Challenge

Summer 2012

Challenging BEHAVIOUR foundation

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

The newsletter of the Challenging Behaviour Foundation

CBF
15th Anniversary
2012

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

Hearing but not listening

We need the decision makers to not just hear, but to really listen, so that real change can happen.

In 1997 I started the CBF because as a mother of a disabled child, I needed to join with others to make people listen. 15 years on, there are more opportunities for the voices of families to be heard- but who is actually listening to what we say?


Vivien Cooper

Learning to listen properly to others helps us to get things right. And when there are lots of voices saying the same thing, it is easier to be heard.

When we do listen, we can get it right

The law says families of people who lack capacity must be consulted about decisions relating to their relative. It makes sense to listen to families because they know a great deal about their loved one. The CBF has worked with partners to develop a new resource that is a practical tool to help families remind others of their duty to listen to them.

When we do listen, we can get it right; if we listen to the individual, their family, to what research tells us - and if we listen to our conscience.
The recent Care Quality Commission report of their inspection of learning disability services found half the locations inspected did not meet the required standards. Family carers who were part of the inspection teams were clear that they and the experts by experience with a learning disability played an important role and provided a level of scrutiny that was previously lacking. This message has been heard by CQC, and they have committed to ensuring that the voice of family carers will be listened to and acted upon.

The interim Department of Health (DH) review report also said that we need to listen to the voices of people with learning disabilities and their families. Their final review planned later this year will be bringing together a range of reports, information and findings, and provides a real opportunity for the Government to lead by example and listen to what has been found and act upon it – even if it is not what they want to hear.

Listening is a skill

Listening is a skill – it is concentrating on hearing and paying attention. We can hear the message and ignore it, or we can listen, learn and adapt our response. I sincerely hope that everyone is listening to all the voices saying we must take action to stop vulnerable people being sent away to inappropriate services, when we say we know how to support people with complex needs, and we can do that locally - and when we say we have to make that change happen, not just hope that it might.

- **Vivien Cooper OBE**

Chief Executive and Founder of the Challenging Behaviour Foundation

Just because

A colleague was once forty-five minutes late for a meeting with a young woman

We sat around waiting, listened to the young woman with autism and tentatively put the world to rights. My colleague held the purse strings and had the authority to decide if our plans would be given permission for take off. The meeting was scheduled to last an hour. After forty-five minutes my colleague arrived and without apologising sat down and began to dismiss our plans. After fifteen minutes the young lady stood up and said, 'There goes your time' and walked out. My colleague watched the door slam and said to me, 'So much for all your work.' Her report concluded the young woman was difficult to work with. She didn't learn to listen well and relied on her authority to compound her mistake by letting someone else take the rap.

After her nose stopped bleeding, my colleague apologised

Another colleague once ignored the advice of a classroom assistant and formally introduced herself to a young gentleman with autism who happened to have an intolerance of formal introductions. After her nose stopped bleeding, my colleague apologised to the young man and the classroom assistant and insisted everyone ignore the teacher who wanted to exclude him. She learned to listen well and didn't rely on her authority to compound her mistake by letting someone else take the rap.

Just because a frustrated parent has had her trust broken by unkept promises and so comes across as a bit abrupt, simply because a parent voices concerns at the lack of choices for her child, simply because a young person lacks the diplomacy or language we ourselves selectively posses, doesn't mean what they know doesn't count and doesn't mean what they say doesn't matter.

Just because the power of decisions rests within the hands of people who do not live with the child or young adult, rests with people who do not have to live with the consequences of their decisions, just because some of us went to university to become half-human and half-professional, doesn't mean we are obliged to be centaurs, roaring at parents for not being grateful for the crumbs we offer.

Just because parents will snap and snip and fear and complain, just because parents will put aside our carefully crafted plans when their world turns upside down (again), just because a parent's voice is often edged with doubt and anger, does not mean their voices are unworthy of being heard.

Parents have the right to hope and demand. Parents have the right to question. Just because at times their words appear hopeless and loveless, does not mean we cannot offer hope and even, damn it, love. Just because it is a parent carrying a weight they did not ask to carry does not mean we cannot help them carry it.

We can surrender our jobs and our centaur-selves, we can go home and relax, we can switch off. Parents seldom surrender their children or their love or burdens.

Amidst our ordinary lives, listening to people well is some small thing we can do that is extraordinary. Listening means taking everyone seriously, regardless of abilties.

- **Tony Osgood**

Lecturer in Intellectual & Developmental Disability, Tizard Centre, University of Kent

HOW YOU CAN HELP

Be a CBF Local Champion

Do you believe in the work the CBF does? Do you have some time to publicise the CBF in your local area?

We are looking for Local Champions to volunteer for us to help raise awareness of the CBF and of current issues for people whose behaviour challenges. We have a small staff team so don't have the capacity to reach as many families across the UK as we'd like to; therefore we need the help of dedicated volunteers around the country to give more people in need of our support the opportunity to access our services.

You could champion the CBF by attending learning disability events, encouraging people to sign the Challenging Behaviour Charter, organising fundraising events or distributing CBF publicity and information materials. You can use your skills and interests to make this role your own and you can give as much or as little time as you have.

To find out more or become a Local Champion, contact the Volunteer Coordinator at holly.butcher@thecbf.org.uk.

YOUR QUESTIONS

Q: We were told it was not right for us as family carers to disguise medication in our son's food and he spits out liquid medication. What do we do?

A1: I fail to see what is wrong with that approach. If we try to give my daughter liquid medicine by mouth, it takes 2 people and considerable force, and everybody gets very upset.

I would choose the least traumatic way. Our children do not usually have a choice as to whether to take these medicines, but I am sure that if they were able to choose the method of delivery, it would be the tasty, stress free way!

A2: It's about whether the person has the capacity to make an informed decision about whether or not to take their medicine and understands the consequences of not taking their medicine. So if someone over 16 can understand the concept that taking their medicine will make them better and that not taking their medicine may make them ill, but still refuses their medication, you cannot override their decision and you will have to try and persuade them with a reasoned argument.

However if your son is over 16 and lacks the capacity to make an informed judgement then it is up to the carer to act in their best interest. For the most part this would mean giving them their medication. The carer should then make a note of this (this is just to follow procedure).

The carer must also give the medicine in the least restrictive way possible, so giving medication in food would be preferable to holding someone.

A3: You could go back to the doctor who initially prescribed the medication and enlist their support.

Q: My son moved into residential care three years ago but I still find this so hard to come to terms with. Am I alone in feeling like this?

A1: The day we drove our son to the home (which is 50 miles away from the family home) and dropped him off was the worst day of my life. He didn't understand why he had been left on his own and kept asking every few minutes to go home. Having dropped him off I cried all the way home, and actually for the first eighteen months had a deep depression, feeling that I had let him down and effectively thrown him to the wolves.

A2: On the day we left him there (our son) pushed us out of the door as soon as we arrived as if to say this is my place you don't need to be here. I know everyone isn't as lucky as we were. He's an adult and deserves a life of his own. We shouldn't feel guilty for trying to do the best for our children. One day we won't be here and that to me is the hardest thing of all. I've got two boys with autism and I think my job now they are adults is to make sure they are safe, secure and have the best possible life.

A3: We put our son into residential care from the age of 9 as it was affecting his brother. He now has his own home and staff team, but he has had four safeguarding incidents in the last three years! I feel so guilty about not having him living with us at home.

A4: We found (our son) a lovely place and I realised that this was it for the rest of his days and that he would never have the kind of life he should have. On the plus side he is able to have holidays, pastimes and a fuller life than the one his father or I could have given him.

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

CBF NEWS

What parents say

Niamh & Carly

Niamh is 8 and has Tuberous Sclerosis (TS). She can't communicate or look after herself in any way. She loves eating and swimming. At around 4 Niamh started to hit and pinch herself and exhibit prolonged episodes of screaming. Niamh's extreme behaviour meant as a family we could not partake in the things a normal family does and I had to give up work as Niamh could not be left alone. The situation left me getting only 4 hours of broken sleep per night.

After a terrible period where Niamh needed someone with her 24 hours a day, otherwise she would constantly hit herself, we finally admitted we needed help to look after our daughter. This made me feel I had failed in some way but my husband Nick helped me to realise this was not true. We received 4 hours of respite in the home and this meant we could devote some time to our son, and to ourselves. Niamh never left our thoughts, but a trip around B&Q or Tesco was a real tonic!

Despite professional help Niamh's behaviour worsened and the school also began to struggle. Nick initiated a multi-agency meeting to discuss routes to support for the family. We received fantastic support from Niamh's school teacher, Family Support worker, School Nurse, TS Nurse, paediatrician, Occupational Therapist, Community Learning Disabilities Nurse - and Niamh's grandmother. We received extra direct payments, two nights care in the home and help with horse riding and swimming.

The extra help has changed all of our lives; we have found ways to deal with Niamh's behaviour and we now feel more confident and better prepared for the challenges ahead.

In September 2010 I attended the CBF core training and now deliver workshops to family carers. This has been very empowering for me to tell my story and to help others.

- **Carly,** *mother to Niamh*

Do you have a photo and story you would like to share? Do get in touch.

Demonstration projects

Sometimes we identify particular issues that require more focussed input and expertise on a short term basis to pilot ways of working to deliver good outcomes for individuals. In our demonstration projects we learn by piloting an approach and demonstrating how others can replicate and adapt the learning to address the issue. These are some of the projects CBF has developed in the past 15 years:

- Sustainable Hub for Innovative Employment (SHIEC): This project identifies individuals with complex needs who are interested in employment and works with employers to show them how they can employ people with complex needs. So far SHIEC has worked with 44 people throughout the UK and supported them into paid or voluntary work placements.

A SHEIC work placement

- Advocacy Project: This project has trained a group of advocates to work long term with young adults in Kent to ensure their voice is heard and their needs are being met. Outcomes for some of the individuals being supported have included supported living, increased participation in community activities and improved communication.
- Personalisation: The aim of this project has been to develop a better quality of life for 26 identified individuals with complex needs. We have offered commissioning advice, housing options advice and positive behavioural support consultancy to the individuals, commissioners and/or families. Where this has been actively taken up, planning for people has moved forward towards a more personalised lifestyle. A report and key findings will be published later in the year

For more information about any of our demonstration projects visit our website www.challengingbehaviour.org.uk or contact info@thecbf.org.uk

Making a

In the last issue of Challenge we told you that we are cel
the history of CBF over the past 15 years. This time we
proud of and some of our key achievements over the las

Resources for families

The CBF was set up because there was no information for families about challenging behaviour readily available. 15 years ago we were sending out single information sheets to families, mostly in Kent. Last year we sent out over 1,000 resources to families and professionals all over the world. Our resources now include DVDs, guides, leaflets and information packs, but they all have one thing in common – they are free to family carers ensuring every family can access the information they need.

Our website allows families to access our resources 24 hours a day. We now have almost 12,000 visitors a month to our website; this has doubled in the last year.

Family support work

Almost from day one, even without advertising, the CBF received numerous calls from families who were in need of support. We now have a small team of people with one Family Support Worker answering enquires each day.

We offer non-judgemental individual information and support by telephone and email to families from across the UK. To speak to Charlie, Holly or Gemma phone 0845 602 7885 or email support@thecbf.org.uk

The CBF support and information line

"I wasn't expecting the support I was given….it has given me the strength to carry on" (family carer)

Training

A CBF training workshop

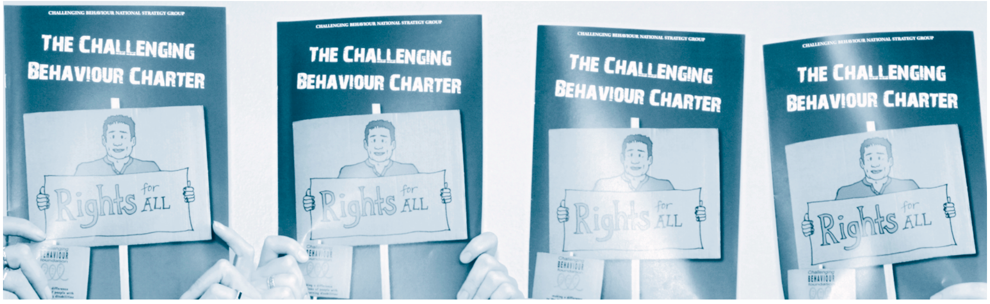
A more recent addition to our work has been training for professionals and families in understanding challenging behaviour and supporting behaviour change. Last year we secured a two year grant from the Department for Education which meant that we could roll out our tried and tested training to special needs schools throughout England. Our training is delivered by a Positive Behaviour Support Trainer and Family Carer Co-Trainer. Since 2010 we have delivered 300 training workshops to families and professionals in England, Scotland and Wales. Evaluation has shown it reduces the frequency, severity and management difficulty of challenging behaviour.

"The Challenging Behaviour training has been really valuable. But what's been the most positive thing for us is that it has developed an equal relationship with the professionals, and we're both working in a complimentary way to support my son" (family carer)

difference

ebrating our 15th anniversary this year and we looked at
e would like to focus on some of the work we are most
t 15 years.

Providing a voice



Supporting the Challenging Behaviour Charter

The CBF always aimed to become a key player in policy influencing which could have been seen as ambitious for a small charity. The Challenging Behaviour National Strategy Group (CB-NSG) was launched in 2008 in recognition that we can all achieve more if we work in partnership.

The CB-NSG now has almost 150 members including: representatives from adult and children's services, the education, social care, health and voluntary sectors and people with learning disabilities, researchers, clinicians and families. The strategy group has worked on a number of high profile projects, produced a number of resources and has influenced Government on issues around challenging behaviour. To read about our campaign led by Mencap turn to pages 6 & 7.

The first document the CB-NSG created was the Challenging Behaviour Charter, which now has more than 200 signatories. If you would like to add your signature please visit our website: www.challengingbehaviour.org.uk

Connecting families

Our parent's email network brings families together to share information and advice and to help each other from personal experience.
The majority of members find the network very valuable in terms of reducing feelings of isolation and receiving good information and support from other with similar experiences.

"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." (family carer)

"I can keep in touch with families who also have children with severe learning disabilities and challenging behaviour. Our situation is normalised, I feel less isolated, I can dip in and out of the network as and when it suits me." (family carer)

200 families currently use our email network. To join them visit www.challengingbehaviour.org.uk to download an application form or contact Charlie Clay, Network Co-ordinator (network@thecbf.org.uk)

Get involved

The CBF has been very lucky over the past 15 years to secure the support of many amazing people. For the first six years the CBF was staffed entirely by volunteers and many are still involved with us today helping to save money so that we can use our charitable funds to reach more families.

In everything we do we always ensure there is equal weight given to professional and family opinion, but we wouldn't be able to do this without the many families and professionals who have generously donated their time and enthusiasm to us.

Here are some ways that you could get involved with CBF in our 15th year:

- **Share your experience:** Perhaps you have a story you are willing to share in our newsletter or on our website.

You don't have to be an accomplished writer - we can help with that – just get in touch.

- **Volunteer:** We have a network of volunteers throughout the country who are spreading the word about our work, helping us to ensure that our support reaches those who need it.

If you think you could help why not get in touch.

- **Fundraise:** This year we are hoping to encourage 15 individuals or groups to raise money for us – and we are half way towards this target.

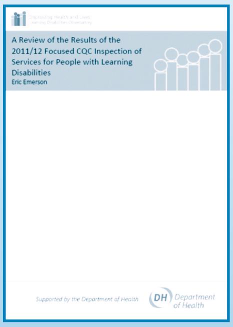
Everyone who has taken part in an event so far has had a great time, and we can help you to identify an event near you. Please get in touch.

- **Friends of CBF:** If you wish to simply donate to the CBF every month you could do this by becoming a **Friend of CBF** and receiving our Friends e-newsletter.

We know that there are many more families that would benefit from our support, but we can only do this with your help.

Visit the 'get involved' section of our website or email info@thecbf.org.uk to find out more. Thank you for your support.

IHaL report on CQC inspections


Improving Health and Lives
Learning Disabilities Observatory

A Review of the Results of the 2011/12 Focused CQC Inspection of Services for People with Learning Disabilities
Eric Emerson

Supported by the Department of Health
DH Department of Health

The Improving Health and Lives (IHaL): Learning Disabilities Observatory has analyse data collected during the CQC review, and produced a report.

Inspections focussed on 2 outcome measures; the care and welfare of the individuals using the services and safeguarding those individuals from abuse.

The report states that overall only one in seven of the residents in the 145 units were being supported in services compliant with both outcomes. Only 14% of people living in assessment and treatment units were in services that were fully compliant with both outcomes.

The report highlights:

- the size of many of the services - the largest was supporting 97 people. Half of the individuals included in the inspection were living in services with 20 or more people.

- the length of time people are spending in services. The majority (64%) of assessment and treatment units were supporting at least one person who had been there for 3 years or more.

- that compliance with the CQC regulations does not necessarily indicate the presence of high quality care. It gives the example of an assessment and treatment unit which had five people living there for over seven years, and a further four people who had lived there for an average of four years with no discharge plans in place.

Emerson concludes "The disjunction between compliance and broader notions of quality in this, and other, instances may call into question the extent to which the current Regulations are fit for purpose for the inspection of Assessment and Treatment Units for people with learning disabilities."

To access a copy of the report, go to: www.improvinghealthandlives.org.uk/publications

BBC Panorama Update

In 2011, the BBC Panorama programme *"Undercover care: the abuse exposed"* showed systematic and pervasive abuse of people with learning disabilities at a private hospital.

At the time of going to print, nine people employed at Winterbourne View, featured in the documentary, had pleaded guilty to neglect and/or ill treatment under the Mental Capacity Act and had been referred for sentencing reports. A further two people had pleaded not guilty and are due back in Bristol Crown Court on 6th August.

In response to the BBC documentary the Government announced that the Care Quality Commission (CQC) would undertake a programme of unannounced inspections of 150 learning disability services and the Department of Health would conduct a review.

CQC report

The Care Quality Commission (CQC) has published a report from a programme of 145 unannounced inspections.

Opening the report Dame Jo Williams, CQC Chair, commented "We found many people have been in assessment and treatment services for disproportionate periods of time, with no clear plans for discharge arrangements in place and too many people were in services away from their families and homes".

Almost half (48%) of the services inspected did not comply with the CQC standards, with moderate or major concerns. Only 24% of the services complied with the standards without any concerns, 28% complied with the standards but had minor concerns raised.

The report found that people were resident in these services for "unacceptably long" amounts of time, ranging from 6 months to 17 years. Concerns were raised around safeguarding with a lack of understanding of what constituted restraint.

Specific safeguarding concerns were also reported at 27 of the locations (18%) which were consequently referred to the local safeguarding team. These are being monitored by CQC.

To read the report in full go to: www.cqc.org.uk

DH Review: Interim Report

The Department of Health (DH) has published an interim report following the Panorama programme. Although unable to cover what happened at Winterbourne View, the report highlights the fact that the health and care system isn't meeting the needs of people with learning disability or autism and behaviour that challenges.

The report identifies several initial findings from the review:

- There are too many people with learning disabilities and behaviour perceived as challenging in assessment and treatment units and they are staying there for too long.

- This model of care has no place in the 21st century. People should have access to the support and services they need locally.

- In too many services there is evidence of a poor quality of care, poor care planning, a lack of meaningful activities and an over-reliance on restraining people.

- The whole system has a role in improving standards of care and demonstrating zero tolerance of abuse.

The report identifies 14 actions at a national level to drive good practice at a local level with the aim of more people being supported to live at home and far fewer people being sent away to hospitals.

A final report will be published when criminal proceedings have concluded and the Department of Health has committed to publish a report one year later to ensure progress has been made.

To read the interim report in full go to: www.dh.gov.uk/health/2012/06/interimwinterbourne/

Action to end poor care and abuse

mencap
The voice of learning disability

Challenging BEHAVIOUR foundation

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

Mencap and the Challenging Behaviour Foundation are calling on the Government to take strong action to end systemic poor care and abuse at large, institutional-style services for people with a learning disability.

We are calling for the phased closure of large, institutional-style services for people with a learning disability, which need to be replaced by appropriate local services.

In a joint statement, Mencap chief executive Mark Goldring, and Challenging Behaviour Foundation Chief Executive Viv Cooper, say:

"One year on from Panorama's undercover investigation into a private hospital for people with a learning disability, there are still too many people in large, out of town units for long periods of time, isolated and at risk of abuse and neglect.

"Action is needed to stop people with a learning disability and behaviour that challenges being sent away to these services.

"The government's proposals on local action will not be enough to create the systemic change needed. We are looking for a direct commitment from Government to put in place a strong, practical action plan with clear targets when it publishes its final review in September."

Mencap and the Challenging Behaviour Foundation are calling for local areas to develop skilled long term support for people with a learning disability and behaviour that challenges. Crisis situations for families can be avoided by a focus on prevention, early intervention and developing a skilled workforce. The charities believe that people should be able to access the support and services they need in their local area and live fulfilling lives within the community.

James

James

When our much-loved son James was a little boy he struggled to understand the world around him and was unable to communicate with others. But all who knew him liked him, and some even came to love him. When a support worker at his school was about to move to a new job she said to him, "James, I love you." James, who normally never speaks, replied "I love you".

James is now 38 years old. His distress and behaviour has grown worse over the years because of everything he has been through.

When James left residential special school, there were no assessments or advice from social services. All we were told was that there were no local services or support available.

Eventually, a residential care home was found, but it was some way from his home. Before long we found him with untreated injuries and suspected he was being abused. We also suspected he was being locked in his room at night. After we complained, a local inspector of services found there was inadequate heating in the home and the residents were not being properly fed.

James was moved to another care home, though still with no proper assessment of his needs. This was far away from home as well. The home claimed expertise in supporting people with autism, but we saw little evidence of this. James was neglected and his health issues, such as an untreated bleeding stomach ulcer, were ignored. They only agreed to take him to the doctor when we threatened to go to the local authority about it.

Crucially, staff didn't know how to manage James's behaviour. It was a vicious circle, where the lack of good support made him more anxious, which then caused his behaviour to get worse. Restriction and restraint became the order of the day. We found out that at one point he had been restrained by five people for 20 minutes until he 'calmed down'. We know how very frightened he would have been by this.

At another care home things deteriorated so badly for James he began self-injuring and we were so concerned that we felt there was no choice but to have him admitted to the specialist learning disability assessment and treatment unit where he still lives.

James has remained in the specialist learning disability unit for the past five years. We are still fighting to get him out. James should never have been placed in the unit to begin with. A year after he arrived, we were told he was ready to leave. But since then, four years have gone by and the authorities continue to argue over the funding package needed to bring James back to where he belongs. So he remains 150 miles from home, too far away from the people who love him.

- **David & Jill,** *parents of James*

Carers Matter Everybody's Business

Skills for Care and Skills for Health have produced **Carers Matter - Everybody's Business**, guidance to help employers and organisations support carers better through staff learning and development.

The guidance is based on a set of 'Common Core Principles for Working with Carers' that were developed in consultation with carers, people working directly with carers, and interested parties across health, social care and other key sectors.

Carers Matter - Everybody's Business is not an 'off the shelf' training package, but rather the tools that enable training to be commissioned or developed to reflect local workforce needs, local settings and context. It aims to be flexible enough to be delivered in a variety of ways to meet differing working and learning needs.

The guidance comes in three parts and provides information about:

- who carers are (as distinct from care workers)
- why carers are important
- how you can support the learning and development of your workforce to improve and enhance your services for the people who use them, and their carers.

As part of its development Carers Matter - Everybody's Business was evaluated by fifteen employer sites across England.

A newly refreshed version including comments from carers, training managers and learners gained during the evaluation is now available. Skills for Care has also worked with The Challenging Behaviour Foundation to make sure it reflects the needs of carers of people whose behaviour challenges. For further information visit: www.skillsforcare.org.uk/cmeb

Tough Breaks

In 2008 the CBF and Tizard Centre asked families for their experience of short breaks, revealing some discouraging results. Last year a follow up to this was carried out by Shan Liu, a student at the Tizard Centre, University of Kent. The overall picture suggests there hasn't been much improvement and there is still a lot of variability in short breaks provision.

Over half of families are still saying they need more short breaks and 1 in 5 families who want short breaks are unable to access any. In the context of the budget cuts, it's concerning that 74 of the families responding to the survey had experienced a short break service being cut or stopped altogether within the past year.

Findings from the 2011 survey

- Almost 1 in 5 families who want short breaks can't access them.
- 74 families have had service cut in the last year.
- Over 50% of families say they need more short breaks.
- Just under half of respondents said some form of short breaks were unsuitable.

If you can access short breaks there is no guarantee that they will be suitable. Just under half of people found some form of short break to be unsuitable for their family member - often due to a lack of training and understanding in challenging behaviour, high turnover of staff or unsuitable activities. Worryingly, these are the same issues that arose in the 2008 survey. Families are still telling us they want more and higher quality short break provision, but it seems that a continued lack of training and understanding of challenging behaviour and the cutting of funding for services is hindering families from getting the breaks they deserve.

We would like to thank all the families who took part in the survey. This information will be used to raise awareness and future campaigning for improvements to short breaks.

SHORT BREAKS - CASE STUDY

A chance to recharge batteries... or mop the kitchen floor

Short breaks have been a great help to our family, but we are learning that they are very unpredictable. Our daughter Harriet, who has a severe to profound learning disability, has been able to access her local Rainbows and Brownies groups through a mix of Direct Payment and Aiming High for Disabled Children funding, but there have been gaps in her attendance because of the inconsistency in funding.

Harriet is now in her third term of Brownies, which she enjoys, but we have just been told that Brownies isn't "meeting Harriet's needs" – a euphemism for her being difficult to include in group activities. We feel it is imperative that our children should socialise with their mainstream peers if at all possible, even if that socialisation may appear to others to be of limited value. Harriet is delighted just to be in a room full of noisy, boisterous Brownies, and her inability to participate in some of the activities is of no concern to her.

There have been sporadic periods when Harriet accessed day trips to different activities with carer's organisations. These were often at weekends, enabling me to catch up on household chores which I cannot do during the week as I work. In the last financial year there was a charge of £1 per hour, and a choice of activity on both days of every weekend from October to the end of March, as well as some activities in school holidays. I thought this was excellent, and Harriet thoroughly enjoyed her days out, but there is no such provision at present.

Short breaks are essential for maintaining a healthy mind and body. If carers are not healthy in both mind and body, we cannot give our children the support they need.

- **Kate and John,** *parents of Harriet*

New tool to ensure families are involved in best interest decisions

A new resource has been developed for parents who feel that they are not being appropriately consulted about the welfare of their loved ones.

The Challenging Behaviour Foundation has worked with Ambitious about Autism, Mencap and Irwin Mitchell Solicitors to develop the tool, following concerns that many professionals are failing to appropriately consult with families, as required under the Mental Capacity Act 2005.

In its latest report into deaths of people with a learning disability in NHS care, Mencap found that many health professionals are failing to abide by the Act and ignoring crucial advice from families.

Alex Rook, solicitor at Irwin Mitchell says: "If an individual lacks the mental capacity to make a decision for themselves, that decision must then be made in their best interests in accordance with the requirements of the Mental Capacity Act 2005. The Act requires all professionals, including those from local authorities and the NHS, to consult with family members when an adult lacks the mental capacity to make the relevant decision themselves. The law on this is clear. We want families to know their rights."

David Congdon, Mencap Advisor, says: "We know from our campaigning work how serious the consequences can be when families of people with severe learning disabilities are not listened to. They often have invaluable knowledge about their son or daughter.

This is not just good practice, it is the law

"It is crucial that professionals listen to family carers and use their knowledge to inform decisions being made. This is not just good practice, it is the law. It is important families understand this and feel able to challenge when they are not being involved."

Family carers can download the leaflet at www.irwinmitchell.com/MCAletter

Don't shut me out

A leaflet is now available which will support family carers who have concerns that they are being excluded from decisions that social care or health professionals are making about their adult son or daughter (aged 16 or over). These may be decisions about where the person lives, what care they are getting, how they spend their time or medical treatment.

Family carers will now be able to use two template letters which are intended to help family members who have not been involved, or are concerned that they will not be involved in the best interest decision-making process in the future.

The leaflet has been written in order to increase understanding of people's rights to be involved in 'best interest' decisions taken in accordance with the Mental Capacity Act.

Ensuring that all professionals act in accordance with their obligations under the Mental Capacity Act 2005 towards disabled adults

This leaflet has been produced by Ambitious about Autism, Mencap and the Challenging Behaviour Foundation in partnership with Irwin Mitchell Solicitors.

We are regularly contacted by individuals who feel that they are not being appropriately consulted about the welfare of their loved ones. For example, many parents phone to voice concern about decisions that social care or health professionals have made about their adult son or daughter, which they have not been involved in at all.

Broadly speaking, if an individual lacks the mental capacity to make a decision for themselves, that decision must then be made in their best interests in accordance with the requirements of the Mental Capacity Act 2005.

Examples of relevant decisions can include those around:
- where the individual lives
- what care is received
- contact with others
- medical treatment.

Importantly, the Mental Capacity Act requires all professionals, including those from local authorities and the NHS, to consult with family members when an adult lacks the mental capacity to make the relevant decision themselves.

We have prepared this leaflet in order to increase understanding of people's rights to be involved in 'best interest' decisions taken in accordance with the Mental Capacity Act.[1]

[1] The rest of this guide refers to 'family members' for ease of reference, but in fact (as can be seen from the attached letters) the Act refers to anyone engaged in caring for the person or interested in his/her welfare.

Key points:

- Family members retain their rights to be consulted when their relative is over the age of 18
- Family members have a right to be consulted and do not need to be appointed as welfare deputies first
- It is not the case that family members only need to be consulted when it is an important decision e.g. where the person lives. Any decisions made on behalf of a person who lacks capacity must be made in their best interests, and this requires consulting with family members before the decision is made.

Extract

I would like to draw your attention to the requirement that a best interests decision must take account of all the relevant circumstances and, in particular, should include the following steps:

1. Encourage ***[insert name]*** to participate as fully as possible in the decision-making process.
2. Consider ***[insert name]'s*** past and present wishes and feelings and the beliefs and values that would be likely to influence ***his/her*** decision if ***he/she*** had capacity. ***[Insert specifics here if relevant, eg your cultural or religious background].***
3. Consider the views of anyone engaged in caring for the person or interested in ***his/her*** welfare. Clearly this would involve me as ***[insert name]'s [insert relationship].*** Steps need to be taken to properly consult.

This does mean that both *[insert name]* and I should be fully involved when any decision is being made on *his/her* behalf.

All text in square brackets should be replaced with individual details.

Family carers can download the template letters from:
www.irwinmitchell.com/MCAletter

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

A special thank you goes to **Daniel Bird** who ran the Manchester marathon for the CBF in pouring rain at the end of April. Dan is autistic and has communication difficulties, but he doesn't let this slow him down. This was his first marathon and he came 50th - he also raised over £1,000 for the CBF. Dan's brother Aiden has severe learning disabilities and a few years ago his Mum received help from CBF's Family Support Workers. We are not the only people who think Dan is a very inspirational young man: he is also to be an Olympic torch bearer this summer.

So far Friends of CBF have raised over £7,600

– so we are now half way towards our £15, 000 target.

Friends of CBF have also helped to raise money for the **Everybody Matters** film project. We needed to raise £25,000 to make this important film about positive life experiences in response to the Panorama documentary about abuse in Winterbourne View.

We are delighted to announce that we have now raised enough funding for the film and are planning the filming schedule with the film makers and our steering group. If you would like to hear more news about Everybody Matters keep an eye on our website and the Everybody Matters Facebook page.

In May we were delighted to host our first **Friends of CFB** event and welcome supporters to join us at an evening drinks reception in London.

The evening was an excellent opportunity for families, professionals and supporters to meet, network and share experiences.

Becoming a friend of CBF is a great way to show your support and find out more about our work and how you can be involved. The donations we receive from our members help to ensure we can continue to reach more families across the UK with vital information and support.

To find out more about **Friends of CBF**, and how you can join us, please visit our website
www.challengingbehaviour.org.uk/get-involved-with-cbf
or email fundraising@thecbf.org.uk.

IN BRIEF

Positive Practices in Behaviour Support

Gary LaVigna, Clinical Director of the Institute for Applied Behaviour Analysis in Los Angeles, California, will be running his internationally acclaimed 4-day training course in four UK centres this autumn: Glasgow, Manchester, Newcastle and London.

For more information contact: jmarshall@iaba.com or telephone Irene Murphy on 01634 405168

Who's challenging who?

Mencap Cymru and Bangor University have been collaborating on a project to help social and health care staff develop positive attitudes towards those whose behaviour challenges, and improve how they empathise with the people they support. A conference will be held in Liverpool later this year to discuss the project's findings. To find out more about this free event, please visit www.mencap.org.uk/wales/projects/who-s-challenging-who or email lisa.hutchinson@mencap.org.uk."

100 Club Winners

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

February 2012:
Sam Judd - (Canterbury)
March 2012:
John Manley - (West Malling)
April 2012:
Kym Mc Millan - (Rainham)
May 2012:
Mr & Mrs Hewett - (Chelmsford)

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

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.

Resource order form

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

	Cost	Number	Total £
CHALLENGING BEHAVIOUR DVD RESOURCES			
An Introduction to Challenging Behaviour: DVD	£31.50*		
What is challenging behaviour? Why does it happen? What can be done about it? Uses interviews with two parent carers, with specialist input from Peter McGill (University of Kent Tizard Centre). *40 minutes*			
Self-injurious Behaviour: DVD	£31.50*		
What causes self-injurious behaviour? What action should parents and carers take? Professors Chris Oliver and Glynis Murphy join forces with two family carers to offer clear and practical information and advice to families. A useful introduction also for professionals. *40 minutes*			
Communication and Challenging Behaviour: DVD	£31.50*		
Four family carers and a speech & language therapist explain the relationship between communication and behaviour and highlight practical approaches to improve communication and minimize challenging behaviour. *40 minutes*			
Challenging Behaviour – Supporting Change: DVD	£63.00*		
In this 2-disc DVD set meet Oliver, Dougie and Dominic and hear the functional assessment process explained. Interviews with family carers highlight the range of causes of challenging behaviour, and how a functional assessment can help put in place appropriate behaviour management strategies for individuals with severe learning disabilities. *(Approx 70 mins)*			
CHALLENGING BEHAVIOUR INFORMATION SHEETS			
Understanding challenging behaviour	All information sheets are available free of charge on the CBF website. To order by post please add £1.00 per sheet*		
Communication and challenging behaviour			
Health and challenging behaviour			
Challenging behaviour – supporting change (functional assessment)			
The use of medication			
The use of physical interventions			
Specialist equipment and safety adaptations			
Parents' perspectives			
Ten Top Tips for Families			
Planning for the future: introduction			
Further information for parents			
Booklist for professionals			
BASIC INFORMATION PACK	£10.00*		
The following additional information sheets are not contained in the basic information pack but may be downloaded from the CBF website or ordered separately:			
Getting a statement	£1.00*		
Self-injurious behaviour	£1.00*		
Pica (eating inedible objects)	£1.00*		
Psychiatric disorders in people with learning disability	£1.00*		
Getting legal authority to make decisions about money, property & welfare	£1.00*		
Difficult sexual behaviour amongst men and boys with learning disabilities	£1.00*		
SUB TOTAL CARRIED FORWARD			

*Free to parents/unpaid carers. Registered charities: DVDs £16.50 (or £33.00 for 2-disc set). Prices include postage & packing in the UK only.

/ Continued overleaf...

/ Resource Order Form continued...

SUB TOTAL CARRIED FORWARD			
	Cost	Number	Total £
SUPPORT OPTIONS			
Planning your House**	Contact CBF		
Provides family carers with practical help with planning for future housing needs.			
8 Ways to get a house**	Contact CBF		
Explains the different ways to get a house and how they are funded			
**Due to changes in funding these resources are currently under review. If you would like a copy of the existing resource please contact the CBF			
Planning for the Future: Information Pack England/ Scotland/ N Ireland/ Wales *(please specify)*	£10.00*		
Contents include: Know your rights; Know the processes; Know your options; Case studies; Understanding the funding: Safeguarding & protecting the individual. With information relevant both for those with children aged 12 and upwards (transition) and those concerned about the support needs of adult sons and daughters.			
OTHER RESOURCES			
A guide for advocates (England and Wales)	£16.00*		
Key 'at a glance' bullet points identify 'what you may encounter' and 'what you should know' – a very practical tool for both professional advocates and family carers advocating on behalf of their family member.			
DONATION – please consider a donation to support our work. Thank you			
TOTAL			

* Free to parents/unpaid carers. Prices include postage & packing in the UK only.

All proceeds go towards helping families caring for individuals with severe learning disabilities and challenging behaviour. Thank you for your support.

Please consider making your gift eligible for Gift Aid. 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 gift paid on this gift and any eligible past or future gifts.

Please note to be eligible for Gift Aid you must pay at least as much UK income tax (and/or capital gains tax) as the amount that will be claimed by all charities you donate to within the tax year.

Parents/ family carers please note: while we are happy to send you our resources free of charge, if you can afford to send a donation this will help us to provide free resources to other families. Thank you.

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

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 ☐

If you would like to support the CBF regularly please tick here to receive a standing order form ☐

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

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

Thank you for your support

The CBF – how you can help

Did you know…..?

- ***We are a registered charity and rely on donations, grants and fundraising to finance our work.***
- ***We have no regular guaranteed income.***
- ***We do not charge family carers for services or resources.***
- ***To keep costs down much of our work is carried out by volunteers.***
- ***If everyone reading 'Challenge' gave just £30 a year the guaranteed income would enable us to take forward a number of important projects. (Please ask for details)***
- ***Regular giving by standing order makes your money go further by keeping down administrative costs.***
- ***Your support really would make a big difference to us!***

Please consider how you could support our work.

The Challenging Behaviour Foundation

Registered charity number 1060714 (England and Wales)

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

Email: info@thecbf.org.uk
Tel. 01634 838739
www.challengingbehaviour.org.uk