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Challenge

Challenging
BEHAVIOUR
foundation



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

Winter 2008

The newsletter of The Challenging Behaviour Foundation

The stress factor

Any parent will tell you that whilst bringing up a child is incredibly rewarding and fulfilling, it certainly isn't simple!

The complexities of parenthood are huge anyway, and when your child has a disability those complexities can be magnified and increased to almost overwhelming proportions. Sometimes in addition to the issues that arise from the disability itself, it feels as though someone, somewhere is thinking up ways to make life more difficult and complicated – exclusion, labels, funding streams, systems and processes.

If there was a job description and person specification for being a parent of a person with a severe learning disability and behaviour described as challenging it would be pages long, and there wouldn't be many applicants! The terms and conditions aren't good either!

If you can get some time for yourself (and that's a big 'if'!) you need to be confident that your family member is not being disadvantaged

Common sense tells us that families supporting a person with a learning disability and challenging behaviour will need some 'time off' – but this is easier said than done. If you can get some time for yourself (and that's a big 'if'!) you need to be confident that your



Vivien Cooper

family member is not being disadvantaged – that it's not a 'him/ her or me' situation - because otherwise you just heap guilt onto everything else.

Families are in it for the long term – we need to keep going, and to do that we do need to look after

ourselves. This can take many forms (when Daniel was very young, just spending 20 minutes in the supermarket on my own getting a few basic provisions was a luxury I needed for my own sanity!) and knowing when you need support or a break is really important. But put it in place before you need it.

Families are in it for the long term – we need to keep going, and to do that we do need to look after ourselves.

The new Carers Strategy emphasises the importance of the role of family carers – and should lead to better opportunities for families to get the support they need, including short breaks. But in the long term we need to support families better by meeting the needs of everyone. As many family carers have said, 'get it right for my son/ daughter/ relative with a disability, and you get it right for me.'

• Vivien Cooper

Chair of Trustees and Founder of the Challenging Behaviour Foundation

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Tying ourselves in knots

Someone sticks a gun through the car window and shouts, 'Give me the motor!' – well, you won't see me ignore this as an inappropriate behaviour

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It can be difficult for families, who are under significant stress, to put behaviour change interventions into place

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New DVD: Challenging Behaviour – Supporting Change

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New 0845 number for families

Individual telephone support around understanding and managing challenging behaviour for the cost of a local call

'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

Tying ourselves in knots

I want my children to be accepted as individuals, as the wonderful people I know them to be.

I want my children to belong and not be isolated, yet also to be unique. Yet society tends to accept those whose behaviour is viewed as appropriate - dressed in a common manner, communicating in traditional ways.... So I spend a lot of time worrying about my children's behaviour, tying myself in knots trying to make challenging behaviour the exception and not the rule.

Sometimes when we're tied up, we need to invest in scissors.

Snip 1: Define success

First, try to put things in perspective. Challenging behaviour does not define the person. Because challenging behaviour is serious and noticeable we focus on it, and may forget to consider the positive things. So sometimes, getting perspective may help, and we can work towards helping Little Max scream for two minutes less this week than last week and this would be a success. Success must be realistic.

Because challenging behaviour is serious and noticeable we focus on it, and may forget to consider the positive things.

Snip 2: Sometimes we need someone else to come and help us free ourselves.

I've learned independence is a bit of a myth. I think my kids and I are interdependent: we rely on each other and people around us - so I don't mind asking for help now.

Snip 3: Consider strategic capitulation

Someone sticks a gun through the car window and shouts, 'Give me the motor!' - well, you won't see me



Someone sticks a gun through the car window and shouts, 'Give me the motor!' - well, you won't see me ignore this as an inappropriate behaviour

ignore this as an inappropriate behaviour, and you won't hear me say, 'No way, buster! I'm not reinforcing your challenging behaviour,' because I prefer to get through the day with my head intact. So in the middle of a crisis, sometimes, sometimes, it's okay to put the fear of reinforcing inappropriate behaviour to one side and think about ways of getting out of the situation with some dignity for everyone. Sometimes it's ok to give the person what they're asking for. (But if the only time Bob gets a sweet is when he's screaming, then there might be a potential issue, so make sure Bob gets good things at other times).

Snip 4: When the world is dark, take off the sunglasses

Cut yourself, your children and the family a break. There's no such thing

as SuperMum, SuperDad, (nor, I pray, SuperNanny) outside TV. We're all learning and struggling; don't beat yourself up. You're doing the best you can in an extraordinary situation. You can do this; you might need more support than others at times, but you CAN help your child achieve.

Snip 5: Why wait for the war?

Make things easier for the person. Arrange things so your children are more likely to do something other than challenge. We teach our children to walk by praising each first step, not expecting our babies to run marathons. When a child can't read we teach them to read; when they can't ride a bicycle, we teach them to ride, and behaviour is not different. We need to teach children to cope with frustration and not getting everything because that's called life. But we can teach by small steps. Antecedent interventions (strategies to avoid a problem) are valuable, and help us avoid tying ourselves in knots in the first place, often.

Snip 6: Be realistic.

Your children will never truly appreciate the love, patience, commitment, time, money and tears you pour into them. So be realistic what to expect for in terms of feedback and gratitude.

Snip 7: Never stop listening

I'm sure there are lots of other snips. But these are my snips for getting me out of the knots I've thrashed my way into.

Snips... all these snips remind me of a vasectomy, so I need to go lie down now as I feel a little faint. Speak soon.

• **Tony Osgood**

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

Q: My daughter is almost five, and hardly sleeps – am I entitled to respite care? I was rejected as my daughter wasn't in full time education as she is repeating nursery. I am a lone parent and I really need the break!

A1: Hi, I had varying amounts of respite care since nursery school. At this age we asked for someone to come in the house to give me a break because I was so tired. After this we got a weekend off every six weeks where my child went to a residential facility. Social services are there to help you, not to make you feel inadequate. Stay strong and you will get there.

A2: Do you have a Social Worker? If not ring your local Social Services Department and explain you have child with Special Needs and you need to be allocated a Social Worker. The Social

Worker will complete a Carers Assessment with you and should discuss what help is available for yourself and your daughter.

A3: Contact Social Services again and tell them how things are. Do whatever you can to get through to them just how bad things are. Make sure they are in no doubt about how badly this situation is affecting your morale and your health.

A4: Make sure you and your daughter are always on the top of the social worker's or health visitor's list, pester them, phone them, don't let them forget you. Eventually they will provide the overnight care you both need.

From the CBF: We regularly hear from families who are denied access to or excluded from much needed short break (respite) provision. In order to campaign for change we need to get a better idea of the problem and so we are asking families to complete a questionnaire about their experiences. Please contact Gemma: 0845 602 7885 or e-mail: gemma@theCBF.org.uk

Q: I support a man with severe learning disabilities and autism. He has developed a behaviour of constantly wetting his clothes in the bath, sink and even the toilet and has begun to urinate in his clothes. Any suggestions?

A1: It's probably worth having a good look at whether the behaviour does have a function of attracting and/or maintaining attention, or whether there may be some other function. The function of the behaviour is important in determining the type of intervention. Individuals with autism often have sensory based behaviours (where the sensation of the behaviour is reinforcing) or 'order' based behaviours, where the behaviour is reinforced because it introduces order into an unpredictable situation (e.g. staff behaviour becomes more

predictable) or the ritualised behaviour is more ordered and replaces the disorder of having to respond to a variable situation.

A2: He could be doing this for several different reasons. For example, perhaps he likes the sensation of the urine, perhaps he's wearing new clothes that he doesn't like, perhaps he does it with some staff more than with others etc. You need to get a specialist clinical psychologist or behaviour nurse therapist to carry out a thorough functional assessment.

A3: It may be that the material in the clothing might irritate the individual's skin. However I agree on the need for a full behavioural assessment and a functional assessment.

From the CBF: Any behaviour we find challenging, such as wetting clothes, may serve a number of different purposes (or functions). To find out more about functional assessment see our new DVD 'Challenging Behaviour – Supporting Change' (details on page 5).

What parents say



Warren

Our son Warren is 30 years old, gorgeous, funny, noisy and never dull. He also has severe learning disabilities and autism, with no speech and can be challenging. People who work with him love him, even though he can be unpredictable. You get a lot of cuddles, though often ending with a pinch (always a lovely smile!)

He has overcome so much: being excluded from a special school, having almost a year at home, then trying to cope with all the changes when he reached nineteen. He is now happily settled at a daily resource centre, and very happy with regular respite. He has learnt to cope with changes in his life and all important routines, hair cuts, showering, having to wait, the list goes on.

He has found so many things difficult over the years, and has learnt to communicate in his own way. He loves watching cars, swimming, having a beer, seeing his brothers, and lying in bed. We wish he knew how proud we are of him, but just hope he knows how much he is loved.

• **Linda & Mike Sanders**

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

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

Research

While those caring for someone with a high level of need without sufficient support appear to experience stress most often, not everyone in these situations experiences stress. Some carers for people with complex needs maintain good mental health. This suggests that the relationship between challenging behaviour and carer stress is not simple and that many factors may help people cope emotionally. More recent research has looked at the things that help protect carers from stress in even the most difficult situations.

Taken together, this work has provided a 'cognitive-behavioural' model of care-giver stress. The model helps explain why two people may respond to similar situations in quite different ways: the carer's thoughts and beliefs (cognitions) surrounding challenging behaviour seem to be strongly related to their emotional reaction.

Carers who view themselves as being competent or in control of a situation and those who reach a point of acceptance for the difficulties they face are found to experience less stress. It is likely that these carers are able to develop good coping strategies by acknowledging stress at an early stage when it can be managed more easily.

Most importantly, the research highlights that with the right support, carers can respond to situations in new ways to bring about positive change. This doesn't mean that caring for someone with challenging behaviour will become less demanding but it does mean that the experience of stress is not an inevitable consequence.

• **Nick Gore**,
*Lecturer in
Intellectual and
Developmental
Disability, Tizard
Centre University
of Kent*

*Further reading
– see page 7*

Practical coping strategies for carers

The Specialist Support and Development Team (SS&DT) in East Surrey is a community based support team, offering support and intervention to children and adults whose behaviour presents a challenge. During the course of the team's work, it has become apparent that it can be difficult for families, who are under significant stress, to put behaviour change interventions into place. Parents may just have enough energy to get through the day, without having to meet the demands of a well meaning Behaviour Specialist!

Most pieces of work carried out by SS&DT start by encouraging parents to consider the importance of their own well-being, prior to implementing any form of behaviour support plan. One of the most useful ways of encouraging families to think about stress has been to use standard stress questionnaires (see p7 – Further Reading). Areas of the questionnaire which score poorly are a good starting point for parents to think about possible coping strategies.

Coping strategies are extremely individual, and each parent needs to select strategies that suit them personally. The following suggestions are intended as a guide, to help pinpoint areas of your life where stress management may be needed:

Eating well. A good diet and good mental health are shown to be linked, as well as good physical health.

Sleep. Addressing any sleep problem, and developing some good sleep habits, are just as important for parents as they are for children. If lack of sleep is directly caused by your son or daughter's behaviour, this would need to be tackled first.

Social contact. Regular contact with friends and family can offer opportunities to talk openly, receive support and feel far less isolated. Sharing concerns with others and feeling connected is helpful in reducing stress.



Minimising alcohol, cigarettes, caffeine, sugary foods. These coping strategies produce a short period of feeling good, but are detrimental to health and should be minimised.

Doing something fun. An activity you really enjoy can be uplifting and energising, and may well be possible without huge resources of time or money. A fun activity that fully engages your attention provides an escape and allows a temporary and healthy measure of detachment from a current stressful situation.

Exercise. Aerobic exercise results in endorphin release, which is the body's natural happy hormone. If getting out of the house is tricky, consider exercise equipment at home, or using DVDs - or an exercise programme on the children's Nintendo Wii.

Spiritually uplifting activities. For some people their faith can be a great source of strength, often going hand in hand with being linked into a supportive network. Alternatively, meditation, being in beautiful places, walking outdoors, particularly green spaces, on a beach, music, can all be spiritually uplifting, and can help to reduce stress. Although finding time for these activities might be difficult, they could prove helpful, even if undertaken for short periods of 20-30 minutes.

• **Maria Hurman**, *Team leader/
Honorary Lecturer. Specialist Support
and Development Team, SABP NHS
Trust / Tizard Centre University of Kent*

New DVD: Challenging Behaviour – Supporting Change

In this new 2-disc DVD set meet Oliver, Dougie and Dominic and hear Mark Addison (psychologist) explain the functional assessment process. 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.

Produced primarily for family carers,

this resource also provides a useful introduction or refresher for professionals. The families' stories demonstrate the importance of functional assessment and provide insight into positive ways to support families. Free of charge to families/unpaid carers.

To order your copy of the DVD 'Challenging Behaviour – Supporting Change', please see page 7.

EXTRACT FROM OUR NEW DVD

"As soon as Dominic pulled somebody's hair it meant that he was either removed from the room or a person was removed from the room. So actually what Dominic was getting was an outcome for that hair pulling. He was indicating to us that he was uncomfortable. But he was having to pull hair to achieve that."



Audrey Giles and son Dominic from our new DVD 'Challenging Behaviour – Supporting Change'. See order form on page 7.

Don't give up

Marie is my daughter; she is my educator, boss and sometimes jailer. Marie is profoundly deaf, has a moderate to severe learning disability, autism, epilepsy and scoliosis. Compulsive obsessions are very much part of Marie's life. One summer we could not open any windows; the following winter we had to keep the back door open all day. Some days Marie insists on having up to five baths.



This photo depicts what happened when I refused to give Marie another bath.

Life with Marie is a rollercoaster ride through unknown territory, not least because of having to fight to get the support she needs. Like most parent carers, I had no experience of disability before Marie was born.

After twelve years of fighting, Marie moved to a small home last year where she is now happier than she has been for a long time. It had taken over two years from the time we first found the service for our local authority to agree funding. I kept a record of all relevant events and conversations with social service officers, and used anyone who might be able to add pressure to local commissioners. My MP was great, he kept writing to the head of social services on our behalf. The Disability Law Centre took up our case. The Commission for Social Care Inspection also wrote to the Council. The final result was a written apology from heads of services and funding being agreed for Marie to move and get the support she needs. Marie has taught me not to give up and not to accept less than what is best for her – and me!

• Miriam Long

Supporters' News

While we cannot mention all our donors by name we would like to say a special thank you at this time to the **Soroptimists International Medway** (£250), **the Rotary Club of Gillingham** (£200), **Wycombe Abbey School** (£597) and the **Rotary Club of Rochester** (£100).

A big thank you also to all those who paddled for us at this year's **Funraisers Dragonboat** event at Bewl Water – sponsor money still coming in, and we hope to have photos in the next issue of 'Challenge'. The team won first prize for their costumes – for which a big thank you and 'well done' to the students at the **University for the Creative Arts, Rochester**.

Carers Strategy

Carers At The Heart of 21st Century Families & Communities was published in June 2008. This ten-year cross-government strategy aims for carers to be:

- respected as expert care partners with access to the services they need
- able to have a life of their own
- supported so that they are not forced into financial hardship
- supported to stay well and treated with dignity

Contact your local LD Partnership Board to find out how you can benefit from the new Carers Strategy.

100 Club winners

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

June 2008 – Mrs B Norman, Sevenoaks

July 2008 – Mrs D Martin, Gillingham

August 2008 – Mrs F Walker, Stoney Stanton

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

Valuing People Now

As we go to press the government is publishing Valuing People Now, which

New 0845 number for families

Families caring for sons/daughters with severe learning disabilities can now receive individual telephone support around understanding and managing challenging behaviour from the CBF Family Support Worker for the cost of a local call*.

Gemma Honeyman, whose previous experience includes

supporting children with severe learning disabilities and working on an autism research project at Oxford University, also develops new resources and runs the Challenging Behaviour

Foundation family support network.

'Families come to the Challenging Behaviour Foundation for lots of different reasons,' explains Gemma. 'Many receive little or no support around challenging behaviour and are looking for new ideas. Others are seeking help because their child has been excluded from short break provision, school, school transport, day centre or residential care home.'

'Many families feel isolated and want to be put in touch with a family who has experienced similar difficulties or just need a listening ear. A lot is known about challenging behaviour and the

Supported by

BBC



Children in Need

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Challenging Behaviour Foundation wants to make sure it gets to the people who need it most – families.'

'Clearly there is a limit as to how much help I can give by telephone, but a lot of parents have never received basic information about challenging behaviour or how to access local information and support.'

The Challenging Behaviour Foundation Family Support Worker post is funded by BBC Children in Need, so if you have made a donation to BBC Children in Need – thank you very much!

Families can contact Gemma on: Tel **0845 602 7885** (individual telephone support for families at the cost of a local call*)

**local call rate applies to calls made from a landline; calls made from mobiles may cost considerably more.*



Gemma Honeyman, CBF Family Support Worker

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**.

updates the white paper Valuing People published in 2001. Valuing People was the government's plan for making the lives of people with learning disabilities, their families and carers better. Valuing People Now is likely to place more emphasis on supporting individuals with complex needs and greater partnership with families. Valuing People Now will be available from www.valuingpeople.gov.uk or contact your local LD Partnership Board.

Further Reading (from page 4)

Lloyd, T & Hastings, RP (2008): Psychological variables as correlates of adjustment in mothers of children with intellectual disabilities: Cross-sectional and longitudinal relationships. *Journal of Intellectual Disability Research*, 52 (1), 37-48.

Hassall, R & Rose, J (2005): Parental cognitions and adaptations to the demands of caring for a child with an intellectual disability: A review of the literature and implications for clinical interventions. *Behavioural and Cognitive Psychotherapy*, 33, 71-88.

The following web link gives an example of a stress questionnaire that you might like to try:
<http://www.internethealthlibrary.com/sq/stress/stress-assess.htm>

Have your say

We welcome articles from parents and professionals. Please get in touch if there is something you would like to write about.

Disclaimer

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

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	Cost	Number	Total £	
CHALLENGING BEHAVIOUR DVD RESOURCES				
An Introduction to Challenging Behaviour: DVD	£31.50*			
What is challenging behaviour? Why does it happen? What can be done about it? Uses interviews with two parent carers, with specialist input from Peter McGill (University of Kent Tizard Centre). <i>40 minutes</i>				
Self-injurious Behaviour: DVD	£31.50*			
What causes self-injurious behaviour? What action should parents and carers take? Professors Chris Oliver and Glynis Murphy join forces with two family carers to offer clear and practical information and advice to families. A useful introduction also for professionals. <i>40 minutes</i>				
Communication and Challenging Behaviour: DVD	£31.50*			
Four family carers and a speech and language therapist explain the relationship between communication and behaviour and highlight practical approaches to improve communication and minimize challenging behaviour. <i>40 minutes.</i>				
Challenging Behaviour – Supporting Change: DVD	£63.00*			
In this new 2-disc DVD set meet Oliver, Dougie and Dominic and hear the functional assessment process explained. Interviews with family carers highlight the range of causes of challenging behaviour, and how a functional assessment can help put in place appropriate behaviour management strategies for individuals with severe learning disabilities. <i>(Approx 70 mins)</i>				
CHALLENGING BEHAVIOUR INFORMATION SHEETS				
Basic information about challenging behaviour	All information sheets are available free of charge on the CBF website.			
Getting a statement				
Communication and challenging behaviour				
The use of physical interventions				
Book list for parents / professionals (please specify)				
Specialist equipment and safety adaptations				
Functional Assessment (understanding the function of the behaviour)				
Self-injurious behaviour				
Psychiatric disorders in people with learning disability		To order by post please add £1.00 per sheet		
Health and challenging behaviour				
The use of medication in the treatment of challenging behaviour				
Pica behaviour (eating inedible objects)				
Parents' perspectives				
FULL INFORMATION PACK	£10.00*			
SUB TOTAL CARRIED FORWARD				

*Free to parents/unpaid carers. Registered charities: DVDs £16.50 (or £33.00 for 2-disc set). Prices include postage & packing in the UK only.

/ Continued overleaf...

SUB TOTAL CARRIED FORWARD			
PLANNING FOR THE FUTURE			
	Cost	Number	Total £
Planning for the Future: Introduction Information sheet	£1.00*		
Planning for the Future Information pack: Wales / Scotland / N Ireland / <i>(please specify)</i>	£10.00*		
Planning for the Future Information pack: England <i>Note: replaces our earlier Transition & Adult Options information packs – content remains the same</i>	£10.00*		
Challenge: Spring 2008 special issue 'Location, Location' <i>while stocks last</i>	FREE		
A New Pathway: DVD DVD overview of the Medway Challenging Behaviour FE service. <i>20 minutes</i>	£5.00*		
A New Pathway: Report A review of the planning model used to develop the Medway Challenging Behaviour FE service. <i>40 pages</i>	£ 5.00*		
DONATION – please consider a donation to support our work. Thank you			
TOTAL			

*Free to parents/unpaid carers. Prices include postage & packing in the UK only.

All proceeds go towards helping families caring for individuals with severe learning disabilities and challenging behaviour. Thank you for your support

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

Parents/ family carers please note: while we are happy to send you our resources free of charge, if you can afford to send a donation this will help us to provide free resources to other families. Thank you.

Please indicate if you are a parent or unpaid carer. If you are a registered charity please give your charity registration number:	
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Name	<input style="width: 95%;" type="text"/>
Organisation	<input style="width: 95%;" type="text"/>
Address	<input style="width: 95%;" type="text"/>
	<input style="width: 95%;" type="text"/>
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Postcode	<input style="width: 95%;" type="text"/>
Telephone	<input style="width: 95%;" type="text"/>

Your personal data may be held on computer and will be kept in accordance with the Data Protection Act 1998 under which we are registered as a data controller. This data will not be passed on to any third party without prior consent.

You can keep informed about new resources through our free newsletter, three times a year. If you do NOT want to receive this, please tick here

If you would like to support the CBF regularly please tick here to receive a standing order form

Please make cheques payable to the Challenging Behaviour Foundation and return to the Challenging Behaviour Foundation, The Old Courthouse, New Road Avenue, Chatham, Kent, ME4 6BE

Thank you for your support

The CBF – how you can help

Did you know...?

- *We are a registered charity and rely on donations, grants and fundraising to finance our work*
- *We support families and professionals across the UK – with just three full time members of staff!*
- *We do not charge parents for services or resources*
- *To keep costs down much of our work is carried out by volunteers*
- *If everyone reading 'Challenge' gave just £30 a year the guaranteed income would enable us to take forward a number of important projects. (please ask for details)*
- *Regular giving by standing order makes your money go further by keeping down administrative costs*
- *Your support really would make a big difference to us!*

Please consider how you could support our work

The Challenging Behaviour

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