

Challenge



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

Spring 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

Well?

Being healthy and feeling well makes an important difference to all of us and in this issue of Challenge we focus on health.

Some families who support relatives with learning disabilities and behaviour described as challenging have good experiences of health support – "reasonable adjustments" are made to ensure that it is person centred and families and professionals work together to meet the needs of the individual. Some of these experiences are described in this issue. But alongside this, the Mencap follow on report from "Death By Indifference" entitled "74 and counting" is disturbing evidence that people are still dying unnecessarily. In addition, the Care Quality Commission inspection reports following the Panorama programme "Undercover Care" reveal that many assessment and treatment units are failing to meet essential standards of care.

disturbing evidence that people are still dying unnecessarily

It is in this context that the CBF is celebrating its 15th year.

The CBF was formed because I discovered that there was a great deal of knowledge and expertise available about how to support my son well – but that it had not got through to our family when we needed it. This simply didn't make sense to me, and after many discussions with friends, other families, professionals, researchers and other charities, it became apparent that something needed to be done.

It cannot be beyond us to make that happen!

The CBF aims to work with others to make sure that children and adults with severe learning disabilities whose

behaviour is described as challenging get the right support, in the right place, at the right time. We know who is likely to develop behaviour that is challenging, and we know how to design support around people. It cannot be beyond us to make that happen!

15 years on, the CBF has made a difference to the lives of many people. We have provided families and professionals with information and support. We have connected people, and we have worked strategically to influence policy and practice. This has been achieved by hard work, individuals and organisations working together, grim determination – and because it is the right thing to do and it makes sense on every level.

There is still much to be done – we have to make change happen. The ultimate aim of the CBF is not to be needed. That is when we will have cause for a big celebration.



• **Vivien Cooper**
Chair of Trustees and Founder of the Challenging Behaviour Foundation

Unreasonable Adjustments

The fact that the CBF is celebrating fifteen years is perhaps testament to the extent of the unreasonable adjustments families and people with learning disabilities with severe reputations endure.

What are these unreasonable adjustments people are obliged to make?

Families are expected to adjust expectations, hopes and rights to what society can be bothered to afford them - in terms of not expecting consistent progressive education provision regardless of whereabouts, in terms of not being encouraged to hold fast to a shared desirable future, in terms of not expecting consistent access to resources and regular support of familiar faces, in terms of expecting often few friendships and social isolation, in terms of having to fight for essential housing, in terms of wild fluctuations in advice, in terms of scraps from the captain's table (also known as respite), in terms of being obliged to be viewed clinically as problems to be solved (not situations to be understood), in terms of a lack of financial opportunities, in terms of a struggle to achieve flexible employment, in terms of attitude, in terms of often never been thought of as 'good enough', in terms of... I could go on.....

Funny how it often doesn't feel as if

we're all in this together...

Make no mistake, the 'elite' of society do not cherish individuality but conformity. So reasonable adjustments to people's needs are too often viewed as unreasonable:

Families are expected to adjust expectations, hopes and rights to what society can be bothered to afford them

We'll adjust only so far as is practicable and not too costly.

What is reasonable, however, is for people with learning disabilities and their friends and families to expect to be treated as everyone else - in terms of education and opportunities, in terms of the actuality of human rights. And to achieve the expectation of being viewed as being capable of contributing to society.

Often, children with disabilities are subtly programmed throughout their education careers to not believe they can be employable. This assumption oozes through the system like a bad case of nits. (It is easily transmitted



and causes discomfort...).

The CBF is here today because fifteen years ago a few people took a look at the world and agreed 'well, we don't call it good enough.'

There is a lesson here: never underestimate the ability of a few good people to change the behaviour and hearts of thousands and thousands of others.

The CBF is here because people were unhappy at unreasonable adjustments.

• **Tony Osgood**

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

HOW YOU CAN HELP



Jim Mansell, CBE

The CBF was delighted to learn that Professor Jim Mansell, long time friend and supporter of the CBF and champion for people whose behaviour is described as challenging, had been awarded a CBE in the Queen's New Year Honours List. Sadly, Jim passed away in March after a protracted fight against cancer.

Jim will be missed by many, but his influence on how individuals with learning disabilities are supported will live on.

Jim features in the CBF's new film project, Everybody Matters, which aims to

promote good practice and provide an urgent call to improve support and services. The film project is one of a series of actions in response to the abuse of people with learning disabilities exposed through the BBC's Panorama programme last year.

To find out more and to view a short trailer of the planned film visit our website. www.challengingbehaviour.org.uk/strategy-group/everybody-matters.html

Please join your voice with Jim's and help change lives for the better.

Q: Who should write behaviour support plans and what skills are needed?

A1: I would suggest anyone could write a behaviour support plan as there is no one pro-forma that needs filling out by an 'expert'. We often ask carers, key workers or others who know the service user best to compile the behaviour support plan as it is often these people who are responsible for supporting the service user and need to understand the plan better than anyone else. Even the more clinically designed support plans could use input from someone non-qualified as long as they had some understanding of the plan and its application and that they drew together the work of clinical professionals, carers etc. when completing the plan.

A2: I would not feel comfortable writing a behaviour support plan independently. Ideally, you should link with other professionals to ensure the plan is completed in the most holistic fashion possible.

A3: In my experience, anyone can write a behaviour support plan, but it is the process we go through to arrive at the behaviour support plan that is crucial. This needs to involve parents and carers and everyone who knows and supports the person whose behaviour is proving to be a challenge. Positive behaviour support (PBS) is unique in that it includes everyone involved in the person's life and everyone who is part of the PBS team is equal, regardless of experience or training.

A4: I think the skills required to write behavioural support plans are: knowledge of the causes and functions of challenging behaviour, knowledge of the fundamental components of positive behaviour support and a good knowledge and understanding of the actual people in question. It's vital to know the service users' skills, likes, dislikes, expressive and receptive communication skills etc. Everybody is different and what works for one person won't necessarily work for another.

Q: My brother is vegetarian and this is part of his culture and religion but his new care home is giving him meat. What can we do?

A1: I think it's really important that your brother's cultural needs be met. You could ask the care home to have a best interests meeting so you can work through what exactly is going on and how your brother's choices are supported. How can they tell you he wants meat and not explain how this choice is made? Is the vegetarian option appetizing or are they giving him a choice between a meat dish and a bowl of boiled cabbage? Please check out the consequences to his digestive health in eating meat after being vegetarian all his life.

A2: They have to respect the fact that he is and always has been a vegetarian. We have a son who is very similar; we insist that the people who provide the care tell us what he eats and his behaviour each day. It does work but you have to be persistent and annoying if necessary.

A3: Take it up with his Social Worker or go get his MP involved. He has a right to eat what he wants.

A4: The home is not valuing his cultural identity and individuality. If the home will not listen you can raise an official complaint with the Contracts Section of your Local Authority. If this fails you could say that you intend to report the home to the Equality and Human Rights Commission (EHRC). I have produced two resources (Race, Faith and Culture - a staff toolkit; and Culturally Competent Care) for Kent County Council that you may find helpful. These can be found at www.kent.gov.uk.




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 CBF website



Over the past 15 years the CBF has supported many family carers and professionals, but we know there are thousands more we still need to reach. To help achieve this aim we celebrated our 15th anniversary with the launch of our new website in March. New features on the website include:

- Film clips featuring family carers and professionals talking about: understanding challenging behaviour, communication, self injurious behaviour, getting help early and more.
- Read about other people's experiences in "Your stories"
- Purchase our resources online
- A "For families" section with separate pages about Children, Teenagers and Adults
- A "For professionals" section, with information about networks and partnership working
- A "Friends of CBF" section, with information about how you can get involved
- Links to the CBF on   

Plus

- A UK interactive map so that you can find out what is going on locally to you.



To view the changes go to www.challengingbehaviour.org.uk

15 years ago...



Vivien Cooper

15 years ago the CBF was registered as a charitable company. At that time we had nothing - no resources or funds - but we did have a firm belief that we could do much better in how we

support children and adults with severe learning disabilities and behaviour described as challenging. Our CBF strapline "Making a difference" was chosen carefully - our intention was (and remains) to change things for the better by our actions. The frustrating thing for me as a Mum is that we know what to do - we know who is likely to develop behaviour described as challenging, we

know how to provide the support those individuals require and we know that building that support around the person enables them to have a good quality of life. But we don't do it.

15 years on, we have made a difference to the lives of many. We have raised the profile of this group of individuals. We have planned carefully how to work together to have the greatest impact, and how to ensure that we remain focused on delivering our charitable objectives - improving the lives of individuals through individual support and strategic influencing.

We know there are challenging times ahead, and we know there is still much to do, and I would like to take this opportunity to thank you all for your support, which is truly appreciated.

• **Viv Cooper**
Founder and Chair of Trustees

2008: The first meeting of the Challenging Behaviour National Strategy Group. Challenging behaviour training workshops for families are piloted.

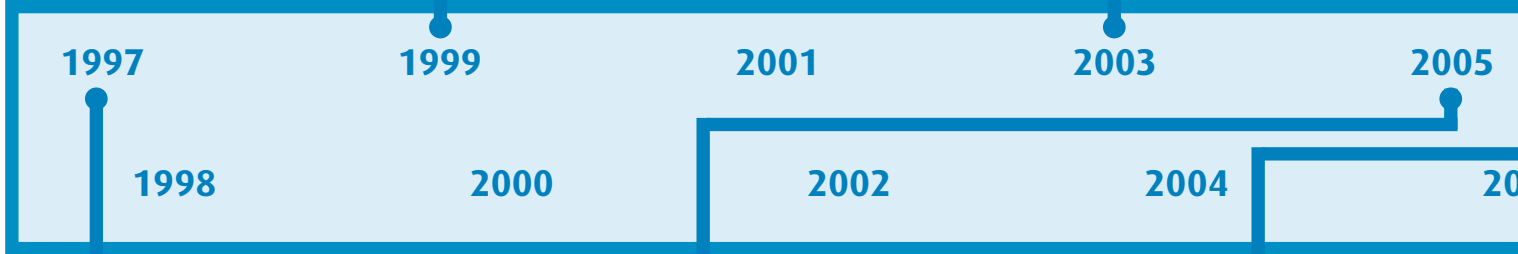


1999: The CBF moves to a small rented office in Rochester with grant funding to print 1000 information packs. Volunteers give up one day a week to process requests for information now coming from across the UK.



2003: A grant from the Lloyds TSB Foundation enables the CBF to employ a Development Manager, the first employee.

The CBF's first DVD (video!) is produced and email networks started.



1997: The Challenging Behaviour Foundation starts out based in Viv's garage. Her friends run fundraising events to enable Viv to provide information sheets for families, all individually photocopied on a single sheet photocopier

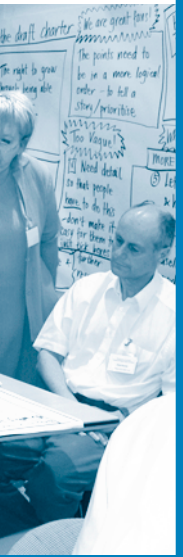
2005: More new DVD and written resources are produced. Major grants from BBC Children in Need and the Big Lottery Fund enable CBF to employ a Family Support Worker and Administrator.

Having outgrown the Rochester office the CBF moves to a larger office space in The Old Courthouse, Chatham.

2007: After ten years at a residential school over 200 miles away from his family, Daniel Cooper finally returns to Medway aged 19. Viv through the CBF continues to campaign on behalf of other families throughout the UK to bring their sons and daughters 'back home' from out of area residential placements.



Challenging
is held.
workshops for

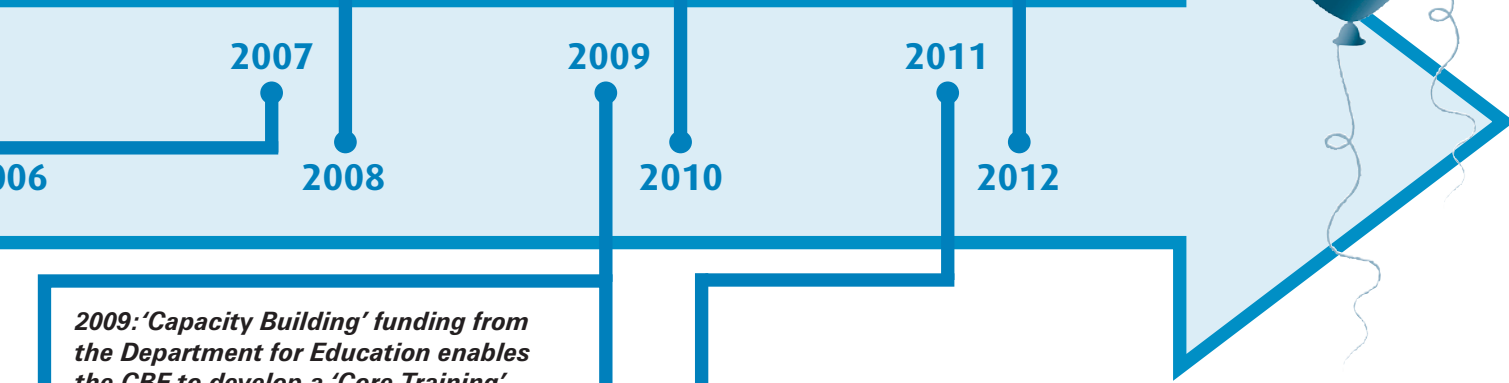


CHALLENGING BEHAVIOUR NATIONAL STRATEGY GROUP

THE CHALLENGING BEHAVIOUR CHARTER

2010: The Challenging Behaviour Charter is launched

2012: The CBF team (now 13 staff and around 60 free-lancers, casual workers and volunteers) celebrates the CBF 15th anniversary with the launch of our new website and our first 'Friends of CBF' event in Bristol.



2009: 'Capacity Building' funding from the Department for Education enables the CBF to develop a 'Core Training' programme, developing a team of free-lance and volunteer family carers and professionals to take forward the work of the CBF across the UK.

2011: The BBC Panorama programme exposes abuse of individuals with learning disabilities at Winterbourne View.

The CBF is actively involved in much of the follow-up work by the Department of Health and Care Quality Commission, providing a voice for individuals who challenge and their families.

Join Us

While the CBF has benefited over the years from a number of short term grants, our funding looking forward to 2013 is not guaranteed. Joining 'Friends of CBF' will enable you to both support the CBF financially and to find out more about our work, putting you in touch with like-minded people, both family carers and professionals. There is no upper limit to how much 'Friends of CBF' may choose to give to the CBF, but we ask all Friends to give at least £30 annually, or to commit to raising funds for us through a range of fundraising events.

Join on line (www.challengingbehaviour.org.uk) or contact the CBF office for a Friends application form.

Consent to treatment



Adam

My son Adam is 23, has a severe learning disability, epilepsy, autism and challenging behaviour. Adam has suffered from stomach pain for a long time. His GP would not examine him because he had previously been slapped by Adam. A consultant he saw was loathe to put Adam through intrusive tests as the outcome would probably not lead to any significant findings.

Now in residential care Adam continues to be in pain and discomfort. The wonderful staff have tried to get him diagnosed and treated without much success either. His doctor seems to have the view that she cannot do much because Adam won't let her examine him. Adam was recently seen by a gastroenterologist, who just felt his tummy and 'found' nothing.

I decided to apply for legal assistance to help Adam access healthcare for this ongoing problem and went to the Court of Protection. I was successful in being made Adam's Deputy for health and welfare for a period of six months, so I can provide consent to treatment as necessary, within strict guidelines written in the Court Order. The NHS will now have to arrange a multidisciplinary team meeting to agree what tests Adam needs and whether he will need sedating in order to carry out the tests. I can now consent to this on his behalf.

Why have I had to pay thousands of pounds to get Adam treatment that he has a right to?

• **Ian Penfold**, family carer

To read the full story please visit our website.....

www.challengingbehaviour.org.uk and click on your stories

Accessing

Everyone should have access to good healthcare, but people with severe learning disabilities and those who also display behaviours described as challenging, this can itself act as a barrier. There is a risk that an individual may display challenging behaviour GPs or medical staff are ignoring the health needs of people with learning disabilities and not listening to carers. This is going undiagnosed. In some instances this has resulted in premature death, as highlighted in the report '74 and counting' who died needlessly whilst under NHS care. Their follow up report, '74 and counting' (see page 9).

Accessing healthcare is achievable but it requires good planning, making "reasonable adjustments" to ensure that people with disabilities can access the service. Communicate effectively and work in partnership. Darryl Chapman, Acute Liaison Nurse. Carers can work together to achieve this:

Making reasonable adjustments within healthcare.

The right of people with disabilities to receive healthcare that is appropriate to their specific needs is supported in law. The Equality Act (2010) replaced a range of equalities legislation (including the Disability Discrimination Act, 1995) and has strengthened individual's rights, as well as introducing new rights to those previously not protected in law (for example with regards to carers or those associated to people with disabilities).

A key element of the Equality Act (2010) is the public sector equality duty which is a legal obligation on providers of public services to seek to remove barriers faced by disabled people. The duty is both anticipatory; meaning that a public body should consider how the service meets the needs of all patients including disabled people; as well as being responsive to individual needs or requests for reasonable adjustments.

Examples of reasonable adjustments:

- Offering a choice of appointment times
- Allowing a patient to be seen as soon as they arrive in the clinic if they have difficulties sitting in waiting areas
- Being placed at the beginning of the list for theatre or investigations
- Considering alternative investigations or treatments that may be less invasive or which the person may accept more easily
- Where possible ensuring that appointments are carried out by the same professional(s)
- Arranging for more than one procedure to be carried out whilst a patient is under general anaesthetic (for example blood tests). Note that there must be a referral for each procedure being proposed
- Meeting with clinical teams prior to investigations or treatment
- Providing easy read information

Understanding reasonable adjustments

A reasonable adjustment is any change to the way a service is normally delivered to ensure that someone with a disability can access the service on an equal basis.

Making reasonable adjustments for disability involves taking into account the individual's specific disability related needs and a commitment to remove any barriers which might otherwise make it difficult or even impossible for a disabled person to use a service. Making reasonable adjustments requires an NHS service to provide a different type or level of support to patients with learning disabilities. Indeed it may be necessary to offer more favourable treatment to patients with disabilities to ensure equality of health outcomes. For example, by allowing a patient to be seen in clinic if they have difficulties sitting in waiting areas.

Individuals with severe learning disabilities and challenging behaviour are likely to require a range of adjustments. The importance therefore of planning early and effective communication with clinical staff cannot be overstated. It is important to remember that reasonable adjustments will be specific to the individual and may differ according to the setting in which the treatment will be undertaken.

healthcare

People with learning disabilities are likely to have greater difficulty in getting the healthcare they need. For many people, it is a barrier to getting access to health services. Many family carers have reported that where specialists may sometimes be reluctant to examine and arrange tests for the person. This can lead to unnecessary prolonged suffering for the individual, with serious conditions highlighted by Mencap in their harrowing report, "Death by indifference", about six people. This demonstrates that people with learning disabilities continue to be failed by the NHS.

The adjustments tailored to individual need and for family carers and professionals to use for Vulnerable Patients, explains more about how medical professionals and family

Sources of support

It is clear that effective communication as well as identifying and agreeing suitable reasonable adjustments are key to ensuring that people with complex needs receive high quality healthcare and support.

Having access to good support or advice is another factor that may be critical to ensuring a good experience. Every hospital has a Patient Advice and Liaison Service (PALS) whose role is to support patients and families who have concerns about their NHS treatment.



PALS will often liaise directly with the relevant clinical staff and seek to resolve problems as quickly as possible.

Advocacy services and the Challenging Behaviour Foundation's Family Support Service may be able to provide additional support or advice. For specific advice regarding your legal rights the Disability Law Service can provide advice.

• **Darryl Chapman**
Acute Liaison Nurse for Vulnerable Patients
Imperial College Hospital, London

A hospital care pathway

Imperial College Healthcare NHS Trust has worked with family carers, social care workers and Hammersmith & Fulham Mencap to develop a set of resources which aim to equip carers of people with complex needs to ensure that individuals receive appropriate support and reasonable adjustments within healthcare settings. The following top tips are taken from a hospital care pathway developed by the group.

1. **Take some time to think about some of the barriers that the person you support might face when using health services;** for example waiting in clinical areas, being unable to eat or drink prior to investigations and anxiety regarding clinical procedures.
2. **Contact the hospital and ask for a named contact who can agree any reasonable adjustments and a care plan;** this could be a learning disability nurse, a senior nurse or clinician.
3. **Keep a record of your discussions with the hospital**
4. **Use a hospital passport document to record the individuals support and communication needs.** Ask your learning disability team or NHS Trust if they have a specific form. Alternatively consider developing something specifically for the person.
5. **As much as possible prepare the person by visiting the hospital or clinic prior to your appointment.** Perhaps go for a coffee there; try to make the experience as enjoyable as possible.

Introduce yourself to the Patient Advice and Liaison Service (PALS) at the hospital.

Ensure that you know how to contact them for advice or support. Copies of the Hospital Care Pathway can be downloaded from:
<http://dl.dropbox.com/u/35131717/Care%20pathway%20%28vulnerable%20patients%29%20Information%20for%20Carers.doc>

Victory for Katie



Katie

My daughter, Katie, has Tuberous Sclerosis, a genetic condition which has produced growths in her heart, kidneys and brain.

Katie had brain surgery in 2004 to remove two of the largest growths in her brain. This was successful but Katie woke very quickly after the surgery and, since no one was expecting this, tore off her bandage and got off the bed.

Katie is unable to communicate verbally, does not tolerate hospital environments easily and can display very challenging behaviour when anxious, which has often resulted in procedures not being carried out.

Last year we achieved two procedures under one General Anaesthetic; an ultrasound scan of her kidneys and an MRI of her brain. This was successful because we were able to plan ahead:

- We carefully coordinated everything
- Katie's school gave us 3 carers for the day
- We played all the games Katie chose and every time she let us know she wanted to go home we diverted her attention.
- Her slot was brought forward so she didn't have to wait for too long.
- She was given Midazolam to calm her before going down to X-ray

Katie got a bit anxious when she saw the trolley bed so the anaesthetist suggested we wheel the trolley out and place a large sheet on the floor. That worked very well. Katie was distracted by 3 carers and mum, all sitting on the floor, while the anaesthesia team did their thing. Although all this may seem easy, it was actually a military operation, which required input from lots of people all working together to ensure Katie got the treatment she needed. What a victory!

• **Kate Farmer, family carer**

To read the full story please visit our website.....
www.challengingbehaviour.org.uk
and click on your stories

Positive mental health

In the last newsletter there was an article on mental health. This is an important health issue for people with a learning disability as they are more likely to suffer from mental ill-health than the general population. Figures vary but it is thought that people with learning disabilities are four times more likely to experience mental health problems than the rest of the population (Borthwick & Duffy, 1994, Emerson & Hutton, 2007). There are many reasons for this including increased risk of social isolation, stressful life events, not being able to communicate due to a disability, having no control or choice in life, psychiatric illness directly related their disability (e.g dementia), or lack of access to psychiatric services. Often mental health in people with a learning disability is missed as the symptoms are seen as part of the learning disability and not a mental illness ('diagnostic overshadowing'). The article suggested that Positive Mental Health, as a preventative process is as important as mental health treatment, which is often overlooked for people with a learning disability due to "diagnostic overshadowing". Positive Mental Health is described at http://arcdev.ichameleon.com/knowledge_centre/999533/default/positive+mental+health.html as about out how an individual feels about themselves. This is made up of lots of different things including:

Good physical health - which is important in mental health. It is important to ensure people are not suffering from treatable physical complaints. This can be done by accessing "Annual Health Checks". It is also important to ensure a good diet and exercise.

Access to education and/or employment - enabling people to feel valued for their contributions to the community.

Relationships - everyone needs friends, families and relationships with the opportunity to meet others with similar interests and hobbies.

Reduction in fear of crime - will improve an individual's mental health.

Strengthening the individual - Increasing self-esteem, coping skills and communication skills.

Strengthening communities - Increasing the number of social supports, promoting inclusion, increasing community safety, anti-bullying plans

Reducing barriers to positive mental health - reducing discrimination, increasing education opportunities and quality of housing.

• **Jo Poynter**,
*Learning disability Programme Lead,
South East Coast SHA*

(with apologies to Jo that we did not have room to carry her full article in the last issue)

Accessing specialist support

Dr Peter Corry, retired community paediatrician, reflects on 25 years supporting families caring for children with severe learning disabilities.

Working as a community paediatrician in a district child development centre, I found my training had left me unprepared for dealing with challenging behaviour.

Today there has been some improvement as most community trainees spend some time with the CAMHS teams. But, even with better training and knowledge, the time allowed for out-patient consultations, and the need to deal with the "medical" issues makes it difficult to address the behaviour support issues these families are facing.

Parents often say that they feel alone and isolated in dealing with behavioural problems

We very much rely on the team approach. And this is where things may differ greatly in many districts. With current emphasis on improving co-ordination between services, things should work better, but many practitioners are still finding difficulty in accessing a seamless service for their families. Many of the front-line staff are hard pressed, and commissioners do not always appreciate the importance of this work. They may also have difficulties accessing the more specialist help which is needed for many. Nursing staff, whether specialist health visitors, learning disability nurses or school nurses with responsibility for children with special needs, along with social workers and teachers, may often provide very helpful advice and support for parents and carers. However, they are not generally able to provide specialist support around challenging behaviour. Access to more specialised staff such as

psychologists, behaviour support teams, and for some children child psychiatrists, can be essential for many families.

Access to more specialised staff can be essential for many families

Parents often say that they feel alone and isolated in dealing with behavioural problems. They may be subjected to uninformed criticism, for instance when challenging behaviour occurs in public. And insensitive attitudes are not confined to members of the public. Realising that somebody else has faced the same situations is usually very helpful for parents. The booklets and DVDs produced by CBF can be invaluable. And sharing experiences by phone, email, Facebook or now through CBF's training workshops can lead to real successes. While continuing to work towards a more "joined up" approach, including specialist behaviour support input, I would also recommend that community paediatricians ensure that the families they encounter are encouraged to access the CBF's specialist information and support.



• Dr Peter Corry

NEW RESOURCES

At a glance

Three FREE 'At a glance' guides aimed at family carers supporting people whose behaviour is described as challenging have been developed by the Challenging Behaviour National Strategy Group in collaboration with the Social Care Institute for Excellence (SCIE).

There are separate guides for adults, teenagers and children.

The guides can be downloaded from the SCIE and CBF websites or FREE hard copies ordered from hugh.constant@scie.org.uk or info@thecbf.org.uk

The guides will also be useful to professionals supporting families of children, teenagers and adults with severe learning disabilities.

An understanding paramedic



Alfie

Alfie is 12 yrs of age, non verbal and with some behaviours that can be seen as challenging.

My only thought was to ring 999

On this particular night I gave him his Melatonin as normal about half an hour before his due bedtime. As the medicine kicked in and he slowed down he began to make his way to his bedroom from his downstairs playroom. I followed him and on his way he decided to sit down at the bottom of the stairs with his back to a radiator. As I leaned down to communicate with him to make his way up the stairs I noticed that he was shivering from head to toes and his teeth were actually chattering – at the same time his hands and feet were freezing. I thought his breathing was affected also. My only thought was to ring 999.

A paramedic came out quickly in an ambulance car. He asked for what had happened which we repeated but by this time the shivering had stopped and apart from feeling warm on his forehead he seemed more of his normal self although a little pale.

As Alfie has autism he hates anybody touching him, so for the paramedic to take his temperature, blood, etc was almost impossible without distressing Alfie. As time went on Alfie seemed more and more himself but the paramedic was quite sure that we, as parents, were worried and that we knew him best. Due to this he asked us if we would like him to be referred to the hospital. He acknowledged that Alfie would not tolerate going along to A&E and waiting around, and although it was now past 8 pm and the children's ward would be closed for admissions he actually got us in at 8.15pm by ambulance. We waited around from 8.15 pm to 11.15 pm with Alfie only presenting a slight temperature and were discharged with 24 hr access if the episode repeated itself.

I have huge respect for paramedics if they all work the same way and have the same attitude as this one did

Thankfully we have not had a repeat of this unexplained episode but I have huge respect for paramedics if they all work the same way and have the same attitude as this one did.

Having a non-verbal child we often find ourselves detectives in what is going on with our children and to be surrounded by people who acknowledge the difficulties that this presents is so helpful. For the paramedic to acknowledge that we as carers are the experts in our children was both refreshing and reassuring for us as Alfie's parents.

• **Linda Dickinson**, family carer

Working together for change

A Panorama programme in May 2011 showed the systematic abuse of people with learning disabilities at Winterbourne View. Since then there has been a range of investigations and reviews including:

- Police investigation & prosecutions: 11 people charged with offences under the Mental Capacity Act
- Serious Case Review of South Gloucestershire Council's safeguarding response
- A Government review led by Bruce Calderwood (Department of Health)
- CQC reviews comprising:
 - Internal CQC review
 - Review of all Castlebeck services
 - Wider review of 150 learning disability hospitals
- NHS review

It is expected that the remaining reviews will be published after the court cases have concluded, and we will report details of the reviews on our website. Members of the Challenging Behaviour National Strategy Group (CB-NSG), chaired by the Challenging Behaviour Foundation, have been active in addressing the needs of children, young people and adults with learning disabilities whose behaviour is perceived as challenging. Since our last newsletter CB-NSG members have contributed to the Government review via two meetings, held in December 2011 and March 2012. The CB-NSG was also proud to hold its first meeting in Wales "Winterbourne View: what needs to change?" in March.

A campaign sub-group has been formed, led by Mencap, which will focus on ensuring that what happened at Winterbourne View never happens again.

Meanwhile, work has continued on the 9 action plans developed by CB-NSG members. For example, Viv Cooper, Peter McGill and Roger Banks have been working with Professor Martin Knapp and Amerah Amin at the London School of Economics to identify the cost effectiveness of a range of interventions. It is expected that the results of this analysis will be available later this month.

To find out more about the above work and the latest news from the CB-NSG visit www.challengingbehaviour.org.uk

NEWS

74 and counting

Mencap's *Death by Indifference* (2007) reported the appalling deaths of six people with a learning disability – deaths that the six families involved and Mencap believe were the result of failings in the NHS.

The publication of the *Death by Indifference* report prompted a number of families to contact Mencap, and they continued to do so in the weeks, months and years that followed. These cases – a total of 74 to date – highlight an NHS that continues to fail people with a learning disability. *Death by indifference: 74 deaths and counting - A progress report 5 years on* looks into some of the traits which are repeatedly seen in the cases and the recommendations made by Healthcare for All.

To read the report visit:
www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference_0.pdf

We launched **Friends of CBF** in November last year and we are really pleased that so many of our supporters have chosen to join our **Friends of CBF** community.

In February we had our first **Friends of CBF** event in Bristol where we shared afternoon tea and cake with some local **Friends of CBF** to celebrate our 15th anniversary (we're sure this is the first of many cakes this year!).



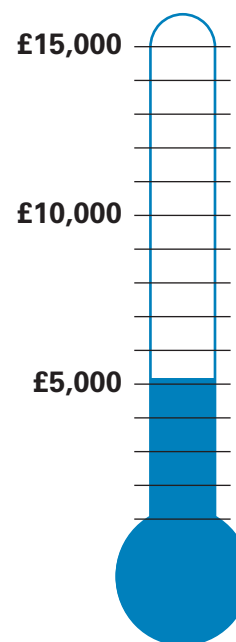
For our 15th Anniversary **Friends of CBF** have been set the challenge of raising £15,000 to help the CBF reach more families. Thank you to **Wesley Beverley and his team of colleagues from Chaucer Insurance** who ran the GRIM challenge for us in December. This involved running 8 miles through a lot of mud! Their fantastic effort raised over £2,000 for the CBF.

Get involved

There will be lots of opportunities throughout 2012 to get involved in sponsored events and celebrations. If your company would like to raise money for CBF in a team event please let us know - we can help you find the right event for you. There is a section on our new website which tells you all about the events we are holding this year and how you can get involved. To become a **Friend of CBF** join via our website or contact the CBF office.

Friends of CBF London meeting

We are planning our next **Friends of CBF** event in London on 17th May (evening – times to be confirmed). If you would like to come along to meet the CBF team, hear from Viv Cooper and to help us to plan the next 15 years please contact Claire Crump (claire.crump@theCBF.org.uk) for more information.



So far **Friends of CBF** have raised over £5000 towards our target.

How does it feel?

Are you a parent of a child with profound and multiple disabilities? Could you spare 25 minutes to complete an anonymous online survey? A psychologist in an NHS CAMHS learning disability service supporting families with the behavioural and emotional aspects of having a child with a learning disability is researching how parents' perceptions of their parenting, coping and their child may influence their own psychological wellbeing. The survey will run until the end of July 2012 – visit: www.survey.ed.ac.uk/parentcarerwellbeing or contact parentwellbeingresearch@gmail.com for more information.

100 Club Winners

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

October 2011:

Mr A McCorquodale (Northfleet)

November 2011:

(special £50 prize)
Mrs I Valenti (London)

December 2011:

Mrs V Howe (Ipswich)

January 2012:

Mrs J Seamer (Bristol)

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.

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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). <i>40 minutes</i> | | | | |
| 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. <i>40 minutes</i> | | | | |
| 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. <i>40 minutes</i> | | | | |
| 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. <i>(Approx 70 mins)</i> | | | | |
| CHALLENGING BEHAVIOUR INFORMATION SHEETS | | | | |
| Understanding challenging behaviour | All information sheets are available free of charge on the CBF website. | | | |
| 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 | | To order by post please add £1.00 per sheet* | | |
| 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...

| | | | |
|--|-------------|--------|---------|
| 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 <i>(please specify)</i> | £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.

Gift Aid means we can claim back the tax on your gift (25p for every £1 you give) at no extra cost to you. If you are a UK tax payer and would like to Gift Aid your donation, please sign here:

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

To pay by credit/debit card please telephone us on 01634 838739 (3% card handling fee applies)

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

Address: The Old Courthouse,
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ME4 6BE

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

www.challengingbehaviour.org.uk