

People and places

What's in this newsletter?

A safe home and good care in hospital are basic expectations we all rely on. Sadly, they are not a given for children, young people and adults with severe learning disabilities and behaviours described as challenging. Everyone should receive care in hospital that is effective for their physical or mental health. As an adult, being supported to live in your own home in the local community helps give a greater level of independence.

In this new-look newsletter the first article focuses on one family's experiences of an Assessment and Treatment Unit, published this week in the report 'Transforming Care: our stories'. An article written by family carer Lynne describes how her son Aaron obtained and recently moved into his own bungalow close to his family. Consultant Learning Disability Nurse Joann Kiernan explains how Alder Hey Hospital is improving its learning disability service for children. Finally there's a sample from the email network and our supporter's news, including Tom Crossland running an Ultramarathon around the Grand Canyon this week.



Viv Cooper, CEO of the CBF

Progress is still needed in Transforming Care

The CBF have contributed to a project along with charities National Autistic Society, Sense, Scope and Mencap, to gather the experiences of people with learning disabilities and/or autism who have been in inpatient settings. A report called 'Transforming Care: our stories' has now been published, containing the stories of 13 families and recommending actions for the Transforming Care programme and wider services. Lorna is a family carer who has been supported by the CBF and now volunteers for the charity as a Local Champion. This is an extract of Lorna and her son Kamau's story, taken from the new report.

Kamau is a 33-year-old autistic man from London. When he was younger, he was admitted twice to inpatient care for short periods, shortly after being prescribed anti-psychotics. In June 2014, he was sectioned after he was put on Depakote, and deteriorated further after being put on lithium. The reason given for the section was Kamau's challenging behaviour. His mother Lorna says that his behaviour hadn't been challenging prior to medication – something that professionals seemed to previously agree with, as anti-psychotics had been successfully withdrawn before. For five months in 2014, Kamau was an inpatient in Doncaster, before moving to a low/medium secure unit in Essex, where he remains.

Lorna worries about the use of medication. She said, "I am concerned that none of the drugs seem to be beneficial to Kamau." Kamau's physical health and wellbeing deteriorated too. "His skin is very bad and is completely cracked on his feet.

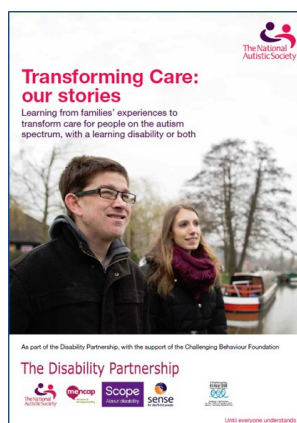
The last blood tests I knew the results for also said that his liver and kidneys were being affected by the medication."

Lorna attended Kamau's latest Care and Treatment Review. She said, "This time, it feels like if a place were identified he could move out... I will need to push for him to leave. I am definitely dissatisfied. I'd like to know the names of the places that are being considered and that the right experts are being consulted. I also feel it is imperative that home is considered as one of those options."

Following the CTR a new psychiatrist was employed and she gradually withdrew lithium. Staff at the unit say they see no deterioration in Kamau since the withdrawal. Lorna is concerned about the staff turnover. Kamau has had multiple psychiatrists over the past two years. The psychologist had resigned, as had a number of the care staff. She is also worried that they don't understand autism. Lorna told us, "I don't

think the staff are used to dealing with people with autism, they're used to people with a mental health diagnosis. It doesn't work with Kamau. If you shout at him, his challenging behaviour will get worse because of the loud, negative way he's being approached."

Read the full story and the 12 others in the report [here](#).



Aaron's New Home



Aaron in his new home

As our son Aaron reached adulthood and the end of his time at school, we immediately began our search for local council homes. Cases such as his, however, do not appear to be a priority and, despite widening our search to include unsuitable shared accommodation and residential placement options, when Aaron turned 19, we were left with nothing.

Luckily at this point, we found an agency prepared to support Aaron while he lived with us. This worked well but as his parents, we felt that it was detrimental to Aaron's development to have him supported anywhere other than his own home.

After a careful search, we found a derelict bungalow not far from the family home that we thought could serve as Aaron's new base. But, although we had the full support of Aaron's social worker, the process of buying the bungalow was far from easy. A buy to let mortgage was impossible and we looked at releasing equity from our own house but this also fell through. We were left with no choice but to sell off our investments and release our pensions. We received no funding or grants of any sort to help us complete Aaron's home. We carried out essential renovations ourselves and appealed to family to kindly help out.

When eventually it was finished we faced another struggle to get Aaron's housing benefit. After an initial rejection, we appealed, but it was only after a meeting with the heads of the council that it was finally agreed Aaron was entitled to it.

Now aged 21, Aaron has been in his home for 8 months. He is extremely settled and we have no doubt this was the best thing we could have done for him. All through we had the support of the care agency looking after Aaron. They understood exactly what our aims were and built a dedicated team to be in place when Aaron moved in, making his transition so much easier.

Lynne, Aaron's mum

Updated resource: Planning Your House

People with severe learning disabilities and behaviours described as challenging have the same rights as everyone else to appropriate local housing and support.

The CBF has recently published an updated the 'Planning Your House' resource, which provides information and advice to family carers who are planning personalised living options for their relative.

This information pack gives guidance on what to consider when choosing a property for a person with severe learning disabilities, such as who to live with, the type of home, ideas for adapting existing homes and what help is available to support your relative living there.

Download the resource [here](#)

or order a hard copy via info@thecbf.org.uk / 01634 838739



*Planning Your House
Information Pack*

Newsflash

Engaging with children and young people

The CBF are working on an exciting project to gather the views of children and young people with severe learning disabilities about what good support looks like. From the families we have visited so far we have learnt a lot about engagement using methods other than speech. Look out for our findings in the next newsletter and on the CBF website.

Medication Information Pack for family carers

Continuing from work to gather the views of family carers on use of psychotropic medication, the CBF will be publishing a new resource in October about what families can do to ensure medication is used appropriately for their relatives. Look out for this interactive online resource and a paper copy to order. The resource is funded by NHSE.

Thank you and good luck!

The CBF team would like to thank the interns who have worked with us over the past year: Alex Truscott, Wilfred Chitembwe, Huw McDonald and Suzi Scott. You have all worked hard and achieved such a lot while at the CBF.

Who are the CBF? We are the charity supporting those with severe learning disabilities whose behaviour is described as challenging.

Download our free resources

We have a wide range of resources for family carers and professionals available on [our website](#)

Improving Services for People with Learning Disabilities and Autism at Alder Hey Hospital

We asked Joann Kiernan, a Consultant Learning Disability Nurse, about her work improving care for children with learning disabilities when they are in hospital.

The recent Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD) and the introduction of Learning Disability Mortality Reviews (LeDeR) are both aimed at trying to understand why the inequalities in access to healthcare faced by people with learning disabilities and/or autism exist. It is clearly a multitude of factors that contribute to these issues for both service users and their families. As part of a strategy aimed at trying to improve access to healthcare, Alder Hey Children's Hospital in Liverpool have created the new role of Consultant Learning Disability Nurse. This post was designed to support the trust in improving services offered to children with learning disabilities and/or autism and their families, and I feel very lucky to have been the person chosen to fill it.

As one of only two posts in the country the role builds on existing work happening across the trust, supporting the development of user-friendly, equal access and provision for all. As a result of the national drivers and in response to the needs of children, families and staff, an acute liaison nurse has also been employed specifically to look at supporting the trust in making access to care and providing reasonable adjustments as easy as possible. As we all know, **hospitals can be scary places**. We hope that if we improve experiences in the early years of a child's life they will be more likely to want to access services to get their needs met in the future.

Key developments for Alder Hey have included the creation of a Learning Disability and Autistic Spectrum Condition Steering Group that incorporates staff, families and local voluntary organisations to direct future developments and ensure real participation in building resources for all in the trust. A local parents reference group feeds directly into the steering committee to help Alder Hey in **listening and working alongside those who use the services**, so they can share their experiences, expectations and most importantly ideas. Working in this way has so far taught us that families and children have the best, most practical, simplistic and often cost-effective ideas that have real impact on care. Their enthusiasm to help us improve is fantastic.



Alder Hey Children's Hospital, Liverpool

All work undertaken at Alder Hey relating to the strategy for learning disability and/or autistic spectrum conditions are shared with the local acute liaison network in Liverpool. This was originally formed by the Liverpool Clinical Commissioning group and has since gone from strength to strength in ensuring that services are working together to support continuity of care for all as they move between services across the Liverpool area, both within hospitals and the community. Working alongside Liverpool Mencap, the network has developed training packages, assessment tools and information for patients and staff. They are to be standardised across services and to **help people negotiate their care through the multitude of providers** that they come into contact with to get their health needs met.

A further exciting area of work for Alder Hey has been the development of Positive Behaviour Support training that has been designed to highlight the needs of children who may particularly struggle with the hospital environment, new faces and often painful procedures. The response from all levels of staff to this type of training has been overwhelmingly positive. The training focuses on how behaviour is perceived and how staff can interpret the message that a child's behaviour sends to allow us to adapt our care approach to their needs and listen more effectively. I think we need more of this across all mainstream services to ensure that responses to people's distress are supportive and proactive. The appetite and level of commitment to get better at this has been overwhelming for me as a learning disability nurse. We must do more to inform and support people on the frontline of supporting people.

I am happy to share the work being done at Alder Hey as part of the much larger agenda to make access to acute health care more effective. We can only do this by working in partnership and really listening to children and their families.



Joann Kiernan
Consultant Learning Disability Nurse

Your questions from the Email Network

Q: Our son, who is non-verbal/ non-communicative, has profound autism and displays challenging behaviour, has recently taken to self-managing by biting his forearms. Has anyone experienced a similar problem and found a solution which worked for them?

A1: I know how distressing this can be. My son tends to hit his face with the heel of his hand, but I do find it is usually when he is in pain or discomfort. If this is a new behaviour for your son, it might be an idea to check his ears, teeth etc. I know this can be difficult to do - it is with my son - but it's worth checking out if you can, although it does involve a lot of detective work.

A2: A sensory free environment reduces my son's behaviours that challenge and his self harming. Provide an environment that is super quiet, clutter and pattern free. A good resource would be Positive Behaviour Support (PBS) to see ways to understand your son's behaviour and why he is using it. Through using PBS with my son I found that his behaviour or self harm was used for 'social escape' and sometimes from sensory overload. This helped me better understand his needs and so how to reduce the behaviours that challenge.

A3: I do understand your concern; our daughter also self-harms in this way. We've tried giving our daughter chewy pendant necklaces to try and persuade her to chew those instead. If your son has only recently started displaying this behaviour, I would be inclined to think about anything that has changed in his life that might be causing him added stress or anxiety, or anything that you think might be making him feel unwell or in pain. I hope you are able to identify the reason for your son's behaviour and help him to stop hurting himself. I know how helpless it can make you feel to witness this sort of behaviour without knowing the cause.

A4: My son does the same. My technique for mitigating it is to not react, remain calm, hand him a chewy stick and say 'here, chew on this' and try to keep it lighthearted (in case he takes a reaction as something to be encouraged). Longer term, the only solution is to figure out why he is doing it. I now know in my son's case it is pain from chronic constipation and perhaps IBS or something similar, so I'm working on managing that. I feel quite strongly that there is a reason for behaviours such as biting arms, and in particular if it is a new behaviour, it is trying to tell you something. If there is no obvious trigger (and it may have a clear trigger, such as sensory issues), then consider pain.

The Family Carers' Email Network enables you to be in touch with a number of families around the UK. You can share experiences, information and receive support - without any obligation to reply or to identify yourself.

Being put in contact with other people who have been in your shoes has proved to be invaluable for many of the families who contact the Challenging Behaviour Foundation. Members of the Email Network have told us they feel less isolated and 85% of members feel more confident in supporting their relative because of ideas and advice from families on the Email Network.

"I just love the email network it makes me feel less isolated"

"It is good to get information, advice and encouragement from other families who have faced similar problems to ours. It is also good to be able to help others from our own experiences"

Want to ask your own questions or share your experience?

Join the Family Carers' Email Network [click here](#)

The CBF also runs a Professionals' Email Network, to find out more and apply to join, [click here](#)

Supporters' News

From Land's End to John O'Groats by Bicycle

Peter Baker, an academic at the University of Kent's Tizard Centre, and his team recently completed a sponsored bike ride all the way from Land's End in Cornwall to John O'Groats at the tip of Scotland raising an incredible £2,390 for the CBF. Over the nine days it took them to complete the journey, they travelled in total 945 miles and climbed over 62,700 feet.

This is not the first time the team have set themselves a formidable challenge. Last summer they cycled 850 miles on the west coast of Italy, but felt the trek wasn't tough enough. The cycle to John O'Groats saw them face gruelling climbs through Cornwall and Devon up to Cheddar gorge, but Peter said the most difficult part of the trip was powering through the border into Scotland where they faced days of heavy rain and battled against a strong head wind.

The challenges weren't enough to put Peter and his team off though. Next year, they will be attempting the 790 miles from St. Malo to Nice in France.

You can still add to Peter's fundraising page at: <http://bit.ly/2rSOWHC>



Peter and his team reach John O'Groats

Tom Crossland's Grand Canyon Ultramarathon

My name is Tom, and I'm raising money for the CBF by running the Grand to Grand Multiday Ultramarathon. Grand to Grand is a seven-day race starting on the north rim of the Grand Canyon and covering 250 km of desert to finish at the top of the Grand Staircase in Utah, USA.

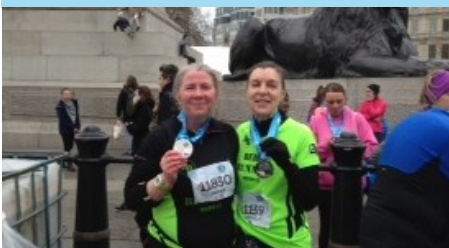
I have been running ultramarathons (50km+) for a few years now and last year I completed the Thames Path Challenge. I was looking for a focus for the next year when I came across the Grand to Grand, which seemed a perfect combination of exploration with adventure and running.

It took me a long time to decide which charity to support. As well as running, I have a passion for human rights and have worked as a clinical psychologist with people with a learning disability and behaviour other people find challenging for many years. I know families who have found the CBF's support invaluable and so when I heard Peter Baker speaking about his fundraising, I was really keen to try and raise money for the CBF. If you would like to sponsor me my link is <http://bit.ly/2uPmlzc>



Tom Crossland

Thames Meander



CBF running enthusiast Helen encouraged Carina to take up the sport last summer. They have since run a few 10k races together. Their next challenge is the Nov 4th Thames Meander half marathon to raise funds for the CBF. Any donations will be greatly appreciated.

Quiz Nights



Our successful quiz nights run through the year at the Millennium Centre, St Margaret's Church, Rainham Kent with the next scheduled for 10th November. If you are interested in helping out as a team or with a prize donation please email info@theCBF.org.uk

Hundred Club Winners



Recent winners of the £25 prize were:

April 2017 - Alistair Cutler, Kent

May 2017 - Paul Cooper, Kent

June 2017 - Carol Smart, Staffordshire

July 2017 - Jackie Cheeseman, London

Want to join for just £12 for a chance to win each month? Email info@theCBF.org.uk

Can you help us?

We rely on donations, grants and fundraising to continue our work helping families. Find out how you can help us on [our website](http://ourwebsite)

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