

Challenge



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

Winter 2011

The newsletter of the Challenging Behaviour Foundation

Out of sight, out of mind?

For most of the public, Panorama's "Undercover care: the abuse exposed" is no longer a talking point.

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Opening my world

Because of my son's challenging behaviour life could be very isolating...

The programme exposed, for all to see, the shocking abuse of people with learning disabilities by people entrusted and paid to support them. There followed public outrage, newspaper articles, letters to Government and TV interviews. With the subsequent closure of Winterbourne View many probably think it has all been sorted out. But for people with learning disabilities and their families it remains uppermost in their minds – because it could have been them, their son, daughter, brother, sister. And it still could be...



Vivien Cooper

How could we get it so wrong?

How could we get it so wrong? How can what happens in people's lives be so different to what all the policies, strategies and best practice guidance say? And how can all the processes, agencies and safeguards we have in place allow people with complex needs to be grouped together, on the edge of an industrial estate, and subjected to abuse?

We know how to support people. We know what works and what doesn't. And yet people with complex needs can be fast tracked away from their families, friends and everything that is familiar – out of sight and out of mind?

The Panorama programme, shocking as it was, provides an opportunity to

see real change delivered. There is no one thing we can do to put things right – it is a range of things, addressed in a co-ordinated and relentlessly determined way. It is about really being person centred, good commissioning, partnership with families, high quality support and services, using legislation and robust regulation and focussing on human rights and outcomes for individual people.

This edition of Challenge focuses on some of the issues that need to be addressed, including how we support people with learning disabilities with mental health problems and how the Mental Health Act should be used to protect individuals but can sometimes be used in ways which are unhelpful.

We all have a responsibility to keep up the pressure

There is no excuse for getting support for people with complex needs wrong – and the consequences for the people we fail are severe. We all have a responsibility to keep up the pressure and take some action – to make sure people are not hidden, but firmly in view, and firmly in our minds.

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

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

A long and bumpy ride

What does the trip through education, family support services and adult options look and feel like for young people with labels of learning disability or challenging behaviour?

To begin with the ride is often bumpy. You might have to stand despite paying for a seat. There are unexpected delays and people are obliged to hop from one platform to another, or buy tickets from different operators. You might have to travel on a coach but don't worry, because "you are important to us", you are told, endlessly. You might arrive at your destination - say, Inverness - only after being obliged to visit Birmingham.

That's presuming Inverness is still available by the time you've navigated contradictory advice on which is the best route. For some, instead of arriving at Inverness, they find themselves stranded in Birmingham.

Now the two places may superficially resemble one another in that they are large conglomerations of bemused humans that possess clock towers but they also exist in different countries, are subject to different laws.

You may wish for Inverness, but only be supplied with Birmingham. But "hey, you are important to us, sorry for the delay".

Our discussions on customer journeys showed the signals on the line were often faulty (sometimes red meant go, sometimes stop) and some operators failed to provide any timetable whatsoever. Some operators had abandoned trains in favour of jets and some in favour of donkeys. "You're entitled to a free sandwich due to the unavoidable delay" is nice but not when you just want to get on the train you've been promised. Where's the regulator? Who is in charge of saying what is good enough?

A customer journey built upon the cheapest bidder may not be the happiest

Most people we spoke with were not customers. Customers have choice. The market says quality will out, but in this market, it's price that counts. A customer journey built upon the cheapest bidder may not be the happiest. Customers should expect satisfaction. Customers can choose how they spend their money. Many people using services are, therefore,



not customers. The journeys are pre-ordained via brokers acting in best interests. They just don't say in whose best interests. But I will. It's in these brokers' best interest to keep the budget in the black even though doing so results in service users and families seeing red

Where's the regulator? Who is in charge of saying what is good enough?

Our conclusions? Best not be a customer on the mindless line of standardised routes. Be a driver. Be your own regulator. Just mind the gap when you step off the train. And don't rely on announcements, because sometimes announcers lie, for example: "Welcome to Inverness" when it's Birmingham, or "Our services are high quality and regularly inspected" when you've arrived at Winterbourne.

Customers are people

Customers are not numbers. Customers are not behaviours to be measured, with needs to be met. Customers are people, with stories and hopes and staggering tales of heartbreak "we should learn from.....please".

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

HOW YOU CAN HELP

Become a Friend of CBF

Are you:

- Wanting to find out more about the CBF?
- Interested in getting involved in CBF projects?
- Looking for opportunities to meet like-minded families and professionals?

Join our NEW "Friends of CBF" scheme, and receive:

- Regular email newsletters
- Invitations to social and networking events*
- Information about CBF projects and how you can get involved

PLUS

- Your annual Friends of CBF donation will be put aside for a specific purpose, of which we will keep you fully informed. This year all Friends of CBF donations will go towards our 15th anniversary appeal to help us reach more families (read more on page 10 and on our website)

***NB.** We will need YOUR help to make this happen! This is a new venture for us - please help us to help you make "Friends of CBF" what you want it to be!

Find out more and sign up online via our website

www.challengingbehaviour.org.uk or contact the CBF office for more information.

Q: I work with a boy of six with Lesch-Nyhan Syndrome. When we go swimming and put him in the water he flails and head butts so that he falls out of the sling. Any suggestions?

A1: Polyotter swim suits with floats in the swimming costume could work, or try a giant float with a swim suit/seat in the middle for him to sit in?

A2: Does he wish to go in the pool? If this is not an issue, what about looking at an Occupational Therapy referral but fundamentally an assessment of his behaviours. Is the water and freedom of it too much sensory stimulation, or is it excitement?

A3: In my experience people who self-injure in this way are trying to tell us something. Does he find the activity/water aversive, or if it is a case of once he is in the water he enjoys it, then it may be a transition issue. The best way to work this out is to complete a functional analysis - a nurse or psychologist could help with this. The difficulty is if you are looking for an aid to do what you have asked and the boy finds the activity aversive in some way all that will be achieved is getting them to perform an activity they do not wish to do. That in itself is restrictive and could potentially make the behaviour worse.

A4: Have you tried a lifejacket? I had a young client who loved the water and instantly put her head down into the water and tried to submerge herself. The life jacket worked well to keep her buoyant.

Q: My 22 year old son with Autism and Cerebral Palsy is now settled in a care home but meanwhile his twin sister has developed a great concern about the future. I think therapy would help. Any suggestions?

A1: SIBS (www.sibs.org.uk/adults) might be a good place to start and also go to the Contact a Family website and view their site on 'Siblings' (www.cafamily.org.uk)

A2: I think this is something we may face in the future with our 13 year old who is quite sensitive and very caring of his autistic brother. I would suggest your daughter's first port of call would be her GP who could possibly arrange some counselling. I also know that Relate do something child centred in schools for children who are having difficulties at school for whatever reason so I am sure that

they will do something for adults too. (www.relate.org.uk/family-counselling/index.html)

A3: My daughter really struggled when her brother left home to go to into residential care. She ended up suffering from depression and hated not having him at home with us, worrying that he was not going to be cared for in the same way he was cared for at home.

She received counselling through a local carer support group, which also supported siblings and found that talking things through with someone removed from our family home really helped. Whilst she now has a life of her own, she makes sure that she is as fully involved in her brother's life as possible. She visits him as often as she is able, attends meetings about him and insists on providing input into the bigger decisions made about his life. She feels happier knowing she can be there to help the brother she loves so dearly to get the quality of life he deserves.

A sibling's perspective



Rekha with her brother, Deepak

My brother Deepak is 28, the youngest of five siblings. Deepak has a wonderful presence and the best smile and we are very close.

Growing up with a brother with severe learning disabilities who is non-verbal has been challenging and demanding - made harder by the fact that language was a barrier. My mum does not speak English (her first language is Gujarati) and my father's health was not good.

I have always been heavily involved in caring for Deepak and supporting my parents by attending meetings, filling in forms, translating letters and interpreting what the professionals say. Without the support I have given my parents they would have found it very difficult to cope. They would have been left in a position where professionals could have made all the decisions about Deepak's life and they would have had to either go along with it or keep Deepak at home and struggle without support, relevant information or access to services.

I now care for my mother (our father passed away some years ago) and even though Deepak does not live at home, much of my time is still taken up sorting things out for him - my role as a carer doesn't stop just because he doesn't live at home.

My own health has suffered and it can be very stressful at times, worrying about how my brother is being cared for. It continues to be a struggle but I wouldn't have it any other way. All Deepak has to do is flash his gorgeous smile to remind me why I do it.

• **Rekha Doshi**, sister & family carer

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

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

Everybody Matters

A powerful new film project is being planned which, following Winterbourne View, will provide an urgent call for the support and services that are needed to enable individuals and their families to lead good lives.

A short 10 minute film is available to view now (see below). This will be developed into a longer film to raise awareness of the impact of challenging behaviour on individuals with learning disabilities and their family carers. The aim is to demonstrate that good lives for people with challenging reputations and complex histories are possible and are happening.

Professor Jim Mansell, who features in the film, highlights the need to build services around the individual instead of sending people to places like Winterbourne View: "There's no doubt that we need to take action to stop these kinds of services being used in this way as dumping grounds as an alternative to developing proper local services for people."

Also featured on the film are family carers David and Jill talking about their experiences with their son James. Their moving account describes how his behaviours have been misunderstood, and the consequence of service failure. As Jill says, "I think that's the tragedy of James.. there's a human being inside there which you don't see..."



To make this film happen we need your support. The film project is an exciting opportunity to make a real impact - and readers of 'Challenge' are invited to get involved. To view Everybody Matters and find out more about supporting the project go to www.challengingbehaviour.org.uk and click on Latest News

Getting personal

Jayne Lingard, CBF project manager (personalisation), introduces a project the CBF is currently running in the East Midlands



The project started in June 2011 and will run until June 2012. It aims to improve personalisation for people with learning disabilities whose behaviour is described as challenging so they can access personalised services like supported living, community involvement and creative employment opportunities.

We are working with a number of local authorities and NHS bodies in the East Midlands. Together they are identifying 20 people for whom they have difficulties in offering personalisation. Their local planning teams will be supported by the CBF with additional housing and behavioural support. The project is also supporting six families to advocate on behalf of their relative to their service commissioners. The families contacted the CBF because they were not getting a suitable response.

The main benefits the project is seeking are to

- Ensure higher quality outcomes for the 26 individuals
- Achieve better outcomes for the same or less money
- Reduce the number of out of area placements, with more people living close to their families
- Improve future commissioning based on the models developed by the project
- Disseminate learning from the project widely.

The main tasks of project are to

- develop viable personalisation plans for the 20 people in the East Midlands
- facilitate productive communications between the six families who have contacted the CBF and the responsible commissioners of their relatives to pursue the same kind of plans
- develop or adapt tools to facilitate the work

The project has the support of the University of Kent Tizard Centre and the Department of Health as well as senior managers in health and social care in the East Midlands.

Along with many other reports, the project is being guided by the document "Think Local Act Personal". This makes the link between the government's vision for social care and all of the work done under the banner of "Putting People First". The seven principles of the government's vision for social care are

- Prevention: promoting health and wellbeing
- Personalisation: individuals not institutions take control of their care
- Partnership: care and support delivered in a partnership
- Plurality: the variety of people's needs is matched by diverse service provision
- Protection: sensible safeguards. Risk no longer an excuse to limit people's freedom.
- Productivity: greater local accountability for agreed quality outcomes
- People: a workforce who can provide care and support with skill, compassion and imagination with freedom and support to do so.

We will have to work hard to complete the project in time as there is so much change underway in local authorities. Many staff have left and will not be replaced, others are reapplying for changed jobs. Primary Care Trusts (Health Authorities) come to an end in 2013 and many face financial pressures.

So far, the families are very appreciative of the support provided by the project and early themes are starting to emerge. One is that some social workers are less confident about leading person-centred planning than you might expect, and another is that families are being asked to choose services without being given any training or support in doing so. These are both things that we can put right!

- **Jayne Lingard**, CBF project manager (personalisation)

Well matched skilled staff



A new resource for commissioners: "Services for children and young people with learning disabilities who display challenging behaviour - Well matched skilled staff" has been produced by Dr Sarah Bernard in collaboration with the Challenging Behaviour National Strategy Group.

This practical resource identifies which professionals should be involved in meeting the needs of individuals who display challenging behaviour, what to look for from a service, what skills the workforce require and how to monitor service provision.

Dr Bernard explains: "Service provision must be directed by the needs of the individual and there should not be an expectation that these children and young people can be fitted into existing services if such services do not address the complexities of their needs. The distress and trauma which can be experienced if someone is placed in an inappropriate and poorly monitored setting is all too evident with the recent exposure of abuse and poor practice. Such situations can and must be prevented. With this in mind, those commissioning often expensive placements must be able to access evidence based information which can demonstrate what a good service should offer."

An accompanying resource "Services for adults with learning disabilities who display challenging behaviour - Well matched skilled staff" by Dr Peter Baker is also available.

Both resources are free to download. Visit: www.challengingbehaviour.org.uk
A limited number of hard copies are also available. Email: info@thecbf.org.uk or phone: 01634 838739.

EXTRACT

Questions to ask

- How does the service engage with parents, carers, education, health and social care?
- What percentage of the children who display challenging behaviour have a behaviour support plan based on a functional assessment?
- How is behaviour recorded?
- How often are behaviour support plans reviewed?
- What processes are in place to ensure the service addresses the full range of the child/ young person's needs?
- How is risk assessed and managed?
- Can the service give an example of how they have implemented current evidence- based best practice guidance?
- Is there written evidence that the service has assessed capacity, gained consent or held best interest meetings for any young person aged 16-18?

Extract from "Services for children and young people with learning disabilities who display challenging behaviour" by Dr Sarah Bernard.

Time for action

Following widespread condemnation of the treatment of people with learning disabilities at Winterbourne View, a collaborative group of 86 organisations and individuals sent a letter to the Prime Minister, and the Challenging Behaviour National Strategy Group developed "Time for action" to set out action required to improve the support and services people with learning disabilities who display challenging behaviour receive. The Association for Supported Living (ASL) has written to every MP in the country calling for community-based supported living services to replace institutional services for people with learning disabilities, and will publish a report with a collection of best practice examples.

As a result of the programme Winterbourne View closed on 24th June 2011. Two further Castlebeck services subsequently closed after the Care Quality Commission inspected and reported serious concerns. The Government announced a review to be led by Bruce Calderwood (Department of Health) with input from Mark Goldring (MENCAP), Prof Jim Mansell (Tizard Centre, University of Kent) and Anne Williams (Former National Director for Learning Disabilities), which will consider information from:

- **The Care Quality Commission (CQC):** their internal review; their review of all Castlebeck services; their wider review of 150 other specialist learning disability services
- The **Serious Case Review** by South Gloucestershire Safeguarding Adults Board
- The **Serious Untoward Incident** investigations by the Strategic Health Authority
- **Police investigation** findings
- **Castlebeck Care internal review**
- **NHS review**

The review team will also be talking to people with learning disabilities, people with autism, families and a range of other stakeholders. The review team will make recommendations in a report due to be published in April 2012.

To contribute your views to the review use the web contact form on the Department of Health website and include "Winterbourne View - DH Review" in the subject area on the contact form:
<http://www.dh.gov.uk/health/contact-dh/>

Regular updates on the action taken as a result of the Panorama programme are available in a new section on our website located within the National Strategy Group pages at:
www.challengingbehaviour.org.uk

No health without mental health

"No health without mental health" is a cross-government mental health outcomes strategy for people of all ages (2011) endorsing better mental health for all. It aims to 'improve the mental health and wellbeing of the population and keep people well; and improve outcomes for people with mental health problems through high-quality services that are equally accessible to all'.

However the Care Quality Commission (CQC) and the Healthcare Commission audit of specialist services (2007) both identified that the services available to people with learning disabilities and mental health needs vary greatly across the country. They stated that people do not always get good assessment and treatment and are too often sent away from their own areas. The CQC stated that it is important "that people with learning disabilities who have mental health issues have the same access to generic mental health services as the general population using reasonable adjustments where needed". This is supported by Valuing People Now (2009) which also recognises that a small number of people with a learning disability will require specialist support and treatment from the NHS, provided by specialist learning disability services or mental health services.

Yet with all the guidance it has been evidenced this year through the Panorama programme that we are still not getting it right for people with a learning disability. So what can be done?

- Sign up to the Outcomes Charter for the mental health of people with learning disabilities launched this year.
(<http://www.southeastcoast.nhs.uk/Downloads/Learning%20disabilities%20toolkit/MH%20Charter%20Feb%2011.pdf>)

- Start with positive mental health where the individual lives.

- **Jo Poynter**, *Learning Disability Programme Lead, South East Coast SHA*

Challenging behaviour & mental

Children with learning disabilities who exhibit challenging behaviour, childhood psychiatric disorder or physical disorder, write



Sarah Bernard

Children and young people with learning disabilities are recognised as being at increased risk of mental health

Children and young people with learning disabilities are recognised as being at increased risk of mental health or behavioural problems including challenging behaviour. The National Service Framework for children clearly states that services should be available to all but, unfortunately, there remains a lack of child and adolescent mental health services for this group of young people. In practice this means that children and young people with learning disabilities and challenging behaviour do not always access appropriate assessments. As a result of this, diagnosis might be missed or might be incorrect with inappropriate lines of management subsequently instituted.

Common mental health and behavioural problems encountered in children and adolescents with learning disabilities include the full range of psychiatric disorders observed in their non-learning disabled peers. In those with significant learning disabilities, challenging behaviour, which is not in itself a diagnosis, becomes a major concern.

When considering the more likely disorders that might account for challenging behaviour these can be listed as follows:

- Autism and Autistic spectrum disorder
- Hyperactivity and Attention Deficit Disorder
- Depression
- Psychosis

Disorders associated with challenging behaviour include:

Autism and Autistic spectrum disorder

This is pervasive, manifests before three years of age and is defined as having abnormal functioning in the three areas of social interaction, communication and restrictive and repetitive behaviours. The child's level of learning disability must be considered when making this diagnosis as certain behaviours that appear "autistic" might, in fact, be appropriate for the level at which the child is functioning.

Management of this group of children includes a combination of developmental, behavioural and educational approaches. Medication sometimes has a role but is not the first line of management and should always be used in conjunction with behavioural techniques.

Hyperactivity and Attention Deficit Disorder

This has an onset during the first five years of life with the child exhibiting over-activity, poorly moderated behaviour and marked inattention. It occurs in all environments and there are associated abnormalities of restlessness, fidgetiness, impulsivity, distractibility and social inhibition. This is often under-diagnosed with children with developmental disabilities as the behavioural problems might be interpreted as due to the learning disability rather than an associated attention deficit disorder.

Management includes a trial of medical in conjunction with behavioural approaches in order to maximise attentional and associated skills.

health in children & adolescents

Challenging behaviour may be experiencing a specific underlying condition by Dr Sarah Bernard

Other, rarer, childhood psychiatric disorders can occur in children with learning disabilities and still require careful and experienced assessments and management.

Challenging behaviour in itself is not a diagnosis. It is a descriptive term for any behaviour which poses a challenge for the individual and their carers or society. Such behaviours require a comprehensive assessment in order to identify positive factors including physical or psychiatric disorders. It is important to emphasise that possible reinforcing consequences of the behaviours are identified. Management should include a comprehensive multidisciplinary assessment with behavioural psychotherapy being the first line of management. Cautious use of medication might be indicated in the most severely affected cases, but this has to be tailored to individual needs.

There remains a lack of child and adolescent mental health services for this group of young people.

Specific types of challenging behaviours include self-injurious behaviour. This can be resistant to intervention and, in general, medication alone has not been successful in managing severe self-injury. Most recently there are concerns that self injury might be driven by pain or severe anxiety thus a careful physical and mental health assessment is essential.

In summary children with learning disabilities who exhibit challenging behaviour may be experiencing a specific underlying childhood psychiatric disorder or physical disorder. Some childhood psychiatric disorders respond well to medication but this should not be used until there is a comprehensive assessment and services in place for monitoring the benefits or side effects of medication.

• **Dr Sarah Bernard**, Consultant Psychiatrist, The Michael Rutter Centre

Depression

Depression is associated with low mood, loss of interest in daily activities, loss of energy, tearfulness, poor concentration and memory. Biological features include a disturbed sleep, poor appetite and mood variation. In those with learning disabilities distress can be mistaken for depression, whilst conversely, depression might be labelled as part of the child's learning disability or challenging behaviour and appropriate treatment not instituted.

Therapeutic treatment includes a behavioural therapy which, if unsuccessful a cautious trial of medication should be considered.

Psychosis

Psychosis (this includes schizophrenia and bi-polar affect disorder) exhibits itself with disorders of thought, hallucinations and delusions, unusual behaviours and apathy and social withdrawal. It is problematic in distinguishing these behaviours in children with severe disability as they cannot communicate their thought content verbally.

Treatment might need to be pragmatic and empirical and diagnosis should only be made by experienced clinicians as once a label has been given it would have major implications for the child's ongoing management. Anti-psychotic medication has to be supervised closely as there is a risk of adverse effects.

Resources for families

Carers can be the first to recognise mental health difficulties by observing behavioural changes. There are a variety of resources available to support family carers to recognise mental health difficulties & information on what support is available.

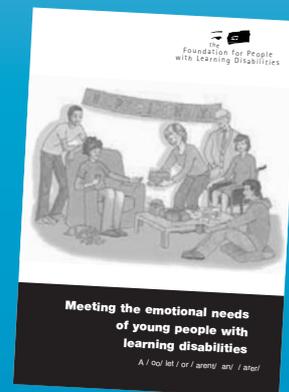


One practical resource for family carers of young people with learning disabilities is **You are not alone** by The Foundation for People with Learning Disabilities.

Aimed at parents and carers, this publication gives guidelines on identifying a mental health problem, help and treatment available if your son or daughter develops a mental health issue and the support available specifically for parents and carers. This resource also provides case studies of individuals and a detailed example of a person centred plan.

Meeting the emotional needs of young people with learning disabilities is another valuable resource featuring family and young people's experiences of mental health.

Information is provided for carers of 14-25 year olds about ways of helping young people to deal with emotional upheaval they may face as well as opportunities to improve self-esteem.



Both resources are free to download from www.learningdisabilities.org.uk/publications

Being sectioned helped my son



Emmanuel

My son Emmanuel was transferred from his residential school on his eighteenth birthday into a group care home. The placement was not matched to his needs and within six months he was sectioned under Section 2 of the Mental Health Act.

I was deeply shocked that he was removed to a specialist hospital without the care home telling me what was going on. I had been visiting him the day before and not a word was said to me of what was being planned. As I hugged my son I had no idea that things had escalated so badly for him.

It was unfair to section him, I believed, as his challenging behaviour had been provoked by being placed and then left in an unsuitable care environment, with carers who had no real understanding of Autism Spectrum Disorder (ASD), or positive behaviour management techniques and would only allow him food if he ate communally.

Once I contacted the hospital where Emmanuel had been taken to I became very relieved to find him in the care of staff who had training in ASD and challenging behaviour and that he was a happier young man. The hospital staff were surprised that there was no evidence of any challenging behaviour as the care home had reported he would harm other people.

Had Emmanuel's needs been met in the first place his behaviour would not have escalated and he would not have been sectioned. However had he not been sectioned he would likely have ended up still being cared for by unskilled staff or in a much worse situation.

• **Helen Cherry**, *family carer*

Understanding

Sometimes people with severe learning disabilities and treatment under the Mental Health Act (MHA). We different experiences...

A person can be sectioned if they are perceived to be a threat to themselves or other people and require treatment that cannot be offered in the community. Individuals with a learning disability may only be detained for treatment under the MHA on the basis of their learning disability alone when it is associated with 'abnormally aggressive behaviour or seriously irresponsible conduct'.

Generally, a person can only be sectioned if two doctors (one usually a Psychiatrist, the other a doctor who knows the person well) and an Approved Mental Health Professional or a close relative of the person believe it to be necessary, however in an emergency one doctor's recommendation may be sufficient. In this case they are detained under section 4 and can be detained for up to 72 hours. If detained under section 2 for further assessment and treatment they can be admitted to a hospital for up to 28 days.

At the end of the 28-day period if the Responsible Clinician recommends further hospital treatment, the person can be detained for up to a further six months under section 3. A patient can be discharged from hospital at any time if doctors believe they no longer require treatment in hospital or are no longer a threat to themselves or anyone else. The Code of Practice: Mental Health Act 1983 (2008) suggests the need to consider frequency, degree, associated risks and context of the behaviour when considering detaining a person for treatment on the grounds of 'abnormally aggressive behaviour or seriously irresponsible conduct'. The Code also states that it would not be good practice to detain a person based on their behaviour without a multi-disciplinary assessment conducted by appropriately trained professionals. This should include an assessment to establish whether the behaviour stems from difficulties with communication.

Questions to Ask:

- Does the person have a formal diagnosis of a mental health disorder? If they do not have a mental health disorder what treatment is proposed that requires a secure setting?
- If the person has a mental health disorder could treatment be provided without the need for detention?
- Are the possible consequences of the behaviour serious enough to warrant detention?
- Who was involved in the decision to detain the person?
- Has the person been formally assessed by a multi-disciplinary team?

Whilst the MHA overrides the Mental Capacity Act 2005 (MCA) in some circumstances (i.e. treatment directly related to the reason the person is being detained), the MCA still applies in all other aspects of the person's care. For example, staff have no right to 'ration' cigarettes in a 'best interests' fashion, as long as the individual has capacity to decide how many cigarettes to smoke, regardless of whether or not they are being detained under the MHA.

The person being detained has a right to be given information regarding why they are being sectioned, the restrictions it applies and their rights under the Mental Health Act, specifically in regards of appeal. The information should be given in a format that is accessible to the individual. The patient's 'nearest relative' is provided rights under the MHA including the opportunity to request the patient's discharge from hospital and to object to an application for admission for treatment. For a helpful information sheet explaining the legal term 'nearest relative' contact Rethink (www.rethink.org)

• **Adapted from 'A guide for advocates', a CBF publication (see back page to order).**

g Sectioning

challenging behaviour may be detained for assessment
examine the facts and hear from two families with very

Sectioning was 'horrific'

Our son "K" was sectioned in 2009. Although we had been warned this was a possibility (K's behaviour had become increasingly difficult to manage in his new residential placement) it was still a great shock for us and even more so for K. He has a severe learning disability and autism and, had no way of understanding the situation.

The sectioning meeting was horrific. Two psychiatrists had already seen K. One knew K; the other had only met him for fifteen minutes. The meeting took place in the kitchen of the residential home with staff wandering in and out. To our distress no local NHS beds were available. We objected to private health care on principle, but this cut no ice.

We protested that we were too old to make long journeys and that we would lose our knowledge of K's ways which made his frequent visits home possible and enjoyable. The meeting broke up with no placement identified.

The Approved Mental Health Practitioner (AMHP) visited us at home later in the day, having identified a place 80 miles away. Nothing he said was at all reassuring except that there was a garden. We were told the hospital bus would pick K up the next morning. K was then moved again four days later to another hospital said to be more suitable. My husband reluctantly signed the form. If he refused, the AMHP said he would go straight to court to dispense with his consent. K remained in hospital for two years.

B, Mother of K

CBF NEWS

CBF on Facebook



The new CBF Facebook page (www.facebook.com/theCBF) is a great way of getting in touch with other people who may be going through similar experiences, or feel the same about current issues in the world of learning disability and challenging behaviour. The CBF Facebook page provides a network for sharing information, mutual support, news and information. We post details of all our events and the conferences we attend, so everyone knows where CBF staff and volunteers will be. When there are important policy decisions or news relevant to severe learning disabilities, we comment and invite discussion.

Around 300 family carers and professionals now 'like' our page and many people regularly read and comment on posts. Future plans include hosting discussions on various topics and inviting guest professionals to the page to answer questions on their area of expertise. We also plan to have some video clips about challenging behaviour and the charity on the page later this year. We'd like to see more discussions and sharing of ideas, so please visit and post a message or question on the CBF wall.

You don't have to join Facebook to see our page, but to post a message yourself you will need to create your own Facebook account. You should be able to do this in just a couple of minutes following the online instructions.

Please visit www.facebook.com/theCBF and tell us if you  our page!

PARENTS PERSPECTIVES

Opening my world



Jen & C

When my son was diagnosed we didn't have mobile phones or computers. And because of my son's challenging behaviour life could be very isolating. The few books in the library portrayed very negative stereotypes.

But with the birth of the internet, accessible to all, things have changed. I have a wealth of information at my fingertips. I have taken part in various consultations, joined campaigns. There are discussion boards and forums. Email support groups - the CBF one is invaluable! You can ask questions, exchange ideas, keep up to date with research and be part of a community. You no longer have to feel alone.

I started blogging a few years ago to share the experiences of my son as he made the transition to adulthood. Through my blog I have made many online friends, express opinions, share information, have discussions and have learnt much from others. As well as raising positive awareness as I have tried to show even with severe behaviour that is challenging my son can have a good quality of life. Through the internet I have given my preverbal son a voice.

More recently I succumbed to Facebook and Twitter - which has proved to be a valuable source of information, activities, expression, inspiration and support. I was a bit nervous to start with as I am not the most social of people but Facebook is what you make of it and is an excellent way of quickly and easily being able to keep up to date - especially now as the CBF have their own page full of useful links and websites. A great way to share knowledge and so encouraging better practice.

• **Jen Fookes**, family carer

<http://motherofshrek.blogspot.com>

THANK YOU...

Thank you to **Mr and Mrs Corner** and **Mr and Mrs Nurse** who gave donations to the CBF recently in celebration of their Diamond and Golden Wedding Anniversaries.

If you would like to give to the CBF in celebration of a special occasion we can help you to set up a giving page on our Virgin Money Giving site.

Getting fit and raising money



Shelley Brady ran the Run to the Beat half marathon in London in September, and despite picking up an ankle injury a few weeks before she managed to complete the race and has raised nearly £400 for CBF. Thank you, Shelley.

A team of walkers including **Lynn Walton, Neil Walton, Laurence Ireland and Michelle Curzon** took part in the North Downs Walk in Kent in July and raised £226 for CBF – well done!

Join the CBF running team!

To mark our 15th Anniversary we have a CBF team who will be running a 10k run in London in 2012. If you would like to join our team please contact us or visit the fundraising pages on our website for more information.

Other events

If running isn't for you there will be other events on offer during our anniversary year - just keep an eye on our website or become a Friend of CBF to ensure you don't miss out on any events in your area.



In September CBF volunteers gave their weekend to run a fundraising stall at a local Kent event called **"Salute to the 40s"**. The CBF was well visited by young people keen to win the marble challenge game and the stall raised £255 over the 2 days. Thank you everyone!

Help us celebrate 15 years of CBF

2012 IS CBF'S 15TH YEAR, AND WE HOPE YOU WILL WANT TO HELP US CELEBRATE!

To mark the occasion we are launching a "15th Anniversary Appeal" – aiming to raise £15,000 to enable us to reach more families that need our support. We are currently in regular contact with over 1500 families – but we know there are many more that need our specialist information, training and support.

If you join 'Friends of CBF' (see page 2) your 'Friends' donation will go towards our 15th Anniversary Appeal – or you can text CHAL 15 £15 (or other amount) to make a one-off donation.

Text CHAL15 £15 to 70070 to donate now

Alternatively, why not plan a simple 15th Anniversary fundraising event for us (a tea party? Dinner party? Or take part in a sponsored event?). Do let us know your ideas – and how we can help you. All money raised will help us to help more families.

We will keep you updated throughout the year with news of how much money we have raised and how we plan to spend it – or see our website for more information.

Siblings research

"Adult Siblings of People with Autism plus Learning Disability – their experiences, perspectives and future support needs" by The University of York looks at individuals with higher support needs and the impact this has upon their siblings. For a summary of the findings or to find out more about the research project contact SIBS www.sibs.org.uk Tel: 01535 645 453

Challenging a refusal to assess your child

The law says that councils must assess every child who is or may be a child 'in need'. Children are 'in need' if they need help from the council for their health or development or if they are disabled. The Every Disabled Child Matters Campaign has produced a leaflet and template letter for parents of disabled children to challenge a refusal to carry out an assessment for short breaks or specialist services. Available free to download from: www.ncb.org.uk/edcm/assessment_letter.pdf

100 Club Winners

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

May 2011: Mrs H Hawkins (Aylesford)

June 2011: Mrs V Howe (Ipswich)

July 2011: Mrs A Giles (Newcastle Upon Tyne)

August 2011: Mr C Hewett (Chelmsford)

September 2011: Mr M Lawrence (London)

All proceeds from the 100 Club help towards CBF running costs. Shares cost just £1 per month. Please get in touch if you would like to join.

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). 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			
Basic information about 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...

SUB TOTAL CARRIED FORWARD			
	Cost	Number	Total £
SUPPORT OPTIONS			
Planning your House	Web Only**		
Provides family carers with practical help with planning for future housing needs.			
8 Ways to get a house	Web Only**		
Explains the different ways to get a house and how they are funded			
**Due to anticipated changes in funding, these new resources will initially only be available to view on our website www.challengingbehaviour.org.uk . Family carers who would like a printed copy should 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,
New Road Avenue, Chatham, Kent,
ME4 6BE

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

www.challengingbehaviour.org.uk