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Challenge

Challenging
BEHAVIOUR
foundation



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

Spring 2007

The newsletter of The Challenging Behaviour Foundation

CBF
10th Anniversary
2007

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*The workload still increasing,
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two much needed new posts...*

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Find the Families

*One mother from Scotland told
us: 'I have been searching for
information for seven years.'
How many more families need
to know about the CBF?*

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Preparing for adulthood

*It's never too soon to start
thinking about future options
for your son or daughter,
particularly if they have severe
learning disabilities and
challenging behaviour...*

'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

How it all began...

Vivien Cooper, parent carer, founded the Challenging Behaviour Foundation ten years ago. Here is her story...

In August 1985, when our son Daniel was diagnosed with Cri du Chat Syndrome, the only information we were given was a single sheet of paper. This wasn't much help when Daniel was pulling the curtains down, ripping his mattress open and eating the stuffing, or banging his head against the wall.

Like many parents of children with severe learning disabilities, we struggled for years without adequate support. The local special school couldn't control Daniel's behaviour either. Initially, to try to contain him, they strapped him to a chair and sandbagged it to the floor. By the time Daniel was nine the school said they were unable to meet his needs. At home, family life was disintegrating.

Eventually a place was found at a residential school that specialised in helping children like Daniel. Within months of starting at his new school,

'The CBF is working hard to champion the cause of people with learning disabilities who have complex needs. Congratulations to the CBF for its passionate commitment to improve lives.'

Rob Greig
National Director: Learning Disabilities

'Knowing something of the challenges faced by families caring for a loved one with severe learning disabilities, I can recommend the resources and support provided by the Challenging Behaviour Foundation. The CBF is doing a fantastic job and I wish them every success for the next 10 years.'

Jo Whiley, BBC Radio One

Daniel was sitting in a chair on his own and making eye contact. Instead of pushing the table over when he'd had enough food, he now made a sign for 'finish'. With specialist help, children like Daniel can learn ways to communicate that mean they don't need to resort to challenging behaviour.

Frustrated that this specialist understanding had not reached us sooner when we had needed it, I set up the Challenging Behaviour Foundation in order to provide information and support to other families caring for children with severe learning disabilities. My motivation was my son and his future, and all other parents and carers in the same situation.

• **Vivien Cooper**

Chair of Trustees and Founder of the Challenging Behaviour Foundation

Distilling Challenging Behaviour

It's the 10th anniversary of the Challenging Behaviour Foundation and in honour of the occasion I've been asked to distil what I know about challenging behaviour into 500 words.

Donald Rumsfeld stunned the world by paraphrasing an Arabic folk saying: *'as we know, there are known knowns; these are things we know we know. We also know there are known unknowns; that is to say we know there are some things we do not know. But there are also unknown unknowns – the ones we don't know we don't know.'* The wisdom of Donald struck me dumb.

It may very well look to people that I've been sitting around for the last twenty years contemplating my navel, the internet, articles and books, but boy have I been travelling. I've met a lot of people with stories to share, anger to vent, frustration to show, pain to express, successes to impart, strategies to try, funny situations to laugh about. After twenty years, I wonder what I know I know.

There are no magic answers. And if I don't know the person, the family or the situation, how can I pontificate? But here are some ideas it can be helpful to think about.

Firstly, people with the catchall label 'challenging behaviour' are a diverse group.

If we were to ask everyone with blonde hair to leave the House of Commons we'd find an eclectic group standing outside on the windswept pavement with a range of interests, gifts, medical issues and dancing skills. In the same way people with disabilities are not a homogenous group, neither are people with the label of challenging behaviour. So we need to be careful we define exactly what we mean by challenging behaviour: who is challenged, when and where, what exactly it looks like,

and go on to work out why.

Challenging behaviour does not lie simply in the person: people do not carry it around with them in a bag. Challenging behaviour is a product of the interplay between the individual and the understanding and ability of the environment to respond to the needs of the person. Defining behaviour as challenging is usually a product of the behaviour's impact. The more dangerous the behaviour, the higher the probability we'll take note of it.

The reason people engage in behaviours varies between and within individuals. Think about it. I raise my hand to be excused. You raise your hand to gain attention. I jump up and groan when my leg cramps..... I do the same when I see a smart young couple holding leaflets opening the garden gate. Challenging behaviours range widely in their appearance and the psychological and biological processes which underpin them. They have varied personal and social consequences.

Therefore one intervention approach should not be applied to all individuals who show behaviours that look the same.

Look closely at the person. We tend to see very distressed people in extraordinary circumstances with few other ways of communicating or effectively behaving in a way that achieves what the challenging behaviour achieves.

Interventions reported as effective tend to be constructive (they teach a functionally equivalent replacement behaviour), socially valid (interventions deal with socially important issues in socially appropriate ways), use non-aversive technology, and meet the person's needs.

Listening and responding, we can call it.

• Tony Osgood

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

HOW TO HELP

CBF 10th Anniversary 2007: 10 ways YOU can help us to celebrate

1. Nominate the CBF as your company or work place adopted charity for the year *
2. Hold a 10th Anniversary tea party – invite your friends / work colleagues for birthday cake and promote the CBF *
3. Talk about Challenging Behaviour to your Rotary/ Church/ Women's group *
4. Help us to organize a special 10th Anniversary parent event in your area *
5. Hold a fundraising event in aid of the CBF *
6. Send a one-off 10th Anniversary donation to help our 'Find the Families' appeal (see page 6)
7. Become a regular donor – set up a standing order
8. Join our 100-Club – proceeds help our running costs
9. Pass on information about the CBF to 10 other people
10. Join us for our 10th Anniversary celebrations in Rochester on Friday 8 June (Tickets £8 per person. Please ask for details)

* Support available. Please enquire.

Q: My son is 11 with severe learning disabilities and we are having a problem at the moment with hair pulling. He will not let go and pulls handfuls out. He seems to know what he is doing but is not aware of his own strength.

A1: You have my full sympathy. My 18 year old son is profoundly autistic with severe learning disabilities and he has always pulled people's hair - particularly mine! It's agonisingly painful, and I don't believe there is an easy solution. Pressing down on his hands is a common answer, or placing your hand over his eyes to blind him ... that usually helps him to release hair or teeth! I always wear my hair tied as tightly as possible and usually wear a hat indoors as well.

A2: We have a very strong 12 year old who will suddenly grab hair and pull hard. We were taught that his hands

should be pressed to the adult's head, firmly but not in an aggressive way, to prevent him from further entwining his hands and fingers and to stop him from pulling it out. We talk to him quietly and calmly whilst doing this and repeat 'put hands down'. When there is another adult around, then that adult will distract his attention which in turn causes him to loosen his grip and then his fingers can be disentangled from the hair.

A3: Your son will be doing the behaviour to create an outcome and you may need to consider why he may do this and what effect it creates. For example giving him attention after the episode may be positive reinforcement for the behaviour.

A4: The real issues will be about why he seems to be pulling hair: what's going on beforehand, what happens afterwards? What does he gain or avoid? Finding out why he does it informs the best strategy. If we get the reasons wrong, the wrong strategy might be recommended and we end with more of the unwanted behaviour. So I'd recommend considering why before developing a strategy.

Q: My son is nearly 13, severely autistic, non verbal with learning difficulties. I am looking for any ideas about how to tackle shaving? He does not like noise and hates having his hair cut! If anyone knows any strategies please let me know....

A1: We have had similar problems with shaving. My son is now 18, and what I think is important is to make it part of the daily routine. Where he is at school they do not do this, so he is difficult. This means that he is not shaved properly, and when the hair grows too much it is more awkward to shave, creating a vicious circle. So I recommend shaving every day even if not necessary, perhaps only for a short period of time. We use an electric razor, twin foil is definitely better than a rotary.

You can play around with it at first, buzzing it on different parts of the body, and on yourself. The area below the nose is the most difficult because it is sensitive. Try and make it less sensitive by rubbing it first, or encouraging him to rub it, with a towel or a finger, and explain what you are going to do.

A2: We have just started such a thing with one of my students. We took off the blades and gave him the stem. It vibrates and makes a noise. This had followed a lengthy time of facial massage and then work with other vibrating toys. The frequency was every day at least once, sometimes more. As he got used to it so we introduced the electric razor. He was allowed to play with the razor - switch it on and off, etc. It took about six months in all but he has just allowed us to shave him.

A3: I would let him grow a beard and wear a pony tail! My son wore a beard for a long time, and felt very happy about it. You have enough problems already; I would forego the formal looks.

What parents say

HAPPY 10TH ANNIVERSARY.

I have found the help and advice and the opportunity to talk on the forum so helpful and sometimes when I have not known where to turn and things are bad I know there is help there. I am sure you will go from strength to strength for years to come.

Liz from Wigan

Living with a child with severe learning disabilities and challenging behaviour is a profoundly hard and isolating experience and one that seems to be largely ignored by politicians and society. The Challenging Behaviour Foundation is unique in attempting to address our needs, sharing information and allowing parents to get in contact with each other.

Every town and city should have its own Challenging Behaviour Foundation!

Juliette, Sussex

What has been particularly helpful to me about the CBF is the feeling that I am not alone - that others have or have had the same or similar problems with their child or young adult, and can offer advice.

Parent, London

I have been in regular contact with the Challenging Behaviour Foundation for around seven years and have found the organisation very helpful. I have needed quite a breadth of information from lists of residential schools catering for the 'severe' end of the challenging spectrum, to advice on transition to adult services.

Through the CBF I've been able to speak at length with a couple whose son is unbelievably similar to mine - something that is quite rare! Huge thanks to Vivien and all the team,

Happy Anniversary, and all the very best for the next 10 years.

Jayne, mother of Oliver, age 18

Want to join the debate? Membership of our email networks is free to both parents and professionals. Application forms from www.challengingbehaviour.org.uk or email info@theCBF.org.uk

The Challenging Behaviour Foundation: 1997 to 2007



Viv and CBF volunteers, 1999 (Left to Right: Fiona, Lynn, Sue, John, Janneane)

1997

The Challenging Behaviour Foundation started out based in Viv and Steve's garage! Professionals and academics were persuaded to write information sheets on different topics, and the first edition of CBF News was produced in April 1997.

Meanwhile, unhappy that a visit to her son's residential school required a 500-mile round trip, Vivien became an active campaigner for local services for children and adults with severe learning disabilities and challenging behaviour.

1999

Having outgrown Viv's garage, the CBF began renting an office in Rochester in 1999. The costs were met by a small but dedicated fundraising committee – whose only connection to challenging behaviour was that they were all friends of Vivien's! A big thank you to Fiona, Janneane, Lynn and Sue for all their support in those early days.

2000

New information sheets were written, and a grant from Awards for All paid for the printing of the first 1000 information packs. The CBF 100 Club was launched, providing regular income to help towards running costs. Vivien, Sue, Lynn, Fiona and Janneane, later joined by Laurence and John, all gave up one day a week to work as volunteers in the CBF office to try to keep on top of the ever increasing requests for information – now coming from both parents and professionals throughout the UK.

2003

After six years the workload had increased far beyond the capacity of the all-volunteer team. Finally, in 2003 the CBF was awarded a grant by Lloyds TSB Foundation, enabling us to employ Karen McKane, our first full time member of staff.

Daniel with his family, before he was sent to residential school



2004

2004 saw the launch of the Challenging Behaviour family support network and linking scheme. Our first video/DVD 'An Introduction to Challenging Behaviour' was released. Now getting rather short of space, we managed to negotiate the use of a second room from our Rochester landlords!

2005

In 2005, after ten years at a residential school over 200 miles away from his family, Daniel Cooper finally returned to Medway, joining three other students in the new Medway Challenging Behaviour transition service. Vivien immediately set about applying for funding in order to be able to support other families throughout the UK to bring their sons and daughters 'back home' from out of area residential placements.

2006

The workload still increasing, in 2006 the CBF was finally successful in securing two major grants. The Big Lottery and BBC Children in Need awarded three year funding for two much needed new posts.

2007

2007, our 10th anniversary year, gets off to a fantastic start, with our new Family Support Worker (Gemma Honeyman), and Service Development Worker (Nancy Hampton), joining Karen McKane (Development Manager), Lynn



Celebrating Daniel's homecoming, October 2005

*The new CBF team, February 2007
(Front: Viv and new employees, Nancy and Gemma. Back, left to right: John, Debra, Janneane, Sue, Laurence, Lynn, Karen)*

Walton (Information Assistant), Vivien Cooper (Chair of Trustees) and volunteers Laurence, John, Debra and Sue.

The BBC Children in Need funding will enable us to respond more effectively to enquiries from families, to produce new information sheets and DVD resources, and to further develop our family support network. The Big Lottery grant will fund information and support for both families and professionals wanting help to develop local individualized specialist services.



The Challenge Ahead

Children with severe learning disabilities are among the most disadvantaged members of society. They can expect to achieve less, to face more barriers and discrimination and to struggle to become socially integrated. The addition of severe challenging behaviour greatly increases the obstacles to their development and integration.

Those with the most severe challenging behaviour often face a lifetime of social exclusion and poor quality of life. The quality of life of their families can also suffer as a result of the frequent lack of adequate support from services and the wider community.

The Challenging Behaviour Foundation wants to see children and adults with severe learning disabilities having the same life opportunities as everyone else. We believe this is possible if the behaviour is properly understood and appropriately managed, and we aim to support parents and carers through education and information to enable this to happen.

We know that we still have a long way to go to achieve our aims, but with *your* help we will take forward our work in four main areas:

- providing information and support to parents and carers
- improving local service provision
- promoting research-informed practice
- acting as a 'voice' for those described as having challenging behaviour and their families

Our objectives for 2007 include the production of two new DVD resources ('Communication & Challenging Behaviour', 'Understanding challenging behaviour') and the development of our family support network and professionals' network. We invite suggestions from both parents and professionals. Ideas include training and workshop events, and regional seminars on identified issues – transition planning being one such issue.

PARENT PERSPECTIVES

Home, Sweet Home?

My husband and I couldn't believe how lucky we were. We just knew we'd make brilliant parents. I'd given birth to two healthy 9lb boys. We'd imagined a lovely future, full of ordinary happiness for our family.

This house used to give me a wonderful sense of security and comfort. Several years, and several diagnoses later, these four walls surround a battle-ground, which even when empty, leaves its scars.

I keep the house tidy, dust and Hoover when necessary, but I have no love for it. We cannot have ornaments out or pictures on the walls. No plants on the window sills (...or in the garden for that matter!) Things get constantly broken. Pictures get pulled down, plants get shredded, furniture and doors get damaged, and hours of decorating get defaced within days. An orderly room can be turned upside down - total chaos - in a matter of minutes.

So I've adapted. Prevention is easier than cure. Limiting the chances of confrontation by stripping the house

back to the basics makes life easier for us all.

If friends visit, our attention is constantly pulled away, making it impossible to have a decent conversation or enjoy company. Guests have a choice: muck in, or be left out. Over the years, this dilemma has lost us most of them.

We have no friends that feel comfortable enough to stay anymore. They cannot tolerate the constant noise, or having to sit on broken furniture in a practically empty shell of a house.

Now when things get too much, there is always 'our room'.

It isn't about shutting the boys out, it's just to have somewhere that we can call our own. Somewhere where I can have vases of flowers, pictures and wedding presents.

We converted the loft into a private place for ourselves.

Ordinary life, crammed into a roof space.

HOW TO HELP

Find the Families

One mother from Scotland told us: 'I have been searching for information for seven years.' Another from the South of England said: 'I wish I'd had this (DVD) when my son was little.'

How many more families need to know about the CBF?

Department of Health figures show some 65,000 children with severe and profound learning disabilities – and that's just in England. If 10 to 15% may show challenging behaviour (ref: Emerson et al, 2001) then there could be some 10,000 families in England alone who could benefit from our resources and support. If we extend this figure to cover all the UK, and if we include families caring for adults, then clearly we have a huge challenge ahead of us to reach all these families.

Will you help us to 'Find the Families'?

It is hugely expensive to advertise in many professional journals, to attend exhibitions and events, or to send out mass mailings. We currently do not have a budget specifically for publicity costs - yet we urgently need to reach these families. Please consider a donation to our 'Find the Families' appeal (page 12). Or if you could distribute flyers for us (either to professional colleagues or to parent carers) please get in touch.

There is so much more we need to do, and the new 3-year grants from BBC Children in Need and Big Lottery Fund will help enormously. However we also want to make sure that we secure the long term future of the charity. We are a small team with big plans – and we hope that you will want to support us as we approach the next ten years.

We were delighted to receive the following messages of support to mark our 10th anniversary:

May I pay tribute to the CBF for your work to date. With limited resources, the Foundation has already achieved a great deal. It is clear from feedback you have received, from families and professionals alike, that many have found the information and support provided by the Foundation to be invaluable. Crucially, the quality of life of the children concerned will have been improved as a result of your efforts. This does great credit to all those involved. I am sure you will go from strength to strength.'

Rt Hon David Cameron MP

Leader of the Opposition

The CBF has given families supporting people with challenging behaviour a real voice. Best wishes.

Professor Jim Mansell

The Tizard Centre, University of Kent

It's been a pleasure to be associated with CBF and to observe how effective it is in bringing together the expertise of family members and professionals in order to meet the challenges we face.

Professor James Hogg

White Top Research Unit, Dundee

The CBF provides an essential life line to families across the UK. It is a highly professional services and I have great respect and admiration for the commitment and dedication of its staff, Trustees and volunteers.

Gillian Wells

Chief Executive, CASE Kent

What an excellent organisation! I shall be distributing your information sheets and web site details liberally.

Community paediatrician

Preparing for adulthood

It's never too soon to start thinking about future options for your son or daughter, particularly if they have severe learning disabilities and challenging behaviour.

We hope our new transition information pack will be helpful to parents of teenagers, and to professionals wanting to support families to think through the options available.

While many aspects of transition planning are common to all teenagers with disabilities, the CBF Transition information pack focuses on issues particularly relevant to young people with complex behavioural support needs.

Contents include:

- ★ Where to begin?
- ★ Know your rights

- ★ Know who can help
- ★ Understand the challenges
- ★ Know your options
- ★ Safeguards and protecting the individual
- ★ How the CBF can help

The Challenging Behaviour Foundation is keen to work with family carers, commissioners and professionals who want to achieve better outcomes for individuals and their families, facilitating equality of access to local mainstream education and participation in the wider community locally. Do get in touch if you would like to find out how we may be able to help support you through the transition process.

To order your copy of the new Transition information pack, please see page 11.

EXTRACT FROM OUR NEW TRANSITION PACK

Aiming High

Transition planning should be part of an overall person centred plan and include a 'vision' of what adulthood will look like for the individual and what support will be required to achieve this.

The key points to remember in the planning process are:

1. Aim high. Think about what an 'ideal' scenario for your son/daughter would be. It may be that not all aspects of this vision will be achieved, but at least some will be.
2. Identify 'allies' that can help and support you. (The CBF is one!)
3. Think creatively. Don't accept that you can only choose from what is currently available.
4. Don't give up if you encounter barriers - barriers can be overcome.
5. Find out what other families have done. Many families known to the CBF are happy to share their experiences and can provide valuable insights into how to make things happen.

Remember that transition planning can be a lengthy process: there are times when you will forge ahead and other times when progress will seem painfully slow. Don't give up! Ask for help if you need it – the CBF is here to support you through the process.

Extract from the new Challenging Behaviour Foundation Transition information pack. See order form on page 11. Cost £5.00; free to families/ parent carers.

Blending Successful Approaches To Challenging Behaviour

This conference, organized by Kith & Kids and the Learning Disability Forum, supported by the Challenging Behaviour Foundation, will highlight continuing concerns regarding the needs of people with learning disability and challenging behaviour. The day will focus on highlighting the latest effective medication and the possible side effects, knowledge of new psychological approaches, programmes and recording techniques, learn what environmental resources are available and understanding the problems of a parent.

A short personal account by Vivien Cooper, family carer and founder of the CBF will be followed by presentations from leading professionals setting out the respective contributions of psychiatry, psychology and staff training. The conference will conclude with an overview of government policy and the changes in commissioning practice which have emerged since the Mansell Report of 1994.

Speakers include: Prof. Jim Mansell, Dr Dene Roberston, Dr Andy McDonnell and Marion Cornick. Dr Philippa Russell, CBE and Commissioner for Disability will chair the day.

Time will be allotted for questions, contributions and discussion

Wednesday 16 May 2007, 9.30 am to 4.30 pm

Britannia Conference Centre, Kings Cross, London

Cost: £85 (professionals), £35 (parents/ carers, voluntary advocates and self-advocates)

For more information or a booking form, contact Sandra Rosen, email ldf@kithandkids.org.uk or telephone 020 8262 0037.

Reading matters

Different Dads

This collection of testimonies has been written by 21 dads, offering direct and thoughtful perspectives on being a father of a child with a disability. They have children affected by rare and not so rare conditions, as well as a father who has yet to be given a diagnosis. Their children range in ages from 2 to 40, some with challenging behaviour.

Cost £12.99. All royalties donated to Contact a Family.

Available from www.jessicakingsley.co.uk or telephone 020 7833 2307

Abuse in Care?

A resource to help health and social care practitioners, adult protection coordinators and advocates to protect people with learning disabilities from abuse, 'Abuse in Care?' identifies early indicators, provides a system for recording concerns and offers practical guidance to practitioners concerned about residents' safety.

Cost £50.00

Available from Carol Parker, the Faculty of Health & Social Care, University of Hull, telephone 01482 463348 or email C.Parker@hull.ac.uk.

Keeping it Together

A guide for support staff working with people with learning disabilities who are new to challenging behaviour or facing it for the first time. Described as a 'self help' guide, the authors provide practical information on how to develop strategies to support people whose behaviour is challenging and to develop their skills in this area.

Cost £19.95

Available from Pavilion, tel. 0870 890 1080, email info@pavpub.com or visit www.pavpub.com/trainingmaterials.

Making decisions

A series of free booklets providing information on the Mental Capacity Act 2005 and how it will affect you if you are caring for people who are unable to make some decisions for themselves.

Titles in the series include:

Making decisions: a guide for family, friends and other unpaid carers

Making decisions: a guide for people who work in health and social care

Making decisions: a guide for lawyers and advice workers

Making decisions about your health, welfare or finance: who decides when you can't? (An easy read guide)

Cost: free

Available from makingdecisions@dca.gsi.gov.uk, telephone 020 7210 0025 or visit www.dca.gov.uk/legal-policy/mental-capacity

DVD

Getting in control

This DVD features people using individual budgets and self-directed support to show what is possible when people with learning disabilities and their families are told how much money is allocated to supporting them, and allowed to decide for themselves how they want to spend their entitlement.

Cost £12.

Available from Robina Mallett, Family Carer Support Officer, HFT, tel. 0117 930 2608 or email robina.mallett@hft.org.uk.

CONFERENCE

Changing practice: reducing the risk

Recent events have reminded us of the need to continually promote high quality services to people with learning disabilities who may display complex and at times challenging behaviour. BILD's 6th Annual Behaviour Support Conference aims to highlight some of the good practices and ongoing challenges in the field of behaviour support and physical interventions.

03 and 04 May 2007, Oxford

For more information contact BILD. Tel: 01562 723025 or e-mail learning@bild.org.uk

Understanding Challenging Behaviour

Exploring information and issues related to the causes of challenging behaviour, the cycle of aggression, basic strategies for de-fusion, de-escalation and personal coping strategies, this training is aimed specifically at parents and families.

5 June 2007, Kidderminster

Cost £47. Contact BILD, tel: 01562 723010 or visit www.bild.org.uk/events.

Connecting with people who are difficult to reach

Using intensive interaction with non verbal adults and children, this one day seminar is taking place at different venues around the UK, including Birmingham, Bristol, Coventry, Chorley, Doncaster, London, Middlesbrough, Reading, Swansea, Taunton.

Cost £188 or £94 for parent carers. Contact Concept Training Ltd, tel: 01524 832828 or visit www.concept-training.co.uk

Positive Ways of Changing Behaviour

Don't just manage challenging or difficult behaviour, use pro-active approaches to support children and adults to make positive behavioural changes. Birmingham, Doncaster, Edinburgh, London, Winchester.

Cost £188 or £94 for parent carers. Contact Concept Training Ltd, tel: 01524 832828 or visit www.concept-training.co.uk

Extreme behaviours within autistic spectrum disorders

Professionals UK-wide are experiencing the emergence of a group of individuals with autistic spectrum disorders who also have very complex behaviours which challenge services. The speakers will examine the possible reasons and causes for these extreme behaviours, as well as considering the varied range of approaches for provision and interventions.

- 18 April 2007, Newcastle
- 25 September 2007, London

Cost £124 or £74 for parent carers. Contact the National Autistic Society, tel: 0115 9113367 or email conference@nas.org.uk

Managing challenging behaviours in autistic spectrum disorders

A one day workshop looking at challenging behaviours in autistic spectrum disorders and the best ways to manage these behaviours. Topics include: how our behaviour can effect the behaviour of others; how to move away from a demand culture; the least aversive way of managing behaviour.

26 April 2007, Birmingham

Cost £124 or £74 for parent carers. Contact the National Autistic Society, tel: 0115 9113367 or email conference@nas.org.uk

Challenging Behaviour & Autism

An introductory course for anyone wishing to develop an awareness and understanding of the causes of challenging behaviour in relation to autistic spectrum disorders.

- 15 May 2007, Kidderminster
- 8 June 2007, London

Cost £141 or £47 for parent carers. Contact BILD, tel: 01562 723010 or visit www.bild.org.uk/events.

Positive approaches to working with challenging behaviour in autistic spectrum disorder

This one-day conference will aim to explore issues within challenging behaviour and give delegates practical advice and approaches to be taken away and implemented appropriately into a range of different settings

5 June 2007, Manchester

Cost £124 or £74 for parent carers. Contact the National Autistic Society, tel: 0115 9113367 or email conference@nas.org.uk

Every Disabled Child Matters

The 'Every Disabled Child Matters' (EDCM) campaign, run by Contact A Family, the Council for Disabled Children, Mencap and the Special Educational Consortium, is campaigning for all disabled children and their families to have the right to the services and support they need to live ordinary lives.

Every Disabled Child Matters wants...

- Families with disabled children to have ordinary lives
- Disabled children to matter as much as all other children
- Disabled children and their families to be fully included in society
- All disabled children and their families to get the right services and support – no matter where they live
- Poverty amongst disabled children and their families to be cut by 50% by 2010 and eliminated by 2020
- An education system that meets the needs of each child and enables them to reach their full potential
- Disabled children and their families to shape the way that services are planned, commissioned and delivered

EDCM is focused on England but will be supporting campaigning activity in the other UK nations, as well as campaigning on non-devolved issues such as benefits.

The EDCM Local Authority Charter calls on local authorities in England to commit to providing a range of services for disabled children and their families by January 2008, and to addressing the needs of disabled children in their strategic planning and local area agreements.

Action

- Sign up to show your support at www.edcm.org.uk
- Check if your Local Authority has signed up to the EDCM Local Authority Charter
- Lobby your Councillor to sign the EDCM Local Authority Charter

For more information call the Every Disabled Child Matters campaign team on 0207 7843 6448 or visit www.edcm.org.uk

Consultation on People with Learning Difficulties Placed, or at Risk of Being Placed, 'Out-of-Area'

Why do people get placed 'out-of-area'?

Who is at risk?

What is being done to address this issue?

What is happening that makes it more difficult to address this issue?

A consortium led from Lancaster University is conducting a 'Knowledge Review' and is inviting input from family carers, practitioners, managers and policy makers. To find out more about the project and how to make your contribution visit www.scie.org.uk/adults/commissioning.asp

Thank you to the Black Bull Hotel, Folkestone

Brendan and Tricia and friends raised a wonderful £120 for the Challenging Behaviour Foundation through sales of their 'naughty' calendar. Many thanks to all those involved, and to their sponsors who made the calendar possible.

Thank you, Tunbridge Wells

A big thank you to Esther Harding and team who sent in a donation of £32 in response to our 10th anniversary appeal. This was collected through a fundraising make-up party at the Community Learning Disability Services at Tunbridge Wells. Thank you to all involved.

'Nightmare' of turning 18 for teenagers with disabilities, say families

Many readers of 'Challenge' will not be surprised by the findings of a recent report from CSCI: *'Growing up matters: better transition planning for young people with complex needs.'*

For many young people with complex needs, turning 18 can be the start of what some families describe as a 'nightmare' as they make the move from children's to adults' social services. The report highlights inadequate commissioning of services, poor coordination and a failure to properly plan ahead with young people and their families. This results in delays, multiple assessments, confusion and anxiety for all concerned.

CSCI will continue to focus on the performance of councils in carrying out their statutory responsibilities for this group and will report on progress. In the meantime we hope the new CBF Transition information pack will help prepare families to think ahead about transition and to be equipped to challenge councils if transition planning is not started early enough for young people with complex needs.

For more information email enquiries@csci.gsi.gov.uk, telephone 0845 015 0120 or visit www.csci.org.uk

Wanted: parents in Wales

Parents living in Wales who might like to become part of a group looking to conduct research into challenging behaviour/mental health issues in children and adults with intellectual disability are invited to join a new group being set up as part of a new initiative entitled the Learning Disability and Autism Network for Wales. You would need to be prepared to commit to coming to 2-3 meetings in the next 12 months or so in order to provide a parental perspective and contribute to discussions on producing some joint research bids.

If you can help, or to find out more, please contact:

Prof. David Allen
Special Projects Team
Unit 3, Cowbridge Court
58-62 Cowbridge Road West,
Cardiff CF5 5BS.
Tel: 02920 569204

Congratulations CBF

It gives me tremendous pleasure on behalf of BILD to send this message of congratulations to all at the CBF on reaching this significant milestone.

Recent events around the country remind us of the need to continually strive towards providing the best quality of service and support. We are grateful to the Foundation which has proved an invaluable partner for a number of past, current and, we hope, future projects we want to undertake together.

Alan Martin

*Development Manager, Behaviour Support,
BILD (British Institute of Learning Disabilities)*

Contact a Family is delighted to celebrate the Challenging Behaviour Foundation's 10th birthday. Parents of children with challenging behaviour tell us how much they value the support of the Foundation in coping with these difficult issues. We hope to continue to work with you for another 10 years.

Francine Bates OBE

Chief Executive, Contact a Family

100 club winners

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

October 2006: Mrs A Stickles,
Gillingham

November 2006: Mrs M Whitehead,
Bristol (special £50 prize)

December 2006: Mrs G Akrill,
Chatham

January 2007: Mrs C Smart,
Staffordshire

A special thank you to Carol Smart, who kindly donated her prize money back to the CBF.

Self Injurious Behaviour DVD

Apologies to those of you affected by the unexpected delay in the release of our new DVD on self injurious behaviour, advertised in our November newsletter. This was due to circumstances outside our control which happily have now been resolved.

The DVD / video gives practical information and advice to those caring for individuals with severe learning disabilities who show self injurious behaviour.

Featuring Professors Chris Oliver and Glynis Murphy and two families caring for young people who show self injurious behaviour, we believe this will prove to be an important resource for both families and professionals alike.

Available in DVD or video format, cost £31.50 (DVD) or £35.00 (video). Reduced rates for registered charities. Free to parent carers.

Thank you, Cranbrook School

A big 'thank you' to all the pupils and staff at Cranbrook School, who raised a fantastic £4000 for us last year.

This donation has been allocated towards the production and distribution costs of our new-look newsletter.

We hope you like it!

Have your say

Do let us know what you think of 'Challenge'. Which are the items you found most helpful? What would you like to see in future editions? Please get in touch and help make this become YOUR newsletter. Contributions welcome.

Disclaimer

While every care is taken in the compilation of this newsletter, the Challenging Behaviour Foundation cannot be held responsible for any errors or omissions, nor accept responsibility for any goods or services mentioned.

Resource order form

All our resources relate to the care of individuals with severe learning disabilities who are described as having challenging behaviour. We are happy to send resources free of charge to parents/ unpaid carers.

	Cost	Number	Total £
Information pack Challenging Behaviour	£5.00		
Information pack Transition: what are the options?	£5.00		
DVD An Introduction to Challenging Behaviour	£31.50*		
DVD Self injurious Behaviour	£31.50*		
DVD A new pathway for young people with severe learning disabilities	£10.00		
Video An Introduction to Challenging Behaviour	£35.00*		
Video Self injurious Behaviour	£35.00*		
Postage & Packing			
<small>All prices include postage. For orders outside the UK please add £7.50 per item</small>			
Donation			
Total			

* Registered charities: DVDs £16.50 or videos £20. Price includes 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 (28p 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

Organisation

Address

Postcode

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.

Please make cheques payable to the Challenging Behaviour Foundation and return to the Challenging Behaviour Foundation, c/o Friends Meeting House, Northgate, Rochester, Kent, ME1 1LS

For more information about our resources visit our website
www.challengingbehaviour.org.uk

Please support our 10th Anniversary 'Find the Families' appeal

YES I would like to support the work of the CBF

Please tick as appropriate:

- I would like to support the CBF regularly. Please send a standing order form
- I enclose a donation to help you to reach more families in 2007
- I would like to Gift Aid my donation*

* Make your gift worth more! If you are a tax payer, Gift Aid enables us to claim tax back on your gift – 28p from the Inland Revenue for every £1 you give. There is no extra cost to you. Gift Aid declaration: I am a UK tax payer and I undertake to pay the CBF all donation I make while a UK tax payer as part of the Gift Aid scheme

Signed

Date

Name

Address

Postcode

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 may be used by the charity for administration and fundraising purposes and will not be passed on to any third party without prior consent.

- I would like to join the CBF 100 Club 2007. Each share entitles me to a chance to win a monthly prize of £25. All proceeds help with CBF running costs. I enclose a cheque for (£12 per share)
- I would like to help you reach more families. Please send me brochures to distribute to families/ professionals.
- I would like to help you celebrate your 10th Anniversary (see page 2 for some ideas). Please send me fundraising leaflets.
- Please remove me from your mailing list.

Please return to:

The Challenging Behaviour Foundation, c/o Friends Meeting House, Northgate, Rochester, ME1 1LS

Thank you for your support

The CBF – how you can help

Did you know....?

- **The CBF does 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 £15 a year we would have a guaranteed income of over £25,000, which would enable us to take forward a number of important projects**
- **Regular giving by standing order makes your money go further by helping keep down administrative costs.**
- **Your support really would make a big difference to us!**

Please help us to 'Find the Families'.

Send a donation to our 10th Anniversary 'Find the Families' appeal, and your contribution could help us reach the families who need us. (see page 6)

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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Email: info@theCBF.org.uk;

Tel: 01634 838739;

www.challengingbehaviour.org.uk