Speaking Out
A “Q & A” with two of our Campaign Families!

What has been the best moment, or aspect, of campaigning?

Helen: Tom Clark MP of the All Party Parliamentary Group mentioned my son by name in a debate in the House of Commons on September 2013. There was recognition for the suffering of my son, who was put away in a hospital which has since been evaluated by CQC as unsafe.

Claire: When I talk within the campaigning group I hear horror stories, but somehow that fact alone gives us a burning desire to fight for change. We are there for each other, we care about each other and we know better than anyone else the pain the care system can cause.

What do you think has changed, or can change, because of the campaign families?

Helen: We have met many officials including the current Minister for Health and Care, Alistair Burt, and the previous minister, Norman Lamb. I have seen most invited officials be deeply moved listening to the campaign families’ accounts of abuse and bad treatment. I like to think some official hearts have been opened by meeting us.

Claire: Huge changes are needed and if we peck at this bit by bit and achieve just something then it is worth it. Let the care sector learn from the good providers out there, listen to their own mistakes and hear from the families who want nothing more than to turn heartbreak into action.

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Advocacy
Speaking out for families, the Gloucestershire Advocacy Project, the Commissioners Guide to Advocacy

Medication
The path to prescription, recent medication reports, a professional opinion, a family perspective

Your questions to the email network
Advice from family carers

News Updates
A round up of what’s been happening, and what’s new on the web

Supporters News
Fundraising art auction, and supporter challenges

‘Challenge’ is the newsletter of the Challenging Behaviour Foundation, supporting those caring for individuals with severe learning disabilities whose behaviour is described as challenging
Thank you for sharing your experiences.

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 and @cbfdn,
or send your comments to communications@thecbf.org.uk

Your Comments

We asked on Facebook, ‘What have your experiences been like of medication being prescribed to people with learning disabilities?’

“My twin sons (they both have autism, severe learning disability and are non-verbal) are prescribed risperidone. […] Although our sons don’t have a mental health diagnosis, the psychiatrist always gets as much information as possible from us and from all professionals involved in their life about how their challenging behaviour is manifesting at any given time. Our sons’ lives and development has improved immeasurably thanks to medication.” (Sophie)

“We felt pressured by my daughter’s special school and consultant to put her on risperidone. It was the worst mistake I ever made and the one and only time we thought we weren’t going to be able to look after her any more. […] As she was still on the lowest dose we said no more and on Dr’s advice gradually withdrew it. NEVER ever again.” (Debs)

“We often try to put myself in Daniel’s position – “if I was him, what would I do?” It can be very revealing as I often conclude: “yep – I would do that too!” Daniel can’t tell me in words how he feels or what he thinks – but if I was him I would want as many people as possible on my side, fighting my corner, making sure I am loved, cared for, and able to do things I enjoy with people I like. Ordinary things – things most of us take for granted.

When Daniel was a baby I quickly realised that unless we were vigilant, an ordinary life would not be what Daniel experienced.

I know one family carer who is a wonderful advocate for her daughter, and has been for many years, who describes herself as “a very private person”. But she has had to attend numerous meetings with “professionals”, negotiate systems and processes across education, health and social care, be assertive and insistent, whilst always remaining reasonable and maintaining positive relationships. It is hard to be a lone voice asking questions – to disagree and to challenge, to be labelled as “difficult”. But what is the alternative?

Some people are able to take this on without support. But most of us need a helping hand – to be armed with information, to know our rights, and to have people alongside us who understand and empathise. And sometimes we need others to help champion our cause – to be the voice where we can’t be.

This newsletter describes how people are speaking out in a range of different ways and what they have found helpful – whether it is advocating for individuals, or trying to effect strategic change through campaigning. For many years the CBF has tried to equip families with information that helps them to achieve good outcomes for their relatives – through individual telephone and email family support, information resources and by connecting people. Alongside this, we campaign on issues such as the overuse of medication. As well as providing specific information resources and practical support for families, the CBF consistently raised this issue at a national level. This summer, reports were published providing clear evidence of the overuse of medication. These reports are a step in the right direction, but what is important is what action will now be taken, and so we will continue to press for change. We can only do this through the families who support our campaigning – who generously share their expertise and experiences, and stand up for their relatives.

But not everyone has a family to advocate for them, and not all families are able to. The families who campaign with us are mindful of those individuals and their vulnerability.

If for any reason I was unable to advocate any more for Daniel, I know that others, friends and family, would continue to do so. We need to get to a place where we all speak up and speak out so that children and adults with learning disabilities have the life opportunities they have a right to. That is the aim of the CBF.

Vivien Cooper OBE
Chief Executive and Founder of the Challenging Behaviour Foundation
Speaking Out

The final edition of Challenge for 2015 is on the theme of “speaking out.” This can take many forms, such as speaking out about mistreatment and abuse through campaigning, or acting as an advocate for somebody with severe learning disabilities.

Our lead story gives an insight into the experiences of some of our Campaign Families, their reasons for speaking out, and their hopes to effect real change for the lives of their relatives, and other people with learning disabilities. On pages 4 and 5 you will find a series of articles on the topic of advocacy. People with severe learning disabilities often have limited communication, or may lack speech entirely. Our double-page spread aims to illustrate the great work advocates do to help give people with severe learning disabilities a voice.

On pages 6 and 7 we discuss the issues surrounding the medication of people with severe learning disabilities whose behaviour may challenge. This is a much debated topic, and the range of the issues is demonstrated by our two perspectives, from a professional and from family carers, and information from the latest reports into medication.

At the Challenging Behaviour Foundation we speak out every day on these issues, but in this Winter edition of Challenge, we would also like to take a moment to “speak out” with some happy news from our staff. As many of our supporters will know, Gemma, our Family Support and Policy Manager, went on maternity leave in August. We are delighted to announce that Gemma gave birth in mid-September to a beautiful baby girl, Isabella, who is now the newest and youngest supporter of the CBF. Congratulations to Gemma and her husband Adam!

*Until people with severe learning disabilities have the same life opportunities as everybody else, the need to speak out remains as great as ever. If you would like to help the CBF’s campaign work by sharing your story, please get in touch. The more voices speaking out, the greater chance we have of making a difference.*

Family Story

We asked CBF supporter Emma Pullar to share her experience of family holidays with her brother

‘Let’s do this,’ Ben’s voice bellowed from behind us as he sprinted toward the plane doors. How worried we had been that we’d be dragging him onto the aeroplane for the first holiday he’d had in years – how wrong we were.

Ben has walked through life with incomparable bravery. His reaction to the aeroplane was just the smallest proof of his positive attitude. The bravery continued as he battled through a holiday hundreds of miles from his comfort zone at home. Some days were hard; every night was a nightmare for us all. But there were moments shared – beautiful moments that we will treasure forever.

Sometimes I imagine how many summer holidays we, as siblings separated by the care system, may have missed and may miss in the future. How many memories might we have made together if life had been different?

My world is as it is because of Ben – because of the responsibility, the harsh reality and the joy that he brings. My every holiday spent away from him, including my recent honeymoon, is spent with him in mind – hoping that he is coping back home. Once we returned from a holiday to find that Ben had been sectioned in the now notorious Winterbourne View. How hurt I was that I might have been enjoying my time abroad as Ben suffered at the hand of relative strangers – how sorry I will always be that Ben entered such a place. It has long affected our lives, our dreams and our holidays.

I am blessed to have my brother. No matter how hard times may be, I can live my life with the knowledge that now, tomorrow, and for as long as we both exist in this world, there are further memories to be made, further holidays to be had, further stories to be created.
Speaking out for families

Our Family Support Manager, Holly Butcher (covering maternity leave until April), describes the advocacy offered by the CBF's Family Support Service.

When family carers first phone the CBF and speak to a Family Support Worker, they often ask what we can offer them. This depends on what the family needs. Many people with a relative with severe learning disabilities want a chat about their situation and information about behaviour support. We send people our information resources on various topics, and signpost to guidance and services from other organisations. Other people need a good long conversation and say it’s great to speak to someone who understands the issues.

Families who are in a complex situation may need longer to talk it through. The problems faced by families of someone who displays challenging behaviour often include a wrong model of support, barriers to accessing their rights and the services they are entitled to, or all of these things! We offer on-going support via phone calls and emails, helping them consider the options and suggesting how we could help. This support may become advocacy – helping the family make their voice heard.

Speaking out is hard when all your time and energy goes into supporting your family member with learning disabilities. All the phone calls and meetings can make it difficult to find time to act on every issue or request additional information from a service. We can help with this. If a family wants to see a care plan or needs a current list of medications, we could contact the relevant professional on their behalf to explain the importance of this information and request it is sent to the family. We can phone someone’s social worker to discuss a problem or share ideas. Families also find our help writing letters really useful, such as complaint letters, where we help to keep the points focused and ask for specific outcomes.

We keep in touch with the family and get their agreement before advocating for them. We can’t attend meetings, but work together with other advocates who can be there in person. The more voices speaking out for a family’s needs, the better.

Family carers who have used our Family Support Service have told us about the support they received and how it benefitted them:

“I was listened to and the support worker understood the problems perfectly. I felt the CBF could support me to advocate for my relative. I knew what had been going on was serious neglect and bad practice and the abuse of my relative’s monies was illegal. For the first time I felt confident there was close support.”

“I was given suggestions for the format to be used when contacting the Ombudsman - i.e. to concentrate on whether the process had been followed.”

“I am feeling more confident - I have very good points to communicate about my son’s care.”

Family carers of children and adults with severe learning disabilities can call 0300 666 0126 or email support@thecbf.org.uk to contact the CBF’s Family Support Service.
**Gloucestershire Advocacy Project**

**A Case Study**

Over the past two years, the CBF has worked on The Gloucestershire Advocacy Project. This project was commissioned from the CBF as part of a wider piece of work, the Gloucestershire Challenging Behaviour Strategy.

The Challenging Behaviour Advocacy Project aimed to provide independent advocacy for people with severe learning disabilities and challenging behaviour. Two independent advocates were recruited and trained to provide advocacy, as there was no local advocacy organisation available to host the pilot project.

Individuals were referred to the project via the Council’s Learning Disability Operations Team. One of our two advocates was linked up with a man who receives support from a provider in his own home and who accesses full time education. As the educational placement was due to finish, the advocate’s role was to ensure that appropriate planning and meaningful occupation were in place.

Our advocate said of her experience:

> “My brief was to visit the individual regularly in order to get to know him and observe his day to day routines, environment, etc. This enabled me to raise some issues and concerns about his welfare with his social worker. […] The relationship was not always easy as the individual has one to one care (which he likes) and he does not respond well to a second person being present. I decided to adjust the length of each visit according to whether he appeared to be happy for me to be around or not.”

Both of our advocates got to know the person they were advocating for, communicated with professionals involved in their support and raised issues on their behalf. The project has not only impacted the lives of these individuals who received advocacy, but has also provided essential learning about planning and running an advocacy project of this kind, and about the commissioning of an advocacy contract.

Gloucestershire County Council has commented:

> “[W]e welcomed the opportunity to work alongside the Challenging Behaviour Foundation to develop our advocacy services […] We are excited to use the feedback from this project to continue with a creative and person led approach to advocacy.”

**Commissioners Guide to Advocacy**

*Advocacy in action: Becky and Charlie*

Good advocacy is essential for those who are unable to express their needs, but there is often a lack of the skills and experience needed to advocate for people with severe learning disabilities who may display challenging behaviour.

For this reason, the CBF has produced a guide to inform commissioners about the benefits of advocacy for this group of people. This new guide aims to encourage commissioners to provide long-term non-instructed independent advocacy in addition to the usual statutory advocacy that tends to be generic, issue-based and short-term. Independent advocacy services are a crucial resource for vulnerable individuals in the health and social care systems.

The guide was written using some of the findings from the Medway Advocacy Project, a pilot project that provided non-instructed independent advocacy for individuals with severe learning disabilities who display behaviour that challenges. The following is a sample from the guide:

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**Introduction**

Independent advocacy services are a crucial resource for vulnerable individuals including those with learning disabilities.

New legislation places increased importance on individual choice and control when making decisions about meeting needs and providing support. Local Authorities must consider the wishes and views of these individuals in the decision-making process, regardless of the complexity of their needs.

This guide has been produced to help those responsible for learning disability services to plan and increase the availability of independent, professional advocacy services for individuals with learning disabilities, who display behaviour that challenges.

“How are we going to check that this group of particularly vulnerable people have good quality advocacy?” – Viv Cooper, OBE, Chief Executive, Challenging Behaviour Foundation

**Non-instructed Independent Advocacy**

- Non-instructed independent advocacy is essential for vulnerable individuals, for example those who lack capacity to make decisions about their own lives or who are unable to communicate their needs.
- There is an absence of the skills that are required to advocate for young people and adults with severe learning disabilities who have complex needs and may display challenging behaviour.
- There is also a general unawareness of specific issues that may affect the care this group of individuals receive, and their quality of life. These issues include limited choices, lack of community inclusion, and issues of restraint and medication.
Medication and Challenging Behaviours: A Guide to the Latest Research

Families and professionals often talk to us about the use of medications in relation to behaviours that challenge and report a range of experiences and outcomes for the person they are caring for. These experiences sometimes raise serious concerns. The CBF has long called for a review of the use of medication as part of the post-Winterbourne View Transforming Care programme. Our voice is now being heard.

Over the summer, several new reports on how medication is prescribed to people with learning disabilities were released. Three pieces of work have been carried out as part of the Transforming Care programme:

1. NHS Improving Quality worked in collaboration with project sites to improve services. The report highlighted the value of integrated pathways of care and of involving people with learning disabilities, their families and carers. Resources developed by the study include pathways, templates and tools, which can be accessed via the case studies listed in the report itself: http://bit.ly/1R9crCK

2. Public health experts examined the use of antipsychotic, antidepressant, anxiolytic, hypnotics and anticonvulsants in primary care through the use of the Clinical Practice Data Link database. The study showed that antipsychotic and antidepressant drugs are being prescribed for people with learning disabilities despite no recording of the conditions for which these drugs are known to be effective: http://bit.ly/1R9cXAp

3. The Care Quality Commission audited medication data relating to the “Second Opinion Authorised Doctor” (SOAD) requirement. This report is due to be published shortly. In addition, UCL has released new research drawn from a six year study of data relating to the prescribing of antipsychotics. The report showed that over 70% of prescriptions for antipsychotic medications are given to those without a record of severe mental illness. The report also found that the proportion of people with a learning disability in the UK who have been treated with psychotropic drugs is much bigger than the proportion with recorded mental illness. http://bit.ly/1LThBUq

Whilst these reports share some concerning findings, it is important to remember that people with a learning disability have a right to access medication that they need. It is vital that medication is managed and reviewed appropriately, and that any withdrawals from medication are carefully planned.

The Path to Prescription

Tragically, there is a long history of excessive use of sedating medication for people who display challenging behaviour. This is a serious misunderstanding of how to respond to behaviour that challenges. Medication may help to improve the challenging behaviour of a person with learning disabilities. However there are several important conditions that should be met before medication is prescribed.

1. A proper assessment should take place, identifying clear reasons for the challenging behaviour. Behaviours which look similar on the surface might arise in different people for very different reasons. Any kind of intervention is only likely to be effective if it is tailored to the reasons behind the behaviour, rather than just tailored to the behaviour itself. This involves looking at the individual’s environment as well as their disability.

2. Before medication is prescribed, it is important to check that the person is not physically ill (if the person’s communication is limited, a carer may be the best person to notice if something is different or wrong). The person’s mental health should also be assessed. Even when a mental health problem like depression has caused, or worsened, the challenging behaviour, medication still needs to be used with caution.

3. A “risk benefit” analysis is needed too, with doctors balancing the possible benefits of the medication against the disadvantages of potential side-effects. People with learning disabilities may be at a greater risk of side-effects. This process of balancing “pros” and “cons” should continue all the while the medication is being taken, with side-effects being continually monitored.

These are just three examples of considerations to take before a person with challenging behaviour is given medication. Another vital condition is that medication should only be given with the person’s consent (or the consent of her/his parent, if the person is a child). If the individual lacks the capacity to make a decision, a decision can be made in her/his ‘best interests.’

The use of medication in the treatment of challenging behaviour is always complex. The information in this newsletter can and should be read in conjunction with our more detailed information sheet – available on our website (go to www.challengingbehaviour.org.uk > Information > Information Sheets and DVDs > About Challenging Behaviour > The Use of Medication in the Treatment of Challenging Behaviour). You can also use the resource order form on the back of this newsletter, or contact us on 01634 88739 or info@thecbf.org.uk. We are intending to update this resource in the coming months, so keep an eye out for a new version on our website appearing soon.
Reducing the Use of Psychotropic Medications in Learning Disabilities

Dr. Dave Branford, Immediate Past Chairman English Pharmacy Board Royal Pharmaceutical Society

A study of GP prescribing published in June estimated that, on an average day in England, between 30,000 and 35,000 adults with a learning disability are being prescribed an antipsychotic, an antidepressant or both without a diagnosis of psychosis or depression. These findings were deemed unacceptable and a ‘Call to Action’ was launched by NHS England to reduce the level of prescribing.

If you are concerned about your family member receiving too much medication or about the impact that withdrawing medication could have, here are some first steps:

- Discuss with others involved with the care (including the GP, or psychiatrist or community team members) whether you think the behaviours or problems could be managed with fewer or no medications.
- Don’t suddenly stop the medication.

Unless there are immediate significant concerns about the side effects it is better to gradually reduce. The speed of reduction or the decision whether to attempt total withdrawal or just dose reduction should be determined by:

a. Whether one or more psychotropic medications have been prescribed
b. What happened when doses were missed or when there were previous attempts to reduce the dose or withdraw the medication(s)
c. The extent to which the medication is actually taken (are doses commonly missed or concealed?)
d. The level of concern about the behaviours
e. The history of the behaviours and the impact of the medications
f. The availability of other ways to deal with any worsening of behaviours

Accept that the reduction may take some time and will occasionally be difficult. Sometimes if behaviours get worse it can be difficult to judge whether it is a withdrawal effect (usually occurs within the first week), the person adapting to the absence of the medication (usually in the first month), or a return of the behaviours for which the medications were prescribed. Some people recommend monthly reductions but it is better to slow down the rate of reduction rather than sticking to a rigid plan if there are concerns about the behaviours.

If you are concerned either that medication is being used inappropriately, or that best practice procedure isn’t being followed for withdrawing medication, then this focus on the use of medication during the Call to Action provides an opportunity for you to raise it. The plan is to publish a number of good practice guides and, as the Challenging Behaviour Foundation is a key member of the programme, you will have access to these resources.

Medication Should Be a Last Resort, Not a First Response

Our son James has a severe intellectual disability and is autistic. James has only very limited means of communicating his needs and wishes. At nineteen, with the right support, he was not regarded as someone who presented significant challenges in terms of behaviour.

Prior to his move into adult care he was never properly assessed and his needs were not understood. As a consequence he suffered twenty years of inappropriate, poor quality support often in environments which he found oppressive and frightening.

James responded by presenting behaviours described as challenging which were met with physical and chemical restraint. The medication used included antipsychotics, an antiepileptic as a mood stabiliser, antidepressants and anxiolytics (medication that inhibits anxiety). We intervened where possible and managed to have some drugs withdrawn. We accepted some medication being prescribed in order to avoid the total and uncontrolled failure of a placement.

These powerful drugs often have side effects that affect quality of life and wellbeing. Some can lower the epileptic seizure threshold. The sedating effect of the antipsychotics was substantial, leaving James struggling to function. Weight gain was a significant problem regardless of the type of antipsychotic. Most recently James was concurrently prescribed an antipsychotic, an anxiolytic and an antidepressant. He had problems swallowing and suffered frequent bouts of violent vomiting for up to two hours. He suffered his first tonic-clonic epileptic seizure for 35 years.

None of these drugs has ever extinguished the behavioural problems. With antipsychotics the time between episodes tended to extend but when they occurred he was unable even to attempt any measure of personal control. The side effects clearly contributed to feelings of distress to the point of desperation.

In James’ current support structure we have now reached a point where his needs are well understood and appropriately met. Physical restraint is rarely, if ever used and medication is significantly reduced.

David and Jill Jack
**Everybody Matters**

*Why did the CBF create the film ‘Everybody Matters’?*

In 2011, the abuse of patients with learning disabilities at Winterbourne View hospital was revealed by undercover Panorama filming. Even though Winterbourne has since been closed, the problem of people with learning disabilities being taken away from their families to facilities hundreds of miles away sadly remains a reality. Too few people realise that individuals with learning disabilities are capable of leading full and active lives in their local communities, and that any challenging behaviour they may have displayed previously can be improved with the right kind of local support. This is where ‘Everybody Matters’ comes in!

*What is the film about?*

‘Everybody Matters’ is a 35 minute film, starring Colleen and Shaun, both of whom have learning disabilities and have been described as having behaviour that challenges. The film shows that, with the right support, they are able to enjoy full and active lives. The contrast between their current situations and the ineffective and damaging “care” they previously received couldn’t be starker. Shaun and Colleen are now involved in decisions about their lives, are able to structure their days around preferred activities, and have staff who fully support their needs.

*Where and how can I see the film?*

Everybody Matters is available now on DVD, and is free to family carers who have a relative with a learning disability! You can order a copy from the CBF, or contact us if you wish to host or attend a screening.

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**Your Questions from the Email Network**

**Q:** What are people’s experiences of applying for financial and/or welfare deputyship?

**A1:** We obtained financial deputyship for our son. It was relatively painless apart from the expense (£650 for the solicitor and the court fees). However, we were told not to go forward with the welfare deputyship, unless in direct need, as these are difficult to obtain.

**A2:** I applied to be deputy for my daughter for financial affairs. I am an ordinary person, capable of managing her accounts. Once I had got my head around the forms it was quite straightforward. I didn’t go through a solicitor. I think it cost about £150.

**Q:** My son has been prescribed Risperidone due to challenging behaviour and rituals. What are others’ experiences of this medication?

*Please note that the CBF recommends that medical advice should be taken before any changes are made to an individual’s medication or diet*

**A1:** When our son began taking Risperidone he did not gain a huge amount of weight, but I understand that most people do. It calmed him down to a point where he could attend school. However, when 3 members of our family died his aggression again became uncontrollable, despite being on 2mg Risperidone. Against my better judgement this was increased to 6mg. At this dose he looked sedated and did not seem to be able to think straight which I feel added to his frustration.

**A2:** Very beneficial, as my son was less frustrated, listened and was more talkative. It stopped working after 9 years, but I took him on all sorts of holidays and he was allowed some calmness in his life - he never lost his personality.

**A3:** Our son was prescribed Risperidone in his early teens. It did have some calming effects at first. Lethargy was one problem (he didn’t like feeling tired) but the main drawback was that he gained a lot of weight, which ironically made him even more challenging because he now had the mass to do some serious damage. When his violence became even more pronounced we saw no point in continuing with the drug and became very vocal in asking that it be discontinued. Overall he was on Risperidone for 5-6 years. It took over a year to wean him off. Once off the drug he lost most of the weight he’d gained and although he still presents challenging behaviour at times it’s significantly less than before.

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](http://www.challengingbehaviour.org.uk) or email network@thecbf.org.uk.*
CHALLENGING BEHAVIOUR FOUNDATION

UPDATE

News

Sir Stephen Bubb’s Six Month Report

Stephen Bubb, author of the report ‘Winterbourne View – Time to Change’ (November 2014), has now published his report of the progress that has been made six months on, ‘Winterbourne View – Time is Running Out’.

www.acevo.org.uk/sites/default/files/Time%20is%20Running%20Out%20%20Con%20Consultation%20October%202015_0.pdf

Stephen Bubb should be releasing his “1 year on” report at the top of 2016. If you wish to be involved in the public consultation that is being run (closing 27th November 2015) you can email your comments to Kate Brittain – kate.brittain@acevo.org.uk. Follow the link for more information about the consultation, and for other ways of having your say.

https://www.acevo.org.uk/sites/default/files/Time%20is%20Running%20Out%20%20Con%20Consultation%20October%202015_0.pdf

Easy read version: https://www.acevo.org.uk/sites/default/files/Time%20for%20Change%20Consultation%20easy%20read.pdf

Draft Service Model of Support Services

A Draft Service Model for five “fast track” areas (Greater Manchester and Lancashire; Cumbria and the North East; Arden, Herefordshire and Worcestershire; Nottinghamshire; and Hertfordshire) has been released, as part of the Transforming Care programme. These “fast track” areas will be putting the new model into practice from autumn this year. The model has been developed by NHS England, the Local Government Association and the Association of Directors of Adult Social Services, and is aimed at commissioners, describing what good services look like.

www.england.nhs.uk/2015/07/28/ld-transforming-care/

NICE Quality Standard for Challenging Behaviour

NICE Quality Standards were published in October. They describe high-priority areas for quality improvement in care or service areas. The quality standard draws on existing guidance and covers the care of children, young people and adults with a learning disability and behaviour that challenges.

https://www.nice.org.uk/guidance/qs101

Learning Disabilities: IAPT Positive Practice Guide

An IAPT (Improving Access to Psychological Therapies) Positive Practice Guide was published in September. Written by experts who support people with learning disabilities, the report gives information about the adjustments that still have to be made in terms of mental health provision, so that people who are in serious need of support are able to access it.


Child Sexual Exploitation Report

Barnardo’s, BILD (the British Institute of Learning Disabilities), The Children’s Society, Paradigm Research, and Coventry University have released a joint report suggesting that children with learning disabilities are more vulnerable to sexual exploitation than their non-disabled peers.

The report argues that children with learning disabilities face ‘additional barriers’, including social isolation, their lack of empowerment and voice, and their lack of access to quality information regarding sex and relationships. If these barriers remain unaddressed, the report warns ‘their sexual exploitation will remain invisible and continue.’

The report was commissioned by Comic Relief, and can be read on the Barnardo’s website: www.barnardos.org.uk/cse-learning-disabilities

WHAT’S ON THE WEB

Innovative, interesting or useful resources available free online

‘Jointly’ App

‘Jointly’ is a new app from CarersUK, available to download to your smartphone, tablet, laptop or PC. The app allows you to set up a “circle of care”, which you can invite all the carers for a particular person to join. All the carers can send each other messages via a group chat feature, create to-do lists, and share a calendar to log time-specific tasks. ‘Jointly’ is free to download if you want to find out more information about how it works – but please do note that there is a small charge of £2.99 to set up a circle.

www.jointlyapp.com

Meeting the Challenge

Mencap have recently released a series of resources, co-produced with the CBF and other organisations, written with input from family carers about in-patient provision and related issues. The series describes what good support looks like, what you need to know about inpatient settings, and how your family member’s rights change as they become an adult.

https://www.mencap.org.uk/meetingthechallenge

Crime Prevention Booklets

Two new crime prevention booklets, designed to help people with learning disabilities stay safe, have been released for free online! They were created by Christopher Langdon, who himself has learning disabilities, and are written in clear, simple English with the use of visual aids.

http://bit.ly/1k5ab4w

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 @CBFdn.
GET INVOLVED

Fundraising Art Auction

Thanks to the kind support of Sun Pier House Gallery, the CBF will be holding a fundraising art auction – along with an exciting programme of events throughout November.

Artists have been invited to submit pieces of work that relate to the subject of ‘challenge’ – up to 100 pieces of work will be chosen for exhibition and then auctioned to raise funds for the CBF.

Thanks to the generosity of Rochester Film Society and the film production company Spicer and Moore, during the exhibition we will be screening ‘A Mission to Lars’ – a film about Kate and Will Spicer’s brother Tom, who has Fragile X Syndrome, the most common form of inherited learning disability. Tom is also a massive fan of Lars Ulrich from Metallica. They made a promise to Tom that they would get him to meet Lars. Tom’s dream is their promise. Together they went on a Mission to Lars.

This event is open to all. To find out how you can get involved please email laura.brown@thecbf.org.uk.

Supporter Challenges

CBF Supporter Peter Baker took part in the Prudential London – Surrey bike ride over the summer, with a 100 mile route and leg-testing climbs. Peter met the challenge head on, raising over £700 for the CBF. Thank you, Peter!

The Wrenthorpe Village Singers and their guests, LB Brass, presented a charity concert in July at St Paul’s Church, Alverthorpe, with the proceeds being split between two charities. The CBF benefitted from a donation of £318! Thank you to everyone involved.

Can you help?

We are always keen to hear from supporters who would like to undertake their own personal challenge on our behalf, be it a marathon, bike ride, cake and coffee morning or charity ball.

As we are based in the south east the majority of our supporters also tend to be here; we do however support people nationally and would love to expand our supporter base further afield. Can you help? We’d love to hear from you if you can!

Please contact laura.brown@thecbf.org.uk

The CBF fundraising team

The CBF fundraising team have been busy printing our new line of fundraising merchandise - just in time for your Christmas shopping!

As we go to print we are fortunate to have received the support from the Rochester Flea, where we will be holding a stall promoting the CBF as well as selling our beautiful range of hand-printed goodies!

We also hope to have a ‘shop’ on our website very soon - where you will be able to buy these items directly from us – please check back soon.

Additionally a further range can be seen here, http://www.redbubble.com/people/thecbf. With over 20 products to choose from and a selection of 12 original designs – making perfect Christmas presents for those who have everything! The CBF will receive a 20% donation from every sale made.

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.
Thank you
We would like to say a big thank you to David Congdon! David kindly provides a range of valuable support to the CBF. This includes co-chairing the campaign subgroup of the CBNSG to help the CBF speak out in a range of ways. We are very grateful to him for all his hard work. Thanks, David!

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

June 2015
Mr. and Mrs. Ingarfield
Maidstone, Kent

July 2015
Jackie Morris
Somerset

August 2015
Pamela Moseley
Dorset

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.

<table>
<thead>
<tr>
<th>Cost</th>
<th>Number</th>
<th>Total £</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHALLENGING BEHAVIOUR DVD RESOURCES</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Everybody Matters DVD</td>
<td>£31.50*</td>
<td></td>
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<tr>
<td>An Introduction to Challenging Behaviour: DVD</td>
<td>£31.50*</td>
<td></td>
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<tr>
<td>Self-Injurious Behaviour: DVD</td>
<td>£31.50*</td>
<td></td>
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<tr>
<td>Communication &amp; Challenging Behaviour: DVD</td>
<td>£31.50*</td>
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<tr>
<td>Challenging behaviour – supporting change: DVD</td>
<td>£63.00*</td>
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Learn about the causes of challenging behaviour, and how to use a functional assessment to put appropriate positive behavior support strategies in place. (Five 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.

<table>
<thead>
<tr>
<th>Cost</th>
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</thead>
<tbody>
<tr>
<td>Understanding Challenging Behaviour: Part 1</td>
<td>£12.00*</td>
</tr>
<tr>
<td>Finding the Causes of Challenging Behaviour: Part 2</td>
<td></td>
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<tr>
<td>Positive Behaviour Support Planning: Part 3</td>
<td></td>
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<tr>
<td>Communication and Challenging Behaviour</td>
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<tr>
<td>Health and Challenging Behaviour</td>
<td></td>
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<tr>
<td>Impact of Caring on Families</td>
<td></td>
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<tr>
<td>BASIC INFORMATION PACK (consisting of the 6 information sheets listed above)</td>
<td>£31.50*</td>
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</tbody>
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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:

<table>
<thead>
<tr>
<th>Cost</th>
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<tbody>
<tr>
<td>The use of Medication</td>
<td>£1.00*</td>
</tr>
<tr>
<td>The use of Physical Interventions</td>
<td>£1.00*</td>
</tr>
<tr>
<td>Specialist Equipment and Safety Adaptations</td>
<td>£1.00*</td>
</tr>
<tr>
<td>Planning for the Future</td>
<td>£1.00*</td>
</tr>
<tr>
<td>Further Information for Family Carers</td>
<td>£1.00*</td>
</tr>
<tr>
<td>Booklist for Professionals</td>
<td>£1.00*</td>
</tr>
<tr>
<td>Difficult sexual behaviour amongst men and boys with learning disabilities</td>
<td>£1.00*</td>
</tr>
<tr>
<td>Getting a Statement (Wales &amp; Northern Ireland)</td>
<td>£1.00*</td>
</tr>
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SUB TOTAL CARRIED FORWARD

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

/ Continued overleaf...
Please consider making a donation to help 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 the 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 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.