

# Challenge



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

Spring 2013

The newsletter of the Challenging Behaviour Foundation

## Everywhere, for Everyone

Having a member of your family with severe learning disabilities who displays behaviour described as challenging can be very rewarding.

### PAGE 4

#### Volunteering

*The CBF are looking for volunteers – find out how you could get involved with the CBF*

### PAGE 5

#### Parents' email network

*The CBF email network allows families to share experiences and knowledge.*

### PAGE 7

#### Study Pack

*A new CBF resource to help schools and colleges reduce challenging behaviour*

### PAGE 8

#### Winterbourne View hospital final report

*Will the new government report make a difference?*

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

### *Certainly Daniel has changed our lives - and often our thinking*

and he continues to provide us with many experiences where he makes us laugh out loud. But alongside this there have also been times of sadness, and feelings of helplessness and frustration. Seeing your child self injure and feeling powerless to help them is profoundly difficult and deeply painful. And there is disappointment and anger when the support and services that should be there to help either fail to deliver, or even make the situation worse.

It can be hard to stay positive when services have failed you or you are being kept awake all night for the tenth night in a row without any help. We know that many families who contact the CBF feel really isolated – and they want good information, to get the right support and to link with other family carers. But we also know that many families don't know about us, and we need to reach more people.

So we are pleased to announce that we have received Big Lottery funding to enable us to expand our support networks to connect more families together.

Over the next 3 years we will develop a network of CBF local champions, to reach more families and share our information and resources. Families contact us when they are struggling –



Vivien Cooper

### *it is not OK for families to be failed by services and we must do something about it.*

The broadcast of the terrible abuse at Winterbourne View showed these failings in graphic detail, and the impact of the Panorama programme continues.

The Government has confirmed there will be focussed work across children and adult services to ensure that there is good local support, and people are not sent away to inappropriate services. This is welcome news; in this edition of Challenge we describe this in more detail.

So there are reasons to feel positive – though certainly not satisfied or complacent, because we know there is still so much to do. But at least we are all agreed that we need to concentrate on children and adults with learning disabilities whose behaviour is described as challenging and improve local support and services –

### *We all need to work together to make sure we get it right everywhere, for everyone*

#### • Vivien Cooper OBE

Chief Executive and Founder of the Challenging Behaviour Foundation

# Counting stuff

## Numbers can't tell us everything

If you needed to count stuff, I was your man. Challenging behaviour? Count it! Services? Count them! Measure satisfaction, the number of complaints, the number of times people got things right. Hours of service received? Counted! It was one of the natural consequences of working in the NHS. It only counts if counted.

And if you're really good, you can run those numbers into computers that will produce really cool looking graphs even when you've no idea what they mean, but even so... a statistical test here, a regression there. "Ah, but the numbers, Mrs Smith, show no tears and plenty of support hours. Stop complaining..."

The numbers are what mattered, because I equated numbers to evidence for all the right reasons, I'm sure. But I had developed a habit. But I too was measured on my measuring.

***We can count plenty: what is harder to count is what these things mean and do.***

I thought I'd start a PhD before I retire, as you do. So I thought I'd try to kick the counting addiction. Boy, did I find some interesting stuff I hadn't noticed, being too busy counting. One of the most obvious things to people busy counting stuff is that a lot of

other interesting stuff isn't counted. Like stories. Or happiness. Or loneliness. It began to dawn on me (my wife would say "D'oh!" at this point) all my counting may not be what it was all about. I was harvesting numbers, not stories.

We can count plenty: what is harder to count is what these things mean and do. My counting your partner winking is fine, but it doesn't tell me how your heart skips a beat when he winks at you. I can count the people in your community, not what they do or why they make you feel like life is worth facing each morning come dawn.

I received an email from someone on the other side of the world telling a story about doing some observations (counting!) in a service that had adopted active support- helping people stay busy and involved. She said the data were good- people were very busy. Staff knew the correct answers to questions. For one man living in this service the data involved being harangued until he did the washing when, she wrote, he clearly didn't want to, and only complied once called names by a staff member, who then rushed off to record a successful activity had been completed.

I still like numbers (some addictions are hard to shake, like Ben & Jerry's Cherry Garcia). But I try to remember Winterbourne produced convincing



numbers too: number of plans, number of staff, number of meetings, money saved, number of regulatory inspections passed and minimum standards passed. As if setting a minimum standard was sufficient to help people get a life! But those numbers are easy to measure compared to listening honestly to families and people using services, to hear when numbers are not enough.

My name is Tony and I'm a recovering behaviourist. Put down your calculator.

• **Tony Osgood**  
*Lecturer in Intellectual & Developmental Disability, Tizard Centre, University of Kent*

## HOW YOU CAN HELP

### Complete our newsletter survey

The CBF is reviewing our newsletter, and we want your opinions!

By filling in our survey, you will be entered into a free prize draw for a £25 Amazon voucher

The survey is inserted into this edition of the newsletter, and it will take about ten minutes to fill it in. Alternatively, it can be filled out at <https://www.surveymonkey.com/s/K5MW3R8>

Our newsletter is an important part of the CBF. It reaches nearly 5,000 people and is a major project for the CBF office. So we need to be sure that we are using it as well as possible. Does it contain interesting information? Which parts of it do you like, and which parts do you ignore? We want the newsletter to help you, so we need to know if it is useful and if there are other topics we should cover

We're asking these questions as part of a general review of our communications. We want to be sure that we are reaching the people who most need our support, and giving them the information they really need.

## Q: I was told to walk away by staff at my son's residential home, leaving me feeling uncomfortable. What are your experiences?

**A1:** I have wrestled with this same issue before. However, I can ring the home anytime and speak with staff, or request a call back if they are busy. We have formal reviews every six months where we receive a comprehensive report and can discuss anything we want. We are also all invited to Head Office occasionally and they are on Facebook and Twitter so they can stay in touch. They are always happy to receive contact.

**A2:** No one knows your child as well as you do! Professionals don't always get it right. I would speak to a senior member of staff and tell them you have to be part of your child's care plan!

## Q: I am facing the biggest dilemma of my life about whether to send my 17 year old son to residential care

**A1:** Have you thought about supported living? Residential care is good if the care is good, but as we have seen from recent examples, it can be from one end of the spectrum to the other. If he set up his own home with his own individual budget, he could employ his own support workers around the clock if necessary. It is a great alternative.

**A2:** Do have a look at the full range of care options available in your local area so that you can make an informed choice without being pushed in any particular direction. Today there are more options for personal budgets and supported living. If it has to be residential, I hope that you will find a suitable place not too

**A3:** I hope you can change the situation from being uncomfortable. My son's present home include me by agreeing to meetings with the home's manager to plan possible outings for my son and discuss any interactions/provision for him. They have easy chats with me over the phone about his progress/food/needs/communication etc. Please persevere and keep your relationship going with your son. It is ridiculous to ask you to leave it to the so called 'experts'. I believe this care home might say this to you, as they like to run things without parents' so called interference and for their own convenience.

**A4:** That's a poor attitude to have. I thought that the whole idea is to work together. I have come across this attitude with staff at my daughter's placement. I am the expert in my daughter's care. Don't let the staff get you down.

far away. You will instinctively know if it's right or not. Remember that the Local Authority has a legal duty to meet the assessed need.

**A3:** We made the difficult decision to send our youngest to a residential school. We would drive 3 hours each way to bring him home once a month, as he enjoyed coming home. We missed him so much and worried about his care. Over time, he moved onto residential care and we moved closer to monitor him. Eventually we returned him back to our home area. We were fortunate to get a shared ownership scheme and get him his own home. He now lives alone, with carers in 24 hour support. He is much happier, and so are we.

**A4:** These decisions are very difficult indeed. Our daughter left home aged 14 as we were barely able to manage any longer due to the very challenging behaviour. It was very difficult not having her home.

*These questions and answers are taken from our email networks.*

*Want to join the debate? Membership of our email networks is free to both parents and professionals.*

*Application forms from [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) or email [info@theCBF.org.uk](mailto:info@theCBF.org.uk)*

## New hands in the office



Subha, Magita, Bex and Amy

The CBF has welcomed some new office volunteers, who enable us to support more families across the country.

Every Friday, we're joined by Justin, who helps us by shredding old documents and stamping envelopes. Justin has severe learning disabilities and his voluntary placement was organised by the SHIEC project, which supports people with complex needs into work or voluntary roles. Justin is one of 36 people who SHIEC are working with. We're really grateful for all of the help he has given us.

A new academic year means new student volunteers. Subha and Magita join us once a week, and Emily, who has recently graduated, helps out regularly. We can offer students useful voluntary work experience and we're interested to hear from people from all academic disciplines. Of course, our volunteers aren't all students – our other volunteers have been as important as ever this year.

In other news, our Fundraising and Communications Team is now complete. Amy has joined us as our Fundraising Officer. She hopes to expand our fundraising activities, and encourage more events in the community so we can get the financial security to take on important long-term projects.

Finally, we're really grateful to the Rank Foundation for funding a new internship. As a result of their generosity, Bex has joined us as a Fundraising Intern. She supports the team by organising and publicising events and applications. If you have any fundraising ideas, they would love to hear from you – drop them an email at [fundraising@theCBF.org.uk](mailto:fundraising@theCBF.org.uk).



## A Local Champion



Maureen

In my role as a Local Champion volunteer for the CBF I was asked to run an information stall at a conference relating to challenging behaviour in Liverpool. This also gave me an opportunity to attend the conference which was excellent and very informative.

The conference was held in a lovely hotel by the waterfront. I met another family carer there who was giving a talk on behalf of the CBF, and it was nice to chat and relax over coffee before the conference started.

I loved running the stall as I felt proud representing the CBF as, from personal experience, I know how dedicated they are to improving the lives of people who display challenging behaviour. Having a son with challenging behaviours myself I found it easy to relate to others who browsed around the stall, some searching for answers and solutions to their own unique difficulties.

One couple began to really open up to me and were happy to tell me about some of the problems they were having with their son in relation to getting the right care for him. As it mirrored my own situation from the past we decided to sit next to each other at the conference and have lunch together so that we could talk further. Since then we have become firm friends!

### • Maureen West

Local Champion for Wirral, Merseyside

## Reaching out

How the Big Lottery Fund is helping us to reach more families.



**LOTTERY FUNDED**

We are delighted to announce that The Big Lottery Fund is supporting the CBF to extend our volunteer, email and social networks. We are proud to be working with the Big Lottery Fund, the largest distributor of National Lottery good cause funding, and are one of 48 organisations to benefit from the latest round of funding from BIG Lottery's Reaching Communities Programme. We hope that through the funding we will be able to reach more families in need of support and information about challenging behaviour.

The grant will be used over the next three years to reach families across England. We will be able to train and support family carers to become Family Link Volunteers, providing a listening ear to other families through our Family Linking Scheme. We will also be able to reach more families on a local level by training Local Champions, who will attend local events and provide information to families in their local community. Ultimately our goal is for more family carers to be empowered to share practical information with each other and respond to challenging behaviour effectively.

We look forward to keeping you updated on our progress in the coming months and we would love to hear from you if you would like to be involved. Please see below for more information about volunteering, and keep an eye on our website for more information on the project.

## The Family Linking Scheme: volunteer interview



Carol

*The CBF is training volunteers to offer emotional support to other family carers through the Family Linking Scheme, which re-launches this year to help families of people whose behaviour challenges throughout the UK.*

*Carol, a Family Link Volunteer, tells us more...*

### **Why did you decide to become a Family Link Volunteer?**

Like many of the other families known to the CBF, I was first put in touch with the organisation when I was floundering with a problem concerning my son David who has severe learning disabilities, autism and challenging behaviour. I was given helpful advice and also listened to by staff who were empathetic, non-judgmental and genuinely concerned.

As I had taken on the role of wellbeing co-ordinator as part of my teaching job and enjoyed the work with parents of the special needs pupils I taught, I thought this was an area where I could be useful.

### **How do you feel the support you've offered has helped the people you've spoken to?**

I understand how lonely it can be to have to fight for a disabled child or relative, and how good it feels to have someone listen to your worries and frustrations, as well as be a lifeline when things are really tough. I have also received some superb, appropriate advice from highly qualified professionals and I hope I can support others in the same way, mostly as a fellow caring parent.

### **What do you think is important when someone is in need of a listening ear?**

Just be that! Listening without giving constant advice is a skill I have had to cultivate, and it can be invaluable for someone who is struggling with problems related to challenging behaviour. Listening without comment can allow the troubled person to clarify their thoughts, plan future actions, and most importantly, feel that there is someone who is there for them when they need it.

## Can you give us your time?



We are looking for family carers who can offer some time to help the CBF reach more families of people with severe learning disabilities, to offer them support and information.

If you are a parent, brother, sister, or other relative and would like to get involved in our work, then we'd like to hear from you. You don't have to have any specific experience or qualifications, just the experience you have from supporting your family member.

You can offer us your time every week or a few times a year, depending on what suits you.

The volunteering roles we are looking for are:

**Local Champion** – you would share our information and resources in your local area, by attending events and joining networks. You can read about Maureen's experiences as a Local Champion in the left-hand column.

**Family Link Volunteer** – you would be a 'link' for family carers, offering them a listening ear from someone who understands. The interview with Carol below left tells you more about being a Family Link Volunteer.

We provide training, induction and support for these roles. More information is available at [www.challengingbehaviour.org.uk/get-involved-with-cbf/volunteer](http://www.challengingbehaviour.org.uk/get-involved-with-cbf/volunteer)

If you'd like to join us in reaching the community of all family carers who support someone whose behaviour challenges, please get in touch on 01634 838739 or [volunteering@thecbf.org.uk](mailto:volunteering@thecbf.org.uk)

## Join the discussion!

Our Parents' Email Network puts you in touch with other families who also have a relative with a severe learning disability, who displays challenging behaviour and enables you to be part of a unique community where you can receive support and relevant information from other family carers who experience similar situations with their loved one.

It is a fantastic way to find solutions to problems and to share your own experiences and knowledge, with others who truly understand (to see examples of the kind of questions that are asked, turn to page three of the newsletter). Members' names are removed from questions and replies and comments are moderated by the CBF before being shared, which supports open, honest and non-judgemental discussion. This is what members say about the network:

"Often, I may have a problem but I don't know what to do about it. I then open an email to find someone else is experiencing a similar problem to mine. When the answers are given, it is so enlightening and gives me knowledge to move forward. I have learnt so much from being part of this network and found strength to carry on".

"Thanks to everyone who participates in this network. Your comments and support are invaluable"

"It provides lots of support and information, especially when the person is feeling very lonely, isolated and doesn't know which direction to go in or who to ask for information and advice. I for one would have run out of steam by now if it wasn't for some of the advice I read from other network users."

If you would like to be a part of this supportive community of family carers, you will receive a very warm welcome from current members. To join either download an application form from our website at [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) or email [network@thecbf.org.uk](mailto:network@thecbf.org.uk)

## A parent's perspective



Jane

I've been a member of the parents' email network for a couple of years now and it's great to feel I'm not alone in facing what often seem like insurmountable obstacles to get my child appropriate support.

The exchange of practical information, insights and emotional support between family carers on the Network has been very helpful. I've filed some of it away for future reference, for example advice about Motability for when my daughter moves back into the community from the assessment and treatment unit she's in. The holiday home and informative literature suggestions were useful too and I followed the thread about Risperidone closely as my daughter has been on it in the past. I have strong views about the way antipsychotics are routinely prescribed to our children so I was interested to see what effects other parents had seen and what their views were.

The thread about going with your gut instinct if you think something is wrong was encouraging. How I empathised with the parent who said: 'over a cup of tea we were promised the world for our son but they were empty words and too easily believed!'

I believe all Challenging Behaviour Foundation family carers would benefit from joining the email network. If you have a question, you can ask it anonymously but if you prefer not to post anything, that's fine too. Not every post will be relevant to you but there's so much on there that's useful and interesting why miss out?

**By Jane.**

Read Jane's blog at [jgregorysharingsstories.blogspot.co.uk/](http://jgregorysharingsstories.blogspot.co.uk/)

## Positive Behaviour Support Workshops

Following the success of our Positive Behaviour Support Workshops in schools and colleges, we have decided to offer the workshops to a wider range of organisations. They are now available to all service providers, including supported living providers, day centres, residential care homes, short breaks services, school and colleges and family carer groups.

The workshops enable everyone who supports a person to come together to create a Positive Behaviour Support plan, and implement it consistently. By ensuring that everyone involved is taking the same approach, each individual can receive quality support which reduces challenging behaviour. In an evaluation by the Tizard Centre, University of Kent, the workshops were found to lead to:

- A significant reduction in the severity and frequency of challenging behaviour
- A reduction in the fear and anxiety experiences by paid workers
- A reduction in negative emotions experienced by parents.

Feedback from participants has been very favourable, including:

"The workshop was very informative and engaging and covered all the issues I encounter across the age range. Having personal experiences from the family carer is invaluable".

"The workshop has given us some good strategies and ways forward for our organisation."

The workshops are suitable for family carers or for professionals, or for groups of family carers and professionals together. They take a holistic approach to supporting an individual and can stand alone or complement other training or support approaches. They are run by a family carer and a Positive Behaviour Support trainer and feature two sessions: the first session investigates the causes of challenging behaviour, and the second session uses this knowledge to develop Positive Behaviour Support plans for each individual who is being thought about in the workshops. The CBF can also deliver a stand-alone one day Communication and Behaviour Workshop.

To find out more, please visit our website, email [training@theCBF.org.uk](mailto:training@theCBF.org.uk), or call 01634 838739

## Summary information sheets



*One of the summary information sheets*

Fourteen of The Challenging Behaviour Foundation's full information sheets have been summarised, so it is now much quicker and simpler to find key facts about challenging behaviour and severe learning disabilities.

Most of our full information sheets have been written by experts in the field of learning disabilities and cover a wide variety of topics linked to challenging behaviour. The new summarised information sheets still contain all the important points of the full information sheets, but in a more accessible, easier to read and understandable format.

Hard copies are also available. Please turn to the resource order form at the back of the newsletter. Email [info@theCBF.org.uk](mailto:info@theCBF.org.uk) or phone 01634 838739 for further information. All hard copy information sheets are free to family carers and cost £1.00 for professionals.

The following summarised and full information sheets are all free to view and download on our website [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk).

- Understanding Challenging Behaviour
- Supporting Behaviour Change
- Communication and Challenging Behaviour
- Health and Challenging Behaviour
- Self-Injurious Behaviour
- Pica (Eating Inedible Objects)
- Difficult Sexual Behaviour
- Mental Health Problems
- The Use of Physical Interventions
- The Use of Medication
- Getting a Statement
- Planning for the Future
- Making Decisions – The Law
- Ten Top Tips

## The Use of Medication: summary information sheet

### ***Here is the new CBF summary information sheet on medication:***

Challenging behaviour may happen for many reasons and it is really important to find out why it is happening. Medication should only be prescribed following a proper assessment and where a clear reason for using medication has been identified. There is a long history of excessive and inappropriate use of major tranquillising medication for "treating" challenging behaviour. Medication should not be used in this way.

The following 5 steps should be taken before medication is prescribed:

- 1.) Make sure an assessment is made identifying the reasons for a person's challenging behaviour. This will take time and may require different professionals to help.
- 2.) Check the person is not physically ill and question whether they have a mental health problem e.g. depression, mania, dementia. Someone who knows the person well (e.g. a parent or carer) may be best placed to know if something is out of the ordinary.

3.) If the person has a mental health problem, such as depression, which may have led to their challenging behaviour, then medication which is known to help treat that condition may help. Care needs to be taken. Starting doses of such medication are usually less than with the general population and must be increased carefully.

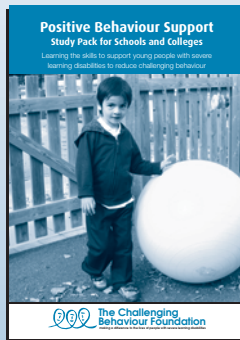
4.) Side effects and the person's mood and mental state should be monitored to determine whether the medication is effective. Frequency and severity of challenging behaviour should also be monitored. People with learning disabilities may be more at risk of side effects.

5.) Medication should only be given with the person's consent (or if the person is a child, the parents' consent). If an adult lacks the capacity to make a decision about taking the medication, medication can be given as long as it is in his/her 'best interests'.

*The full version of this information sheet was written by Professor Tony Holland, Department of Psychiatry, Cambridge University.*



## New: study pack for schools



*The PBS Study Pack*

The CBF has produced a new study pack which gives staff the skills to understand and reduce challenging behaviour in young people with severe learning disabilities.

The Positive Behaviour Support Study Pack contains detailed, practical information, as well as video clips of families and professionals. It is designed to be used by schools for staff learning and development, and as an ongoing resource.

While piloting the study pack, the CBF received very encouraging feedback: "The pack is well presented and the video clips are relevant and of interesting content" – SEN teacher

"The study pack was very clear and easy to use" – Specialist Teacher for Positive Behaviour Support

"It is excellent to have this type of resource" – Headteacher

The pack has been developed especially for teaching staff. It is designed to reduce challenging behaviour by showing staff how to create and implement a Positive Behaviour Support plan for each young person. The pack also encourages cooperation between teachers and families, and seeks to increase the confidence of teaching staff in responding to challenging behaviour.

The Study Pack is based on our successful Positive Behaviour Support workshops and Supporting Behaviour Change DVD. It can be ordered by schools using the resource order form on the back page of the newsletter or from our website. Alternatively, for more information please email [training@thecbf.org.uk](mailto:training@thecbf.org.uk)

Please check back later in the year for more information on the planned launch of a bursary scheme for family groups.

## New Information Sheet: The Impact of Caring on Families



*Mindy with her family.*

Life isn't easy for families with a child or adult who displays challenging behaviour. At times it can push people to breaking point, but can also bring laughter and happiness.

We have written a new information sheet, with the help of families, to reflect the wide variety of experiences people have. 'The Impact of Caring on Families' acknowledges the barriers and battles, and recognises the effects caring can have on all aspects of life. It covers topics such as diagnosis, mental and physical health of carers, sleep and finances. Throughout the information sheet we hear from family carers about their personal experiences, and at the end they give supportive messages to readers.

If you are a parent, brother, sister or other relative reading the information sheet, you may find yourself thinking 'so it's not just us then'. For anyone else reading, the information sheet provides a window into families' lives.

Practical guidance and signposting towards sources of help are given for emotional and health needs, short breaks, carers assessments and financial support.

We hope The Impact of Caring on Families will be helpful for families just starting out in their caring role, as well as those feeling isolated or looking for more support.

An extract of the information sheet is given below. Please use the resource order form at the back of the newsletter to order, or see [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

### Extract: emotional and social well-being

Reactions like stress, frustration, anger, guilt, shame and loneliness can all feature at times for family carers. These are natural reactions to the way severe learning disabilities affect your family member's life and your own; that doesn't make it easy to talk about though. Many carers say that no-one understands how they are feeling, so seeking support from other families with similar experiences can really help.

Family carers are often socially isolated and can be excluded from family events, friendship groups or community facilities because of their family member's behaviour.

*'It's a lonely place to be when you're a parent of a child with challenging behaviour.'*

Mother of a son with severe learning disabilities

*'We are very much isolated due to Christopher's disability, but in particular, with regards to his challenging behaviour. We visited family until it was no longer safe to do so and few family members now visit us in return. We have never attended family celebrations together as this has not been possible.'*

Parents of Christopher

Even if family and friends are supportive, it can be difficult to find the energy to get out and get involved in things. It's important to fit in quality time with people who care about you and find ways to include your family member in things you all enjoy doing. Spending time with different people can bring new ideas and coping strategies for behaviour support and other challenges.

*'Most support you get is from other families and friends that have lived that experience, and I think that's really important.'*

Mother of son with autism and severe learning disabilities

*'I'd say try and involve your friends. All my friends have become involved they know all about Daniel now and a lot of my friends are doing fund raising. Don't be afraid to talk to your friends and because they all think it's fine and they like coming round to talk to Daniel when he's down.'*

Sister of Daniel

## Michael



Michael

Michael is one of the people who Salford Council and NHS Salford have brought back to live in their local community. He lives in his own tenancy with two others and receives 24 hours support from experienced staff. When Michael gets stressed and anxious the staff know how to reassure him that everything is OK and how to help him calm down. Michael has made lots of progress since moving back.

'I am 31. I enjoy gardening, swimming, looking after my tropical fish, word searches and jigsaws, and following my football team, Blackburn Rovers. I also enjoy visiting my sister and baby niece. I do voluntary work at a tourist attraction nearby. I also like shopping, holidays and going to Gateway Youth Club on Friday evenings.

I was at an Assessment and Treatment unit for about 12 years. It was not nice being there. It had high fencing. I didn't get out much.

Before I went there I was living with my foster parents. I ran away from their home and I can't remember much more. I then went to the unit.

Now I'm living in my own home. I get lots of support and my life is good. I am much happier now.

I don't think it is a good idea for people with a learning disability to be sent away.' Michael

Extracted from "Out of Sight" by Mencap and the Challenging Behaviour Foundation. To download a copy visit: [www.mencap.org.uk/outofsight](http://www.mencap.org.uk/outofsight)

## Winterbourne View – What do local areas have to do now?

The horrors of Winterbourne View that Panorama exposed nearly two 2 years ago shocked the nation. Eventually 6 staff were jailed and 5 received suspended prison sentences. Today, people are still trapped in places like Winterbourne, and more are being sent there. This has to stop.

The Department of Health (DH) published an interim review in July last year and then in December their long awaited final report plus a Concordat. Behind the scenes, there were many months of hard lobbying to get the DH report and Concordat strengthened. The DH seemed like rabbits paralysed in the headlights of localism. The final report is now much stronger, and probably as good as we were going to get. But we should not be deluded, it is only words on paper. The challenge now is to force health and social services to deliver.

For over 18 months, there has been broad agreement on what the policy should be in meeting the needs of those whose behaviour challenges. We want to see the closure of large Assessment & Treatment Units and a significant reduction in NHS funded in-patient beds. In parallel, we want to see the development of local community support services.

The mandate from the Secretary of State to the National Commissioning Board (NCB) makes it clear that they must bring about a substantial reduction in reliance on inpatient care for people with a learning disability. This is a powerful lever for change. The NCB will need to encourage Clinical Commissioning Groups (CCGs) to work with local authorities (LAs) to develop alternative local preventative services. By April 2014, CCGs and LAs are required to set out a joint strategic plan to commission a range of services to meet the needs of those with challenging behaviour in their area.

The challenge nationally is going to be to keep the pressure on to drive this agenda forward. The danger is that with all the changes going on in the NHS, this will slip off the agenda. But the most difficult challenge is at the local level. Most of the money is tied up in NHS funded provision. The changes need the NHS to transfer money from institutional to community provision. But it also requires investment by LAs in community provision.



David Congdon

The challenge for organisations like CBF and Mencap is how to equip people locally to campaign for change. Local people need the ammunition to challenge locally by asking awkward questions. These could include the number of people with a learning disability in NHS funded in-patient beds, how many have been there more than 6 months, how many new admissions have there been in the last 6 months, how many are placed out of area, what plans are there to bring them back home, and what plans are there for the development of local intensive support services?

There is no excuse about there not being enough money to do this. It is a scandal that the average cost of a place at Winterbourne View was £3,500 per week. There is ample evidence that this money could be better spent providing good quality

local community services to meet local needs. Now is the time to stop the talking and deliver a better life for those whose behaviour challenges.

### • David Congdon

Advisor to the Challenging Behaviour Foundation



# How Salford are making it happen



Dave Clemmett

*“Supporting people with a learning disability and behaviour that challenges is everyone’s job – social care and health professionals, commissioners, providers, housing, and children’s services.*

*“It is not quick work - you need a long term strategy, but the benefits are clear. The quality of people’s lives is improving. Before, when we were sending people out of area, money was just disappearing out of Salford. Now we are spending money investing in local services to ensure that people with a learning disability and behaviour that challenges can have a fulfilling life in Salford.”*  
**Dave Clemmett**

In the last 5 years 16 people with a learning disability and behaviour that challenges living out of area have returned to Salford. We asked the team at Salford to tell us how they made it happen:

## 1. We made it a priority

For the last 6 years we have been committed to developing the right local services to make sure that people who are out of area can move back to Salford.

## 2. We have a joint service with a pooled budget

Here in Salford, the NHS and the council have become a joint service. This means no arguments about continuing health care or what contributions health and social care should be making. We can just concentrate on what people need, make sure this in place and get them back to Salford as soon as possible.

## 3. We have good information about people, starting with children

Getting good information about how many people were out of area had to be the starting point. We then reviewed their needs and over the last 6 years we have been working to bring everyone back. We made sure we included young people from the age of 14 who are at risk of going into placements out of area, for example those currently at residential school.

## 4. We work in partnership

The community team, made up of both health and social care professionals, is the core team working with people with a learning disability and behaviour that challenges. Joint assessments are done with the mental health team and children and young people’s team. When doing a multi-disciplinary assessment we think ‘what does this person need?’ Sometimes it will just be a matter of getting an appropriate flat for someone with the right support. Other times, more specialist input is needed, for example a psychologist might need to come in and work with the person’s support team.

We work closely with housing associations to get the right housing for people. We make sure it is high-quality and near local amenities, so people can be active citizens. We are deeply committed to making sure people can live in an ordinary house on an ordinary street.

## 5. We provide training and build capacity

We want to de-mystify behaviour that challenges. Salford City Council and NHS Salford run training in managing behaviour that challenges for everyone supporting people with a learning

disability – including independent providers, day services staff and respite. We want to make sure that everyone has the skills and confidence. The training involves families and it focuses on positive behaviour support.

Six years ago, local respite services might not have been able to support some very complex people, but through training we have built up the skills and confidence of staff so that they can.

We are skilling up generic services not just learning disability services. We work with acute hospitals so that they are able to support people with behaviour that challenges who come into hospital.

## 6. We focus on human rights and the Mental Capacity Act

When planning people’s support and doing risk assessments, human rights is at the centre of this. We think ‘what can we do to give the person as much freedom and choice as possible?’

In line with the Mental Capacity Act we want to ensure everything is done in the least restrictive way possible. We do an annual restrictive practice audit, which covers all providers, respite services, day services, schools. We ask what restrictive practices are being used and why. Everything needs to be justified from a locked cupboard in someone’s house to the use of physical or chemical restraint. We have been doing this for 3 years and it is going well – we get 95% responses back on time. It is not about telling services off for doing it wrong, it is about finding out what support is needed to make services better.

## 7. We all work to the same policy

In Salford we have one policy around managing behaviour that challenges that covers health, education, local authority, third sector. It means everyone is on the same page and committed to supporting people with behaviour that challenges to live in Salford. As well as making sure adults do not have to go out of area to get their needs met, we are equipping schools with the right skills so that young people do not have to go to school out of area, however complex their behaviour.

Extracted from “Out of Sight” by Mencap and the Challenging Behaviour Foundation. To download a copy visit: [www.mencap.org.uk/outofsight](http://www.mencap.org.uk/outofsight)

***Our supporters have been as busy as ever fundraising for us. Here's what they have been up to:***

The London Marathon is fast approaching, and Nick Gore is supporting the CBF by taking part. Nick told us 'Time to start putting in the miles so have started running home from the Tizard centre two nights a week plus another run or two at weekends. **The home run is around 10 miles so plenty of time to think through the early intervention projects I'm working on at the moment!**' If you'd like to sponsor him you can online by visiting his Virgin Money Giving page, just search for Nick Gore, or contact the fundraising team at fundraising@thecbf.org.uk.

We encourage all our supporters that may be interested in taking part in next year's London Marathon to apply for a ballot place when the ballot opens later this year.

If you're not ready to take on the full 26 miles of a marathon, maybe the British 10k London Run is for you. We're recruiting a team of 6 to run (or jog, or walk!) for the CBF. If you'd like to take part, please email us at fundraising@thecbf.org.uk



Susan Kinsella

We would also like to say a huge 'Well done' to Susan Kinsella for daring to do a 12,000 foot skydive for the CBF. Susan says 'The CBF is a fantastic charity and needs more local and national support. If you'd like to come along and watch the skydive please do!'

Weather permitting, this was scheduled to take place on Friday 15th March, and she is still collecting sponsorship – find her on Virgin Money Giving or contact the CBF at fundraising@thecbf.org.uk

Keeping on the theme of big challenges, Royal Engineers from Invicta Park Barracks, Maidstone will be taking on Nettle Warrior later this summer! Watch this space for an update.

The CBF fundraising team, as part of the group Medway Charities Together, have also been busy organising an indoor boot fair at Medway Park in Gillingham. Check our Facebook page for updates. And Sue Carmichael held a tabletop sale on her street and with the help of her husband and neighbours sold 48 bacon sandwiches for the CBF.



The tabletop sale

- Inspired by Nick, Susan, or any of our other fantastic fundraisers?
- Maybe 2013 is the year for you to take part in a personal challenge.
- Our fundraising team are here to support your journey and help you along the way. Maybe you'd like to do a skydive, or take part in a running challenge? Or maybe something else? We'd love to hear your ideas and ambitions however big or small, so please do get in touch by emailing fundraising@thecbf.org.uk or calling 01634 838739



## The Confidential Inquiry

The Confidential Inquiry into the deaths of people with learning disabilities released its findings on the 20th of March. The inquiry investigated the reasons for the premature deaths of people with learning disabilities in hospitals. For more information, please visit the Improving Health and Lives website: [www.improvinghealthandlives.org.uk](http://www.improvinghealthandlives.org.uk)

## Challenging behaviour conference

Our CEO, Vivien Cooper, has been invited to chair a conference for the National Autistic Society (NAS). The conference, called "Understanding and Managing Challenging Behaviour" will take place on the 16th of May. Speakers will discuss the causes of challenging behaviour in people with Autism, as well as presenting case studies and exploring the impact of sensory issues on behaviour. For more information, visit the NAS website: [www.autism.org.uk](http://www.autism.org.uk)

## 100 Club Winners

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

### September 2012:

Audrey Giles (Newcastle upon Tyne)

### October 2012:

Kate Dickens (Lincolnshire)

### November 2012:

Mr & Mrs Offord (Kent)

### December 2012:

Chris Parsons (Kent)

All proceeds from the 100 Club help towards CBF running costs. Please get in touch if you would like to join by emailing [fundraising@theCBF.org.uk](mailto:fundraising@theCBF.org.uk) or calling 01634 838739

## Have your say

We welcome articles from parents and professionals. Please get in touch if there is something you would like 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](http://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 £
<b>CHALLENGING BEHAVIOUR DVD RESOURCES</b>			
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.			
<b>An introduction to challenging behaviour: DVD</b>	£31.50*		
<b>Self-injurious behaviour: DVD</b>	£31.50*		
<b>Communication &amp; challenging behaviour: DVD</b>	£31.50*		
<b>Challenging behaviour – supporting change: DVD</b>	£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.			
<b>CHALLENGING BEHAVIOUR INFORMATION SHEETS</b>			
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.			
<b>Understanding challenging behaviour</b>	All information sheets are available free of charge on the CBF website.  To order by post please add £1.00 per sheet*		
<b>Communication and challenging behaviour</b>			
<b>Health and challenging behaviour</b>			
<b>Challenging behaviour – supporting change (functional assessment)</b>			
<b>The use of medication</b>			
<b>The Use of Physical Interventions</b>			
<b>Specialist equipment and safety adaptations</b>			
<b>Impact of caring on families</b>			
<b>Planning for the future: introduction</b>			
<b>Further information for family carers</b>			
<b>Ten top tips</b>			
<b>BASIC INFORMATION PACK (consisting of the 11 information sheets listed above)</b>	£10.00*		
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:			
<b>Booklist for professionals</b>	£1.00*		
<b>Difficult sexual behaviour amongst men and boys with learning disabilities</b>	£1.00*		
<b>Getting a statement</b>	£1.00*		
<b>SUB TOTAL CARRIED FORWARD</b>			

\*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 £
<b>Getting legal authority to make decisions about money, property &amp; welfare</b>	£1.00*		
<b>List of specialist 52-week schools and colleges</b>	£1.00*		
<b>Pica (eating inedible objects)</b>	£1.00*		
<b>Mental health problems in people with learning disability</b>	£1.00*		
<b>Self-injurious behaviour</b>	£1.00*		
IN-DEPTH RESOURCES			
<b>A guide for advocates (England and Wales)</b>	£16.00*		
A comprehensive and practical guide for professional advocates, as well as family carers advocating on behalf of their family member. Includes information on challenging behaviour, advocacy, and the key issues which are likely to arise.			
<b>PBS study pack for schools and colleges</b>	£45.00		
An interactive introduction to Positive Behaviour Support. The study pack is designed to be used by teachers to increase understanding of behaviour and develop a support plan for a student whose behaviour is challenging. Note: This resource is only available for schools and colleges.			
<b>Planning for the future: information pack</b> England / Scotland / N Ireland / Wales	£10.00*		
Written for people planning for the future of children aged 12 and upwards (transition), and those concerned about the support needs of adult sons and daughters. Contents include: Know your rights; Know the processes; Know your options; Case studies; Understanding the funding; Safeguarding & protecting the individual.			
<b>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.</b>			
			TOTAL
*All resources are free to parents/unpaid carers. Prices include postage & packing in the UK only.			

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](http://www.challengingbehaviour.org.uk) to order online.

# The CBF – how you can help

*Did you know.....?*

- **We are a registered charity and completely 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](mailto:fundraising@theCBF.org.uk)

## The Challenging Behaviour Foundation

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