

Challenge



making a difference
to the lives of people with
severe learning disabilities

Spring 2015

THE NEWSLETTER OF THE CHALLENGING BEHAVIOUR FOUNDATION

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'Challenge' is the newsletter of the Challenging Behaviour Foundation, supporting those caring for individuals with severe learning disabilities whose behaviour is described as challenging

Joshua's Story

Joshua's world and our world changed in 2012 never to be the same again. We became insignificant and powerless as the system took control, overlooking Joshua's right to a family life and our rights as parents. While we should have been celebrating our child's 12th birthday, plans had begun to send him away.



Josh and Sarah

Authorities in Cornwall deemed that Joshua's needs could only be met in an Assessment and Treatment Unit (ATU). We strongly felt that this move would overlook his emotional and environmental needs, and could end with devastating consequences. It was clear that our voice was not going to be heard. We were led to believe that Josh would be sent away for a 12 week assessment. It soon became apparent that Cornwall did not consider Joshua's return an option – they felt they did not have the facilities.

It's a 6 hour journey from Cornwall to the ATU. We fear that something awful will happen and we won't reach him in time. The ATU provides 24-hour protection for Joshua in case of emergency, but is an incredibly restrictive environment, and the number of new faces makes him anxious. There is so much focus on practicalities that Josh – the cheeky, free-spirited, emotional boy – has become forgotten. On one of my first visits he took me to the door, tears in his eyes, picked up his blanket and asked to go home. This killed me inside; how do you explain to a child with autism that he has been sectioned

and you have no power to take him home? The ATU soon realised that Joshua was incredibly distressed being away from us, and backed us up in saying he needed to be near his family and home. As parents we felt unsupported and not listened to. The powers that be were going to do as they

wished, and our views and knowledge of our child were unimportant. It took the support of the CBF and Mencap to very slowly get Joshua's voice heard, through first the public petition and then the consequent meeting with Norman Lamb (Care Minister) and his team. Though the change.org petition was our last resort, without this public campaign I don't believe there would ever have been a chance of Joshua returning.

I will always believe that if Josh and our family had been listened to from day one, it just may have reduced the need for the ATU and he may still be living with us now.

The only advice I can give is to fight for what you believe in, know your rights, and get lots of backing from the CBF, Mencap, the Local MP, the health minister, etc. My son and many others have paid a terrible price at the hands of the system and the government needs to wake up and take action.

Sarah Pedley
Joshua's mother

Your Comments

After recommendations made in the NAO report (see page 5), the NHS pledged to close residential hospitals for people with learning disabilities in a Public Accounts Committee (PAC) hearing. Read a transcript of the hearing on www.bit.ly/pachearing. On Facebook, we asked what you thought about the closure programmes.

"Future change depends on if his words are followed by meaningful action and not just more papers and reports. It will also depend upon effective sanctions on those who commission services to make sure they actually provide effective and person-centred local provision, and on the Government to make sure that adequate funds are made available locally as CCGs and Local Authorities don't have the resources to cope by themselves". (Ian)

"They need to assess the individual needs of the people. This includes thinking about how they will access communities (if possible and they not a risk to themselves or the general public) with specialised staff and support, and if they need specialised buildings and environments." (Karen)

"They also need to make sure the correct support is available for the people moving out of hospitals, if indeed what they are saying happens at all. Call me a sceptic!" (Debs)

"Is the pledge they have made legally binding? If not then it won't happen, we all know this and yet we settle for report after report saying the changes we need, whilst in reality nothing changes." (Jane)

Thank you for all of your fantastic comments!

If you'd like to feature in this column we'd love to hear from you! Look out for our posts on

[facebook.com/theCBF](https://www.facebook.com/theCBF) and
[@cbfdn](https://twitter.com/cbfdn),
 or send your comments to
communications@theCBF.org.uk

'Knowledge Is Power' When It Comes to Rights and Choices



Vivien Cooper

This edition of Challenge focuses on rights and choices, two words which should be, and often are, used when considering how people with learning disabilities are included and supported in our society. But as always, translating the words into concrete and meaningful outcomes for people can be a challenge.

My disabled son has the same rights as his non-disabled sisters – it never entered my head that there would be any difference between them. But too often I have heard it said that people with learning disabilities should have the same rights as everybody else, when the reality is that they actually already do. This is clearly spelled out in a Government document about people whose behaviour challenges services: "They have the same human rights as everyone else." (Mansell 2 report, 2007). However, in practice it is not just having rights, but exercising them that makes the difference. And the starting point here is knowing about your rights in the first place. Even then, as one parent put it, "knowing about your rights is not much use if you can't make it happen".

Children and adults with learning disabilities who display behaviour described as challenging can end up

being excluded from local schools, support and services because the right support to meet their needs is not designed around them. This can lead to placement in out of area residential schools and homes, automatically denying them to them their right to a family life. But challenging such decisions on these grounds is rare.

"Choice" is another widely used word, but again it can be misused. I have witnessed several occasions where there is a "choice" but only from restricted options, the most extreme example of this being "you can have this or nothing"! Sometimes there is an attitude of, "you can choose, but only if you choose what I want you to have". So the key thing here is to ensure that there is a real and proper choice, from the full range of options available, and that people are supported to make an informed choice.

There is a saying: "knowledge is power". When it comes to rights and choices, good information about what those rights and choices are, along with good support to exercise them and make informed choices, can be very powerful. At the CBF we try to equip families with good information about rights and choices so that they are empowered to help their loved ones access the same life opportunities as everyone else. In this issue of Challenge there is a range of information about people's rights and choices, and we share some practical tips and ideas from families and professionals that we hope will help people to exercise their rights and make informed choices, and ultimately have better lives.

Vivien Cooper OBE

Chief Executive and Founder of the Challenging Behaviour Foundation

Driving Change: Rights & Choices

The first Challenge of 2015 focuses on the right to choose. This includes the right of an individual to make choices, the right of carers to have a say in their relative's care, and everybody's right to a family life.

All too often, we hear from families who are struggling to have their voice heard when decisions are being made about the support that their family member will receive. The articles on the front page and page 5 are written by family carers whose relatives were sent to Assessment and Treatment Units far from home, and who have fought to have a say in their care. If you are worried about not being involved in decisions made about your relative, go to page 8, where our 'Spotlight on...' column talks about how to use our Mental Capacity Act template letters. For more information on carers' rights, look at the Care Act 2014 graphic on page 6, and an upcoming rights resource on page 7.

We believe that people with severe learning disabilities and behaviours that challenge should have the same life opportunities as everybody else. This includes being involved in choices about how they live their life, from everyday decisions to life-changing ones! Communication Passports are a fantastic tool for giving a voice to people who find communication difficult; we talk about Passports and the new website www.mycommpass.com on page 4. With the 2015 General Election approaching, we all have a big choice to make. Go to page 7 for information on how to get involved in Mencap's Hear My Voice campaign, which is helping people with a learning disability and their families send messages to local candidates about the things that they want to see change.

We have information sheets on our website about the rights of people with learning disabilities and their carers. Our Family Support Service can also tell you about your rights. Remember that the Family Support phone number has changed! You can still email support@theCBF.org.uk, but the number is now **0300 666 0126**.

About Us

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK through:



Information



Supporting You



Workshops



Driving Change

Our vision is for all people with severe learning disabilities who display challenging behaviour to have the same life opportunities as everyone else and, with the right support, to live full and active lives in their community.

Our mission is to improve understanding of challenging behaviour, empower families with information and support, and help others to provide better services and more opportunities to children and adults with severe learning disabilities who display challenging behaviour.

To access our information and support, or find out more about what we do, call **01634 838739**, email info@theCBF.org.uk, or visit our website: www.challengingbehaviour.org.uk

Richard



My son, Richard, is nearly 40 years old, is diagnosed with severe autism, and sometimes displays challenging behaviour. He currently lives with two other young men in our community, in a shared home.

I first contacted the CBF several years ago. I was desperate for answers about Richard's living situation – he was depressed and his behaviour was deteriorating day by day. When I had contacted organisations previously, I found they didn't understand Richard's specific needs. Their judgemental and sarcastic comments made me feel awkward, and information they sent me had nothing to do with what we had spoken about.

The CBF listened to my anxieties and worries without judgement. They sent me information about challenging behaviour, including DVDs which I found very helpful, as I realised that my emotions were 'normal'. I became aware that there was a reason behind Richard's behaviour – he was trying to communicate that his needs were not being met. The CBF helped me to contact different people to improve the situation, including social services.

Through the CBF I have found a network of support. I have been able to meet other parents who had similar experiences. When I first contacted the CBF I was rejecting my son as I didn't see a way out. Now I have become close to him again; I understand his needs and have the energy to fight for them!

Maria Magadan
Richard's mother

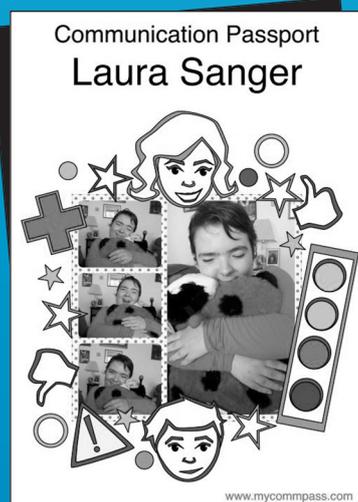
Creating a Communication Passport

Communication Passports are a guide explaining how best to interact with someone. Some Passports, for example Laura's, go further and include drawing relations between events that happen in the environment and the effect on the person's abilities and behaviour, as well as vital information about things like diet and medication. Passports are usually written as if the individual it is about has written it themselves – this will help readers to remember that it is what they would be saying if they could.

A good Passport gives explicit details of what to do and what not to do when it comes to an individual's care. This means that if there has been a mistake or an incident, a meeting can be established and it is possible to see what happened, compared to what should have happened. This way, Passports provide a strong standard to which all those involved in care should work to meet.

Some things a Passport can include are:

- Emergency contact information
- Medication
- Diagnostic information
- Best methods of communication
- Staying safe (e.g. outside the house)
- Sensory profile
- 'Things I like' and 'things I don't like'
- Behaviour support plan (you can find out more about this on our website, in our information sheet 'Positive Behaviour Support Planning: Part 3')
- Functions of challenging behaviour
- Diet and eating habits
- Personal care and hygiene



Laura's Communication Passport



Laura and her sister, Jenny

Laura is 22 years old and has Cornelia de Lange Syndrome. I discovered quite early on that there were going to be many different professionals involved in Laura's life.

Having so many people involved with Laura's care results in lots of different information to communicate. Each individual who works with her needs to know about all the important information that we collectively have learned about Laura, who she is, and how she understands the world around her.

As Laura's mother, through our experiences, I have learned what certain facial expressions mean; and what particular behaviours are likely to have been caused by. Additionally, I am the central point at which all reports regarding Laura's care come together.

The challenge for me was: How do I convey all this accumulated knowledge to each professional Laura will encounter? Someone told me about something called a "Personal Passport" and gave me the address to a website that explained all about it. After checking the website I decided to make one for Laura. It has proved invaluable. She

carries it with her at all times in the form of an A5 booklet. I also email a copy to anyone who is concerned with her care.

We used the CBF's template of a behaviour support plan and traffic light system in Laura's passport. When we first discovered the CBF, we were struggling to make sense of Laura's behaviour, and they provided the support and tools to help us understand the function of Laura's behaviour. I am so grateful to the CBF for the knowledge, skills, and training that I have received from them over the years. They have made a huge difference to not only Laura's life but to all of us as a family.

Laura's Communication Passport has come with a long list of benefits, including accountability, versatility/mobility, empowerment, and helping Laura feel and act her best! Laura's Passport teaches others the best way to communicate with Laura, and where there is good communication, there are much better outcomes for that person.

Kate Sanger
Laura's mother

The information about Communication Passports on this page is taken from Kate (Laura's mum), Jenny (Laura's sister) and Laura's fantastic new website. Go to www.mycompass.com to find out more. You can download Laura's and Daniel's Passports, and there's a template and guide to help you make your own.

Fauzia

My niece, Fauzia, was transferred to a forensic psychiatric hospital in Northampton in 2012, when number of factors had caused her Tourette's, self-injurious behaviours, and anxiety to worsen. There was minimal handover communication and the hospital was not prepared for Fauzia's admission. She was immediately fully restrained for the first time in her life and placed in seclusion, where she remained for a number of weeks to months. She suffered a catastrophic deterioration in her emotional health, as she was repeatedly medicated, restrained, and kept in isolation. The inpatient team did not have expertise in, or an understanding of, Fauzia's complex needs. I came to understand that not only is the system not able to meet the needs of our most vulnerable children, it is damaging and lacks understanding.

Until we gained support from the CBF, we felt powerless and increasingly hopeless. The hospital's interactions with the family were defensive and aloof and the hospital's complaint system was ineffective. We were advised to submit a formal complaint, which prompted a poor quality response from the hospital, and over a year later we have still not received a full response from NHS England. Fauzia finally moved to a specialist provision with the right expertise at the end of 2014. She is no longer restrained or medicated; the improvement



Fauzia and her mother, Sarah

in her life has been profound and immediate.

Changes need to be made so that families and professionals can secure the right care for young people like Fauzia. There needs to be expert commissioning of the appropriate services and interventions for this group of highly complex patients. There should be a responsive, independent, complaints process, and families should be given clear

information about who is ultimately accountable, as well as advocacy for the patient.

My advice to other family carers is to try to work collaboratively with professionals and organisations as far as you can. If you are not being listened to, use formal complaint structures. Seek advice from the CBF and experienced solicitors, and try to find good advocacy for your relative. Be consistent, calm, and polite. Always be confident in your knowledge of your child/relative. When it comes to your family member, you are the expert. If the professionals do not appreciate this, it is an indication of their lack of understanding. It is deeply distressing and exhausting. Do not give up.

Shahana Hussain

Fauzia's aunt, and Consultant Child & Adolescent Psychiatrist

National Audit Office Report

On February 4th, the National Audit Office (NAO) published a report called 'Care services for people with learning disabilities and challenging behaviour'. The report was a result of an examination of the public money spent by the Government on learning disability services and meeting its 2012 Winterbourne View Concordat commitments.

£557m spent on people with learning disabilities in hospitals 2012-13.

£5.3b spent on community services for adults with learning disabilities 2013-14.

"The process of moving people with learning disabilities and challenging behaviour out of hospital, where appropriate, is complex and defies short-term solutions...NHS England has made a disappointingly slow start to this task. Although it has now increased its activity, there are formidable care, organisational and service hurdles to overcome in establishing a new model of care in more appropriate settings."

Amyas Morse, head of the NAO

Here is a summary of the key findings of the report. To read the full report, go to: www.bit.ly/naoreport2015

1. In 2012, the quality of data on inpatients with learning disabilities was poor.
2. Only 2% of people in hospitals were assessed as posing such a risk that they needed to be there.
3. The Government underestimated how hard meeting its commitments would be, and left it to hospitals, commissioners and Local Authorities to make changes.
4. There was no financial incentive for local areas to bring people home.
5. Hospital placements and new admissions have not been reduced as promised, and there is no timetable or ambition to do so.
6. The CQC made unannounced inspections at 150 services after the Winterbourne View scandal.
7. NHS England lacks adequate and reliable data to monitor progress.
8. NHS England have acknowledged slow progress, and set a new target of transferring 50% of inpatients by 31 March 2015.
9. Sustainability of discharges depends on joint work between health and social care commissioners.
10. Developing good community services for this group of people will take time.

Wellbeing

Focus on improving the wellbeing of adults needing care, and those caring for them.

Prevention

Local authorities (LAs) must provide what families need early on, to prevent crisis point being reached.

Integration & Cooperation

Local authorities and the NHS must work together and promote integration.

Information

LAs must provide information about local care and support, and how to access it.

High Quality Providers

LAs must offer a variety of high quality providers and services.

Adult Assessments

All adults have the right to an assessment based on having a need.

Carer Assessments

All carers can have an assessment, taking into account the whole family.

CARE ACT 2014

The Key Points

Transition

LAs must do a needs assessment as a child approaches 18, if the child is likely to need adult care.

Advocacy

LAs must provide advocates for carers or people needing care during assessments if needed.

Eligibility & Funding

Eligibility criteria for accessing LA services and a cap on what people pay towards their own care.

Care & Support

LAs must meet adult/carer needs when they are not able to fund their own care.

Planning

LA must produce care and support plans for people with care needs, and support plans for carers.

Money

LAs must provide a personal budget statement. Direct payments can be requested by anyone eligible for care.

Safeguarding

There are new adult safeguarding procedures. LAs must establish boards to investigate abuse/neglect.

The Care Act 2014 will be partially implemented in April 2015 and fully in place by 2016.

Mencap's Hear My Voice Campaign



Hear My Voice: Simon and Ann

Jo, from Mencap, tells us about their Hear My Voice campaign.

What is the campaign?

Mencap's Hear My Voice campaign (www.hear-my-voice.org.uk) is all about the 2015 General Election. In the last generation, progress has been made in advancing the rights of people with a learning disability, but we still have such a long way to go before they are recognised and treated as equal and valued members of society. At election time politicians are more open to listening to the views and concerns of voters. We want this election to be an opportunity for the millions of people with a learning disability – and all family members and others connected to them – to join their voices together and make political parties and candidates sit up and listen to what matters to them.

Each month we focus on a different issue, and in February we looked at Assessment and Treatment Units. This was a great opportunity to shine a spotlight on the campaign that Mencap and the CBF have been fighting since the Winterbourne View abuse scandal, and to get the issue on the election agenda.

How can you get involved?

1. Share your story with your local election candidates. All you need to do is go to this link – www.bit.ly/1JVaoi0 - fill out your details, and write your story.
2. Join Mencap and the CBF in calling on the three main political party leaders (David Cameron, Nick Clegg, and Ed Miliband) to personally commit to driving the post-Winterbourne agenda forward if they are the Prime Minister after the May 2015 election. You will hear from us nearer the time about how to do this!

If you have any questions you can contact Jo Davies in Mencap's Campaigns team, by phone on **0207 696 5462** or by email on jo.davies@mencap.org.uk. Thank you for supporting the Hear My Voice campaign!

Jo Davies

Campaign Lead, Mencap

Meeting the Challenge: A new resource for families

Emma, a family carer, introduces the rights resource that she has been working on with charities, solicitors, authorities and other family carers

There is no manual for the complexities of life with a family member with a learning disability and behaviour that challenges, no guide to walk you through the knowledge and information that you must gather and make use of as your loved one grows older, no one single way to navigate the system that fringes the day-to-day lives of so many.

Inevitably, families approach the same complicated system in a number of different ways often struggling to negotiate and adapt to the many legalities, policies and processes developed to underpin the lives of those we love. It is accessible, understandable and relevant information that we need; information to support families in the avoidance of the crises that we hear of and experience so often.

The Challenging Behaviour Foundation has worked with Mencap, Respond,

the Winterbourne View Joint Improvement Programme and family carers as well as Irwin Mitchell solicitors to develop 'Meeting the Challenge' - a series of factsheets and films to enable families of adults with a learning disability and behaviour that challenges to gain relevant, helpful knowledge. The films enable people to gain first-hand knowledge from families who have 'been there' and learnt from the experience

The resource has been funded by the Department of Health and the JIP and aims to inform readers about issues such as what good support looks like, what challenging behaviour is and what people need to know if their loved one is sent to an inpatient unit. Also included is a legal factsheet explaining the legal rights of individuals and their families in a variety of difficult situations.

The intention of this piece of work is to offer family members the basic information they need to develop their awareness and expertise, while also providing effective signposting to other

relevant information and organisations for support and assistance where required. We hope that this resource may allow people to 'meet the challenge' with the backing of appropriate knowledge and a true sense that they are not alone.

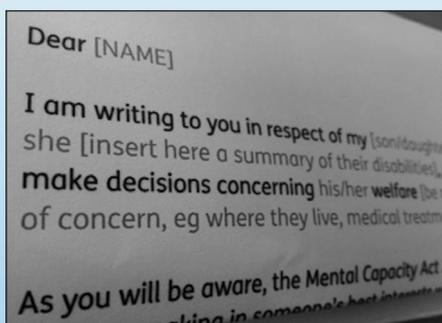
The resource will be available soon on the Challenging Behaviour Foundation, Mencap and Respond websites.

Emma Garrod

Family carer involved in creating the Rights Resource



Mental Capacity Act Template Letters



The CBF, Mencap and Ambitious about Autism have worked with Irwin Mitchell Solicitors to produce template letters for carers who are concerned that they are not being involved in decisions affecting their relative.

If an individual lacks the capacity to make a decision for themselves, then the decision must be made in their best interests in accordance with the requirements of the Capacity Act 2005. This Act says that family members must be consulted as part of the process to make a decision on behalf of a person who is over the age of 16. Family members do not need to be appointed a 'legal deputy' in order to be consulted.

The two template letters included in the resource are intended to help family members who have not been involved, or are concerned that they will not be involved, in the best interests decision-making process.

- Template letter 1 is for when family members are concerned that they may not be involved in a future decision. It clearly sets out the legal requirement to involve them.
- Template letter 2 is for when decisions have already been taken without family members' involvement.

The Mental Capacity Act Template Letters, and relevant guidance, are available free to download from our website. Go to Information > Information Sheets and DVDs > Education, Housing and Social Care.

Q: We are constantly battling with professionals over our son's care and support. Have other families found ways of overcoming these difficulties? It's really draining.

A1: I have learnt not to get too emotional no matter how hard that is, as you may be seen as being over protective. I try to encourage and empower staff rather than nag! Have a carers' assessment and use direct payments for some sort of wellbeing support for yourself like a massage or reflexology.

A2: I received free counselling sessions from a local charity and that helped me get things clearer in my own mind and to keep persevering. I try not to push against something 'I don't want', and instead look for what 'I do want'. I have become a much better negotiator and now have an ability to write a fast, concise, unemotional and brilliant letter!

A3: Any organisation not following a 'co-production' model is now well

behind the times. You could write a letter to say that the lack of co-production shows that they are out of step with present best practice. Then, try to arrange a co-production meeting. Keep records as you will find this very useful as evidence to show that the 2005 Mental Capacity Act is being followed by everyone. Try to find an experienced, knowledgeable yet neutral meeting facilitator.

A4: I used to give in to professionals when they pushed their own plans because I was so overwhelmed by our problems. Slowly I became stronger as they were faced with consequences of their bad decisions. Now they are looking to me for answers and I'm listened to more. I feel we have mutual respect.

A5: I found going on a Mindfulness course really helped me.

A6: Just remember not all professionals are the same. They have a job to do often under huge constraints due to budget cuts. Yes at times dealing with them is frustrating but I have also been very grateful for their input..

Q: Our daughter moved to supported living a year ago. Her carers let her help herself to food whenever she likes and give her crisps/snacks as a reward. We're worried about her health. What can we do?

A1: I have guardianship over my 19 year old daughter who still lives at home. It means, even away from home, I can have an influence on her eating. My response to her carers about her right to have what she wants is that she has a right to a healthy life and they have a responsibility to ensure she is not put in situations where her health will suffer.

(Please note, guardianship only applies in Scotland. Legal deputyship applies in England and Wales)

A2: I can only suggest you get medical support and involve the funding authority who have a duty of care towards your daughter. People over eat through boredom with such high support they should ensure this doesn't happen. I do know what you are up against!

A3: Our son is very food-focussed and this has caused a number of health problems. We have had to fight his care providers as every protocol they have in place involves giving him food to aid compliancy. We argued that this is undoubtedly makes their job easier, but that it is not in our son's best interest, as he does not have the capacity to understand the health implications.

Recommendations for specific products in this article are made by people on our Email Network; inclusion doesn't constitute endorsement by the CBF. Readers are encouraged to evaluate the benefits and risks of each product before use.

These questions and answers are taken from our email networks. Want to join the debate? Membership of the networks is free to both families and professionals supporting children or adults with severe learning disabilities. Application forms are available to download at www.challengingbehaviour.org.uk or email network@thecbf.org.uk.

News

A roundup of what's been happening

Early Intervention Project (EIP) Video Competition



Alfie, who loves playing football!

At the end of last year, the EIP ran a video competition to find out what young people with learning disabilities enjoyed doing outside of school, and who helped them to do these things. Thank you to everybody who entered the competition – the videos were a joy to watch! Congratulations to our winner, Alfie! A compilation has been made which will be shown at commissioners' events around the country. Keep an eye on the EIP section of our website for when this is uploaded.

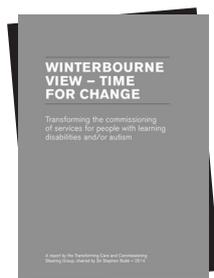
You can read more about the EIP on our website:

www.challengingbehaviour.org.uk/driving-change/early-intervention-project.html

Summary of Reports Published

Over January and February, many reports were published regarding post-Winterbourne View campaigns and strategy. What does each report tell us? Here is a summary, and links to where you can read the reports in full.

'Winterbourne View – Time for Change'



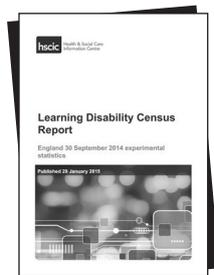
NHS England commissioned this report to address the lack of progress in moving people with a learning disability back into their community from ATUs. The report sets out recommendations made by Sir Stephen Bubb, alongside key stakeholders including the CBF. www.bit.ly/bubbreport

'Transforming Care for People with Learning Disabilities – Next Steps'



This is NHS England's response to Sir Stephen Bubb's report. Mencap and the CBF have said it is 'the first recognition that collectively they understand the scale of the problem but does not do enough to take us nearer to delivering the key recommendations from the Bubb report.' www.bit.ly/nhsresponse

'Learning Disability Census 2014'



This report contains data and information about people with learning disabilities who are inpatients in NHS or independent service settings, including total numbers, length of stay, distance from home, and numbers of incidents. Mencap and the CBF say the data show that 'things aren't getting any better'. www.bit.ly/ldcensus14

'Winterbourne View – Transforming Care Two Years On'



Two years ago, following the Winterbourne View scandal, the Department of Health wrote a report called 'Transforming Care: A national response to Winterbourne View Hospital'. This latest report is a two year follow-up, outlining what has been done and what remains to be achieved. www.bit.ly/2yrson

Innovative, interesting or useful resources available free online

Carers' Rights Guide

Each year, Carers UK publish Carers' Rights Guides for England, Scotland, Wales and Northern Ireland. These cover the essential rights of carers and outline financial and practical support available. www.bit.ly/rightsguide

Human Rights Video

Want to know more about what our fundamental human rights are? This 8 minute animation, produced by the WissensWerte project of e-politik, gives a great overview. www.bit.ly/rightsvid

Human Rights and Learning Disability

How is the Human Rights Act relevant to people with a learning disability? This BILD guide outlines the key points of the Human Rights Act from a learning disability perspective, and signposts to other useful resources. www.bit.ly/bildrights

Learning Disability Alliance Blog

The Learning Disability Alliance (LDA) England is an independent movement to advance the rights of people with learning disabilities. Discover more about LDA England, download information about rights, and find opportunities to share your opinions on their website: www.learningdisabilityalliance.org

SEN Resources

The Council for Disabled Children (CDC) have developed resources about the new Special Educational Needs (SEN) rights. They have a range of other useful guides on their website too; you can find them all on this webpage: www.councilfordisabledchildren.org.uk

Found something interesting online you'd like to share? Email it to communications@thecbf.org.uk, post it to our Facebook page or tweet it to us @CBFd.

A Big Thank You to Our Volunteers



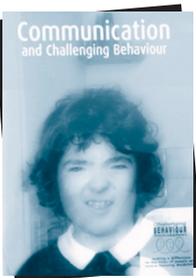
Local Champions Ian, Jen and Jan manning CBF stands at events

We are hugely grateful for the ongoing work of our fabulous team of CBF Local Champions and Family Link Volunteers. Last year our Local Champions attended more than 30 events all over the country, representing the CBF and sharing our information and services with hundreds more families. Family Link Volunteers have continued to provide invaluable support via telephone and email to other family carers.

Are you interested in joining the CBF volunteer team? We're looking for family carers supporting someone with severe learning disabilities whose behaviour is described as challenging to get involved in our growing network around the country. You will need to fill out an application form, and come along to our Volunteer Welcome Workshops. Email volunteering@theCBF.org.uk to find out more.



And Thanks To Our Supporters Too!



The response to our December appeal has been fantastic. We asked supporters to contribute towards the production of our new Communications DVD, and have so far raised £1345. Without your generosity we would not be able to continue our work supporting family carers of children and adults with severe learning disabilities and behaviour that challenges.

During the coming year we need to raise £35,000 to produce the DVD and distribute it free of charge to family carers across the country. If you would like to contribute towards the making of this essential resource, please send a cheque to our usual address. Supporters giving £25 or more will receive a copy of the DVD when produced.

Fundraising Opportunities

Nightrider

LONDON



There are a few places left for this summer's Nightrider cycling event. This really is a fantastic experience, cycling through the City when the rest of the population sleeps! There are 60km and 100km rides, starting from Crystal Palace or Lee Valley Velo Park. Enter the discount code CBF at www.bit.ly/cbfcycle to save £60.

Pottery Workshops



Have you always fancied trying your hand at pottery? Well now you can, and you can raise funds for us at the same time! We can book for groups of 8-12 to take part in a pottery workshop in Maidstone, Kent, for just £15. Get in touch with Laura (details below) to book a workshop.

Assault Course Challenge



The KM Charity Challenge has assault course challenges, abseiling, cycling, dragon boat races, and much more, taking place throughout the year. We have been chosen as one of the charities to benefit from sponsorship raised over the next year. To save £12 on a team booking for the assault course challenge, use the code KMACDL15.

The Challenging Behaviour Foundation is the charity for children and adults with severe learning disabilities whose behaviour is described as challenging and those who support them. We rely on people donating their time and money to us to continue our work.

If you want to find out more about fundraising, or have an idea for a fundraising event, contact Laura Brown on laura.brown@theCBF.org.uk, or 01634 838739.



Students packaging our Winter 2014 newsletter

Thank you

Thank you so much to students and staff at Meadowfield School (Sittingbourne, Kent) for all of their help with our newsletter. Three times a year, when the newsletter has been printed, student teams come into our office and package the newsletter into envelopes ready to be sent off. Thank you – we couldn't do it without you!

100 Club winners

Recent winners of the CBF 100 club, winning £25 each were:

October 2014

Mr and Mrs E Graham
Northumberland

November 2014 (£50 winners)

Frank and Tim Offord
Kent

December 2014

Guy Foster
Kent

Have your say

We welcome articles from parents and professionals. Please get in touch if there is something you would like us to write about.

Disclaimer

While every care is taken in the compilation of this newsletter, the Challenging Behaviour Foundation cannot be held responsible for any errors or omissions, nor accept responsibility for any goods or services mentioned.

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Resource order form

Please note that all of these resources can be downloaded free of charge on our website: www.challengingbehaviour.org.uk

All our information and resources relate to the care of individuals with **severe learning disabilities** who are described as having challenging behaviour. We are happy to send resources **free of charge to parents/ unpaid carers**.

	Cost	Number	Total £	
CHALLENGING BEHAVIOUR DVD RESOURCES				
The DVDs provide practical support from professionals and family carers. Academics or learning disability professionals give expert guidance while family carers share their experiences. The DVDs introduce each topic clearly, explaining the key ideas and offering a wealth of practical information.				
Everybody Matters DVD	£31.50*			
An Introduction to Challenging Behaviour: DVD	£31.50*			
Self-Injurious Behaviour: DVD	£31.50*			
Communication & Challenging Behaviour: DVD	£31.50*			
Challenging behaviour – supporting change: DVD	£63.00*			
Learn about the causes of challenging behaviour, and how to use a functional assessment to put appropriate positive behavior support strategies in place. (Two disc set)				
*Free to parents/unpaid carers. Registered charities: DVDs £16.50 (or £33.00 for Challenging Behaviour – Supporting Change). Price includes postage & packing in the UK only. Outside UK p&p £7.50 per item.				
CHALLENGING BEHAVIOUR INFORMATION SHEETS				
The information sheets are written by experts and provide practical support on a wide range of topics. Each information sheet contains a one-page summary, as well as a longer document providing more detailed information. The information sheets are suitable for both family carers and professionals.				
Understanding Challenging Behaviour: Part 1	All information sheets are available free of charge on the CBF website.			
Finding the Causes of Challenging Behaviour: Part 2				
Positive Behaviour Support Planning: Part 3				
Communication and Challenging Behaviour				
Health and Challenging Behaviour				
The use of Medication				
The use of Physical Interventions				
Specialist Equipment and Safety Adaptations		To order by post please add £1.00 per sheet*		
Impact of Caring on Families				
Planning for the Future				
Further Information for Family Carers				
Ten Top Tips				
BASIC INFORMATION PACK (consisting of the 12 information sheets listed above)	£12.00*			
The following additional information sheets are not contained in the basic information pack but may be downloaded from the Challenging Behaviour Foundation website or ordered separately:				
Do We Have to do This Alone? A FAQ on Circles of Support	£1.00*			
Difficult sexual behaviour amongst men and boys with learning disabilities	£1.00*			
SUB TOTAL CARRIED FORWARD				

*All resources are free to parents/unpaid carers. Prices include postage and packing in the UK only.

/ Continued overleaf...

SUB TOTAL CARRIED FORWARD	Cost	Number	Total £
Getting a Statement	£1.00*		
Making Decisions - The Law	£1.00*		
Pica (eating inedible objects)	£1.00*		
Mental health problems in people with learning disability	£1.00*		
Self-injurious behaviour	£1.00*		
Education, Health and Care Plans (for families)	£1.00*		
Education, Health and Care Plans (for professionals)	£1.00*		
IN-DEPTH RESOURCES			
8 Ways to Get a House A guide to help families think about the different types of accommodation and how they are funded.	£12.00*		
Planning Your House This guide has been developed to enable families to work with others to plan for future housing needs.	£12.00*		
A Guide for Advocates (England and Wales) A comprehensive, practical guide for professional advocates; or family carers advocating for their family member.	£16.00*		
PBS Study Pack for Schools and Colleges The Positive Behaviour Support study pack is designed for teachers to increase understanding of behaviour. Note: This resource is only available for schools and colleges.	£45.00		
Planning for the future: information pack England / N Ireland / Wales	£10.00*		
i			
Read more about all our in-depth resources online at www.challengingbehaviour.org.uk			
DONATION - please consider a donation to support our work. All proceeds go towards helping families caring for individuals with severe learning disabilities whose behaviour challenges. Thank you.			
*All resources are free to parents/unpaid carers. Prices include postage & packaging in the UK only. Outside UK p&p £7.50 per item.		TOTAL	

Please consider making a donation to help us support more families. If you would like to donate regularly, please tick here to receive a standing order form.

Gift Aid means we can claim back the tax on your gift (25p for every £1 you give) at no extra cost to you. Please tick here to confirm that you would like CBF to claim tax paid on this gift and any eligible past or future gifts.

Please note that to be eligible for gift aid you must pay at least as much UK income tax as the amount that will be claimed by all charities you donate to within the tax year.

Please indicate if you are a parent or unpaid carer. If you are a registered charity please provide your charity registration number

Name

Organisation

Address

Postcode

Telephone

Email (please print)

Your personal data may be held on computer and will be kept in accordance with the Data Protection Act 1998 under which we are registered as a data controller. This data will not be passed on to any third party without prior consent.

You can keep informed about new resources through our free newsletter, three times a year. If you do NOT want to receive this, please tick here

Please make **cheques payable** to the Challenging Behaviour Foundation and return to the Challenging Behaviour Foundation, The Old Courthouse, New Road Avenue, Chatham, Kent, ME4 6BE

Alternatively, go to www.challengingbehaviour.org.uk to order online.

The CBF – how you can help

Did you know.....?

- **We are a registered charity and rely on donations, grants and fundraising to finance our work.**
- **We do not charge family carers for our services or resources.**
- **To keep costs down much of our work is carried out by volunteers.**
- **Regular giving by standing order makes your money go further by keeping down administrative costs.**
- **You can 'Gift Aid' your donation if you are a UK tax payer, this allows us to receive 25% extra on top of your donation without any further cost to you.**
- **You can fundraise for free! There are a number of ways to donate and raise money for us without spending any extra money. See our website for details.**

Your support really does make a big difference to us. So, thank you!

For more information please email fundraising@theCBF.org.uk

The Challenging Behaviour Foundation

Registered charity number 1060714 (England and Wales)

Address: The Old Courthouse, New Road Avenue, Chatham, Kent, ME4 6BE

Email: info@theCBF.org.uk
Tel. 01634 838739

www.challengingbehaviour.org.uk