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Challenge

Challenging
BEHAVIOUR
foundation



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

Spring 2009

The newsletter of The Challenging Behaviour Foundation

Making it happen

Recently, Daniel and I were invited to a formal event in London. I agonised about whether to take him.



Vivien Cooper

It would have been so easy to decline. We needed to be there for 9 a.m. and were given the option to stay in a hotel overnight. But an overnight stay with Daniel would mean we would simply be up all night, so we decided instead to set off at 6 a.m. and drive.

Nearly three hours later we arrived and Daniel was pleased to be out of the car, 'whooping' loudly as we ran along the road. But of course there was no guarantee when we got there that Daniel would choose to go into the event, so it could all be a wasted journey. And if we did get in, it could all go horribly wrong! But we had negotiated a treat for successfully sitting nicely and being quiet, and we went over this again before going in.

Daniel and I had negotiated a treat for successfully sitting nicely and being quiet

There were three of us supporting Daniel, and we all knew him well enough to know when he needed reminding about something, or diverting from someone (for example, Daniel finds it very amusing to slap on the head people with little or no hair). So it wasn't exactly a relaxing time – but Daniel was a star! He introduced himself to virtually everyone, and asked who people were. He sat quietly and

ate fruit and biscuits through the speeches and DVD presentation.

Daniel enjoyed the event and behaved impeccably. As we left, he ran along the corridor, 'whooping' loudly. All heads turned to see what was happening!

The event was the launch of *Valuing People Now*, the Government strategy for people with Learning Disabilities. Daniel met the Secretary of State for Health, Alan Johnson (signing to him that he wanted a house, to go to college and

All heads turned to see what was happening!

do some work). He met Phil Hope (Minister of State for Care Services – see page 7), Anne Williams (National Director for Learning Disabilities), and Christian Raphael (the young man who stars in the *Valuing People Now* launch DVD).

Valuing People Now is about enabling people like Christian and Daniel to have the same opportunities as everyone else – 'making it happen for everyone' – and it was important that they were there; they were powerful ambassadors for people who are often hidden and excluded.

• Vivien Cooper

Chair of Trustees and Founder of the Challenging Behaviour Foundation

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Psychology is nothing more than the discovery of the blindingly obvious

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Everyone, everywhere

Anne Williams was appointed as the new National Director for Learning Disabilities in November 2008. Here she explains what she will do to make sure that Valuing People Now improves the lives of more people

'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

Stress!

Some years ago I attended a lecture on families of children with learning disabilities.

I thought it would impress my girlfriend - you know, rub shoulders with the bigwigs, free wine, that kind of thing. (Never pass a complimentary buffet is my advice). A world-famous researcher was presenting his findings. A detailed study. Longitudinal, even. 'Should be fascinating,' I assured my girlfriend as we sat down.

At the end of an hour that felt more like a lifetime, the researcher (who, it transpired, could bore trilobites to tears with a monotone voice of various shades of dull) concluded, with a sense of yawny awe, that after years of interviews, years of observations, discussions, literature reviews, travels to exotic locations (East Kent?), that parents, siblings and extended families of children with disabilities and challenging behaviour often experience higher levels of stress than other families.

Was *that* audience hushed, flabbergasted and astonished (those of us awake).

My girlfriend stabbed my thigh with a Biro. Said she'd choose the next venue for a date. She said the whole experience confirmed her suspicion that psychology is nothing more than the discovery of the blindingly obvious. I begged to differ, but chose to do so very very quietly and only in my head. Talk about stress.

Working with families of children who challenge has taught me a thing or twelve. That stress is normal and to be expected; it's how we cope that counts (see *Challenge*, Winter '08 edition). That dealing with difficult behaviour in a family can be isolating, thankless and lonely. It taught me I finish work at some point. Whereas families don't.

Working with families of children who challenge has taught me a thing or twelve

I learned to listen and offer practical, unique suggestions; to not become



stressed when parents laughed at my dumber ideas. Not to be dogmatic. (I also learned taking your beloved to the most boring lecture in the history of the universe is not an impediment to lawful matrimony.)

People tend to expect their kids to be fun, happy and for the life course to go according to plan. Having a kid with learning disabilities and challenging behaviour can be fun, happy, a hoot even, but it's also seldom part of the plan, it's often difficult and frustrating and anger-provoking (and that's just dealing with the professionals...just kidding!)

And deviating from plans can cause unease & stress. Sandy Toogood once said *It's good to have a plan. If only to deviate from it.* So! Time to learn to dance, to not be dogmatic, to cut yourself (and the rest of the family), a break. To allow yourself a scream, a tear, a moan and not to decry yourself for getting stressed at what is one of the hardest situations any family could face.

The current focus on family support, on recognising the vital role of family carers is great. Provided it results in actions not words.

• **Tony Osgood**

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

NEWS

Valuing People Now: what is it?

Valuing People Now, launched January 2009, is the government's new three year strategy for people with learning disabilities. The new strategy re-affirms the four guiding principles set out in 'Valuing People - A New Strategy for Learning Disability for the 21st Century', published 2001:

Rights: having the same human rights as everyone else

Independent Living: having the support needed to go about their daily lives

Control: having information and support to make decisions about their own lives

Inclusion: able to participate in all aspects of community, and to have the support to do so

Valuing People Now strengthens the original strategy to ensure that it is inclusive of those groups who are least often heard and most often excluded. This reflects concerns expressed by respondents to the *Valuing People Now* consultation that service providers, commissioners and policy makers were not specifically addressing the needs of people with more complex needs, such as challenging behaviour. The strategy also highlights the vital importance of family carers as key partners in delivery, as well as people with their own needs and lives.

More on pages 6 & 7

Q: We have always used a travel cot when travelling away from home. This keeps our daughter, and us, safe and she seems to get comfort from the security of it. She is now too big to use the cot - any suggestions?

A1: We have a son with autism and challenging behaviour. Holidays were always difficult. For quite a few years we got mileage out of using cheap small dome tents or beach tents for one or two persons. We used a baby monitor and CD story tapes etc. We used to spend time checking out dimensions of hotel rooms/holiday destinations etc. so they would fit a

small tent - raised a few eyebrows! Soon you can erect a tent in five minutes, even under stress, in a hotel room after a long journey!

A2: Fledglings have lots of information on all sorts of equipment for disabled children.

Website: www.fledglings.org.uk
Tel: 0845 458 1124

A3: A company called Tomcat make a lightweight, cot which you can dismantle, the size of a single bed. The mattress is 6' x 3' so you don't need to take that if you know there is one available at your destination. I hope this is helpful.

A4: We have an 11 year old son and on holiday we manage with a pop up tent. He tends to respect the boundary that it gives him and he stays there until it's morning.

Q: I have a teenage client who collects incontinence pads (used and clean) at his school then takes them home. My client simply says he likes the smell. My gut feeling is that this behaviour is meeting some form of sexual need. Any suggestions?

A1: I think it's more likely that the strong smell of faeces is meeting a sensory need rather than a sexual need. I would suggest getting a sensory assessment for the young person. Has anyone used social stories with him to explain why people see this behaviour as unpleasant? He probably doesn't understand that other people don't like the smell.

A2: If you allow him a ready access to unused incontinence pads, and at the same time make it more difficult to access the used ones, then what happens next should tell you quite a lot. If he switches entirely to the clean ones (because it's behaviourally easier to access them) then this would

suggest that the reinforcer is not sensory, and the bonus is that you've at least sorted out the hygiene problem of the situation. I think you're right to look at all possible functions of the behaviour rather than limit yourself – it may be sensory, it may be sexual, it may be reinforced by the attention of others, it may allow him to avoid demand, it may be all or any combination etc.

A3: I have also had a similar experience with a teenage boy. We completed a functional analysis and were leaning towards sensory as a function, however strategies put in place increased him seeking out these items. We then referred him onto Psychology services who identified that the behaviour was in fact sexual in nature and a programme was put in place to allow him access to these items in a pro-active way.

A4: It sounds like sensory needs this young man has. It may be that he does love the smell. There's no point in trying to completely stop his obsession – replacing first is the better way forward, as if you try to stop it completely, another 'behaviour' will start.

What parents say



This is my daughter Amy taken at her 15th birthday party. At the age of three she was diagnosed with autism, severe learning difficulties and challenging behaviour. She has little speech and she also has absence seizures.

She loves to draw, watch DVDs and videos, jump on the trampoline with her brother Thomas and dance (with all the grace of an elephant!) to music. Amy also loves the computer but does things to it I cannot fathom!

Amy is very challenging to us physically and mentally. It is why I love this photo so much: it says happy, beautiful and calm – it doesn't say autism.

Most days she lives in her own little world that is almost impossible for us to reach, which is why moments like this photo are so precious. She steps into our world for a second and that smile that lights up a room makes everything worth while. We all love her so very much.

• Debbie

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

Men in Suits

Never mind worrying about Men in Black, Spooks and Bikers, Punks and Goths. What you have to watch out for are the Men in Suits. Those insidious grey-formed people are more ghost and ghoulies to my mind. They flit into and out of your life, like just glimpsed shadows at the edge of vision, but they leave behind such weight, such constrictions, such feelings of helplessness. This is the way it has to be, they say impassively; there is no other way....drone, drone.

The list of why you can't have what you want, and what your son needs, is endless. Sometimes I think that they are put on this earth to bore you into endless sleep, with their monotone, monochrome view of the world. I was told I had to set up a Trust Fund to continue to receive Direct Payments after my son turns eighteen in March. A Trust Fund, meeting at least four times a year with unknown others, to discuss how I look after him? For the rest of his life? Forgive me if I thought that there must be another way!

But, there IS another way.

This species does not survive by being hidebound by convention. It thrives on change, adaptation and mutation. We adapt to our circumstances. So, faced with yet another immovable statement, I went to the Court of Protection and became a deputy for my son, who lacks the capacity to consent to important decisions about his finances. Now we don't have to set up a Trust Fund: as my son's deputy I can make decisions in his best interests.

• **Solveig Jörgensen, Parent**



Solveig and Seth Jörgensen

Direct Payments and Deputyship

Direct payments offer Seth and Sol a care package that is flexible. They are used very effectively and imaginatively by Sol to meet the needs of Seth, as detailed in his care plan. Seth is due to turn 18 in March 2009. Although Seth will officially become an adult and receive support via the Adult support services his care needs will remain the same.

I know how important it is to both Sol and Seth that the package works well and meets Seth's needs. I can also understand how the Transition process can be such an anxious and difficult time for parents. One of the main concerns for Sol is whether Direct

Payments can continue post 18, as Seth has not got the capacity to consent for direct payments. But, as Sol has discovered, applying for deputyship has assisted with this and made this process easier. Sol has now obtained an Order from the Court of Protection entitling her to manage Seth's financial affairs and she is in the process of applying for the second part of deputyship (welfare). This will hopefully now allow for the local authority to be in the position to continue with direct payments following Seth's birthday.

• **Rebecca Conlon** – *Community Nurse/Case Manager*

Difficult sexual behaviour

"We must learn lessons directly from parents and carers who have to confront so many difficulties particularly through the time of 'transition' from childhood to adulthood. I look forward to hosting an event in the Assembly to discuss these issues during Carers Week, as well as providing the opportunity to hear from other carers and organisations engaged in work and campaigns on these matters."

• **Jane Hutt**, *Welsh Assembly member for the Vale of Glamorgan*

What is a deputy?

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.

There are two types of deputyships:

1. Property and affairs. Decisions about property and affairs cover any possessions owned by a person (such as a house or flat, jewellery or other possessions), the money they have in income and any expenditure.

2. Personal welfare. Personal welfare decisions are any decisions about a person's healthcare, where they live, what clothes they wear, what they eat and anything needed for their general care and well-being.

Further information and application forms are available from the Office of the Public Guardian. Tel: 0845 330 2900. Website: www.publicguardian.gov.uk

Try to find a solicitor specialising in this area.

A new information sheet "Difficult sexual behaviour amongst men and boys with learning disabilities" is now available from the Challenging Behaviour Foundation.

The information sheet gives some suggestions about understanding and responding to difficult sexual behaviour displayed by men and boys with learning disabilities, including masturbation and unwanted sexual contact with other people. A wide range of issues are discussed, including: what is difficult?, sexual contact with other people with learning disabilities, pornography and other sexual stimuli, sexual suppressant

medication, and access to a sexual partner. The information sheet also considers difficult sexual behaviour and the possibility of the man having been sexually abused.

The information sheet has been written by David Thompson who has spent over ten years working directly with men with learning disabilities on sexual issues.

The information sheet can be downloaded free of charge from the Challenging Behaviour Foundation website: www.challengingbehaviour.org.uk

To order your copy of the information sheet, please see page 11.

EXTRACT FROM OUR NEW INFORMATION SHEET

The new CBF information sheet "Difficult sexual behaviour amongst men and boys with learning disabilities" gives some suggestions about understanding and responding to difficult sexual behaviour. Men and boys with learning disabilities are more likely to present challenges in this area than women with learning disabilities. A wide range of issues are described – not all will be relevant to what is a very diverse group of individuals.

Masturbation

General work which could happen during school years could include teaching masturbation is good (this could be done by showing pictures / videos to help men understand the normality of masturbation) and where are good / private places to masturbate: identifying private and public places. For some men this will need to be done by responding when they masturbate in public. This could involve taking them to a private place at that time.

Day centres and schools often say that these are places where people should not masturbate – even in private and during breaks. Responses should be realistic and fair (some individuals will not cope with not being able to masturbate for prolonged periods and there is little to stop staff masturbating in their breaks). Rather than constantly trying to stop a man masturbating publicly (and so exposing themselves inappropriately to other people) it can be more effective to give the man some private time.

Look for patterns in masturbation. Often men do it when other activities offer little interest. For example, a man may not masturbate on a bus but often does it in specific sessions. This can show that the men are making some choice about when they masturbate and so it is more hopeful to be able to put boundaries on time and place

The full information sheet 'Difficult sexual behaviour amongst men and boys with learning disabilities' can be downloaded free of charge from the CBF website, www.challengingbehaviour.org.uk. To order a copy by post please see page 11.

Making it happen for family carers

The *Valuing People Now* delivery plan identifies the following targets for family carers:

- Family carers are valued partners and are well supported
- Family carers understand the role of their local Partnership Board in decision making, influence and its relationship with other local strategies
- Family carers are linked in to networks
- Family carers are informed (locally, regionally and nationally) and know where to go for information, support or advice
- Family carers ask the right questions
- Family carers are involved in developing outcomes/targets
- Family carers have a formal monitoring role

The National Valuing Families Forum (NVFF) will lead this work, and the CBF has strong links with this network. Via the NVFF, the CBF will ensure that the needs of people with challenging behaviour are represented at national level. The NVFF has two family carer representatives on the Learning Disability Programme Board (chaired by Phil Hope, Minister of State for Care Services, and David Behan, Director General of Social Care) which will oversee the implementation of Valuing People Now.

ACTION: Contact your local authority and find out about your local Learning Disability Partnership Board – there will be family carer representatives on the Board and you can link with them to provide and receive information about local, regional and national delivery of *Valuing People Now*.

(To find your local Learning Disability Partnership Board contact your local authority or visit www.valuingpeople.gov.uk – click on “regional pages”, select your region then click on “Find your Partnership Board”)

Everyone, everywhere

Anne Williams was appointed as the new National Director for Learning Disabilities in November 2008. Here she explains what she will do to make sure that *Valuing People Now* improves the lives of more people with learning disabilities and their families:

I was really pleased to be appointed as National Director because it is a real opportunity to build on the work so far and to really make a difference to the lives of all people with a learning disability and their families. *Valuing People Now* sets out what the Government will do over the next three years. The consultation responses demonstrated that most people think that we have got the policy right – it is translating that into practice for people, making a real and positive difference to their lives that is the challenge. I believe that we have to focus on delivering real outcomes, which is why we have a delivery plan. We have looked at how we make things happen, what needs to be in place at a local, regional and national level to support those actions, and how we will check if it is working.

Families have told us very clearly that we need to get better at supporting people with complex needs to enable them to have the same opportunities that the rest of us take for granted. Families are valued partners in this and in every aspect of my work I am mindful of the role that families play and the importance of ensuring that the voice of people with complex needs is heard.

In my previous post as the Director of Adult Services and a member of the Learning Disability Partnership Board in Salford we had as a priority improving services for people whose behaviour challenged services. I was especially

Most people think that we have got the policy right – it is translating that into practice for people, making a real and positive difference to their lives that is the challenge



Anne Williams

pleased when we were able to work with three young men and their families to develop supported living for them in their local community. Instead of being placed miles away in residential units they had their own property, designed to meet their needs, with support workers especially trained to work with young people with autism and learning disabilities.

we need to get better at supporting people with complex needs

The difference in their lives was so good to see: more independence, greater involvement in the community, and activities tailored to their interests. The challenging behaviour reduced significantly and their families were pleased to have more contact with them and see them thriving.

It is not acceptable that people have to move away from their families to get the support they need, or that they are excluded from community life because we cannot organise appropriate housing and support, or include them in local education, employment and leisure opportunities.



Phil Hope, minister of State for Care services, shows Daniel Cooper and mum Vivien the new Valuing People Now strategy document

Making it happen for everyone, everywhere is my goal. I do not underestimate the enormity of the task, but am encouraged by the commitment from a wide range of stakeholders, from individuals with learning disabilities, their families, support organisations and service providers through to local, regional and national Government. People with learning disabilities and challenging behaviour are some of the most disadvantaged and excluded groups in our society, and require individualised support and services to meet their needs. Families of people with learning disabilities and behaviour described as challenging

I am determined that we get it right

need good practical information and support and by working together we will make greater progress.

Delivering what is in *Valuing People Now* is a huge task, but is exciting and a great opportunity. I am determined that we get it right for people with complex needs, including people with challenging behaviour, and that we work positively with families to achieve this.

• **Anne Williams** National Director for Learning Disabilities

Making it happen for people with complex needs

Valuing People Now identifies the characteristics of a good service for individuals with complex needs as follows:

Good services for people with complex needs start with person centred planning, and with the assumption that everyone can benefit from direct payments and personal budgets.

Good services for people with complex needs develop and use appropriate communication systems where people have little or no verbal communication, taking guidance from families and friends to understand what gestures or sounds may mean.

Good services for people with complex needs do not assume that behaviours that seem challenging are simply part of a person's disability; we know that these behaviours serve a function for the individual and it is essential to identify what that function is. Often these are the only way that individuals have of communicating that their needs are not being met and it is essential to address this; ignoring them may put lives at risk.

Valuing People Now emphasises that the vision for people with more complex needs (including challenging behaviour) is the same as for everyone, ie. inclusion and participation in all areas of community life, including living independently and having paid work:

"To assume that some people cannot, and will never, achieve these is to set a ceiling on what progress can be made, both by an individual and by a society."

To obtain a copy of *Valuing People Now* Tel: 0300 123 1002, or download from

www.valuingpeople.gov.uk

Deprivation of liberty safeguards

People with severe learning disabilities should be cared for in ways that promote their independence, well-being and choice. However sometimes people with severe or profound learning disabilities are deprived of their liberty for treatment or care because this is necessary in their best interests to protect them from harm.

From 01 April 2009 new safeguards come into place in England to protect vulnerable individuals from being deprived of their liberty unnecessarily. All hospitals and care homes who are caring for a person in a way which takes away a person's freedom must ask for an assessment to decide if it is right to take away the person's liberty.

Read more on these new safeguards in the Summer edition of 'Challenge'.

Planning for the Future

"My sixteen-year old daughter has a severe learning disability, with complex communication problems; she will also display challenging and self-injurious behaviour. I know that her future adult placement is going to be far from easy!"

Transition is a word I have come to dread, as it usually involves a major upheaval in my daughter's life, and from previous experience I know if I don't get it right the consequences for both her and me can be dire.

The Challenging Behaviour Foundation's "Planning For The Future" information pack contains information and advice on how to plan and prepare for transition, plus a guide to what financial help you could be entitled to in order to get the best suited placement that will meet your child's future needs.

I have found it a great tool in helping me through the mountain of information and questions that I want to ask, and I have given copies to my child's school and social worker so that we can all use it together as a point of reference."

'Planning for the Future' contains information relevant both for those with children aged 12 and upwards

(transition planning) and those concerned about the support needs of adult sons and daughters. The pack has been written to provide both parents and professionals with the information they need to understand the support options available for individuals with severe learning disabilities and challenging behaviour.

Cost: £10.00 (free to family carers). To order, please see page 12.

Supporting Change DVD wins approval

- *A big thank you to the Challenging Behaviour Foundation for their excellent new DVD. Having just viewed 'Challenging Behaviour - Supporting Change' I will be asking my child's school and respite provision to view this fantastic source of much needed information.... This DVD should be viewed by anyone involved with children or adults who have severe learning disabilities and display challenging behaviour...*



- *The DVD explains the function of challenging behaviour for the child; it will enable parents and professionals to gain a better understanding as to why our children use their behaviour to get their needs met.*
- *Well done to the three families that allowed us into their lives. I could really identify with their everyday situations, and the impact challenging behaviour can have in a family....*

'Challenging Behaviour – supporting change' explains how a functional assessment of challenging behaviour can help identify appropriate behaviour management strategies for individuals with severe learning disabilities. Interviews with three families show how to identify the purpose (function) of the behaviour (eg. social attention, tangibles, escape, sensory feedback), and how a functional assessment can help put in place effective strategies – both reactive (short term) and proactive (long term) strategies.

Running time 70 minutes (approx).
Cost £63.00 (free to family carers).

To order please see page 11.

I sylw'r holl siaradwyr Cymraeg!

Mae fersiynau iaith Gymraeg o'r pecyn 'Cynllunio ar gyfer y Dyfodol' gan y Sefydliad Ymddygiad Heriol yn awr ar gael. Gweler tudalen 12 i archebu, neu ewch i'n tudalennau gwe newydd yn y Gymraeg.

Attention all Welsh speakers!

Welsh language versions of the CBF 'Planning for the Future' pack are now available. See page 12 to order, or visit our new Welsh-language web pages.

Sleep or behaviour problem?

The DCSF's Centre for Excellence and Outcomes (C4EO) has funded an evaluation of behavioural interventions for sleep and/or behaviour problems for families with a disabled child. The research team, based at the University of York, is currently mapping practice in supporting or working with families whose child has a sleep or behaviour problem.

If your job involves such work and you are willing to complete a very brief questionnaire, please contact Dr Bryony Beresford (bab3@york.ac.uk). Alternatively, the questionnaire is available online via the project's website:
<http://www.york.ac.uk/inst/spru/research/summs/c4eo.html>.

Two exciting new job opportunities at the Challenging Behaviour Foundation

At this time of economic uncertainty we are delighted to report that the Challenging Behaviour Foundation has been successful in securing funding enabling us to advertise two new posts.

Details are being finalised as we go to press, and by the time this newsletter finds itself in your hands we will have details available on our website. Please help us by passing on news of these job opportunities to anyone you know

Please help us by passing on news of these job opportunities to anyone you know

who may be interested.

The two new posts will enable us to build on our current work providing information and support to families and in our strategic work influencing policy and practice nationally. One area of work we have long wanted to develop is in providing training in understanding challenging behaviour and supporting behaviour change, and the new funding will enable us to build our capacity to do this.

The Challenging Behaviour Foundation wants to see both children and adults with severe learning disabilities who are described as having challenging behaviour having the same life

If you share this vision and believe you could help to make this happen, do get in touch

opportunities as everyone else, including home life, education, employment and leisure. There is much that we need to do!

If you share this vision and believe you could help to make this happen, do get in touch to find out about the two posts and how to apply: Telephone 01634 838739, email admin@theCBF.org.uk or visit www.challengingbehaviour.org.uk

PARENT PERSPECTIVES

Slow death

I couldn't attend the usual night time events with my community and friends. I had so dearly wished to be included in the daytime ones for a token inclusion and to abate the isolation. Wasn't to be.

You don't blame your kids; it's just an overwhelming sense of despair and exclusion and utter hopelessness of any kind of quality of life that other people of your own age take for granted.

It's hard to find anyone to conduct a conversation with about the finer details of how it makes you feel about scraping poo off walls. Tend to be no takers when you need to or want to talk about that. My friends tell me they

My friends tell me they don't know how I cope. The presumption that I cope annoys me a lot.

don't know how I cope. The presumption that I cope annoys me a lot.

I used to be a dancer. Not being able to go and do that, which for me is existing, leaves me feeling crushed inside.

They believe, because they hear you talk, see your presentable face to the world, that it's manageable what you do day to day. What they don't think about is that you are a human just like them, not a superhuman with a bottomless never-ending supply of endurance.

So we are back at home today. I've broke my heart over it, I'm thoroughly sick of what it is and how it feels. I used to be a dancer. Not being able to go and do that, which for me is

existing, leaves me feeling crushed inside.

People have talents and abilities and what's forgotten is you are a person inside yourself, not just a cleaning, tidying machine. Living vicariously through other people means you as the person, the individual, as the unique, interesting, valuable person you are is utterly overlooked, like you have no worth as the individual you are.

Use it. It's what I do. Get very angry and direct it straight at the relevant people who should be providing support and assistance and clearly are not. Ring up the social services and give them hell.

Why on earth should they get 4 hourly breaks and a lunch time, a pension and holiday leave paid for – just to let you die a slow death in your own four walls?



Mythical Creatures win first prize



A special thank you to all those who took part in the **Mythical Creatures Dragonboat team**, who won first prize for best dressed team in the Funraisers Dragon Boat Festival at Bewl Water, Kent, in September 2008, and have raised nearly £3,000 for us in sponsorship money.

Thanks to all those who trained so hard for this event, to Lynn for organising, and for all those who helped on the day.

J Dowle Fencing & Garden Services Ltd, Maidstone paid our entry fee for the event and raised a further £350 through donations from their customers.

Thanks also to **Alison Fisher** and students of the **University for the Creative Arts, Rochester, BA (Hons) Modelmaking** course, who designed and made the team's prize-winning costumes, earning us an extra £150 in prize money.

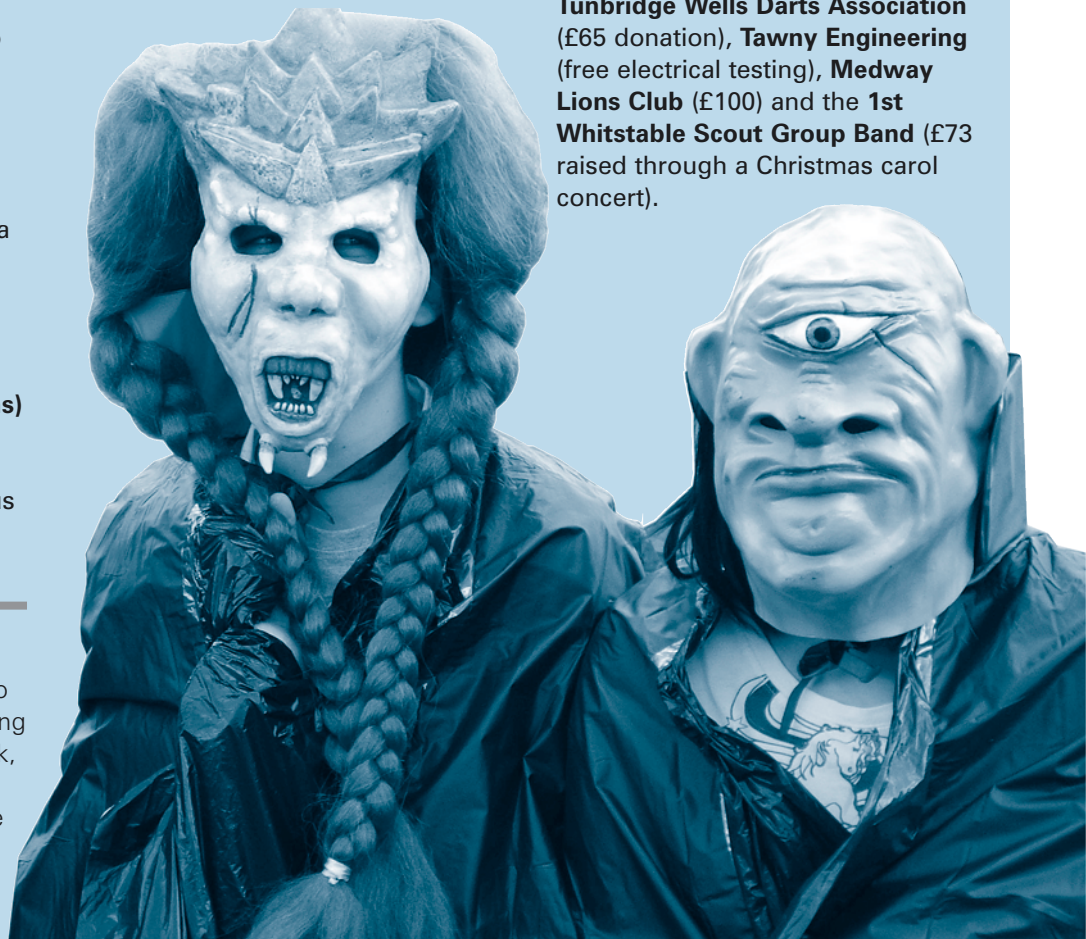
Fundraising opportunities

If you live in Kent do get in touch to find out about our regular fundraising events (quiz nights, sponsored walk, dragonboat race). And if you live outside Kent but would like to raise money for us do let us know your plans and how we can help... "every little helps!"

Thank you

While we cannot mention all our donors by name we would also like to say thank you at this time to **Premier Furniture Solutions, Rochester** (£100),

Gillingham Round Table (£300 raised through a quiz night), **Margaret Holliday** (donation of £110 in lieu of birthday gifts), **The Tunbridge Wells Darts Association** (£65 donation), **Tawny Engineering** (free electrical testing), **Medway Lions Club** (£100) and the **1st Whitstable Scout Group Band** (£73 raised through a Christmas carol concert).



Can Melatonin improve sleep?

Does your child have moderate to severe learning difficulties? Is he/she aged between 5 and 15 years old? Has he/she had problems getting to sleep or staying asleep at night for the past 5 months or more?

If your answer to the questions above is yes, you may be interested to take part in a research study aiming to find out whether the drug melatonin can improve children's sleep.

For more information please contact: Dr Paul Gringras, Paediatric Neurosciences, Evelina Children's Hospital, London (Paul.gringras@gstt.nhs.uk) or Dr Richard Appleton, Paediatric Neurology, Alderhey, Liverpool (Richard.Appleton@alderhey.nhs.uk).

100 Club Winners

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

September 2008: Mrs A Martin, Gillingham

October 2008: Mrs V Lindsay, Preston

November 2008: Ms Lisa Balmer, Litherland (special £50 prize)

December 2008: Ms Kym McMillian, Rainham

January 2009: Mrs J Crisp, Maidstone

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.

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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Resource order form

Please note: all our information and resources relate to the care of individuals with **severe learning disabilities** who are described as having challenging behaviour. We are happy to send resources **free of charge to parents/unpaid carers**.

	Cost	Number	Total £
CHALLENGING BEHAVIOUR DVD RESOURCES			
An Introduction to Challenging Behaviour: DVD	£31.50*		
What is challenging behaviour? Why does it happen? What can be done about it? Uses interviews with two parent carers, with specialist input from Peter McGill (University of Kent Tizard Centre). <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. To order by post please add £1.00 per sheet*		
Communication and challenging behaviour			
Health and challenging behaviour			
Challenging behaviour – supporting change (functional assessment)			
The use of medication			
The use of physical interventions			
Specialist equipment and safety adaptations			
Parents' perspectives			
Planning for the future: introduction			
Further information for parents			
Booklist for professionals			
BASIC INFORMATION PACK	£10.00*		
The following additional information sheets are not contained in the basic information pack but may be downloaded from the CBF website or ordered separately:			
Getting a statement	£1.00*		
Self-injurious behaviour	£1.00*		
Pica (eating inedible objects)	£1.00*		
Psychiatric disorders in people with learning disability	£1.00*		
Difficult sexual behaviour amongst men and boys with learning disabilities	£1.00*		
List of specialist 52-week schools and colleges	£1.00*		
SUB TOTAL CARRIED FORWARD			

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

/ Continued overleaf...

SUB TOTAL CARRIED FORWARD			
	Cost	Number	Total £
SUPPORT OPTIONS FOR CHALLENGING BEHAVIOUR			
It's never too soon to start thinking about future support needs. Both children and adults described as having challenging behaviour need individualised support designed around their needs. These resources have been designed to help both parents and professionals understand the support options available for individuals with severe learning disabilities and challenging needs:			
Planning for the Future: Information pack England / Scotland / N Ireland / Wales <i>(please specify)</i>	£10.00*		
Contents include: Know your rights; Know the processes; Know your options; Case studies; Understanding the funding: Safeguarding & protecting the individual. With information relevant both for those with children aged 12 and upwards (transition) and those concerned about the support needs of adult sons and daughters.			
A New Pathway: DVD 20 minutes	£5.00*		
An overview of a specialist transition service developed to bring four young people back to Medway from out of area residential schools, including access to a specially designed Further Education course at the local FE college.			
A New Pathway: Report 40 pages	£ 5.00*		
A review of the planning model used to develop the Medway Challenging Behaviour FE service.			
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

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 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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Address: The Old Courthouse,
New Road Avenue, Chatham, Kent,
ME4 6BE

Email: info@thecbf.org.uk;

Tel: 01634 838739;

www.challengingbehaviour.org.uk