

# Challenge



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

Winter 2010

The newsletter of the Challenging Behaviour Foundation

## PAGE 2

### Comment

*Competent environments give confidence to people living and working within them...*

## PAGE 4

### Resources

*The CBF has developed a new information sheet on becoming a 'Deputy'...*

## PAGE 5

### Housing Matters

*The CBF has published two new housing guides "Planning your House" and "8 Ways to get a House"...*

## PAGE 8

### The Right Support

*The CBF course focused on issues that I could relate to....*

'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

## Right support, right place

Where you live and who you live with is important.

We all want to live where we feel comfortable, in an environment that we like, that ticks our boxes! This depends on individual preference and choice, as well as the actual design and features in our home.



Vivien Cooper

### Who we live with is fundamental

We know a great deal about key design features of good accommodation for people whose behaviour is challenging to services. Much is common sense – enough space, robustness, soundproofing, concealed pipework, shatterproof windows...A small low ceilinged cottage with frilly curtains, lots of ornaments and fluffy carpets simply won't do for my son – nor would a flat in a block as the fellow tenants would soon complain about the noise!

Who we live with is also fundamental. Many of us will have experienced sharing a house or flat with people who we thought we got on with – only to discover that living with them is not going to work! Would I like to live with other people I don't know? Would I like to live with other people whose behaviour is difficult and disruptive and may impact on me? Would I like to live with someone if it meant I could not do things I liked doing, or use my kitchen when I wanted to? And if I don't, why would my son?

**Would I like to live with someone if it meant I could not do things I liked doing**

My son needs extra support to meet his needs - 1:1 support, often 2:1. This is a skilled task, and requires individuals who are well trained and supported themselves.

Since my son was young I have been puzzled by the lack of useful training in positive behaviour support for families. It has been on the CBF "to do" list since it started in 1997, and at last we have been able to take this forward.

The CBF approach is to develop, pilot and deliver the training jointly with families. A family carer and a positive behaviour support trainer deliver it with a focus on practical information and support. Feedback has been really positive – from both families and professionals.

**The CBF approach is to develop, pilot and deliver the training jointly with families**

These two essential components - the right support, in the right place are featured in this issue. The complexity of each should not be under-estimated and we are working hard to provide information that is straightforward and practical. The challenge is to make this information widely available – and then to deliver at the right time.

#### • Vivien Cooper

Chair of Trustees and Founder of the Challenging Behaviour Foundation

# Competent Environments

Competent environments give confidence to people living and working within them.

They can help us all feel safe. They help us feel heard. They are places where we can all contribute. Where actions, not words, count. Where behaviour measurement means measuring smiles, rapport, involvement and choice, learning. It doesn't just measure problem behaviour. (It may be self-determination, not challenging behaviour; it's probably exotic communication.)

So we're not talking Greenpeace with NVQs. Not competent ecologists. We're talking about what we want for people in terms of places and people therein to listen and support the people we love.

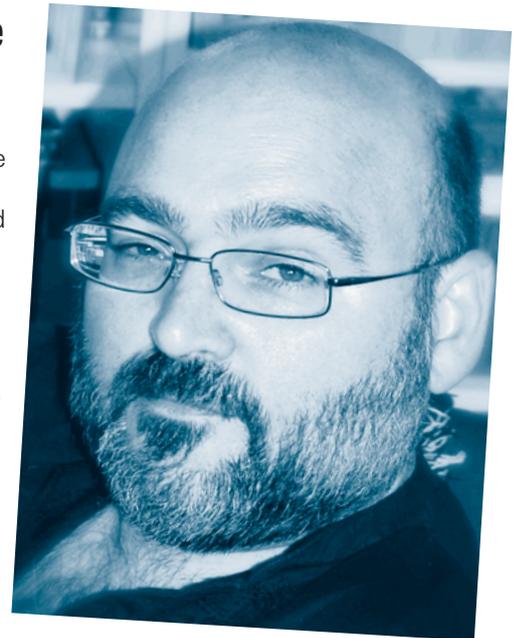
There are some general principles I've been pondering. First issue is design. Seems to me we've choice right there. We can build them according to archaeology (what has gone before), based on evidence (red is a colour, drums make a sound and other research topics), or based on a shared understanding of what the person needs to get them through the day and into the future. Here's a hint: the lowest bidder is not always the best

and the past was not always rosy. One size fits no-one, and if we're looking over our shoulder to see what they did in Virginia thirty years ago we'll stumble over the future.

I think Valuing People suggested we start by finding out what the person prefers and building our environments around that vision. Now for services supporting families, that means we don't assume we know what's best: we turn up, we shut up, we listen to the family.

A competent environment is explicit in its values. It recruits to its values, it monitors staff and organisational performance in relation to its values, and it changes in response to humans inside and outside. Values aren't just statements about wishes and aspirations, but about actions. We Promise To... So, if you see an environment that says they've adopted positive behaviour support yet blame the person for their behaviour, then words don't match the rhetoric. End of story.

The key competency in environments is the ability to learn from the



successes and problems they are part of, how to remember these lessons, how to communicate them to everybody, and how to change. As a manager, you want to empower kids or adults with severe disabilities? Empower your partners in the work: support staff.

***If only they measured what was important to the people using services***

The problem is very simple and endemic: we don't give enough money to people who need it, we give too much money to beds, voids, placements, programmes and professionals. If only those designing and commissioning services and environments were more competent, we might see competent environments. If only they measured what was important to the people using services, we might see real benefits. Damn heuristics without reflection! We all deserve competent environments because we all qualify as human, as having potential, as having the ability to learn. Regardless, you don't have to defend having an expectation for competent environments; let others defend incompetence.

• **Tony Osgood**

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

## HOW YOU CAN HELP

### 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 is a registered charity, relying on donations, grants and fundraising to finance our work. We have no regular guaranteed income.

If you would like to support the work of the Challenging Behaviour Foundation

#### PLEASE SEND A DONATION TODAY.

Cheques should be made payable to 'The Challenging Behaviour Foundation', or donate online at [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk).

Please contact [info@thechbf.org.uk](mailto:info@thechbf.org.uk) or telephone 01634 838739 to request a standing order form.

**THANK YOU FOR YOUR SUPPORT**

**Q: My 15 year old son is severely autistic. He wants the same song played again and again. The more he plays the song, the more his anxiety goes up. Any ideas?**

**A1:** Look at sensory integration information on the internet to understand why he does this and other autistic behaviours. The repeating is enjoyable and may help to block out things that annoy him.

**A2:** Perhaps buy a CD/DVD player which allows you to play a section A to B and repeat it automatically. That's what my son does and sets it on his own now. I don't even need to be in the room.

**A3:** My son, who is also 15 and has some autistic traits, is also doing the same repetitive playing of CDs and DVDs. He is able to rewind the DVDs himself, and would some time do it for a very long time. He finds certain sounds very funny so he wants to hear them again and again.

**Q: I am working with a mother who is awaiting chemotherapy. Her daughter is terrified of any mention of cancer/illness/death. Any advice whilst Mum is going through the cancer treatment?**

**A1:** There are several excellent books and other resources (such as the Books Beyond Words series) designed to help support adults with learning disabilities in difficult situations like this. I suggest contacting the local Community Team for Adults with Learning Disabilities to make a referral to a Clinical Psychologist.

**A2:** Suggest to mum that she finds some scarves/hats that she feels comfortable wearing. Get her to try

**A4:** I have autistic twins, both have special favourite things that are always wanted for a time then each will move on to something else that becomes the particular favourite. I try to bring in variety by introducing new CD/DVD's by leaving them out to gradually introduce them. If/when my kids become interested in them I phase out the CD/DVD which causes the behaviour that stresses them.

**A5:** You could restrict the time spent on the music that does make him so anxious and tell him in the communication you have with him that you have 5 minutes of this music (use of clock and showing where 5 minutes ends would help, depending on the abilities of your son) and then you are going to turn it off and do another activity.

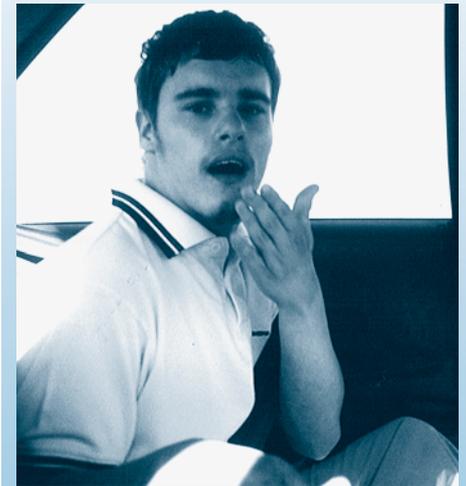
**A6:** Do not use expensive DVD players, buy the inexpensive unbranded ones, that way breaking and replacing them is not going to hit the pocket so hard. Maybe one way to encourage different DVD's would be to remove the DVD covers and replace them with something that will catch your sons eye, like shiny silver wrapping paper or stick on pictures.

them out now so that her daughter is accustomed to them. Ask for an emergency care plan and ask social services and the hospital to liaise.

**A3:** Does the hospital have a learning disability liaison nurse who may be able to help or contact the community team for visual support, and clear guidance? Maybe the cancer services at the hospital may have easy read information about positive outcomes that may help her daughter.

**A4:** My staff supported a lady with autism and complex needs who used to go home every weekend, but when the mother was ill there were real problems for staff being unable to 'manage'. We used social stories to explain to the daughter what was happening to her mum, when she would see her mum again etc. It was difficult for everyone but it got easier, with good communication between the daughter and staff.

## What parents say



Christopher

If there is one thing that sticks out in my mind about my son Christopher, who has autism and severe learning disabilities, it has to be shopping. It would start with getting dressed - then kicking, screaming, biting and pulling my hair. Whilst out people would stare and make rude comments about his behaviour, my son would be screaming, grabbing anything or anyone in arms reach and trying to bite them.

We had been thrown out of several well known high street shops because other customers complained even though I explained he was disabled. I can't tell you the amount of times I was reduced to tears.

Walking home I saw a shop that did t-shirt printing, I had three t-shirts printed up one said on the front I HAVE AUTISM and on the back it said WHAT IS YOUR PROBLEM?, the second t-shirt said I HAVE AUTISM and on the back it said IF YOU DON'T KNOW ASK the third said I HAVE A DISABILITY and on the back it said ITS CALLED AUTISM.

These t-shirts actually worked, people would still look but see the slogans smile and turn away. Some people did ask what Autism was and I explained as well as I could at the time. I got toughened to the outside world and would not allow other people to faze me anymore. It was bad enough coping on my own with Christopher let alone fighting the rest of the world. I don't think I would have got through without those t-shirts.

• **Donna, 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)**

## Paula's story



William

When our son William was diagnosed with Tuberous sclerosis we decided that stairs and complex epilepsy were not a good combination, so we moved to a bungalow. We could only afford one that had two bedrooms, it was in a real state, but it had potential.

When William was six his sister Jessica was born. Jessica's cot was put in our bedroom but William's sleep problems and challenging behaviour became a major issue. All four of us regularly had broken sleep. We decided that the only way forward was to move William in with us and give Jessica her own room.

Eventually, as William was sharing with us, we were reassessed for the Disabled Facilities Grant. The powers that be looked into whether the children could share (our comment being not if you want Jessica to sleep or live!)

After much arguing and a huge amount of stress we eventually reached a plan but at £60000 it was £30000 in excess of the grant. We set about raising £30000, no mean feat but we did it over two years. William now has his own bedroom and ensuite bathroom.

The new room hasn't been a magic wand, but it gives William his own space and the rest of us space too. We now have a sofa bed in his room - I sleep on it most nights as otherwise he would scream the place down, but its progress.

• **Paula Davis**, mother to William aged 11

# New information sheet

The Challenging Behaviour Foundation has published a new information sheet "Getting legal authority to make decisions about money, property and welfare."

If you have a relative with severe learning disabilities they may not be able to make all of their own decisions e.g. choosing where to live. In some circumstances you may need to get legal authority to make decisions on behalf of your family member by applying to the Court of Protection to be appointed as a 'deputy'. One example is applying to be a deputy to get legal authority to sign a tenancy agreement on behalf of your relative so they can rent their own property.

Our new information sheet has been written for family carers who wish to gain legal authority to make decisions about money, property and/or welfare on behalf of a family member who has severe learning disabilities. It provides a practical step by step guide to the application process.

Are you a family carer?   
 Do you support a family member aged 16 years or above?   
 Does your family member have severe learning disabilities?   
 Do they live in England or Wales?

If the answer is yes to all these questions, then visit [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) and download this information sheet free of charge or turn to page 11 to order a hard copy.

**INFORMATION SHEET**  
**Getting legal authority to make decisions about money, property & welfare**

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

This information sheet has been written for family carers who wish to gain legal authority to make decisions about money, property and/or welfare on behalf of a family member who has severe learning disabilities.

Are you a family carer?   
 Do you support a family member aged 16 years or above?   
 Does your family member have severe learning disabilities?   
 Do they live in England or Wales?

If the answer is yes to all these questions, then this information sheet is for you.

If you have a family member with severe learning disabilities they may not be able to make all of their own decisions e.g. choosing a house or deciding whether or not to have a major operation etc.

In order to get legal authority to make specific decisions on behalf of your family member you may need to apply to the Court of Protection to be appointed as a 'deputy'.

**What is a deputy?**

"Deputies" were introduced in England & Wales in 2007 when a new law called the Mental Capacity Act was introduced.

A deputy is someone (usually a family member) appointed by the Court of Protection with ongoing legal authority to make decisions on behalf of a person who lacks capacity to make particular decisions for themselves.

There are two types of deputy:  
 1. Property & affairs  
 2. Personal welfare

- What is meant by the term "mental capacity"?
- What is the Mental Capacity Act 2005?
- What is the Court of Protection?

To find the answers to these questions please refer to:  
 • Making decisions. A guide for family, friends and other unpaid carers (reference number OPG602). Office of the Public Guardian: [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk) Tel: 0300 456 4600 (free publication)

Making decisions - An introduction to the Mental Capacity Act. National Family Carer Network. [www.familycarers.org.uk](http://www.familycarers.org.uk) Tel: 01883 722 311 (free publication).

© The Challenging Behaviour Foundation. Registered charity no. 1080714. [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)  
 Registered office: The Old Courthouse, New Road Avenue, Chatham, ME4 6BE. Tel. 01634 828739

### EXTRACT FROM OUR NEW INFORMATION SHEET

## He needs me to do this

When my son Seth was seventeen years old, I became his deputy for financial affairs. I did this because although I accepted Direct Payments for my son's care when he was sixteen; there had been rumblings from the Local Authority that it would finish when he became eighteen - because he lacked the capacity to consent.

At the time I didn't know that becoming a deputy was a very new thing, and that I had applied in the first year it became a law in England and Wales. This did mean that the Local Authority were unsure of the process, and needed time to educate themselves as to its legality. I was just looking for the best way to support my son, and protect his interests and rights to appropriate care and support at home. ....he needs me to do this.

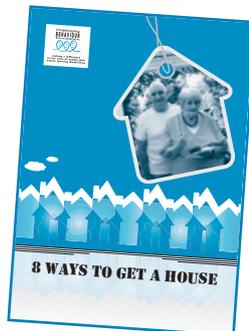
It had taken years to negotiate a higher rate of pay than was normal for Personal Assistants on Direct Payments. I did not want to go back to Agency Staff. Direct Payments were working well for us and I wanted it to continue, so that I had more input into the choosing and training of the personal assistants who came into our home and lives. With Direct Payments they get the appropriate training to work with Seth's complex needs. I have found becoming a deputy invaluable in meetings with both Social Care and Health professionals.

• **Sol Jorgensen**, mother to Seth, Wales

# Two new resources from the CBF



The Challenging Behaviour Foundation has published two new housing guides "**Planning yourHouse**" and "**8 Ways to get a House**".



"Planning your house" aims to help you and your relative with thinking about living arrangements (who to live with or whether to live alone), where to live, the type of house to

live in, the design of the accommodation, what help and support is needed to live there and how to work in partnership with others.

"Eight ways to get a House" covers the different types of accommodation and how they are funded. The following are proposed as 8 ways to get a house.

- Registered care homes
- Rented social housing
- Rented private sector housing
- Social housing from capital programme
- Home ownership & the use of discretionary trusts
- Shared ownership
- Buy to let
- Remaining in the family home & other family solutions

**England only.** Due to anticipated changes in funding, these two resources will initially only be available to view on online: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk). Family carers who do not have internet access should contact the CBF for a hard copy

## Extract from "Planning your House"



*Craig's Shower*

**Security and risk management** should be part of the thinking in design: concerns about safety, use of equipment and fittings, occasional damage but taking care to retain the 'ordinary home' idea.

### Case study: Craig's Bathroom (walk in wet room)

Craig is 20 and has severe learning disabilities and autism. In the past Craig displayed destructive behaviour; breaking furniture, pulling down curtains /shower rails and smashing mirrors. The following are details of the adaptations made to Craig's bathroom to meet his needs:

- Motion sensitive lighting
- Unbreakable steel mirror
- Fully enclosed pipe work
- Magnetically held towel rail
- Magnetically held shower curtain
- Wall mounted shower, fully enclosed

For further details & photos of a refitted house please contact The Challenging Behaviour Foundation

## Housing Choice and Control



*Karyn*

Choice and Control over where you live and who you live with is a fundamental part of life for most adults. People with learning disabilities rarely get that

choice, with more than half living with their families, 30% living in residential care, and only 15% having the status of tenant or home owner.

Valuing People Now recognises the importance of having a home of your own and housing is one the three priorities for 2010-11.

We have worked to increase the range of housing options by;

- Providing resources and information for people with learning disabilities, families, carers and professionals (see [www.valuingpeoplenow.dh.gov.uk](http://www.valuingpeoplenow.dh.gov.uk), and [www.housingoptions.org.uk](http://www.housingoptions.org.uk))
- Developing a toolkit for local authorities to help them analyse, resource and implement housing programmes increasing the range of housing options
- Representing the interests of people with learning disabilities across government departments and agencies
- Highlighting the particular housing difficulties faced by people with complex and/or challenging behaviour in Raising our Sights by Jim Mansell.

The recent changes to housing benefit, support for mortgage interest, ILF (Independent Living Fund), and the changing landscape around housing planning and development have created some uncertainty about the future. However Valuing People Now is clear that every local authority should offer a wide range of housing options and people should have control over where they live and who they live with.

• **Karyn Kirkpatrick**  
*Valuing People Now*  
*National Housing Lead*

Rhys rents from a private landlord, Sheila lives with her brother who plans to leave the family home to her, Andrew owns his own home. These are just some of the housing options for individuals with severe learning disabilities and are included in the new Challenging Behaviour Foundation Guide “[Eight Ways to Get a House](#)”. To order a copy turn to page 12.

## Rhys' first home



*Rhys outside his home with a support worker*

When my son's care home announced that it needed to close giving us and our local authority only two months to find an alternative for a young man with Autism and challenging behaviour we were worried about how this could be done in such a short period of time without causing him emotional distress.

We decided that it would be better for him not to go into a new residential care home but to try a “Supported Living” package, which meant that we had to find a house for him to rent which was separate from the provider who now comes in as domiciliary care.

***Having his own home has meant that the care staff are aware that it is his home and not a residential setting where he has to fit in.***

Fortunately we found a small house in the middle of a quiet village, near to us, that was available to rent from a private landlord. We then asked our local authority to grant him “Housing Allowance” to cover the cost of his rent. Having his own home has meant that the care staff are aware that it is his home and not a residential setting where he has to fit in. He has settled in very well and now enjoys going shopping for groceries to fill his kitchen cupboards and fridge!

• **Jackie Edwards** (*Rhys's Mum*)

## Living close to family



*Andrew outside his house*

Andrew's house is a 'shared ownership' i.e. he has invested a small amount of money and has a landlord who has invested the remainder of the cost. The landlord, Mencap's housing branch Golden Lane, charges rent, which includes a component for maintenance. Housing Benefit pays the rent.

It was a complicated process led by Andrew's person centred plan which identified it

was essential that he lived where he grew up, where his family lives and where he is known. He had been excluded from local education aged 14 and at 18 excluded again this time from residential special school. It was likely that this pattern would continue into adulthood and I was keen to reduce the chances of that happening. To be able to live in his own home, with staff selected for their personalities and energy, doing each day what would make sense seemed a good plan.

His name had to be on the council's housing list and I had to get confirmation that they could not provide suitable accommodation.

As he needs someone to sleep-in at night, he needed a 2-bedroomed property. We searched in vain for a house with 2 bedrooms. There are limited 2-bedroomed properties in the area. New build was unsuitable, just too fragile! Others had no front garden, out of the front door and straight onto the road, too dangerous. It was finally agreed that we could have a 3-bedroomed house which, in fact, was no more expensive than a 2-bedroomed house.

Eventually we found a nice semi with a garage, in a cul de sac, with enough car parking space to reduce impact and annoyance on neighbours. Andrew moved in just before Christmas 2005. He introduced himself to his neighbours via some handmade Christmas cards and was delighted to receive a card from everyone in the cul-de-sac in return.

• **Jan Seamer** (*Family Carer*)





Don &amp; Sheila



## Planning ahead

My sister Sheila is an adult with severe learning difficulties, she lived with our mum and dad all her life. We both live in the family home. After our parents passed away, I set up a Trust in her name and appointed four Trustees.

The Trust employs eight personal assistants (PA's) on a seven day a week, twenty four hour a day basis. A PA appointed from the team makes sure the monthly spread sheets containing hours worked by the team, are sent to the accountant. The accountant does all the necessary deductions and forwards the wages straight into the PA's bank account, and then I am sent a copy of the wages paid in. We have also appointed a team co-ordinator to arrange holidays and training.

My sister has Independent Living Fund (ILF) and Direct Payments paid into the Trusts bank account. This is for the sole purpose of paying her Personal Assistants (PA's). I did not want to manage the money side of the wages, paying tax or National Insurance contributions.

### ***We have very independent lives but I can always be there if needed***

I live in the middle of this support as this is where I can advise when PA's need any personal information about my sister. I understand this will not be for every one but for me this is a perfect way of having a sister and just being her brother. We have very independent lives but I can always be there if needed.

I have also made plans to ensure Sheila's independence if she outlives me. I have a will that states that my trustees will activate my Discretionary Trust. My house will be placed into this fund along with any assets I may have e.g. money, valuables etc. with a clear statement that my sister can live in this house, for the duration of her life. As I would not be living in the house anymore, my trustees will be able to apply for Housing Benefit, this will then be paid into the Discretionary Trust. This money can help pay for any personal item like house insurance, repairs, food etc.

I have also made it clear that my part of the house can now be let to another person with learning disabilities, this could also generate more funds that can be paid into my Discretionary Trust. This additional money can also go towards supporting the house and will be managed by the trustees, who I have asked to manage my Discretionary Trust.

• **Don Jones** *Brother*



## Thank you CBF!



Kate Farmer and her daughter

When I attended the Challenging Behaviour Foundation (CBF) course, organised at my daughter's school, I was expecting yet another "pep talk" on strategies and trigger identification followed by an "off you go and practice- Easy!", which invariably left me feeling as lost as I had been before attending.

The CBF course focused on issues that I could relate to, extreme behaviours that I was dealing with on a daily basis and it provided clear information on what is available out there for support and where to find it, as well as how to go about getting the necessary support put in place.

They provided a comprehensive guide to what my daughter might be going through and how she might be feeling during her outbursts which I found very reassuring and made me feel that things were not that 'abnormal' in our lives; that there is a way to create a fulfilling relationship with my teenage daughter.

The course was led and moderated by people who had first-hand experience in bringing up children with challenging behaviour. I felt understood and encouraged. Hearing other parents express their concerns and difficulties was inspiring and helped me realise that I was not alone.

I believe the realistic and hands-on approach offered by the CBF is exactly what we need right now to increase awareness of challenging behaviour and bring about the changes urgently needed in most areas of society to enable our wonderful children to be heard, understood, supported and respected.

• **Kate Farmer**, Family Carer

# CBF Workshops for Families & Professionals

The Challenging Behaviour Foundation (CBF) has received frequent requests for training from both families and professionals caring for individuals whose behaviour is described as challenging.

In 2006 we surveyed families across the UK on their experiences of training. The majority of respondents commented that the training they had received had not met their needs and over half had received no training at all.

Based on this feedback the Challenging Behaviour Foundation, working in partnership with family carers and a professional trainer, developed a training programme for family carers (parents, sibling, other relatives) and professionals (school staff, short break workers, residential care staff, day care staff etc.).

The training aims to equip these carers to successfully support individuals with severe learning disabilities and behaviour described as challenging. The content is also appropriate for those who are supporting individuals with a diagnosis of autism and severe learning disabilities.

## What is different about CBF training?

Each workshop has been developed in partnership with family carers and is delivered by 2 trainers:

- A Positive Behaviour Support trainer
- A family carer co-presenter

A professional trainer explains positive behaviour support and a family co-presenter gives real life examples, with opportunities for discussion and group work.

*"Throughout the training I use personal examples of real life experiences to demonstrate how having a child that challenges affects family life and share how I've worked out what works and what doesn't. Professionals and especially school staff have said that they valued and benefited from the training being delivered with a family carer as well as the professional trainer."*

- **Jan Seamer**, CBF family carer co-presenter

This approach helps to explain how the theory can translate into practice for family carers and direct support staff.

*"Theory and practical balance was excellent"* – Teacher

It **facilitates partnership working between family carers and staff**. The training is most effective when delivered to all the staff and carers who support the child or adult with severe learning disabilities.

Family carers and professionals attend separate workshops on the first day of the training (the 'Understanding Challenging Behaviour' workshop). After the completion of the first workshop, one month later, the family carers and professionals are invited to attend the second workshop together to produce a behaviour support plan by working in partnership. The workshops are based on positive behaviour support.

*"Excellent – particularly listening to parents' points of view- it is so easy to forget about a child's home life"* – Teaching assistant

## Evaluation

These workshops have been extensively piloted and evaluated across the UK over the past two years. Excellent feedback has been received from both family carers and professionals. 96% of family carers would recommend the training to other carers.

*"Brilliant workshop! I have learnt so much"* – parent

*"I found I was not alone"* – parent

*"What's had the greatest impact is working as a team. We all know that we are all doing the same thing and consistency has had a huge impact"*.- parent

Following the success of the pilots, we are currently undertaking formal evaluation of our training in partnership with the University of Kent Tizard Centre (the results will be available in March 2011).

So far this year (January – September 2010) over 250 families and professionals have taken part in the CBF training in 39 workshops held in Kent, Birmingham, Bristol, London, North of Tyne and Dundee. Some workshops were organised with support from Local Authorities whilst others were organised by a service provider or carers group.

*"What I liked best about the workshop is working alongside parents, having the time to reflect on challenging behaviour, to step back from a situation and reflect upon it, and then plan together."* – Speech & Language Therapist



**Three workshops are available:**

- **Understanding Challenging Behaviour**
- **Supporting Behaviour Change and Working in Partnership**
- **Communication and Challenging Behaviour**

Each workshop last approximately 4 hours, with a maximum of 30 participants. Our workshops are suitable for family carers, professionals or both together.

**Expected learning outcomes include the ability to:**

- **Understand the reasons for challenging behaviour**
- **Identify strategies to reduce challenging behaviour**
- **Access ongoing support**
- **Develop practical communication strategies**
- **Improve partnership working between families and professionals**

**For more information about the training contact:  
The Challenging Behaviour Foundation  
Tel. 01634 838739  
Email: [info@theCBF.org.uk](mailto:info@theCBF.org.uk)  
[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)**

## Working in partnership

The workshops provided the perfect platform to bring the school and parents together and be able to focus on one thing - behaviour. The workshop allowed everyone involved a voice to share experiences and suggest strategies that have been tried and tested - with varying levels of success!

The second workshop brought all these ideas together and got Teaching Assistant's and parents working together to try and find out why the problem behaviour was occurring and then as a whole group look at ways of changing the behaviour to a more positive alternative.

At the end of the workshop there was a really positive atmosphere of parents and school working together - it's now up to us to keep these positive links together for the benefit of the children.

• **Russell Ames,**  
*Behaviour & Learning Leader,*  
*Foxwood School*

The Challenging Behaviour Foundation (CBF) recognised that family carers and parents get very little in the way of training and education about how to understand challenging behaviours and how to support behavioural change.

The CBF has started to train parents and carers in understanding behaviours that challenge and supporting behavioural change, as well as training for carers and family members alongside the professionals that work with their son/daughter. Most importantly they have done this with a professional trainer alongside a family carer co-trainer.

The family carer co-trainer brings their own experience, skills and knowledge to the training. In addition the professionals who attend the training are able to see the importance of partnership working and the value of working with family members.

• **Andy Fenwick,**  
*Freelance CBF Trainer*

## Sleep Practitioner Training

Sleep problems are a common and major source of stress for disabled children and their families. The Handsel Trust provide 2 day workshops to equip professionals with the skills to assess sleep problems and design effective sleep interventions in partnership with families. The training has a special focus on the complexity of working with disabled children. For further details contact [joanne@handseltrust.org](mailto:joanne@handseltrust.org)

## Equality Act

Part of the Equality Act came into force in October 2020. To see how this could effect you visit: [www.equalities.gov.uk/equality\\_bill.aspx](http://www.equalities.gov.uk/equality_bill.aspx)

## Health inequalities

Improving Health and Lives Learning Disabilities Observatory aims to provide better, easier to understand information on the health and wellbeing

of people with learning disabilities. Recent reports include:

- Health inequalities & people with learning disabilities in the UK 2010
- Health checks for people with learning disabilities: A systemic review of evidence



Both can be downloaded from the Learning Disabilities Observatory website: [www.ihal.org.uk](http://www.ihal.org.uk)

## SUPPORTERS' NEWS

## Fundraising for CBF

Since the last newsletter staff and volunteers from the Challenging Behaviour Foundation have been busy fundraising. A group of walkers completed the North Downs Walk and raised £100, and our last quiz night raised £480. Helen, our Team Administrator, ran the British 10k and raised £150, completing the event despite falling and fracturing her collar bone. Finally, the CBF had a charity stall at the "Salute to the 40's" event held in Chatham Dockyard. CBF staff and volunteers led by Wing Commander Cooper (Vivien) all dressed up for the occasion and raised over £200. Well done and thank you to all our fundraisers.

Whilst we cannot mention all our donors by name we would like to say a big thank you this time to **Bob & June Corner** who recently celebrated their 80th Birthdays with a joint party and raised £500 for the CBF in lieu of gifts.

With no guaranteed income the CBF needs volunteers to help raise funds and continue our work.

If you would like to fundraise for the CBF or have any good fundraising ideas then please get in touch, we would love to hear from you.

*CBF staff and volunteers at the 'Salute to the 40's' event*



## Not sure what to do for your holiday next year?



Another way to raise funds for the CBF is to take on a challenge, whether it is walking/trekking, cycling, survival or sailing.

Discover Adventure [www.discoveradventure.com](http://www.discoveradventure.com) have a fantastic selection of Open Challenges in the UK, Europe and further afield. The trips are self funding - you pay for the trip and then choose to

raise however much you can for the CBF. There are a range of trips on offer including:

Hadrians Wall Weekend - UK

Paris - Geneva Cycle - Europe

Mount Kilimanjaro Trek - Nepal

Take a look at the brochure on their website, choose your destination, start training and fundraising for the CBF.

# 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**.

## Need a grant?

The Boparan Charitable Trust aims to help children, up to the age of 18, across England & Wales who are disadvantaged through poverty, disability and terminal illness. Parents (or legal guardians) can apply for a grant for specialist equipment. To find out more visit: [www.theboparancharitabletrust.com](http://www.theboparancharitabletrust.com) or Tel: 0845 0786634

## 100 Club Winners

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

July 2010: Frances Walker, (Leicester)

August 2010: Pat Croft, (Rainham, Kent)

September 2010: Audrey Day, (Gillingham, Kent)

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.

## Join now for 2011

For Christmas, why not buy shares for a gift that really makes a difference. For £1 extra we can send the gift in a seasonal card with your message. Please contact us for more details.

## 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.

© The Challenging Behaviour Foundation. All rights reserved.

	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 & 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 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>Getting legal authority to make decisions about money, property &amp; welfare</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>SUPPORT OPTIONS</b>			
<b>Planning your House</b>	Web Only**		
Provides family carers with practical help with planning for future housing needs.			
<b>8 Ways to get a house</b>	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 <a href="http://www.challengingbehaviour.org.uk">www.challengingbehaviour.org.uk</a> . Family carers who would like a printed copy should contact the CBF. Final copies will be available by the end of the year.			
<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>OTHER RESOURCES</b>			
<b>A guide for advocates (England and Wales)</b>	£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.			
<b>DONATION – please consider a donation to support our work.</b>			
<b>Thank you</b>			
<b>TOTAL</b>			

\* 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

**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](mailto:info@theCBF.org.uk)

Tel. 01634 838739

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