

Challenge

Spring 2019



Transforming Care

Welcome to this edition of Challenge focussing on Transforming Care – a national programme due to end on 31st March 2019. Transforming Care followed national outrage at the abuse of people with learning disabilities uncovered by a BBC reporter at a private hospital in 2011. The Department of Health Transforming Care report (2012) acknowledged ‘the system’ did not provide the right support, in the right place, at the right time and as a result people ended up in inpatient services, often out of area, long distances from their families and at greater risk of restrictive practices and overmedication.



Vivien Cooper

The date for transformation has been reached but care has not been transformed. The families we support tell us that there is still a lack of timely, skilled, local support in place and the CBF will continue to campaign for change. The Government and all parts of ‘the system’ must learn from past failures and work together to deliver the changes they promised so children and adults have the life opportunities they have a right to.

A key lesson is to properly invest in families – who provide long term love, care, support and advocacy for their relatives, something the CBF embeds in all its work. We now have an exciting opportunity to access funds to deliver free workshops for families about Positive Behaviour Support across Meridian East. Find out more on page 3!

Transforming Care Policy Update

In October 2015, ‘Building The Right Support’ was published, setting out a plan for investing in high quality, community based support. The NHSE Transforming Care (TC) programme set targets for March 2019 to reduce the number of people with learning disabilities and/or autism in inpatient units by 35-50% (based on data for March 2015), and simultaneously to improve local support for these people to live well in the community.

NHS Digital has been publishing data on the number of people with learning disabilities and/or autism in inpatient units, including age, transfers and distance from home. In March 2015, there were 2,865 inpatients and the latest figures (and the trend over the past three to four years) show a disappointing failure to meet the TC targets. At the end of December 2018, 2,325 people with learning disabilities and/ or autism were in inpatient units - a reduction of around 19%. Of this total, 260 were under the age of 18. The NHS long term plan was published in January 2019 which moved the deadline for bed closure targets of 35-50% reduction to 2023/2024.

NHS England commissioned an evaluation of Building The Right Support, which is due to be completed by July 2019. An interim evaluation report has just been published, available on The Strategy Unit website (<https://www.strategyunit.co.uk/publications/building-right-support>). The report makes a series of recommendations including for better policy alignment, increasing commitment to co-producing solutions with individuals and

families at local and national level, and support for the social care workforce.

What next?

NHS England will publish a document in the spring that should set out how they will achieve the targets in the long-term plan. This needs to address the challenges in developing appropriate community support that have prevented bed closure targets being met since 2015. It also needs to outline how these can be overcome as soon as possible and before 2023/24.

What are we doing at the CBF?

Delivery of the ambitions of TC requires multiple organisations across health, social care and education to work together in a co-ordinated and structured way to drive the transformation that has yet to be achieved.

The CBF, along with other stakeholders, is pushing for a **cross-government, joined-up approach** to tackle the barriers to TC. We are calling for this approach to include the Department of Health and Social Care, the Department for Education, the Department for Housing, Communities and Local Government, and the Ministry of Justice.

We have written to Ministers in these departments and, on behalf of the Challenging Behaviour National Strategy Group, to the Prime Minister setting out the issues and solutions and why must commit to action now. In partnership with families, we have met with government ministers, worked with the media, and will continue to press for effective and immediate action.

By Coral and Mary, CBF

Nine years on: Winterbourne nurse who punched patient is struck off by nursing regulator

A nurse who punched a patient in the face at Winterbourne View hospital, breaking his jaw and leading to the loss of teeth, has been struck off by the Nursing and Midwifery Council (NMC), following a Fitness to Practice Hearing.

The assault took place in 2009. A previous NMC hearing in 2017 found that the nurse had committed the assault, but that the physical force used was proportionate. This shocking conclusion was overturned in the High Court and the NMC was ordered to hold a further hearing.

Emma, sister of the victim of the assault Ben, said 'This case followed an incident that should simply never have happened, the impact of which will likely be felt for the rest of Ben's life. Whilst we can take no joy in an outcome that takes away the livelihood of a practising professional, we welcome the justice afforded to Ben, and the protection that this decision provides for other vulnerable patients, now and in the future. We hope that this sends the necessary message to professionals who abuse their positions of power, that the voices of vulnerable people can and will be heard, and that there can be no excuses for abuse and neglect in our health or social care systems, or in our society.'



Ben with his dog

Viv Cooper of the CBF, said 'Ben's case is shocking on a range of levels: that a trained nurse could inflict such a violent assault on a patient, and that the system to protect him and hold people to account should be so slow and difficult to navigate. People with a learning disability and behaviour that challenges continue to experience unacceptable treatment in inpatient units, where they are vulnerable to assault, over-medication, seclusion and restraint, and experience trauma with long term consequences. Concerns raised by families, advocates and whistle-blowers must be taken seriously and be swiftly acted on.'

Mental Capacity Act Update

The Act, which provides safeguards when people lack capacity to make decisions, is being revised by Government. There have been many problems in implementing the Act in health and social care, so changes are needed. However, CBF and campaigning partners are keen to see appropriate changes are made that benefit people with learning disabilities and ensure individuals and their families are at the centre of decision making.

The major change will be from Deprivation of Liberty Safeguards (DoLS) to a new process of 'Liberty Protection Safeguards', that serve the same purpose of legally authorising restrictions to an individual's liberty but have key differences.

The reading of the Bill in Parliament took place in December 2018, following which there was a public consultation which the CBF responded to. The Bill passed its third reading, with amendments, in February 2019.

It is important the MCA is fully understood and adhered to in practice and the MCA Code of practice is currently being updated. The CBF, in consultation with families, have provided recommendations to the updated code of practice and will continue to input alongside other key organisations as its developed.

Information resources

The CBF have updated several information resources since the start of the year.

Understanding Challenging Behaviour, Finding the Reasons for Challenging Behaviour and Positive Behaviour Support Planning. These three-part information sheets about behaviour have been reviewed and updated. Practical information has been added and they have been made more accessible. Aimed primarily at family carers, these information sheets are also useful for support workers and professionals.

Specialist Equipment and Safety Adaptations has been checked and new products added. It contains ideas on ways to make the home safe, lists relevant products and suppliers, and includes a section on funding.

Family Carers Information Directory is a handy reference of specialist organisations, books, websites and blogs covering various topics that families encounter, but are not part of the CBF's main information offer. New entries have been added on topics such as sibling support, personal accounts, advocacy and education.

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 at: www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/info-sheets-and-dvds.html

The People's Projects

A partnership with



Vote for: Learning Disabilities – Supporting Families

Challenging behaviour impacts the whole family – from limiting what the person is able to enjoy, to disrupting family life for siblings, to physical and mental health problems for family carers. Specialist information and support is needed, but there is not enough practical help and support available to families.

The CBF need your vote to provide this support to families.

Our project *Learning Disabilities – Supporting Families* has been shortlisted for funding from National Lottery's The People's Projects. If we get this funding we will run challenging behaviour workshops for families throughout the Meridian East region. The workshops have already been delivered to many families, who have told us how helpful they were. Now we want to reach more families who we know are struggling or in crisis.

Our workshops will give around 500 families the skills and knowledge to understand the reasons for the behaviour, and how to prevent it or respond to it safely. They really do make a long term change to the person and their whole family's lives.

Please vote for *Learning Disabilities – Supporting Families* now, to make a difference to families' lives.

Watch the film about our project and **VOTE FOR US** here! www.thepeoplesprojects.org.uk/projects/view/learning-disabilities-supporting-families

The voting is open from 9am on 1st April to midday on 15th April. You can vote from anywhere in the country and you can vote in more than one region, but you can only vote for one project per region.

The winners will be announced on Thursday 18th April on the 6pm regional ITV news broadcast and on the Peoples Postcode website after 6.30pm at www.thepeoplesprojects.org.uk

Thanks for your support!



VOTE NOW!
www.thepeoplesprojects.org.uk



T&C apply. See website for details. Voting opens 9am 1st April 2019 to midday 15th April 2019.

A home for Philip at last



My son Philip is 21 years old. He has autism, severe learning disability, epilepsy and challenging behaviour. In February 2008, Philip moved to a residential school in Bristol. In 2014, he was diagnosed with bipolar disorder and, as a result, his residential school gave notice on his placement.

Philip with his mum, Caroline

It took the Local Authority (LA) ten months to relocate Philip. He moved to a private hospital near Nottingham, in July 2015. While he was settling there and making good progress, we looked for a care home nearer to home (South London). We identified a new home which was just 50 minutes' drive from home.

It took eight months for Philip to move to the care home in July 2016 because of changes in management and a difficulty in recruiting staff. When he moved, Philip displayed aggressive behaviour, which prospective parents complained about. This resulted in Philip being given notice only five weeks after he moved there. It took the LA three months to find another placement. The transition process had already started when I went to visit the home. However, I didn't think it was the right placement for Philip, even though staff claimed to be experts in autism and challenging behaviour.

Philip moved to the next home at the end of November 2016 and he never settled down. He ended up spending all day locked in his room. After six weeks, he head-butted his bedroom window and he was taken to A&E in Nottingham. The home refused to take him back. He was sectioned under section 2 of the Mental Health Act and moved to an assessment and treatment unit (ATU) in the North East (more than five hours drive away from home) in January 2017.

Philip was first put in seclusion, then he was moved to the 'long-term segregation' area. He was 'care away' from others and the staff never attempted to let him use the communal area with the other patients.

I contacted the CBF to ask for help and advice on how to move Philip out of the ATU. It was clear to me that he needed a person-centred service and I decided to look for a bungalow. I was surprised that the LA did not support the offer I had made on a property in July 2017, saying that I shouldn't rush into it and that Philip was not ready for

discharge yet. As a result, I fell out with the complex care reviewer and a new one was appointed in December.

In January 2018, the ATU gave notice to the local CCG to move Philip out as they could not meet his needs. The complex care reviewer worked really



Philip cooking in his bungalow

hard to identify care providers and other hospitals nearer to home. Two potential care providers went to assess Philip in the ATU and one was selected in May 2018 to care for Philip back in South London. It took another four months before the CCG identified a suitable property.

Philip finally moved into his bungalow, which he is renting, in November 2018. He is supported by three carers 24/7. He has his own motability car and he is enjoying going out for a drive.

I see Philip every week in his own place, but I can't wait to take him out for walks and for him to visit us at home. However, I have to be patient, as I have been advised to take things slowly, stage by stage, so that he is more settled and more predictable. Above all, we want to avoid Philip becoming distressed and displaying aggressive behaviours where he has to be restrained and that caused him to spend 22 months in an ATU.

Philip's new care team has started taking him out in the park and he loves running free and interacting with the staff. They also let him in the kitchen and near the cooker so that Philip knows his meal is on its way.

By Caroline, family carer



Philip enjoying time in the park

Questions from the email network

Q: I'm looking to purchase a special needs bike/trike for my adult daughter, as she doesn't like walking much and needs to get some exercise. As her only income is benefits and her father and I are on a very low income, we can't afford to buy this ourselves. Does anyone have any ideas as to where we could go for some financial help with purchasing something like this?

A1: Cycling is a great idea. My son loves it.

Have you tried any local inclusive bike clubs? To give your daughter a chance to try different types of bikes out and give advice about purchasing one.

Try this website to find a club near you:
www.cyclinguk.org/community-outreach/inclusive-cycling-network

A2: Many parents raise money for special needs equipment from GoFundMe: www.gofundme.com/

A3: The bike idea sounds wonderful.

I would approach your Learning Disability team/adult social services and propose this so your social worker or the duty social worker can make a request via panel.

This is something that could help reduce frustration, potentially? It could help fill time positively when not everything can for our sons and daughters. There's obviously a reason: social experience or quality of life for your daughter, given her level of need.

It's helping your daughter to access her community and is investing to save as it is a special piece of equipment that she needs to be happier, thus less challenging.

A4: My son has a Di Blasi Folding Trike, which is great for him, as it will go in the boot of his vehicle so his support workers can take him to different traffic-free places to ride it.

www.missioncycles.co.uk/product/diblasi-r32/

Want to ask your own questions or share your experience? Join the Family Carers' Email Network by emailing network@theCBF.org.uk for an application form.

Newsflash

Restrictive Interventions

The CBF published a joint report with Positive and Active Behaviour Support Scotland (PABSS) in January called 'Reducing Restrictive Intervention of Children and Young People'. <http://bit.ly/2HCtMdc>

This work was undertaken due to significant concerns about harmful restrictive intervention of the disabled children and young people whose families we support. The report shares data collected through a survey and case studies, showing hundreds of restrictive intervention cases, with some children being restrained or secluded regularly.

The report recommends action to better understand the scale of this issue; to ensure staff have the right skills; better family support; and accountability at all levels. We have formed a group of families and other organisations to work together to try and influence these changes.

#HumanToo Campaign

#HumanToo is uniting people, families, campaigners and charities behind a simple ask that people with a learning disability and/or autism should have what every human deserves: an ordinary life and a home not a hospital.

#HumanToo aims to get everyone listening and government acting so the 'right support' is built in the community, and homes not hospitals can become a reality.

How you can help

When you tweet about autism, learning disability or both, please use the #HumanToo hashtag.

Change your social media profile picture to this #HumanToo avatar to show your support.

Sign and share this petition: <https://petition.parliament.uk/petitions/231406>

Thank you for your support and please follow us **HumanToo** and Twitter: **@HumanToo2**





How I became a family carer trainer

Last year we planned to recruit a mix of new co-trainers to enable us to deliver more workshops to families and professionals around the country. We were awarded funding from two organisations: the People's Postcode Lottery and the Big Lottery Awards for All fund. By October, we had everything in place to run the Core Training induction days and so we started. This article is written by Jan, one of the successful candidates.

I'm the mum of a 26-year-old son with a severe learning disability and challenging behaviour.

I knew about the CBF so, when I heard they were recruiting family carers as co-trainers, I thought this would be a fantastic opportunity to do something outside my usual routine. I haven't worked for many years and this was an ideal way to dip my toe into an area in which I have expertise, among individuals who understood my circumstances.

My application led to two fascinating days at head office undergoing Core Training. My co-trainees were family carers and professionals from across the country. It was encouraging to meet people who were genuinely committed to improving the quality of life for people like my son.

I returned a few weeks later to deliver a presentation alongside a professional co-trainer – we collaborated via email and as a 'technophobe' I even managed to pick up new computer skills to put it together.

Delivering the presentation was the biggest challenge. Other trainees were doing a great job and I couldn't remember the last time I'd stood to speak to a group. All did go well, and feedback was supportive and positive. Then the final stage: delivering two workshops alongside an experienced professional co-trainer.

I arrived ridiculously early for the first workshop, and spent a nervous time flicking over my notes and drinking more coffee than was good for me. My co-trainer was very relaxed and supportive. The abiding memory of this workshop is a feeling I was among friends. The attendees had different experiences and circumstances, but we all had much in common.

I arrived at a more reasonable time for the second workshop and meeting the same attendees made me feel more relaxed. I felt comfortable speaking without recourse to my notes.

In the past six months, I have gone from making an enquiry to becoming a CBF family care trainer. The benefits have been considerable. I have reflected upon what is working for us as a family, how we might improve in some areas and how I can offer support to others.

Next month, I'm doing more workshops. I still feel a healthy amount of nervousness, but it was a great feeling when a friend recently asked what I was doing on a particular day to say 'I'm working.'

Jan, Family Carer Co-trainer



New CBF Co-trainers, October 2018

Supporters' News

How I became a CBF volunteer!

My name is Ian, dad to a now adult son who lives with a severe learning disability, autism, epilepsy and severe and challenging behaviour. I first contacted the Challenging Behaviour Foundation for help when things were getting more and more difficult as my son approached his teenage years and his behaviour was becoming ever more challenging.

I can still remember the feeling of helplessness that came with not knowing who to ask for help and am so grateful to have found the CBF who have been there through the difficult challenges that we have faced offering support, advice and information whenever we needed it.

When I found out about the Local Champion volunteering scheme, it seemed a great way to help others in my situation using my lived experience and to help the CBF reach more families.

For me, being a CBF Local Champion is as enjoyable as it is rewarding, and it's wonderful being able to meet people facing similar challenges to ours and make a small difference to their lives.

The CBF will provide you with the training, support and resources that you will need, commitment is completely up to you. If you have lived experience to share and some time to help, please give it a try.



A Local Champion's information stall at an event

There are many ways to raise awareness about the CBF including:

- Representing the CBF at a conference
- Talking to people in a group or organization about how the CBF can support them
- Giving out CBF publicity and information resources to parents and professionals at an event
- Showing CBF films to a group, for example our short film about good support - Everybody Matters.

The CBF is will be recruiting volunteer Local Champions from around England over the next two years. You need to be a family carer but no experience is necessary as we are holding training days for new volunteers. If you are interested, please email Gemma at volunteering@thecbf.org.uk

100 Club!



To find out how to join and see a list of recent winners, please see the Donate page on our website: <https://www.challengingbehaviour.org.uk/learning-disability-files/100-CLUB-APP.pdf>

London Marathon!



Good luck to Josie Warner who will be running the London Marathon on Sunday 28th April and raising funds for the CBF: <https://uk.virginmoneygiving.com/JosieWarner>

Cake sale!



Nawsheen and Sonia held a cake sale at Fort Pitt school to raise money for the CBF. Their drive and passion for it to be a success meant that they raised a total of £305. Their support is greatly appreciated by us all!

Can you help us?

We rely on donations, grants and fundraising to continue our work helping families. Find out how you can help us at: www.challengingbehaviour.org.uk/support-us/support-us.html

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The Challenging Behaviour Foundation. Registered Charity No. 1060714 (England and Wales). Address: The Old Courthouse, New Road Avenue, Chatham, Kent, ME4 5BN. Email: info@thecbf.org.uk. Tel. 01634 838739. www.challengingbehaviour.org.uk