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# Challenge

Challenging  
**BEHAVIOUR**  
foundation



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

Spring 2010

The newsletter of The Challenging Behaviour Foundation

## We all need champions!

Like most mums, I hope that I am someone my children can turn to for advice, or to be their champion when they need one.

Most of us have family members who fulfil that role, as well as friends and colleagues who also provide important input to our lives. Even though I am reasonably able to advocate for myself, it is good to know that there are people "there for me" if I need some support.



Vivien Cooper

I worry that my son, who is more in need of support than most, is least likely to have it. He does have a supportive family, but he is more reliant on us because he is very vulnerable. There are many who do not have family or a circle of support, and they are even more vulnerable.

### **Advocacy is a powerful tool and we need to ensure that we make it available**

Ironically, it is those who are most in need of independent advocacy support who are least likely to access it. It seems it is a bit too expensive and too complicated to put in place. I have personally encountered "well why does he need an advocate, he's got you" (countered of course by "well, you are his Mum and may have a conflict of interest" when it suits!), and "it's not in his best interest to have one"(astounding!) .

I am fully aware of the dangers of appointing an advocate who is not properly independent, or who does not

***Ironically, it is those who are most in need of independent advocacy support who are least likely to access it***

have the expertise to fulfil this important role. (Beware the person who says

confidently "yes I can advocate for him" without spending significant amounts of time to get to know the person!) But advocacy is a powerful tool and we need to ensure that we make it available to those who need it - and that it is of high quality. That is why we have produced a new resource specifically for advocates and we are dedicating this issue of Challenge to the topic.

### **My son has the same rights as everyone else**

My son has the same rights as everyone else to a good life. He just needs more support than most to access those rights – and independent advocacy is an important means to champion them.

#### **• Vivien Cooper**

*Chair of Trustees and Founder of the Challenging Behaviour Foundation*

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### **Comment**

***Hitting myself, or the window (or you) might guarantee a response***

#### **PAGE 4**

### **News**

***Many families and paid carers are often unaware how the Mental Capacity Act applies to people who challenge services***

#### **PAGE 5**

### **Resources**

***The CBF has developed a new resource for advocates who find themselves supporting individuals perceived as challenging.***

#### **PAGE 8**

### **Join us!**

***Opportunities to support the work 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

# Learning to listen

If my voice was not heard, if I had no voice, how might I let people know I didn't know what was expected? How might I tell people those things (and people) I find disagreeable? If I feel pain?

Signing, holding up a symbol, using the few words I'd been taught (why always *please*? Why always *thank you*?), might not be heard. Hitting myself, or the window (or you) might guarantee a response, though.

What if challenging behaviour might be a way of expressing pain, frustration or discontent? Imagine challenging behaviour as small (and large!) acts of self-determination: *my wants don't match what is being done for me*. Think of the money we'd save if rather than employing expensive consultants we listen to the person! (He said as an *inexpensive consultant*...)

It's all too easy to recognise today the late Herb Lovett's assertion that service institutions speak *for* groups of people; they present as experts *on* people, their illnesses, their needs, and even, all too often, their supposed goals.

I've plenty of children hanging about the house, making it look untidy; I know *about* my children, but I wouldn't

be foolish enough to presume this makes me an expert on *all* kids, to be able to say what is good for *all* children.

In a way, as a society, we, get the services and professionals we deserve. Services do things to people. Who works *with* people? Who listens to the small voices? Read Lovett's 1996 book 'Learning to Listen'. Herb Lovett argued advocacy can counter hierarchical power. Advocacy can help small voices be heard.

Lovett, and many others, argues for competent, strong advocates. People who won't be averse to rattling those caught up in the cages of the *status quo*. People who won't run from the dark looks of those they question. People who won't accept the *status*

***What if challenging behaviour might be a way of expressing pain, frustration or discontent?***



*quo* as sufficient. If we complain, if we are angry, it is because the *status quo* is just not good enough.

I'd like to advocate for services to listen, for Government to fund advocacy, for busy professionals to spend that most precious of resources, time, on people who seek to be heard. Many of the advocates I've met simply want the system to meet people halfway, to hear small voices, to respond not in services', but in the person's best interests.

It's not helpful for serviceland to expect families to advocate for their family member constantly. Try asking for years. Try living with the disappointment of finding your questions unanswered, your pleas unheard, your pain unrecognised, time and time and time again. It can be sufficiently hard to live with challenging behaviour without being ignored by the very system intended to help you. That's exhausting. That's cruel.

Surely it falls to all of us to listen, to respond, to advocate for people who challenge, who say, in many ways, *my wants don't match what is being done*.

Wouldn't that just make more sense?

• **Tony Osgood**

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

## NEWS

### Are we making a difference?

We want to improve the lives of individuals with severe learning disabilities. If our resources or support have helped make a difference

#### PLEASE LET US KNOW.

The CBF has no regular guaranteed income and we constantly need to provide evidence to our funders and potential funders that our work does make a difference...

#### YOU CAN HELP US

by providing stories, anecdotes, or examples (anonymously if you prefer)

Please email, write or telephone:

The Challenging Behaviour Foundation,

Freepost RRRH-GCJS-BRZJ

The Old Courthouse, New Road Avenue, Chatham, ME4 6BE

Tel. 01634 838739 Email: [info@thecbf.org.uk](mailto:info@thecbf.org.uk)

**THANK YOU FOR YOUR SUPPORT**

**Q:** We are having real problems with our son in the shower - I think the confined space scares him and he bangs on the glass. We also have a shower over the bath, but he pulls the curtain and the shower down. He will go in the bath but floods the bathroom each time, and if we try to stop him he bites us. Could we get a grant to have a wet room put in?

**A1:** We have had a Disabled Facilities Grant (DFG) for a wet room. The DFG also paid for other alterations that were to do with safety because of behavioural problems. My child has some physical disabilities but his main problems are behavioural and he needed a wet room for exactly the same reason. Can you test him in an

open shower, e.g. in a disabled changing room in a swimming pool or at school? If it is the feeling of the shower, not just the confined space that freaks him out, it could be a disaster if you take the bath out.

**A2:** I had a very similar problem to you - my daughter refused to get in the bath, so we had to lift her, and as she got older and heavier it became quite a problem. We went to our local joint agency team who arranged for our bath room to be converted into a wet room.

**A3:** You can apply to your Occupational Therapist or via your social worker or your Local Authority for a DFG - Disabled Facilities Grant. This is not means tested. There has to be a response within 18 weeks of request so do it now! You could go on [www.direct.gov.uk](http://www.direct.gov.uk) and type in Disabled Facilities Grant and if you check on [www.cafamily.org.uk](http://www.cafamily.org.uk) (Tel: 0808 808 3555) and download/request their fact sheet on 'Aids and Adaptations' all will be explained.

**Q:** We would like to develop guidance for use by primary health care staff when working with people with challenging behaviour to guide them to check health conditions. Does any one know if such a tool already exists?

**A1:** Have you seen "meeting the health needs of people with learning disabilities" (available through [www.rcn.org.uk](http://www.rcn.org.uk)). It covers physiological causes, psychological and environmental.

**A2:** The Disability Distress Assessment Tool (DisDAT) [www.disdat.co.uk](http://www.disdat.co.uk) is designed to help identify distress cues in people who because of cognitive impairment or physical illness have severely limited communication.

**A3:** "Common 'problem' behaviors and

speculation about their causes" might help. Information can be found at [www.dimagine.com/page66.html](http://www.dimagine.com/page66.html)

**A4:** We use a Healthcare Checklist which allows people to identify that they may display certain behaviors when experiencing a headache, toothache, when they're tired etc. Overall the tool may take some time to set up. Once it's up and running however, it makes life much easier.

**A5:** We adapt our health assessment tool according to individual service user's syndrome/condition, eg. Down's Syndrome being related to conditions like heart/neck /respiratory; in PWS a high pain threshold; oedema in Autism; Gastrointestinal symptoms in CdLS etc. Unless you understand the condition, you may not ask the right questions. I take the view of researching and developing assessment tools tailored to the known diagnosis rather than a general one size fits all.

## What parents say



*Christopher Telfer*

It was lovely to learn that the elderly are to get additional help with heating costs this year. However, many disabled people often have accompanying health difficulties and are also very vulnerable, yet this minority is being ignored.

For families who are in receipt of benefits, low wages, etc there is little help available and many of us cannot afford to use our heating for fear of exorbitant bills. Some families might receive a cold weather payment, but there are criteria to meet for this, i.e. you have to be in receipt of certain benefits, the weather has to fall below a specific temperature for a specific period of time, etc; and this means that many families typically have to meet the full cost of their winter fuel bill with no financial assistance.

We have contacted our gas provider to request to be placed on a social tariff, but although we are full-time carers for our disabled son and we receive Income Support and he receives DLA, we have been refused.

More awareness has to be raised of the plight of vulnerable, disabled people, particularly with heating costs soaring and during the extended cold weather.

• **Julie Telfer**, mother to Christopher

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



# Best interests decision making

The Mental Capacity Act (MCA) provides a legal basis for family members and paid carers who may need to take action in the best interests of adults who challenge services. David Thompson explains



The MCA (which applies in England and Wales only) sets out how decisions should be made for all people aged 16 and over who are unable to make specific decisions themselves. However, many families and paid carers are often unaware how the MCA applies to people who challenge services. It requires anyone supporting adults with learning disabilities (and other people who have cognitive impairments, e.g. dementia) to be clear whether they are providing the care or treatment because this is what the person wants OR because the person lacks capacity to make decisions with regard to the specific support and it is being provided in their best interests.

The MCA gives responsibility for deciding between the two to everyone who needs to provide the support, including family carers. It requires people to be given all possible support to make their own decisions. There needs to be a reasonable belief that the person lacks capacity to make a decision before action is taken in their best interests. This applies to the carer who insists that someone does not go out unaccompanied as much as to the psychiatrist who prescribes medication.

Controversially family members have no specific powers to make decisions for their adult relatives when they lack capacity to make decisions themselves. The MCA only gives them a right to be consulted in making best interests decisions together with other people closely involved with the person's care and support.

**Many families and paid carers are often unaware how the MCA applies to people who challenge services**

Further requirements of making best interests decisions include: involving the person as much as possible; considering all relevant circumstances and exploring whether the support can be provided in a less restrictive way.

The MCA supports the use of restraint where this is in a person's best interests. Provided people have followed the MCA when making decisions they are protected from liability (eg. a staff member using physical restraint might otherwise be committing assault). There are however limits on the degree of restraint or

**This applies to the carer who insists that someone does not go out unaccompanied as much as to the psychiatrist who prescribes medication.**

## Case study

Decisions need to be made about how to support John who has severe learning disabilities. Of concern is his repeated self injurious behaviour of hitting his head with his hand. John lives in a residential care home attending a day service two days a week. He regularly stays with his family.

John's social worker calls a meeting to discuss how best to support him. They invite his family, as well as key staff from both the day centre and residential care home. They also contact his GP who is unable to attend the meeting but instead sends in a report setting out their views. Consideration is given to including

restrictions that can be used in a person's best interests without the person accessing additional safeguards. This is where the restrictions might amount to a deprivation of liberty (under Article 5 of the European Convention of Human Rights). The MCA has been amended to make available the necessary safeguards for people in either hospitals or care homes. In other settings, authority to do should be sought from the Court of Protection.

The MCA Code of Practice recommends that for complex decisions best interests meetings are held.

### • David Thompson

*Practice Development Manager: IMCA Social Care Institute for Excellence*

*For further information:*

*The Mental Capacity Act 2005 Code of Practice. Cost £15 (free to family carers considering being a lasting power of attorney). Tel. 0870 600 5522*

*The Deprivation of Liberty Safeguards Code of Practice. £16.25. Tel. 0870 600 5522 for £16.25.*

*Visit [www.scie.org.uk/mca](http://www.scie.org.uk/mca) or [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk) for a range of resources including free training films ([www.scie.org.uk/socialcare/tv](http://www.scie.org.uk/socialcare/tv)).*

John in the meeting but this is dismissed as he doesn't like being in large groups.

It is agreed that John lacks capacity to make decisions in this area and so best interests decisions need to be made. It emerges that there are distinct patterns to when John self injures but also different people respond in different ways. Most notably the day centre staff gently hold his arm and involve him in a favoured activity whilst the residential care home will at times use a splint. It is agreed that there are less restrictive and effective ways of supporting John than using a splint. It is made clear in the minutes of the meeting that using a splint is not in his best interests and so must no longer be used.

# Family advocacy

It would be great if individuals with a disability had all the support they needed to challenge things themselves. The reality, however, is that it is the family who have to take on this role.



Parents in Partnership Northamptonshire have been providing a high quality advocacy service since 1992. As an independent charity, carers tell us that we are important to them, as we provide impartial support. Others go so far as to say we keep them sane! We help by taking some of the pressure off, and empowering family carers to make the right decisions for their family. We work throughout Northamptonshire, and believe that we may be unique as the only advocacy service solely for carers of people with a learning difficulty. We support carers both to get their voices heard and their rights, but also to ensure that the voice of the person they care for is not forgotten.

Measuring success is hard; what is important is making a positive difference to the life of both the carer and the person they care for. One recent example has been the case of a young woman with profound disabilities and behaviours that challenge services, who was placed out of County. An advocate visited the family and discussed the options and what they wanted to happen. They also agreed a plan of action. In this case the family were happy to take things forward themselves with the evidence we provided.

Armed with this information they were then able to argue with confidence against the placement, despite what all the professionals were saying.

• **Caroline Jewell,**  
*Advocate Manager*

*Parents in Partnership  
Northamptonshire  
(www.parentsinpartnership.org)*

# A guide for advocates

The Challenging Behaviour Foundation has developed a new resource for advocates who find themselves supporting individuals perceived as challenging.

Children and adults with learning disabilities and behaviour described as challenging are often a marginalised and significantly disadvantaged group of individuals. Independent advocacy is a very useful tool to empower and protect them. However, the complexity of providing advocacy for these individuals should not be underestimated

In the new guide, due to be released in May, key 'at a glance' bullet points identify 'what you may encounter' and 'what you should know', aimed at equipping advocates in England and Wales to effectively champion the rights and best interests of individuals with severe learning disabilities.

Through providing advocates with an understanding of why a person may behave in a certain way, and by creating an awareness of the impact behaviour can have on the support that someone receives, advocates will be better equipped to act on behalf of their advocacy partner.

The guide looks at issues such as the use of medication, physical intervention, barriers and seclusion, sectioning under the mental health act and alleged offending, offering

suggested 'questions to ask' for each situation.

Another chapter looks at the characteristics of good support for people perceived as challenging to services, with suggested questions for advocates to ask around personalisation, activities and opportunities, staff training and communication skills.

Contents include:

- Before you begin
- Start with the person
- Understanding challenging behaviour
- Supporting behaviour change
- What are the issues?
- Services and support
- A suggested approach
- Checklist
- Case Studies
- References and further information

Intended for advocates working in England and Wales, the 'guide for advocates' is also a useful resource for family carers acting on behalf of sons and daughters described as having challenging behaviour.

An extract from the forthcoming 'guide for advocates' can be viewed on pages 6 & 7.\*

The guide costs just £16 (free to family carers). To order a copy, please see below.

(\* Note: used as an illustration; final content may vary)

Supporting people with learning disabilities who are described as having Challenging behaviour

A guide for advocates



## HOW TO ORDER

### Advance orders now being taken

Advance orders will help us ensure we print enough copies of the guide for all those who want one.

To order your copy please complete a resource order form (back page)

and enclose a separate cheque for £16 marked on the reverse 'advocacy guide'. Cheques will be held until the resource is published in May.

The guide is free to family carers (although donations are always welcome if you are able to support us). Contact the CBF office by post, phone or email to order your copy.

Services and support

# Section 7: Services and Support

## 1. CHARACTERISTICS OF GOOD SUPPORT

- People who display challenging behaviour have the same needs as anyone else.
- They also have the same human and civil rights as anyone else, regardless of the challenges they present to those supporting them. (See the 'Challenging Behaviour Charter, Section 10)
- Research has consistently shown that people labeled as having severe learning disabilities and complex needs are more likely to receive poor quality services <sup>4,5</sup>
- Characteristics of good support include:
  - ✓ Personalised
  - ✓ Local
  - ✓ Providing a range of activities and opportunities, including education and employment
  - ✓ Emphasising the development of communication skills
  - ✓ Skilled staff

*"The vision for people with more complex needs is the same as for everyone: inclusion and participation in all areas of community life, including living independently and having paid work. To assume that some people cannot, and will never, achieve these is to set a ceiling on what progress can be made, both by an individual and by society."*

*Valuing People Now, 2009 <sup>5</sup>*

### • Key Point

**People with challenging behaviour have the same rights as everyone else but often experience exclusion both on a small scale (e.g. from going to particular places or joining in particular activities) and on a large scale (e.g. sent away to out of area placements).**

## 2. SKILLED STAFF

### What you may encounter

- The most common model of support in services for people with complex needs utilises unskilled staff, who are unlikely to facilitate personal growth and development. <sup>29</sup>
- The focus of most external training for staff supporting people with challenging behaviour seems to be towards more reactive interventions such as physical restraint. This may lead to staff losing sight of the more positive, proactive options essential to achieving person-centred support.

- High staff turnover a

### What you should know

- Staff changes and un... how safe a person fe
- Support staff require support (e.g. Person-communication, etc)
- Support staff need re support (i.e. understa behaviour change), a training around beha
- Staff need training to behaviour in order to and reduce their nee
- Rather than the react should be spent ens person are skilled at challenging behavio
- Mansell<sup>29</sup> has outline useful. These include
  - ✓ Positive Behaviour S
  - ✓ Person-centred Activ
  - ✓ Total Communication

1. Are staff trained to manage challenging beha
2. Is a positive beha used by staff sup
3. Are all staff train
4. Have staff been t restraint safely?
5. What proactive s
6. Could better beh staff are needed t

Services and support

and the use of agency staff are common.

and unpredictability are likely to have an impact on feelings and how they behave.

a range of training to deliver person-centred and person-centred Planning, active support,

recognised training in positive behaviour and managing challenging behaviour and supporting people as well as personalised person-specific support for behaviour.

to understand the reasons for challenging behaviour and to be able to support the person effectively and not to display challenging behaviour.

alternative approach of adding more staff, time and ensuring that the staff already working with the person have a good understanding and responding to the person in a positive and helpful way.

and some person-centred training that may be used:

support  
 Active Support  
 Person Centred Approaches

**Questions to ask**

How do you support people who display challenging behaviour?

How is the behaviour support approach understood and implemented in supporting the person?

How are you trained to use person-centred approaches?

How are you trained in how and when to use physical support?

What strategies are used by staff and why?

How do behaviour support strategies mean fewer incidents to support the person?

Services and support

For example....

**Skilled staff will:**

- Know how to communicate with the person
- Provide an activity schedule that is used by both the person and staff supporting them
- Make sure the person knows what the next activity will be, and who will be supporting him/her
- Provide a choice of activities within the schedule
- Support the person to do things
- Facilitate socialising time (eg visits or telephone calls with family & friends), making sure the person has access to the telephone, PC, camera, etc.
- Communicate well with other staff

**Skilled staff will not:**

- Leave the person with no activity or simply waiting for the next activity
- Make demands on the person that are too difficult
- Change the person's routine without warning or reason and without trying to explain
- Do things for the person without getting them to do as much as they can themselves to assist
- Talk about the person as if they are not there

**• Key Point**

**Supporting a person with severe learning disabilities and behaviour perceived as challenging is a skilled role and support staff must have appropriate adequate and ongoing training and supervision.**

**'Supporting people with learning disabilities who are described as having challenging behaviour – a guide for advocates' is due to be published May 2010.**  
 See page 5 for more information and how to order your copy.  
 Note: the extract here is used as an illustration; final content may vary



## Opportunities

Opportunities to support the work of the Challenging Behaviour Foundation (CBF) include:

- Attending events or conferences on behalf of the CBF
- Speaking on behalf of the CBF
- Training family carers ('co-presenter' role)
- Training professionals ('co-presenter' role)
- Offering emotional or practical support to other families
- Consultancy work (government/ local authorities)
- Fundraising
- Organising local fundraising events
- Speaking to local Rotary groups, etc
- Social media networking
- & more!

Training and support provided.

While we are primarily wanting to recruit and train family carer volunteers, we also have a limited number of opportunities for free lance professionals interested in working with the CBF in a consultancy or training capacity. If you have professional experience caring for individuals with learning disabilities who challenge services and relevant qualifications in behaviour analysis and positive behaviour support please get in touch to register your interest.

We would also be interested to hear from any professionals, friends or family members willing to help with fundraising for the CBF.

Please note, this is a long term project and by indicating your interest you can help us to plan how we take our work forwards. Places for training are limited and you may find yourself on a 'waiting list' – please be patient! By registering your interest you can help us to plan a training event in your area.

Thank you for your support.

## Please join us!

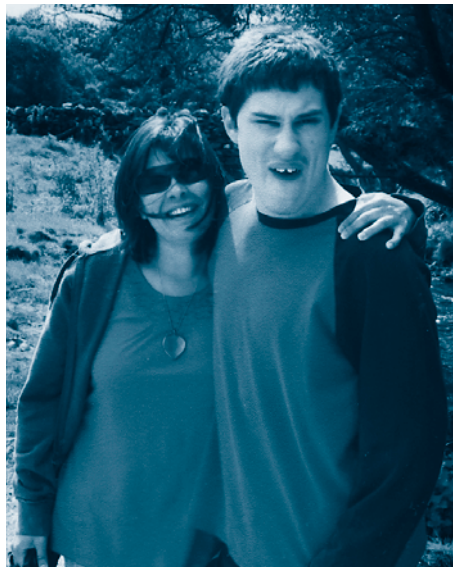
The CBF is currently looking for volunteers to help in a number of different roles. Training and expenses will be provided, and some paid work may also be available. Will you join us?

**Caring for Andrew**, now 24, has taught me that if he is well supported he does not need to show challenging behaviour - that's a message I am keen to help the CBF to spread! I have been working with the CBF to help develop and deliver training for both family carers and professionals. Please join us!

*CBF training is delivered by a professional trainer together with a family carer co-presenter. If you are interested in finding out how to become a trainer or co-presenter please get in touch to register your interest.*



Jan Seamer



Audrey Giles

**My son Dominic**, 21, is a fantastic young man but can be extremely challenging. I was so impressed and motivated by the work of the CBF that I wanted to become involved.

I am currently training with the CBF to become a co-presenter and hope to use my experience to help other families. Please join us!

*The CBF provides training and support to trainers and co-presenters, with opportunity to 'practice' delivering training modules in a friendly and supportive environment. Please get in touch to register your interest.*



Sooty Asquith

**My first contact** with the CBF was when we were looking for a residential school for William, now 21. I've enjoyed being part of the CBF email network, and have helped out when the CBF have needed volunteers to man stalls at various events, explaining what the CBF does and giving out CBF literature and information to visitors. Please join us!

*We frequently receive requests to attend a wide range of events up and down the country – all valuable opportunities to publicise the work of the CBF and to reach both families and professionals. The CBF will provide training and support as needed to volunteers wanting to help in this way. Please get in touch to register your interest.*

David & Jill Jack



**Our son James**, now 35, has suffered a series of injustices in the care he has received throughout his life. Now in our retirement years we want to work alongside the CBF to try to bring about change on behalf of individuals who are described as challenging. We have spoken about our experiences to a variety of professionals – the CBF has provided support for us to do this. Please join us!

*The CBF is looking for volunteers with a variety of experience, both good and bad, to help spread the message of what good support for individuals who challenge should look like. Please get in touch to register your interest.*

**My contact with** the CBF came through meeting Vivien and finding out about her son. Hearing how the CBF is supporting families I asked how I could help. Over the years I have helped organized a range of fundraising events – quiz nights, discos, treasure hunts, fashion shows..... It's been a lot of work, but it's been worth it – and the CBF team is always there to help. Please join us!



Lynn Walton

*The CBF is currently developing DVD clips that could be used by volunteers to give presentations about the CBF. If you would like to help fundraise for the CBF – whether through fundraising events or speaking about the CBF to potential supporters – please get in touch to register your interest.*



Jen Fookes

**Working with the CBF** has been very rewarding – from writing for the newsletter to giving input to the draft Autism Strategy. I recently gave the CBF Trustees ideas how they might better use the web (watch this space...!) and will shortly be going on a course so I can help support other families by telephone. Please join us!

*Whatever your skills, whatever your interests – whether writing or speaking, listening or blogging, campaigning nationally or working locally – please get in touch to register your interest.*

**Whether you are** a family carer or professional please consider how you could join us in improving lives for individuals described as having challenging behaviour.

*If you don't have the capacity yourself to get involved at this time perhaps you have friends or family who may be interested in supporting the CBF, or perhaps you would like to find out about training with us so that you are equipped to volunteer in the future. Please get in touch to register your interest.*

## Could this be you?



## Register your interest

Name \_\_\_\_\_

Address \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Email \_\_\_\_\_

Telephone \_\_\_\_\_

**I am a**

Family carer  
 Age of family member \_\_\_\_\_

Professional

**I am interested in**

Volunteer opportunities only  
 (expenses will be paid)

Paid opportunities only

Both

**I would like to register my interest in**

Attending events or conferences on behalf of the CBF

Speaking on behalf of the CBF

Training ('co-presenter' role)

Offering emotional or practical support to other families

Consultancy work

Fundraising

Organising local fundraising events

Speaking to local groups

Social media networking

Other \_\_\_\_\_

I'm not sure but would like to find out more

I could travel to London for a training event yes  no

Please organise a training event in my area yes  no

Thank you for your interest. This is a long term project and we will keep you informed of opportunities and training in your area.



## Think Family

'Support for All – the Families and Relationships Green Paper' sets out a wide range of measures to support families. The proposals recognise that while all families need some help, there are families in our society with complex needs and others who require additional support.

Plans to help families of disabled children include trialling ways to extend key worker support to families with a disabled child up to the age of 19 so they can get access to the care and services they need, and funding specialist relationship counselling services for families with disabled children

Some of the policy proposals can be implemented straight away; others are for consultation or will take longer to put into place. The closing date for input to the proposals is 21 April 2010.

For more information visit [www.dcsf.gov.uk/consultations](http://www.dcsf.gov.uk/consultations)

## Improving health and wellbeing

Recent reports and investigations have demonstrated the health inequalities faced by people with learning



disabilities - their higher levels of health needs and greater difficulty in accessing the healthcare services they need.

To assist in overcoming these inequalities, the Department of Health has produced a World Class Commissioning guide 'Improving the health and wellbeing of people with learning disabilities'. This is a practical guide to support commissioners to meet the needs of this group, and ensure they are fulfilling their duty to promote equality.

Copies of the guide can be ordered at [www.orderline.dh.gov.uk](http://www.orderline.dh.gov.uk) or telephone 0300 123 1002. Quote reference: WCCLD1109/ Improving the health and wellbeing of people with learning disabilities

## Supporting Me

"Supporting me – a guide for personal assistants employed by or for someone with challenging behaviour" is a new guide for PAs produced by Southdown Housing Association on behalf of Sussex Skills for Care. Produced in an easy-to-read format, the guide aims to help personal assistants employed through Direct Payments or Individual/Personal Budgets to better understand the needs of people who use services and assist



in providing a better care experience.

Visit [http://southeast.skillsforcare.org.uk/news/Supporting\\_Me\\_guides.aspx](http://southeast.skillsforcare.org.uk/news/Supporting_Me_guides.aspx)

## Still waiting

New research from Mencap has revealed that despite increased levels of government funding for short breaks, some families with severely disabled children are actually receiving a reduced level of service compared with 2008.

As part of Mencap's 'Breaking Point' campaign, 'Still waiting for a break' reveals that a £370 million package provided to local councils in 2008 – along with another £270 million

for primary care trusts – is failing to meet the needs of many families of children with profound and multiple learning disabilities (PMLD).

"Families of children with PMLD are still not a priority for local councils and primary care trusts," says Lesley Campbell, Mencap's national children's

officer. "Children with PMLD provide the litmus test for the new funding for short breaks. If it is not reaching the families with the most complex needs then this investment is failing to reach its target. The government funding that was designed to provide a 'step change' in short breaks is not having the positive impact that was envisaged for these families."

To find out more about the 'Breaking Point' campaign visit [www.mencap.org.uk](http://www.mencap.org.uk).

The Challenging Behaviour Foundation's own report "The Challenge: Getting a break" showed that many families caring for individuals with challenging behaviour are experiencing exclusion from short breaks services. The report highlights the need for consistent staffing of short breaks services, and training for staff in challenging behaviour, autism and communication.

Copies of the CBF report are available from [info@theCBF.org.uk](mailto:info@theCBF.org.uk) or telephone 01634 838739.

## SUPPORTERS' NEWS

### Donations 25% down

Thank you to all those who responded to the letter enclosed with the last issue of 'Challenge', particularly those who have set up standing orders to give monthly to the CBF. A special thank you to those who have chosen to give anonymously through 'Just Giving' ([www.justgiving.com](http://www.justgiving.com))

Unfortunately, even with the donations and pledges that arrived in December 2009, donations received last year were 25% down on the previous year.

The CBF does not have any regular guaranteed income and we will need

to see an increase in funding this year in order to continue our work supporting families across the UK.

If you could afford to support our work financially at this time your gift would be much appreciated. Please make cheques payable to the Challenging Behaviour Foundation or give by credit card on the CBF website.

To make a regular donation please ask us for a standing order form, or visit [www.justgiving.com/Challenging-Behaviour-Foundation](http://www.justgiving.com/Challenging-Behaviour-Foundation) to set up regular gifts electronically. Thank you – your support really will make a difference.

# 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**.

## Autism Strategy

Watch out for the new autism strategy from the Department of Health, due to be published as we go to print.

## Changes to direct payments

From 9 November 2009 new regulations will extend the Direct Payments scheme to people who lack the capacity to consent.

The Department of Health publication: 'A guide to receiving direct payments from your local council' has been updated with the new changes.

The guidance (ref 296235) and user guide (ref 296787) are available in hard copy from the Dept of Health order line (Tel. 0870 600 55 22) or can be downloaded from [www.dh.gov.uk](http://www.dh.gov.uk)

## 100 Club Winners

Recent winners of the Challenging Behaviour Foundation 100 Club winning £25 each were:

October 2009 – J Goodyear (Cannock)

November 2009 (£50 prize) - F Walker (Leicester)

December 2009 – Mr & Mrs Ingarfield (Maidstone)

January 2010 – K McMillan (Rainham)

All proceeds from the 100 club help towards the CBF running costs. Shares cost just £1 per month. 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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	Cost	Number	Total £
<b>CHALLENGING BEHAVIOUR DVD RESOURCES</b>			
<b>An Introduction to Challenging Behaviour: DVD</b>	£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>			
<b>Self-injurious Behaviour: DVD</b>	£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>			
<b>Communication and Challenging Behaviour: DVD</b>	£31.50*		
Four family carers and a speech and language therapist explain the relationship between communication and behaviour and highlight practical approaches to improve communication and minimize challenging behaviour. <i>40 minutes.</i>			
<b>Challenging Behaviour – Supporting Change: DVD</b>	£63.00*		
In this new 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>			
<b>CHALLENGING BEHAVIOUR INFORMATION SHEETS</b>			
<b>Basic information about challenging behaviour</b>	All information sheets are available free of charge on the CBF website.  To order by post please add £1.00 per sheet*		
<b>Communication and challenging behaviour</b>			
<b>Health and challenging behaviour</b>			
<b>Challenging behaviour – supporting change (functional assessment)</b>			
<b>The use of medication</b>			
<b>The use of physical interventions</b>			
<b>Specialist equipment and safety adaptations</b>			
<b>Parents' perspectives</b>			
<b>Planning for the future: introduction</b>			
<b>Further information for parents</b>			
<b>Booklist for professionals</b>			
<b>BASIC INFORMATION PACK</b>	£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:			
<b>Getting a statement</b>	£1.00*		
<b>Self-injurious behaviour</b>	£1.00*		
<b>Pica (eating inedible objects)</b>	£1.00*		
<b>Psychiatric disorders in people with learning disability</b>	£1.00*		
<b>Difficult sexual behaviour amongst men and boys with learning disabilities</b>	£1.00*		
<b>List of specialist 52-week schools and colleges</b>	£1.00*		
<b>SUB TOTAL CARRIED FORWARD</b>			

\*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 £
<b>OTHER RESOURCES</b>			
<b>A guide for advocates (England and Wales)</b> Due for release May 2010. Advance orders welcome. Please see page 5 for more information	£16.00*		
<b>Planning for the Future: Information pack</b> 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.			
<b>A New Pathway: DVD &amp; report</b>	£10.00*		
This 20 minute DVD provides an overview of a specialist transition service developed to bring four young people back to their local area from out of county residential schools. An accompanying 40-page report reviews how the service was developed.			
<b>DONATION – please consider a donation to support our work.</b> <b>Thank you</b>			
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 give your charity registration number:	
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Name	<input style="width: 95%;" type="text"/>
Organisation	<input style="width: 95%;" type="text"/>
Address	<input style="width: 95%;" type="text"/>
	<input style="width: 95%;" type="text"/>
	<input style="width: 95%;" type="text"/>
Postcode	<input style="width: 95%;" type="text"/>
Telephone	<input style="width: 95%;" type="text"/>

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

**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 parents 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** is a company limited by guarantee. Registered in England & Wales No 3307407. Registered as a charity No 1060714

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[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)