

Challenge



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

Winter 2012

The newsletter of the Challenging Behaviour Foundation

CBF
15th Anniversary
2012

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

A stitch in time...

Recently my son had to have two wisdom teeth removed under general anaesthetic at the local hospital.

All seemed to go well: he was discharged after a few hours, and he seemed fine the next day. Unfortunately he spent the second night after the operation poking the wounds, and he lost a lot of blood.



Vivien Cooper

After a journey through various NHS services which were unable to help, we arrived at a specialist dental hospital. He had another general anaesthetic, and the wounds were packed with a clotting gauze and stitched in place. This allowed the healing process to take place, without my son being able to disturb it with his fingers or his tongue.

Looking back I ask myself – why didn't we do that in the first place?

I had no idea the clotting gauze was an option – if I had, I would have insisted we did it that way from the beginning, which would have saved a great deal of pain, distress and upset, not to mention the risks (and cost) of a second general anaesthetic

For years, families have said they want good, practical information

and good quality support for their relative to enable them to lead interesting and fulfilling lives. Unfortunately, although there is a lot of knowledge and expertise about how to do things well, too often it

doesn't get through to the right people and it doesn't get used.

If we do the right thing early on, it prevents problems and issues later.

It is a simple and basic concept - a stitch in time saves nine. For both the small and bigger things in life.

When we get it wrong there are terrible consequences for people. Our joint campaign report with Mencap, "Out of Sight," describes how the systems and support which should be helping people can result in them being placed in the wrong services, which can lead to significant harm. We are calling on the Government to show strong leadership to drive the actions that will change people's lives for the better.

We know this can be done and in this issue of Challenge we highlight some work that is starting early and is putting in the right support for children with learning disabilities and their families.

Surely it makes sense to start doing more of what works and stop doing what doesn't!

• **Vivien Cooper OBE**
Chief Executive and Founder of the Challenging Behaviour Foundation

Words

To really change things, we need action, not words

We're busy people, us humans. Particularly female humans. And little humans just don't stop. And so not to interrupt our daily doings, humans summarise complex information. Our thinking has evolved to weed out things of low priority, and when dealing with words, we are so keen to abbreviate, abridge, condense and concisely summarise everything that we sometimes mistake the word for the deed. We presume everyone knows what we're saying and what we mean. Such shortcuts can be useful but like all Mother Nature's gifts, it can be double-edged. We're so smart, us humans, we can cut ourselves, or more often, others.

So yes, we can say Harry Potter is about some kid with glasses who learns a few magic tricks. But the nuances become lost in such summaries. Marriage? It's just about getting along and compromising, right? There is often more to our shorthand, our words. War & Peace is not just about a cold winter in Russia, as John O'Brien reminds us.

It's almost as if the whole care system is set up to produce words.

A care plan cannot care, a policy document cannot determine what people do and how they act. Anyone familiar with the Winterbourne fiasco,

or Brompton, or Cornwall, or Sutton, or Ely... there's an awfully long list suggesting we shouldn't rely on words or guidelines or professional codes or regulation to make sure people do what is right by people. Words. Report after report. It's almost as if the whole care system is set up to produce words.

I've seen care plans and person centred plans and individualised plans and support plans that do not care, are not person centred, not individualised and do not support.

The grand and moving words we read in policy, the care plan outlining who should do what by when, and the statement of special educational needs that outlines precisely how little will be done for our children, are not synonymous with doing what is required, what is right for people. Don't mistake words for deeds. Saying sugar does not make the tongue sweet. Naming something a person centred plan does not make it one.

Words can lead us astray. Intervention plans for challenging behaviour may outline reinforcement schedules but seldom acknowledge the consequences for emotions and relationships, for rapport and long-term positive goals the person might select. If I read in one more plan someone writing in the first person "I need to learn to behave appropriately" I'll show



you some challenging behaviour. How dare we?

These children did not ask to be born with such difficulties. Did one of our children ask to be unheard? To have no voice? Did even one ask to be taught challenging behaviours? So the least we can do is move beyond well-crafted words of plans and (I hate this phrase) 'management guidelines' and toward a space of meeting on an equal footing. Because words are not doing. It is doing that matters. And we owe our kids that much, surely.

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

HOW YOU CAN HELP

Fundraising for the CBF

During our 15k for 15 years campaign, our supporters have raised money for us in many ways. If you're thinking of getting involved here are some ways you could help:

Organise a quiz: there have been many successful CBF quizzes. If you would like to organise a quiz, we can send you an advice guide to get you started, as well as our stock quiz questions.

Have a fundraising stall at a local fete or fair: Sell cakes, paint people's faces or run a tombola. By telling your customers about the CBF, you can raise awareness as well as money.

Do a sponsored run: this is the most popular way of fundraising for the CBF. If you are planning to run for us, do get in touch so that we can help to publicise your event, and advise you about setting up your Virgin Money Giving account.

Make a monthly donation: we particularly value regular giving because it allows us to plan for the future. Click on the "make a donation" icon at the top right of our website at www.challengingbehaviour.org.uk, or call 01634 838739.

Q: My daughter's behaviour becomes very challenging whenever the car stops. Distraction techniques have been tried, but do not work. Any ideas?

A1: My son's behaviour was the same when he was young but has now grown out of it. I found that talking and showing him pictures of our destination provided him with reassurance. He is now 23 and really enjoys travelling in the car.

A2: I have had a similar problem over the years with my daughter. I would suggest that you ensure she knows exactly what is happening throughout the journey, use pictures, explain what a red light means and provide her with treats.

A3: I would suggest that a graded exposure is the best thing for this. For instance, try stopping the car for

just a few seconds at a time and provide her with plenty of praise and perhaps a small edible treat as you gradually stop the car for longer periods. You would probably benefit from support from a specialist psychologist or behaviour nurse therapist as this technique is quite tricky to perfect.

A4: My daughter had challenging behaviour in the car for a couple of years, mainly when we stopped in a traffic jam or at traffic lights. I discovered that providing a running commentary of the journey offered her reassurance. For instance, if approaching a traffic light that was about to turn red, I would say 'red for stop' and similarly 'green for go'. I would also tell her if we were due to travel on an unfamiliar road. If my daughter was self-injuring, I would find a quiet place to park the car and explain that we would not continue the journey until she sat calmly. She now understands this message.

Q: Is it worthwhile applying for Deputyship to protect my son's future care?

A1: What you can do as a deputy is to sign a tenancy agreement for your son. A tenancy means that if a provider decides to terminate the contract and no longer care for your son, or you decide to change provider, he cannot be evicted from his home.

A2: I have had deputyship for finance and welfare for my daughter since last year. It cost us about £1200.00 for both. The finance one is beneficial for the future as even if my daughter leaves and lives somewhere else it carries on. The welfare deputyship is worth it so you can have a big say where your son should live, on operations etc.

A3: I am a welfare deputy for my son. Any decision about his health and

welfare from now on has to involve me as an equal partner. Without this right, as a parent of a young person over 18 you only have a right to be consulted - and that doesn't mean a lot sometimes. You could potentially apply, spend time and money on the application and then walk away with nothing. Despite the risk, I would say that it is worth applying as you are worried about past failings happening again and you wish to be fully involved in his future. Prepare your case upon sound evidence, e.g. why do you need Deputyship, what has failed and when, and letters and documents in support.

A4: Don't forget that even if you are not a deputy for your son and he lacks the capacity to make some decisions himself then the Mental Capacity Act must be followed. You must be invited to attend any best interests meetings and you can also request an independent advocate if you feel this will be helpful.

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 or email info@thecbf.org.uk

New staff



Catryn, Chris, Danielle and Becky

There have been changes in the CBF office, with some old hands leaving us and new faces arriving. We have expanded our staff numbers to help us secure our future as a charity, and reach out to more families who are caring for someone with behaviour that challenges.

Our Family Support Interns, Adam and Kerri, have both left us after a year. They have contributed to evaluating the family support phone line and got involved in many of our other projects, including helping to coordinate the Challenging Behaviour National Strategy Group and updating our written resources.

The new Family Support Interns are Becky and Danielle. They will continue to update our written resources, help with family support enquiries, develop a new DVD, and help coordinate the Challenging Behaviour National Strategy Group.

Karen McKane has left us after nine years work as our Development Manager. Karen was the CBF's first employee, and she has guided the steady growth of the CBF to the position we are in today. We are really grateful for all the work she has done for us. Some of Karen's financial responsibility has been taken over by Rup, who joins us as our new Finance Assistant.

Fundraising has been taken over by Catryn Ladd. The CBF is reliant on grants and donations for most of its income, and Catryn's role is to secure funding to allow us to plan for the future. She is also responsible for communications, with the support of our new Communications Intern, Chris Lack. Together, they aim to improve the way we communicate with families, professionals and decision-makers.

Helping families



Gary

The CBF has always been based on the needs of real people. So to celebrate our anniversary, we have collected some stories about how our work has made a difference.

Kate Sanger told us about life with her daughter, who has severe learning disabilities and complex communication disorder: The most difficult part of living with my lovely daughter is her challenging and self-injurious behaviour. There were times when I felt I couldn't carry on.

"The CBF was like a light at the end of what had been a very dark place. The information pack was the first positive information I had received in seven years' search."

A member of our email forum commented: "One of our twin girls is severely disabled. She has very challenging behaviour, screaming, head banging, slapping, pinching, biting, scratching. It is not possible to underestimate how valuable it is to parents to know that we are not alone. The email forum has been a lifeline to me for this reason."

Steph Chapman's brother Gary has learning disabilities, autism, and challenging behaviour. She said: "The CBF saved our family. My brother's escalating challenge was ripping us apart leaving us in tears about how much more we could take. The training on supporting behaviour change has been invaluable – rather than challenge back and make a contest of it with him we look for much better strategies to bring him out of a challenge."

SHIEC – the next chapter



Carl

The CBF's special projects demonstrate ways in which services can be improved. One example is the Sustainable Hub of Innovative Employment for people with Complex needs (SHIEC). SHIEC helps increase employment opportunities for people with the most complex needs, and it is the only organisation of its kind in the UK. People with complex needs are usually excluded from employment services, but SHIEC's members have generated several examples that prove employment is truly possible and beneficial for all.

Carl from Essex has gained a paid position as a waiter at Lilliput's Café. Carl has a learning disability and limited communication abilities. He also has cerebral palsy and epilepsy and is a wheel chair user.

Carl, who is supported by Sheila Morgan and others at Care Management Group (CMG), had previously completed an ASDAN in food preparation at the centre where his progress so impressed the manager that he was asked to apply for a job as a waiter.

Frank Proctor provided staff at CMG with materials to help Carl prepare for an interview, which he evidently did very well at!

Carl has also continued to carry out voluntary work at Wellgate Farm where his duties include cleaning animal pens and feeding livestock. He is also being supported to find further work opportunities related to Dagenham and Redbridge football club (he is a bit of a fan to say the least!)

Dr Nick Gore
Research Fellow – Tizard Centre

Frank Proctor
Project Manager for SHIEC

Family support evaluation



The family support line

The CBF's family support service, which helps families on the phone or by email, is a core part of our work. We have recently evaluated this service, and we found that it has had a real impact on the lives of family carers. The evaluation was based on a questionnaire and telephone interview.

The results were very promising, and families reported a positive impact as a result of seeking support from the CBF. Their comments included:

"My son has a better quality of life in the type of care home that better serves his needs"

"I felt empowered to make a difference"

Family carers also highlighted that the CBF support service was unique and that the information the CBF provides is very useful:

"The understanding of challenging behaviour, and on a previous occasion, knowledge of the law, was most helpful."

"The suggestion that my son needed a functional analysis helped me read up more and find out where to go to get one."

The evaluation highlighted that families felt more confident, calm, and well informed after receiving support from the CBF. Family carers also gave some helpful recommendations to improve the support service. It was clear from the evaluation that the CBF support service is valuable and the CBF will therefore continue to offer this service to families. The CBF would like to thank the families who took part in the evaluation.

Plans for the future

As well as continuing with our existing work, the CBF has some exciting plans for the future

Reaching more families

Our website, information resources and family support line already reach many hundreds of families, but we know there are more people out there that we haven't reached yet who are feeling isolated and need advice. So we want to spread the word about how we can help. We want to publicise our family support line and raise the profile of our website so we can reach more families and help provide them with information and support.

Helping family carers represent the CBF

We plan to help more family carers speak out for the CBF on behalf of children and adults with behaviour described as challenging. We know that family carers are experts by experience, and we know that they have powerful messages based on lived experience. So we want more family carers to have a voice in a range of ways - from training events and conferences to meeting decision-makers - to encourage change.

Strengthening our partnerships

We have always believed that we can achieve more by working in partnership with others, and now we want to build on the positive impact this has had. Working with other charities means we can combine our resources and build on individual strengths to achieve common goals. Our Out of Sight report, in partnership with Mencap, is a good example of this - we want to continue to strengthen our relationships with similar organisations. We have already developed close working relationships with a range of stakeholder groups, and we plan to continue to build on these relationships and develop new ones to deliver better lives for children and adults whose behaviour challenges, and their families.

The CBF needs you!



Daniel

The CBF exists to make a difference to people's lives, and with your help we can reach out to even more families.

All of our projects, from the family support line to the DVDs, are designed to improve people's lives. We have supported thousands of families and trained hundreds of professionals and family carers.

In the future, we want to contact more families so that more people can

benefit from our advice. We are also planning to expand the information services we offer by producing more leaflets and expanding our collection of DVDs.

At the same time, we want to continue to influence government policy. After the scandal at Winterbourne View, the care system is back on the government's agenda. We need to keep it on the agenda, and we need to use this opportunity to improve the way that people are treated.

But we can't do these things alone. If you have been inspired by our 15th Anniversary fundraising efforts, or are as passionate as we are about our plans for the future, please get involved. We would love you to share your story with us, help us reach new families through sharing information or volunteer your time to support other carers. Please email communications@theCBF.org.uk to find out more. To find out about fundraising for us please email fundraising@theCBF.org.uk.

We're incredibly grateful to all the people who have donated to us in the past: without you, we wouldn't be able to offer the services that we now provide.

15k for 15 years



A fundraising team

When we launched our 15k for 15 years campaign at the end of last year, we called on our supporters to hold events to raise money for the CBF. The response was overwhelming. So far, we have reached £13,513, which is 90% of our total. Just as importantly, this money has come from over 240 individual donations. This really has been a mass fundraising movement.

Friends of CBF have run a total of more than 200 kilometres to raise sponsorship money. A team from Chaucer Insurance ran through very muddy conditions in December, while members of the CBF office dressed up as Father Christmas to take part in the Santa Dash. Dan Bird ran a Marathon in April, and two supporters ran 10k each during the summer.

Other supporters have helped us in different ways. The hundred club has continued to provide much needed funds, and the regular donations from the Friends of the CBF are helping us to develop a steady source of income. Some of our supporters have even celebrated their birthdays or wedding anniversaries by asking for donations to the CBF.

In addition to the 15k for 15 years campaign, we have received over £8,000 in individual donations towards the Everybody Matters film. This money was raised by 39 generous private donors, as well as a large contribution from the funeral collection of the late Jim Mansell.

Thank you to everyone involved: your donations help us reach out to more families.

Simon



Simon

Simon spent 15 long months at Winterbourne View. We now know that during that time he was hit, pushed, abused and tormented. Can you imagine the horror I felt when the Panorama team showed us what was happening to my son?

What Simon needed was more support in the residential care home where he lived – certainly not to end up in a place like that. We tried so hard to stop them taking him there, but we were stripped of our role as parents and sidelined while those in ‘authority’ made the decisions for us. They used their power to just ship him off, sending him many miles away from home – away from the people who love him, too far from us to protect him from the terrible things that happened.

Simon is now back living near us, and he is loving every minute of his life – he is out more than he is in! He has a voluntary job as a caretaker at the local community centre. He is so proud of the reflective jacket he gets to wear. He also enjoys shopping in his local town where everyone knows him.

Simon's package of care now costs about half as much as it did for him to be in Winterbourne View. The staff he has now have been wonderful and are truly dedicated. I know that not only is Simon happy, he is safe.

You've seen what happened to our son. Please help to stop this – we must end the scandal of sending people like Simon to places where they are out of sight and out of mind, because we know what can and does happen.

• Simon's mum

Out of sight

Stopping the neglect and abuse of people with a learning disability

The care system is failing people with a learning disability and behaviour that challenges. Out of sight; a report by Mencap and the Challenging Behaviour Foundation says enough is enough. The way we support people with a learning disability and behaviour that challenges must change.

Panorama exposed appalling abuse at Winterbourne View – an assessment and treatment unit for people with a learning disability. Simon was one of the people abused at Winterbourne View – here Simon's mum tells his story and asks you to demand change so that people cannot be sent so far out of sight that what happened at Winterbourne goes on happening to others again and again.

Mencap and The Challenging Behaviour Foundation have worked together to produce “Out of Sight” which tells the stories of James, Chrissy, Joe, Emmanuel and Victoria through the words of their families.

Through their stories, this report shows how providers, commissioners, regulators and the Department of Health have failed to act on the substantial amount of available guidance. It shows how they have allowed the care system to fail its most vulnerable by not developing good quality local services for people with learning disabilities who display behaviour that challenges.

Here are some extracts from the report. To read the report in full go to www.mencap.org.uk/outofsight

“At the moment, we are spending large amounts of money putting people in places like Winterbourne View – very expensive services that are harming people. There is no doubt we need to take action to stop these kind of services being used in this way as dumping grounds.” The late Professor Jim Mansell CBE, to whom this report is dedicated.

Winterbourne exposed



Terry Bryan

Terry Bryan was the member of staff who blew the whistle on Winterbourne. Here he explains why he did so:

“I blew the whistle because I had seen bad practice and poor attitudes, staff ignoring people when they were distressed and the threats – staff saying, “if you don't stop banging your head against the wall then you won't see your mum at the weekend”. I started recording what I saw and then wrote the email. It was quite low-level stuff, but it was enough to get people suspended.

It took a secret camera to expose the scale of abuse going on. They wouldn't have done what they were doing in front of me, as they said I was a “do-gooder”. As I watched the programme, I couldn't believe what I was witnessing. I thought it would just be more of the low-level stuff I had seen. I didn't think it would be that extreme.

It was like a perfect storm – it wasn't just one thing. Commissioners were happy to send someone to a place like that. The management was inept. The training was sub-standard. They recruited strong-armed people, not caring people. The staff weren't paid enough. There was no supervision. When the safeguarding team were alerted, they didn't act. When I alerted CQC they, didn't act. What else do you do?

If people want to abuse someone, they will. They will do it behind closed doors. Generally, you can't stop it. But when they do it in front of someone like a nurse, and the nurse doesn't do anything about it, that's the worry. That's when it has become routine. That's when it has become part of the culture and it self-perpetuates. New staff come in and that is what they learn.”

Joe



Joe

Our son Joe is 36 years old. He's a boisterous person, with a wicked sense of humour. He loves being out and about, and he has a big family who love him to bits.

For 18 months, we had been voicing our concerns about the quality of care Joe was getting. In the end, there seemed to be one incident that resulted in Joe being sectioned, which there was just no need for. He was unsettled and unhappy with the many different staff coming into the house to support him. The change was too much for him, and the staff didn't have the skills.

Joe was sectioned and sent away to an assessment and treatment unit 130 miles from where we live. It's a five-hour round trip. We agreed to drive him there after he had been sectioned. It was heartbreaking having to leave him there. We visit Joe every other weekend, but in the winter we can't visit because the unit is in a very isolated area and there is too much snow.

It breaks our heart when we've spoken to him on the phone. Sometimes he's been upset and crying, but there was nothing we could do. Being at the unit means he hardly gets to see his three nephews, as they are too young to visit. He misses them and talks about them constantly.

It has not been good for Joe being at the unit. It is a real ‘institution’ with 26 beds. There are set times for things, and everything revolves around set activities. When we visit Joe, we often find that his clothes have gone missing and he is wearing other people's clothes. He often hasn't had a bath or a shave. We always see the same faces – people seem stuck there.

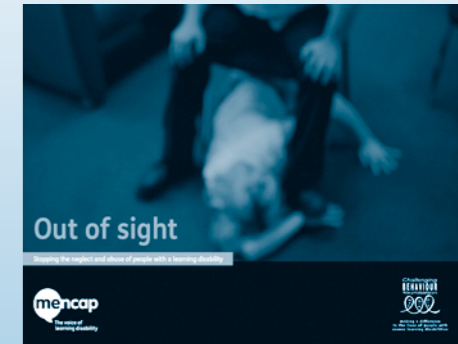
We have been fighting to get Joe out since he got there two years ago. We have had to find a provider we are happy with and contact housing providers to find a suitable house for Joe. It was left to us to sort all this out. Had we not been doing it ourselves, nothing would have happened. It was a real struggle to get the PCT to agree to it all. After a year of hassling, they eventually agreed.

We've been decorating the property, and now it's all ready for Joe. We've interviewed staff, and they're now completing their training and getting to know him, so hopefully he will be in his new place soon. It has been a horrendous two years, as we just haven't been able to get Joe home. At times, we thought we would never get to where we are now.

We find it very distressing that Joe will have to adjust to ordinary living because he was left in an environment he should never have been in.

• Joe's mum

Time to take action



The Out of Sight Report

What happened to Simon and Joe and other people whose stories are told in the report makes utter nonsense of the decision to place any of them in assessment and treatment units or other institutional settings. It is outrageous that the NHS spends such large amounts of money sending people away to services that fail them. But more importantly, it is unforgivable that our most vulnerable citizens have been so seriously neglected and abused by the very services that should have supported and protected them.

We need leadership from the government – things must change. It is unacceptable for people with a learning disability to be abused. It is unacceptable for them to be sent miles away from home. It is unacceptable for their human rights to be trampled on. The government must ensure that the final Winterbourne Review report on Winterbourne View sets out a clear Action plan and that it must be delivered.

Please think about what you saw happen to Simon and the other people on Panorama. How you would feel if what happened to Simon had happened to your son, daughter, brother or sister?

If what happened to the people in this report is not good enough for the people you love, then take action with us to make sure these things don't happen to anyone else.

There are a number of things you could do, from writing to your MP to sharing your own story.

Go to www.mencap.org.uk/outofsight
Email campaigns@mencap.org.uk
Call 020 7696 5613

Early intervention project

Dr Nick Gore writes about an exciting new research project.

The case for early intervention is very clear. Behaviour that challenges impacts the wellbeing of individuals and families, yet far too often support is only provided when a crisis point is reached. Providing support at this stage can be costly, complex and uncertain as professionals attempt to address years of unmet need, understand behaviours that have developed across an individual's lifetime and work with families who are often burnt out and isolated.

Even when these efforts are successful, families and professionals alike will be painfully aware of the years of heartache that might have been avoided, and the positive experiences that might have been possible, if this had just been provided before. There is a fair degree of research highlighting which children are most likely to develop behaviour that challenges but very little that has been done to try and prevent this from happening or limit the impact from an early stage.

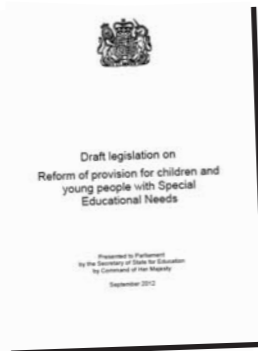
The Early - Positive Approaches to Support (E-PATs) project is however now working to develop improved ways of meeting the needs of families and children with complex needs at risk of challenging behaviour, well before a crisis is reached. The project is run from the Tizard Centre in collaboration with the Challenging Behaviour Foundation and an advisory group of family carers and professionals.

E-PATs will deliver a package of supports to families with children who are under 5 years of age and support other services and teams to develop early intervention initiatives. The ultimate aim is to develop models of best practice that can help to inform future service provision.

The E-PATs team are very keen to hear from people who are interested in early intervention and have ideas or questions about the project – so please do get in contact by emailing n.j.gore@kent.ac.uk

• **Dr Nick Gore**
Research Fellow – Tizard Centre

All change for under 25s



The draft legislation

The government is planning to change the way it helps children and young people with special educational needs (SEN). It wants to pass new laws about the help it gives to people aged 0-25 with SEN.

The government has already published consultation documents (Support and Aspiration and Next Steps) about the new laws. It has recently published a new document of SEN draft legislation, which explains the laws the government want to pass.

Here are the key changes that the government has suggested:

- A new duty for joint commissioning of services between education, health and social care; meaning local authorities and health trusts are jointly responsible for providing services for children and young people with SEN.
- Local authorities will be asked to publish a local offer of services so families can easily access these services.
- New protections for people aged 16-25 in further education and more support to prepare them for adulthood.
- Parents and young people will be entitled to have a personal budget to buy in the support they choose.
- Further Education colleges and academies will have the same duties as maintained schools for the education of young people with SEN, who will be able to attend any mainstream school if they wish.
- People will still have the right to appeal if they think they have been treated unfairly. However, they must take part in mediation before making the appeal; this means that they have to formally discuss their problems with the local authority. If this does not solve the problem, they can then make an appeal at an SEN tribunal.

These suggestions are being tested in 20 areas of the country, called pathfinder areas. To find out what's happening in the pathfinder areas, go to www.sendpathfinder.co.uk The government will revise the laws and produce final legislation in 2013.

Mainstream school



Chris in his uniform

Chris is 13 years old, and he loves to climb and run. He attends the same local secondary mainstream school as his older brother. This is in spite of his diagnosed autism, and the labels he has of speech and language impairment, severe learning disabilities, challenging behaviour, and pica. Chris has some very difficult behaviours, such as disappearing from home in the middle of the night, biting and picking at himself, running down the middle of the road, climbing tall structures, and licking or chewing dangerous objects like batteries.

After years of positive support in primary school, Chris's move to secondary school had to be very carefully planned, and as parents we had to keep faith in Chris's ability to adapt to a much bigger, busier environment. What made it a real success was that Chris's presence was strongly supported by the students who already knew him from his "circle of friends" at primary school. The circle members have been informal ambassadors, enabling and expecting the other students in secondary school to interact with Chris respectfully. We were enormously proud when Chris was awarded a certificate in year 7, recognising his "positive approach to all school activities".

Just recently, with help from school staff, we recruited two 6th form students who now take turns to walk with Chris between home and school. This helps develop his independence, increases his interaction with peers, is healthier and more "ordinary" than any arrangement we've had before, and most importantly, Chris really enjoys it.

• **Jo, Chris's Mum**

Person-centred planning



Chris Harlan-Marks

Family Footings is a project which helps the families of people with learning disabilities.

Family Footings encourages parents and carers to use person centred thinking tools. These tools help us talk about and address challenging behaviour in positive ways that recognise the preferences of our children.

Communication Charts encourage people to look past the behaviour to the underlying want or need and give instructions on how to respond. Divide a page into four columns so you can:

- Identify time/place where the behaviour occurs
- describe what the child does
- explain what you think it means
- give instructions for how to respond

You can also use this tool to encourage people supporting your child to notice and respond to warning signs before things escalate.

The Working/Not Working tool provides a helpful framework for families that want to problem-solve together or for meetings with professionals. Divide a page into a 'Working' column and a 'Not Working' column, and divide into rows for each person taking part in the conversation. This tool encourages us to stop and acknowledge the positive as well as the negative and gives everyone a chance to have their views heard and taken seriously. After using this tool it can be helpful to make an action plan with Who/What/When columns and include an action to address each thing that was 'Not Working'. For examples, other tools and stories by parents, visit www.familyfootings.org.

• **Chris Harlan-Marks, Family Footings Facilitator**

Family Carers meet MP

Care for people with learning disabilities has been debated in parliament following the abuses in Winterbourne View.

Mencap and the CBF helped family carers meet an MP hours before the debate took place. The families told Tom Clarke MP about their experiences of care.

In the debate, Tom Clarke referred to their experiences and to the Out of Sight report, which was produced by the CBF and Mencap (see pages 6 and 7). He went on to say: "It is nothing short of a national scandal that we've allowed people with learning disabilities to be so marginalised and ill treated... The current care model, and the regulation of it, led to these abuses. It is the system that we are challenging."

He then called for the provision of more localised care: "The Government should begin closing large assessment centres and set a time scale. Local commissioners should develop local services that meet the care requirements of those with learning disabilities."

Tom Clarke also suggested that funding needs to be reviewed to ensure there is no incentive for keeping people in large centres for long periods of time.

The then Minister for Care Services, Paul Burstow, also spoke. He admitted "The events at Winterbourne View that the right honourable gentleman so clearly described were horrifying and depressing. They were depressing because, as the report by Mencap and the Challenging Behaviour Foundation, "Out of Sight", reminds us, it is not the first time that closed institutions have let down people with learning disabilities.

Every part of the system—NHS and social care commissioners, providers, regulators and health and care professionals—has a part to play and, indeed, has questions to ask itself about what has passed." The debate has helped to raise the profile of these issues in parliament.

CBF training: evaluation



Dr Nick Gore

Dr Nick Gore, from the University of Kent, has evaluated the CBF's training workshops.

The CBF have continued to deliver challenging behaviour training workshops over the last year. These workshops are unique in that they are delivered to both family carers and teaching staff to help ensure close working relationships and consistency of approach.

In 2010 a pilot evaluation reported promising outcomes. It was found that participants gained knowledge of the causes of challenging behaviour, rated challenging behaviour as happening less often and experienced less negative emotional reactions in response to challenging behaviour following training. A further evaluation was completed in the summer of 2012. On this occasion, family carers were interviewed in-depth following the workshops. This allowed the real voices of participants to be heard. Family carers described a range of benefits from taking part and provided clear examples of how they had put ideas from the workshop into practice: "It's as if he thinks well they understand now so I don't have to take it up a level – I don't have to attack anybody" 'He has choices about "do you wanna shower? Or a wash?" before it was very you know "you will have a shower" or "you will have a wash" it's not like that now – now he's got more choice and he's happier.'

Findings from the second evaluation have been written into a report for publication and are being used by the CBF to help inform the future delivery of workshops.

• **Dr Nick Gore**
Research Fellow – Tizard Centre

When things go wrong

"When things go wrong" is a new factsheet about dealing with problems with care. It is written by the National Family Carer Network. It contains advice about your legal rights, how to deal with cuts, how to make a complaint, and what to do if you suspect abuse. To read the document, go to <http://www.familycarers.org.uk/default.aspx?page=27558>

Autism research project

Goldsmith's College are looking for participants in a research project looking at people's experience of autistic spectrum diagnosis. They are looking for adults with autistic spectrum diagnoses, the parents or guardians of people with autistic spectrum conditions, and professionals who diagnose these conditions. If you would like to fill in some surveys for the research project, go to <http://www.gold.ac.uk/psychology/research/asd-diagnosis>

100 Club Winners

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

June 2012:
Mr & Mrs E Graham (Cramlington)

July 2012:
Mr & Mrs S Ingarfield (Maidstone)

August 2012:
Nicky Leggat (Bexhill on Sea)

All proceeds from the 100 Club help towards CBF running costs. Please get in touch if you would like to join.

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

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For our 15th Anniversary **Friends of CBF** have been set the challenge of raising £15,000 to help the CBF reach more families

As ever, CBF supporters have been busy doing sponsored runs. Helen Marron has raised sponsorship money by running the British 10k in London. She completed the run despite the hot weather, and raised valuable funds for the CBF with the help of her generous sponsors.



Daniel Bird featured in our previous newsletter after he ran his first ever marathon in 2 hours 56 minutes. He came 50th out of over 5,000 entrants and raised over £2,000 for the CBF. Daniel explains that he supports the CBF because of the help we have given with his younger brother, who has severe learning disabilities and challenging behaviour.

Now, Daniel has been in the news again after he was one of the bearers of the Olympic torch in Huddersfield. Daniel's mother commented "Dan was the 2nd person to run once the Torch had arrived at Huddersfield, so he ended up at a fantastic spot. The crowds were huge and he received a fantastic welcome and loads of cheering and flag flying." Daniel, who is on the autistic spectrum, has also been named the Disability Sports Achiever of the Year at the Bury Sports Award.



Lots of people have been running for CBF recently, but of course people have found many other ways to help us out. We'd like to say a big happy birthday to Clare Pierce, who asked for donations to the CBF instead of birthday presents, which has so far raised £635 and counting. And a very happy anniversary to Barry and Deirdre Yager (right), who have asked people to make donations to the CBF to celebrate their wedding anniversary.

Finally, Kate Sanger (left) was invited to have Jubilee lunch with the Queen, in recognition of the work that she has done to support people with learning disability in her community.



In this edition, we're asking those who can to make a donation to help secure the future of CBF. But there are also many ways to help without spending money. One great thing to do is to nominate us as a good cause at your local Waitrose. The John Lewis partnership, which runs Waitrose, gives out £3,000 per month to good causes nominated by its customers. If people nominate CBF, we will receive some of this money. So, to help us fundraise without the need to spend, ask about this scheme in any Waitrose branch.

Challenging Behaviour Workshops



A training workshop

The CBF is offering free Challenging Behaviour workshops. The workshops are for professionals and families, and they are hosted in schools.

Due to funding from the Department for Education, the workshops are free to schools when inviting parents and staff. The workshops are extremely popular and we have delivered to 55 schools so far this year.

The workshops have been evaluated by the Tizard centre, University of Kent, and found to lead to

- A significant reduction in the severity & frequency of challenging behaviour
- A reduction in the anger and depression experienced by parents
- A reduction of fear and anxiety experienced by paid workers

And people say they are enjoyable!

The workshops take a holistic approach to supporting an individual and can stand alone or complement other training such as team teach. They are run by a family carer and a positive behavioural support trainer and feature three sessions: the first for families, the second for paid workers, and a third for everyone following a break of around four weeks. This final session is used to reflect on what's been learnt and to develop a positive behavioural support plan for each individual who is being thought about in the workshops.

We are aiming to book all workshops by the end of the year, because we can only use the grant money for free workshops until the 31st of March 2013. If you would like to attend a workshop, please let us know by filling in the form on the back page of this newsletter.

Challenging behaviour workshops available

Are you a family carer or a professional?

Do you want training to help manage challenging behaviour?

We are looking for schools to host our free workshops, funded by DfE

To find out more

email training@thecbf.org.uk

call 01634 838739

or fill in the form below. For more information, see the training article on page 11.



If you'd like us to provide training at your school, please email training@thecbf.org.uk, call 01634 838739, or fill in this form and post it to : The Challenging Behaviour Foundation, The Old Courthouse, New Road Avenue, Chatham, Kent, ME4 6BE.

I am a

Family carer Professional

Please tick box

- I would like you to contact my school to offer them training.
- I am happy for you to tell the school that I requested the training.
- I prefer to remain anonymous.
- I would like more information about the training so that I can contact the school myself.

Your contact details

Name

Address

Postcode

Email

Telephone

School contact details

Name

Address

Postcode

Email

Telephone

We like to keep you updated with our free newsletter. If you do NOT want to receive this newsletter, please tick here.

If you WOULD like occasional email updates from the CBF, please tick here

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.