance to explore the now, thinking about changing needs in the next few years, planning and identifying support options.
- The information given to families is not always accurate and independent.

Continued overleaf 1

IHAL People with Learning Disabilities in England 2011


Improving Health and Lives:
Learning Disabilities Observatory

People with Learning
Disabilities in England 2011

Eric Emerson, Chris Hatton, Janet Robertson, Hazel Roberts, Susannah Baines, Felicity Evison & Gyles Glover

Supported by the Department of Health
DH Department of Health

In May an annual report on People with Learning Disabilities in England 2011 was published. It summarises information collected by several government departments about people with learning disabilities.

It includes estimates of how many people with learning disabilities there are in England and information about the health of people with learning disabilities, the education of children with learning disabilities and health and social care services used by people with learning disabilities.

The report is available at http://www.improvinghealthandlives.org.uk/publications/1063/People_with_Learning_Disabilities_in_England_2011

Alternatively try: http://snipurl.com/23nzgxd

Mental Capacity Act resources

"This is not just good practice – it's the law."

A new tool highlights legal requirements to involve families in best interest decisions of their loved ones.

Mencap, Ambitious about Autism and the Challenging Behaviour Foundation have worked together with Irwin Mitchell Solicitors to develop a new best interest decision-making resource. It was prompted by concerns that professionals are failing to appropriately consult with families, as required under the Mental Capacity Act 2005.

Under the Act, all professionals – including those from local authorities and the NHS – must consult with family members when adults lack the mental capacity to make the relevant decision themselves.

The new resource outlines the key points of the Act, and includes two template letters to help family members challenge service providers when they have not been involved, or are concerned that they won't be involved, in the best interest decision-making process.

Ensuring that all professionals act in accordance with their obligations under the Mental Capacity Act 2005 towards disabled adults

This leaflet has been produced by Ambitious about Autism, Mencap and the Challenging Behaviour Foundation in partnership with Irwin Mitchell Solicitors.

We are regularly contacted by individuals who feel that they are not being appropriately consulted about the welfare of their loved ones. For example, many parents phone to voice concern about decisions that social care or health professionals have made about their adult son or daughter, which they have not been involved in at all.

Broadly speaking, if an individual lacks the mental capacity to make a decision for themselves, that decision must then be made in their best interests in accordance with the requirements of the Mental Capacity Act 2005.

Examples of relevant decisions can include those around:
- where the individual lives
- what care is received
- contact with others
- medical treatment.

Importantly, the Mental Capacity Act requires all professionals, including those from local authorities and the NHS, to consult with family members when an adult lacks the mental capacity to make the relevant decision themselves.

We have prepared this leaflet in order to increase understanding of people's rights to be involved in 'best interest' decisions taken in accordance with the Mental Capacity Act.[1]

[1] The rest of this guide refers to 'family members' for ease of reference, but in fact (as can be seen from the attached letters) the Act refers to anyone engaged in caring for the person or interested in his/her welfare.

David Congdon, head of campaigns and policy at Mencap says: "It is crucial that professionals listen to family carers and use their knowledge to inform decisions being made. This applies to all decisions – those about medical treatment and social care, as well as any other decision that affects the person's life. This is not just good practice – it's the law. It is important that families understand this and feel able to challenge when they are not being involved."
Download the best interest decisions tool:
www.irwinmitchell.com/MCAletter

Other Mental Capacity Act resources:
HFT's MCA guide: www.hft.org.uk/Supporting-people/family-carers/Resources/MCA-guide

Mencap's resource for family carers of people with PMLD: http: www.mencap.org.uk/all-about-learning-disability/health/mental-capacity-act

Specialist schools congregate for sports festival

Specialist schools from throughout Surrey have congregated for a Paralympics-themed Sports Festival, held especially for young people with profound and multiple learning difficulties.

Young people at The Children's Trust in Tadworth welcomed fellow pupils, with each school representing a different country during the event on June 27th.

After a triumphant opening ceremony, over 120 children enjoyed a variety of games on the Trust's lawns, including hockey, football, rugby, boccia and archery.

Ali Lalani, 2007 World Cup Boccia Champion and a Vice-President of the Trust joined in the day's fun.

Speaking to the children, he said: "Today has reminded me of when I was at school, and these opportunities were not possible.

"Each one of you, individually is a champion every second of everyday, always remember that."

Rosemarie Glithero, activities co-ordinator at the Trust said: "It has been a happy memorable morning with a lot of smiley faces and laughter."

The event was also attended by the Mayor of Reigate and Banstead, Cllr Roger Newstead and Mayoress, Mary Newstead.

Participating schools: Brooklands (Reigate), Clifton Hill School (Caterham), Ridgeway (Farnham), Portesbery (Camberley), Rutherford (Croydon), Walton Leigh (Walton-on-Thames), Manor Mead (Sheperton) and Chailey Heritage FE (Sussex)

Photo by Andy Newbold

Families launch legal battle on cuts

Families of disabled adults have been forced to take legal action to stop the closure of day care centres in Hillingdon, which they have relied on for up to 25 years.

The families are campaigning against funding cuts that will see the closure of three day care centres, run by Hillingdon Council, and their replacement with a single centre. None of the current users of the services know if they will get a place in the new centre.

Experts in public law at solicitors Irwin Mitchell are seeking a judicial review to stop the proposed closure of the day care centres. The families and their lawyers claim the council's consultation on the cuts was unlawful and did not provide enough information to the public, families, local campaigners or the council's decision-makers.

"Our clients consider that the consultations on the closures were inadequate in order to allow them to contribute in an informed way," said Irwin Mitchell's Alex Rook. "The information provided to the centre users was missing several key details about what it meant for them and what alternative services might be available, and our clients remain in the dark about how the changes will actually affect them."

Cuts put people with a learning disability at risk, say nurses

Cuts to services are hitting some of the most vulnerable people in society, according to a new survey published in May by the Royal College of Nursing (RCN).

The survey of almost 500 learning disability nurses found that nearly three quarters (74%) of respondents have seen cuts to services in the past year, and of those, 73% have real concerns about the safety of their patients. They fear that people with a learning disability could be missing out altogether or face a reduced service.

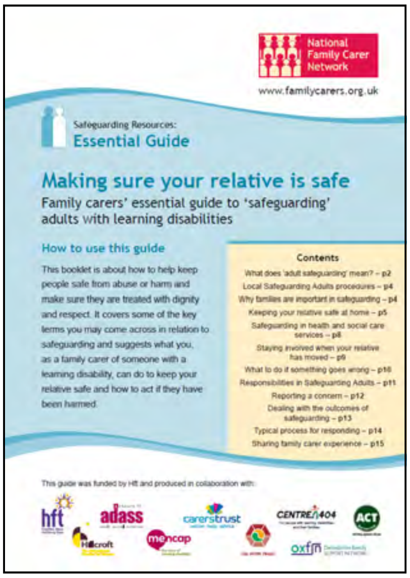
The survey also found that, in the past year, over half of nurses have seen a decrease in the range of NHS services offered to people with a learning disability. Just over half of nurses surveyed said the area in which they worked offered a patient passport, while personal care packages or person-centred plans are only being carried out in around three quarters of areas.

The findings, released at the RCN's annual congress, come on top of news that over 60,000 jobs are to be lost across the NHS. Amid these reductions in staffing levels, around three quarters of nurses said their caseload had increased and they were dealing with increasingly complex health needs.

Investment needed
The RCN has called for urgent investment in learning disability services. This includes an acute learning disability nurse in every hospital, a guarantee that one-to-one specialist learning disability nursing is given to all those who need it, and training and development opportunities for all learning disability nurses. The RCN is also calling on people to sign its pledge to show their support for learning disability nurses.

Safeguarding

Responding to an urgent need for information about safeguarding that addresses the concerns of family carers of adults with learning disabilities, the National Family Carer Network, funded by Hft (www.hft.org.uk) has produced two publications:



National Family Carer Network
www.familycarers.org.uk

Safeguarding Resources:
Essential Guide

Making sure your relative is safe
Family carers' essential guide to 'safeguarding' adults with learning disabilities

How to use this guide

This booklet is about how to help keep people safe from abuse or harm and make sure they are treated with dignity and respect. It covers some of the key terms you may come across in relation to safeguarding and suggests what you, as a family carer of someone with a learning disability, can do to keep your relative safe and how to act if they have been harmed.

Contents

This guide was funded by Hft and produced in collaboration with:

· The 'Top Tips' is a 4 page briefing, based on the views of family carers, that provides suggestions about preventing harm from happening in the first place and what you can do if things go wrong.

· The 'Essential Guide' is a 16 page booklet covering some of the key terms you may come across in relation to safeguarding and suggests what you can do to keep your relative safe and how to act if they have been harmed.

A Resource Pack (including useful examples of good practice around safeguarding, supported by film clips featuring people's stories), produced by Hft, will follow in the Autumn. www.familycarers.org.uk

National Family Carer Network
www.familycarers.org.uk

Safeguarding Resources:
Top Tips

Making sure your relative is safe
Top tips for family carers about 'safeguarding' adults with learning disabilities

What does 'safeguarding adults' mean?

Some adults may be unable to protect themselves from harm because of their disability, age or illness. They have a right to be supported to keep themselves safe and for action to be taken if they are abused or neglected. 'Safeguarding adults' refers to activities and procedures that do this. It involves a range of people in official roles in health and social care services and the police, but family carers are important to all aspects of safeguarding: from helping their relatives stay safe to responding when they have been harmed.

The priority should always be to keep people safe in a way that does not unduly restrict their lifestyle. This means balancing risks and recognising the potential for harm. Harm is often called abuse and can be caused:

- physically (e.g. hitting, pushing, unnecessary restraint, etc.),
- sexually, psychologically (e.g. use of threats, humiliation, abandonment, etc.),
- financially, or
- through discrimination.

This might include disrespecting someone's culture or belief by, for example, providing them with the wrong type of food. Neglect occurs where something has not happened that should have happened (e.g. ignoring a person's medical or physical care needs, failing to provide access to appropriate healthcare, or withholding the necessities of life, such as adequate nutrition and heating).

This leaflet contains 'top tips' about what family carers and friends can do to ensure that adult safeguarding works for a relative with learning disabilities. Based on the views of family carers, many of the tips are about preventing harm from happening in the first place. Others are about what you can do if things go wrong. Sometimes these can be resolved quite easily, but if the matter is a serious one you should refer to the other resources in this series (see the end of this leaflet for details).

This guide was funded by Hft and produced in collaboration with:

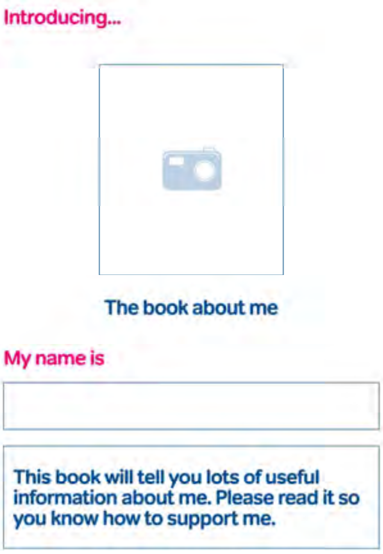
RESOURCE

An Ordinary Life: supporting families whose child is dependent on medical technology or has complex health needs


An ordinary life:
supporting families whose child is dependent on medical technology or has complex health needs
by Jill Davies
foundation for people with learning disabilities

The booklet is based on the initial findings of a project called 'An Ordinary Life'. We called it this because many children and young people with complex health needs and/or who are dependent on medical technology find it very difficult to do ordinary things like going to the lcoal leisure centre or cinema, or visiting friends and family.

An Ordinary Life: Passport


Introducing...

The book about me

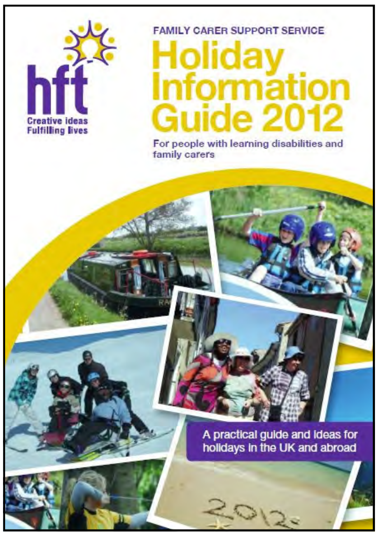
My name is

This book will tell you lots of useful information about me. Please read it so you know how to support me.

The purpose of this booklet is for others to find out crucial information about a child or young person with high support needs in a short time-frame. It could be used by a new support worker at home, staff at a short-term break service, a learning assistant or teacher at school or a nurse if the person has had to be admitted into hospital. It also contains essential information should an emergency situation occur – whether it is a social care or medical emergency.

http://www.learningdisabilities.org.uk/publications/

Hft's Family Carer Support Service's 2012 Holiday Information Guide


hft
Creative ideas Fulfilling lives
FAMILY CARER SUPPORT SERVICE
Holiday Information Guide 2012
For people with learning disabilities and family carers
A practical guide and ideas for holidays in the UK and abroad

This free guide is designed for people with learning disabilities and their families, but many support staff also request copies.

This year's edition has 48 pages and includes sections on:

- Useful advice
- General Guides
- Tour Operators
- Places to stay – UK
- Meeting specialist health needs
- Places to stay – abroad
- Special interest holidays
- Benefits and help
- Insurance
- The Family Carer Support Service

The guide can be downloaded at www.hft.org.uk/holidayinformationguide

Or you can request a copy by sending an A4 self-addressed envelope, with the appropriate postage to the address below. Each guide weighs 158 grams. 1 x guide = £1.20 first class and £1.10 second class.

If you would like multiple copies please calculate the postage cost by the number of requested guides and their combined weight.

Please contact us if you would like more than 4 guides at:
Hft / FCSS,
5/6 Brook Office Park,
Folly Brook Road, Emersons Green,
Bristol, BS16 7FL
Telephone: 0117 907 1751

Email: familycarersupport@hft.org.uk

REPORT BACK

Creative Communication Training

This was a packed programme with lively, interested participants, from a variety of backgrounds; education, health, advocacy, families, group homes and the community.

There was a good balance between interaction and responsive activity, with more traditional presentation and discussion. The presenter Kate Burns, created an environment that felt relaxed, but business like - empowering people to take part.

The day started with some mood and scene setting activity - that certainly broke the ice and got people communicating. Well, what would you expect from a training course called Creative Communication? The activity led effortlessly into an overview of some of the theoretical approaches to creative communication. These drew from management training to more traditional and familiar models from education, social care and health, including intensive interaction. All were contextualised and developed for people with PMLD and opened up discussion at each point.

Speaking personally I went with the intention of looking for ideas that could support a 'book club' for my son - provide him with an opportunity to have his friends round, with a purpose that was meaningful for him and gave a focus for the friendships. It would, in a rather contradictory but contrived way support what others regard as 'naturally occurring' friendships.

So the training for me was to be a sort of ideas fest, from which I could harvest what I needed from the creativity I was hoping to see. In fact it delivered more. In particular it served as a reminder that friendship and communication is built both around the bigger project - such as the book club or a jubilee weekend - but also, on everyday conversation we have just for the sake of it. However much we like to gloss in reviews and assessments this conversation doesn't happen easily or as often as should for people like my son who cannot speak, don't have the fine motor skills or abilities to use complex communicator or sign. As family we often forget that others may need support and encouragement to converse with our son. Everyday conversation and chat sometimes has to be planned and opportunities created - scaffolding carefully placed. We don't really like to think about it, but people need to be trained and reminded that just having a chat needs to be part of everyone's experience - even if they cannot speak words back. So, there were broader issues briefly, but importantly raised during the day around Human Rights; inclusion, respect and dignity. (sowing seeds and timely reminders)

The afternoon was largely devoted to the Creative Communication part on Mencap's Involve Me project. For more information regarding this important project to include people with PMLD in decision making for them as an individual and to influence the wider agenda for people with PMLD go to www.mencap.org.uk/involveMe , where you can view videos of the project, download a report and an independent evaluation.

The afternoon was packed with information regarding creative ways of using a range of objects, devices and strategies. All of which would be of interest to new teachers in special schools, teaching assistants, mainstream staff, any one from children or adult health and social care, or advocacy services hoping to promote the voices of people with PMLD. The power of the creative communication project appeared useful in promoting more choice, control and communication within one social care setting, that continued beyond and outside the life of the project - the films made have been shown at a Learning Disability Partnership Board and had influenced further funding decisions. There were controversial and challenging aspects to the projects - these were raised and discussed. All of which supported the learning experienced on the day of the training.

For those with a playful nature the day was rounded off with an opportunity to do just that, play.

Future Creative Communication Training offered by Kate Burn can be found on her website:
www.can-communicate.co.uk
07976528659

Helen Daly PMLD Editorial Group and mum.

PMLD and Communication – Looking to the Future

A Study Day at Penhurst School, June 15th 2012

This biennial event is always over-subscribed, so once again Action for Children's Penhurst School's facilities were crammed to capacity with eager delegates, presenters and exhibitors as experts in PMLD from around the country gathered in Chipping Norton in anticipation of a stimulating and inspiring day. We were not disappointed!

We were delighted to welcome back, as keynote speaker this time, Dr. Penny Lacey, from the School of Education at Birmingham University (pictured below). As well as engaging her listeners with her incorrigible enthusiasm for anything to do with PMLD, Penny gave us feedback on her research, commissioned by Mencap, into the shape of future PMLD provision in this country. Being a self-confessed fan of inclusion, Penny discussed possible models in which this could take place, whilst retaining the need for a personalised curriculum with individuals' needs being met. Her vision, backed by her research findings, is that:' Every child, wherever they are placed, should be guaranteed these 4 things:

1. Appropriately trained teachers, support staff and therapists working together with the children and their families
2. A curriculum and teaching approaches that are based on their specific individual needs
3. Participation in meaningful learning experiences
4. Inclusion in their learning community'

Penny was also pressed into running one of our six varied seminars which ran throughout the day. Penny spoke on 'Teaching learners with PMLD to think', and passed on her passion for all things to do with cognition in early learners. All the seminars were of particularly high quality this year:

- delegates were introduced to TaSSeLs, a brand new soon-to-be-published tactile cue system (very professionally presented by Joe Woodall and Denise Charnock)
- Laura Blake delivered a very practical session on how to bring stories to life for people with PMLD with interactive story-telling
- improving engagement was the focus of Bev Cockbill's seminar on using the Complex Learning Difficulties Disabilities (CLDD) Engagement for Learning Framework
- Hector Minto used his insatiable energy to wow his audience with the latest advances the use of eye-gaze in sensory environments
- and Penhurst's own Rosie Bailey, who is a specialist in Intensive Interaction, outlined how we sustain the approach at Penhurst.

In addition, our Occupational Therapist, Gillian Taylor, who specialises in IT and communication, gave a stimulating presentation of a case study of a student at Penhurst who, although officially cortically blind, has been using an eye-gaze system to operate a paged communication system.

We were grateful to several top companies for exhibiting their resources and ideas for delegates to browse round during refreshment breaks. Inclusive Technology and Liberator brought a plethora of equipment suitable for PMLD, and we were brought up-to-date with the latest technologies by Ability World and Sensory Guru. Breadth of interest was provided by stands by Soundabout and SMILE. And many thanks to Penhurst's wonderful chef, Shane Newman, who provided the most wonderful lunch and refreshments.

It was evident that the high quality of the day extended to our delegates, who were keen to lap up all nuggets of inspiration, and stimulated interesting discussion from beginning to end. Delegates had travelled from far afield (from Manchester to Sussex) and clearly appreciated the day.

Reflecting on the day, it was clear that the level of expertise in, and commitment to, the field of PMLD is high, which bodes well for maintaining excellence of practice. As we looked to the future, there was real optimism that the skill and enthusiasm present at the conference would be taken back to a wide variety of settings to make a difference to the lives of many children and young people with PMLD.

Janet Trebilcock
Head of Therapies, Penhurst School

Kith and Kids - conference with Luke Clements - Law Professor and Solicitor

Luke Clement's presentation was based on questions submitted by members of Kith and Kids. Although the questions were focused on residential care, very helpfully Luke drew on the boarder principles of community care law. There was an enormous amount of detail - all of which was highly relevant. The hall was packed mainly with family carers, but there were also professionals and service providers.

Below is a list of the questions asked (some have been conflated) and a few sentences teasing out Luke's main points. Applying legal principles is always highly specific to each person and their circumstances. This is an interpretation of what was said.

1) What statues apply to residential care for people with a learning disability?
In Adult services the main statute is the National Assistance 1948. Luke's favourite Act! Basically if you are an adult and in need of accommodation or care and attention for any reason then the local authority has a duty to help you.

Unless you qualify for Continuing Care in which case this is NHS law. Sometimes there is a joint funded package Children are accommodated under the Children's Act section 17 for respite care or accommodated under section 20 of the Act.

2) Who is eligible for what type of residential provision?
This depends on the person's assessed needs. The assessment must be undertaken by someone with the appropriate skills and they will need knowledge of the type of person they are assessing. So if the person has autism or profound needs they should have skills appropriate to do these types of assessment. This is not a form filling exercise.

An assessment is about what if. 'What if we don't help Fred, what if we don't do what Fred or his family want….WHAT WILL BE THE CONSQUENCES? If the answer is significant harm will happen then the provision has to be made; if the answer is nothing much will happen then they don't have to provide.

Significant harm may be that someone will become depressed or run over by a car etc. The job is for a skilled professional to assess risks, based on their experience and evidence about an individual; including things like social isolation or a person's ability to live in the community. Evidence can be based on many things and it will be helpful to the assessor if you are able to provide letters, school or college reports, current risks assessments, statements from friends or family or circles of support etc.

If a person is 18 or over the initial assessment should assume that there is no 'liable family'. This is based on section 1 of the National Assistance Act - Section 1 abolished the Poor Law of 1531. At later stages when the care planning begins family may want to be involved in care giving and looking after their family - but they don't have to do this. For example if Fred needs 24/7 care - family may say they are happy to look after someone at the weekends and in the evenings - but not during the day in the normal working week.

Theoretically an assessment is triggered by the appearance of need - in practice most people have to ask for one.

3) How are decisions made about residential placements?
Decisions should be made based on evidence given for the assessment and care plan. A reasonable body would look at the evidence and come to a decision based on the evidence.

LA/NHS must act reasonably; they cannot reject an existing suitable placement for a non-existing hypothetical future plan.

If an alternative placement does exist and it meets the need of the person and is cheaper then the person may need to accept that alternative provision/placement. However, the placement must meet all the needs - if a person's needs are around permanence, continuity, location, environment etc - then the alternative placement/provision may not be suitable and may not meet all the needs. The care plan must meet all needs.

4) How can we protect the existing placement?
Answering this question Luke addressed 3 important issues; i) local authorities have a target to bring people back to an area, ii) pressure to reduce the number of residential placements and iii) best interest decisions.

i) Bringing people back to an area he said - there is no legal requirement for services to do this. People can legally choose to stay where they are. Although it is a good thing for services to be provided close by - if people moved away because there were no services they cannot just be dragged back. Cost can however be taken into account unless there is evidence that assessed needs cannot be met - see also point 3 above.

Regarding costs - a council may have to produce the evidence that a placement is cheaper - and this is not always as obvious as it appears. Cheaper options do not always include all the costs.

ii) Reducing residential placements - Luke noted that many residential homes had deregistered and so were no longer residential homes, thus the number of residential placements had reduced.

iii) Best interest decisions are taken when someone lacks capacity to make the decision themselves. Whether someone has capacity can be quite a subtle issue. It is covered by sections 2 and 3 of the Mental Capacity Act. A person must be able to understand, retain and weigh in the balance factors involved in a decision.

MC is largely indicated by the consequences of making or not making a decision. The more serious the consequences of making or not making a decision the more understanding a person would need to have about the decision.

Best interest decisions can be made regarding where a person lives if they lack capacity. If the decision has to be made on someone’s behalf using section 4 of the Mental Capacity Act the Act requires people making that decision to consider a number of things. Two of these are of particular interest.

You must get the views of the person and go as far as you can with the grain of those views, ensuring the happiness of the person. You must also seek the views of significant others. That means family and other carers, including providers as providers have a lot of information and are crucial to supporting a decision.

A best interest decision must be based on a best interest assessment that should produce a balanced view with evidence regarding the best path to take. There should be a best interest balance sheet if a package is to be changed. This sets out the good and the bad things that a move would produce.

A very important case regarding the absence of a best interest assessment involved Ealing who tried to bring someone back from a residential farm in a rural setting to a ground floor flat in Ealing London. The person had been sent to a rural setting 30 years ago - the last 10 years they lived at a residential farm in Hertfordshire. The judge remarked ' Ealing is not local for Alan and there is no community there which would be meaningful for him....It is not enough to say that the benefits of community living may matter to Alan if one cannot show that they will. Facing up to these realities does not in any way diminish or demean Alan, but values and respects him for who he is.'

The Judge went on to say ...that guideline policies cannot be treated as universal solutions, nor should initiatives designed to personalise care and promote choice be applied to the opposite effect.'

The local authority can appoint an Independent Mental Capacity Advocate - but they need to either think that a person has no relative or friends or there is a safeguarding issue. Sometimes safeguarding is misused, by and large IMCAs see through this.

5) What are the issues and rights around deregistering charity care homes and which is best, supported living or residential care?

There is law which is particular to charities and their responsibilities to the people they are helping.

In general there is nothing great or bad about supported living or residential care - people should concentrate on what works well for a person.

If a care home is deregistered then the people in the care home become the responsibility of the local authority even if until that point they have been funded by a different authority. Registering means the home is subject to monitoring by the Care Quality Commission. Both types of provision are in a difficult position in the current climate. Some of the funding streams around supported living are turned on and off and are not always secure; contracts in residential homes are under scrutiny. What ever option is decided on - realise behind the scenes what the implications are around budgets.

What happens if a placement is unsatisfactory?
Collect evidence, keep records, take photographs or even film. You must first tackle this locally and insist on a process with timescales. There used to be timescales now there aren’t. But do check if there are any local or organisational guidelines - if there are not - then still attempt to get the issue resolved within what could be regarded as reasonable time scales. If you have done this the next stage is to go to the Ombudsman.

Frequently there are very good people in local authorities who can and do help. Look for people and networks that can help. Look at new mechanisms for information.

Helen Daly PMLD Editorial Group and mum.

SHORT COURSES & CONFERENCES

Providers Details

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

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

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

Free training opportunities in Glasgow, Highlands and Island, and Grampian

Our programme of free self-directed support capacity building training (funded by the Scottish Government) is now set and you can view details of our courses on our website at http://www.viascotland.org.uk/training

Courses include An introduction to being a Personal Assistant Total communication Recognising harm Risk enablement Supervision Assertiveness Moving and handling If you direct your own support, are employed in a supporting role through self directed support or are a family member who supports, please book now for any of our courses.

From August	
Title:	**Free courses in Scotland**
Locations:	Glasgow, Highlands and Island, Grampian
Provider:	Values into Action Scotland
Contact:	Web: http://www.viascotland.org.uk/training Email: cath.hurrell@viascotland.org.uk Tel: 0141 880 9055.
September	
Title:	**Intensive Interaction: Connecting with non verbal children and adults with Autism or Profound Learning Disabilities**
Date:	September 6th Glasgow, 13th Chorley, October 4th Middlesbrough, 18th Birmingham, 18th Leeds, November 12th Manchester, 13th Chorley, 14th Brighton, 15th London, 22nd Cardiff
Provider:	Concept Training
Title:	**Making information and communication easier to understand**
Date:	September 17th, November 12th
Location:	Birmingham
Provider:	Building Bridges Training
Contact:	Email: admin@building-bridges-training.org Tel: 0121 559 9197
Title:	**Safeguarding and protecting people with intellectual disabilities**
Date:	19th
Location:	London
Provider:	Royal Society of Medicine
Contact:	Ruth Threadgold. Tel: 020 7290 3942 Email: intellectual.disability@rsm.ac.uk

Title:	**In Action: Storytelling & Storysharing with people with severe & profound disabilities**
Date:	20th
Location:	Frome, Somerset
Provider:	Openstorytellers
Contact:	Tel: 01373 471 171 Email: info@openstorytellers.org.uk
Title:	**Practical and Effective Ways of using Multi-Sensory Equipment**
Date:	September 19th Glasgow, 25th London, October 11th Birmingham, 12th Manchester, 17th Belfast, 18th Dublin, November 9th Ipswich, 12th London, 21st Doncaster, 22nd Middlesbrough, December 6th Liverpool, 10th Glasgow,
Provider:	Concept Training
Title:	**Families and Early Childhood Intervention: Ecology of Development**
Date:	13-14th
Location:	Braga, Portugal
Provider:	EURLYAID Annual Conference 2012 Web:
Contact:	eurlyaidconference2012@gmail.com
Title:	**Intensive Interaction: Connecting with People Who are Difficult to Reach**
Date:	September 13th Chorley, October 4th Middlesbrough, 18th Birmingham, November 15th London
Provider:	Concept Training
Title:	**Intervenor Course, and for those assigned to work with a Deafblind/ Multi Sensory Impaired child or adult**
Date:	17th- 21st
Location:	Peterborough
Provider:	SENSE (in partnership with the University of Northampton)
Contact:	Email: sam.cook@sense.org.uk Tel: 01778 392244
Title:	**Rebound Therapy for SEN**
Date:	27th- 28th
Location:	Newcastle upon Tyne
Provider:	EQUALS
Title:	**iPads and iPods in special and inclusive education**
Date:	September 27th Edinburgh, October 1st Liverpool, 10th Nottingham
Provider:	Hirstwood Training Ltd.

October	
Title:	**Tackling mobility challenges in children**
Date:	1st
Location:	London
Provider:	Royal Society of Medicine
Contact:	Helen Whitman Tel: 020 7290 3949
Title:	**Promoting the well being of children with complex needs**
Date:	2nd
Location:	London
Provider:	The Royal Society of Medicine
Contact:	Ruth Threadgold. Tel: 020 7290 3942 Email: intellectual.disability@rsm.ac.uk
Title:	**Intensive Interaction Co-ordinator Course**
Date:	*Beginning* October 2nd, 21 days in 7 blocks of 3 days through to November 2013
Location:	Great Malvern, Worcestershire
Provider:	Intensive Interaction
Contact:	Web: www.intensiveinteraction.co.uk/ events/co-ordinators.php
Title:	**Positive Practices in Behavioural Support Through Nonlinear Applied Behaviour Analysis**
Date:	October 9-12th Glasgow, 15-18th Manchester, 22-25th Newcastle-upon-Tyne, 30- Nov 2nd London
Provider:	Institute for Applied Behaviour Analysis, Los Angeles
Contact:	John Marshall. Email: jmarshall@iaba.com
Title:	**Intensive Interaction (with Dave Hewett)**
Date:	October 12th Birmingham, November 9th Barnsley
Provider:	INTERACT
Contact:	Helen Janes: Email: events.made.easy@ntlworld.com Mob: 07778178346

Title:	**PMLD – Engaging Children in Learning**
Date:	October 9th Taunton, 16th Birmingham, November 22nd London, 27th Brighton
Provider:	Concept Training
Title:	**Whole Person Communication** – *communicating and connecting with children and adults with profound communication needs*
Date:	16th London, 23rd Chorley
Provider:	Concept Training
Title:	**Sensory Approaches for Autism**
Date:	October 19 Leicester, November 9th Newcastle, 30th Sheffield
Provider:	Hirstwood Training Ltd
Title:	**Communication through sensory interaction, with Clive Smith**
Date:	October 22nd Manchester, November 28th Birmingham, December 7th Bristol
Provider:	Hirstwood Training Ltd.
Title:	**Horizontal Teamwork in Dufferin County**
Date:	23rd
Location:	Orangeville Ontario, Canada (an hour north of Toronto)
Provider:	Child and Family Services in Orangeville Ontario
Contact:	Email: dorothy.mclachlan@dcafs.on.ca
Title:	**How to be an Effective Learning Support Assistant for Pupils with Special Educational Needs**
Date:	October 24th Chorley, 25th Manchester, November 9th London, 14th Birmingham, 15th Leicester
Provider:	Concept Training
Title:	**28th Annual Conference on Young Children with Special Needs and their Families: Realizing the vision**
Date:	28th – 30th
Location:	Minneapolis, Minnesota, USA
Provider:	Division for Early Childhood (DEC) of the Council for Exceptional Children
Contact:	Email: presenter@dec-sped.org Web: www.dec-sped.org

Title:	**Possibilities in the Field of Early Childhood Intervention**
Date:	29th - 31st
Location:	Budapest
Provider:	The Early Intervention Centre of Budapest
Contact:	Email: info@eciconf-2012.hu
Title:	Making information and communication easier to understand
Date:	19th October, 7th December
Location:	Austin Court Birmingham
Provider:	Building Bridges
Contact:	web: www.building-bridges-training.org email: admin@building-bridges-training.org
November	
Title:	**Maximising the Effectiveness of your Multi Sensory Room**
Date:	6th
Location:	Manchester
Provider:	Equals
Title:	**Storytelling for Change**
Date:	15th
Location:	Frome, Somerset
Provider:	Openstorytellers
Contact:	Tel: 01373 471 171 Email: info@openstorytellers.org.uk
Title:	**Play for People with Autistic Spectrum Disorder**
Date:	15th Birmingham, 20th London, 23rd Taunton, 26th Chorley, 27th Doncaster
Provider:	Concept Training
Title:	**Introducing the Great Goal Setting System**
Date:	November 16th Glasgow, 19th Preston, 23rd Nottingham, December 5th London
Provider:	Hirstwood Training Ltd.
December	
Title:	**Developing a Maths Curriculum for Pupils with Very Special Needs**
Date:	7th
Location:	London
Provider:	EQUALS

LONGER COURSES (with accreditation)

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

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

BPhil, PGDip and MEd Inclusion and SEN
Year 1 Learning Difficulties and Disabilities (Severe, Profound and Complex) Year 2
Autism (Children) or Autism (Adults)
Distance Education
This two/ three year course contains 6 modules and students study the required number from this list for their chosen award plus a dissertation.
1. Understanding Learning Difficulties and Disabilities
2. Interventions for People with Learning Difficulties and Disabilities
3. Learning Difficulties and Disabilities: Communication and Behaviour
4. Special Educational Needs of Children with Autism *or* Autism (Adults) Understanding and Working with the Continuum of Need
5. Curriculum and Treatment for Children with Autism *or* Autism (Adults) Intervention, Care and Education
6. PGDip includes a practical project based on your work

MEd includes a research methods module and a dissertation
For further details: The University of Birmingham, Penny Lacey p.j.lacey@bham.ac.uk or Helen Bradley h.bradley.2@bham.ac.uk

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

MSc in Advanced Practice

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

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

Postgraduate Courses in Profound and Complex Learning Disability

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

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

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

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

AdCert, BPhil, PGCert, PGDip, MEd.

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

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

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

AdCert, BPhil, PGCert, PGDip, MEd.

Multisensory Impairment (Deafblindness) - *Distance Learning*

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

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

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

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

Adults with learning disabilities who have significant and complex needs

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

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

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

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

PMLD LINK
sharing ideas and information

Subscription Year 2012

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PMLD LINK
sharing ideas and information

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

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

About Us

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

Rob Ashdown	Headteacher of St. Luke's Primary School, North Lincolnshire, for children with complex learning difficulties
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	National officer for 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
Penny Lacey	Coordinator of the University of Birmingham course in severe, profound and complex 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
Carol Ouvry	Retired special education teacher, trainer and consultant in the field of PMLD. Previously editor and administrator of PMLD Link

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Vol 24 No 2. Issue 72

ISSN 2042-5619