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# Challenge

Challenging  
**BEHAVIOUR**  
foundation



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

Summer 2010

The newsletter of the Challenging Behaviour Foundation

## All Change

When my son was born I made a number of assumptions.

My first assumption was that there were lots of people who knew a great deal about my son's condition and how to support him well. This was correct.



Vivien Cooper

My second assumption was that we would be connected with those people. This proved to be incorrect.

My third assumption was those people who knew a great deal about how to support Daniel would work in a co-ordinated way to ensure that he received the support he needed. Another incorrect assumption.

There were people who knew Daniel was likely to develop behaviour that would challenge. There were people who knew how to identify the reasons for his behaviours, how to support him and how to equip him with key communication skills. But they never reached us and we didn't know that knowledge existed.

### **Another incorrect assumption**

My experience, and that of most of the families who contact the CBF, is that although there is considerable information available about individuals who are at risk of developing behaviour described as challenging, and how to support them in a positive way, there is no coherent implementation plan. This doesn't make sense on any level. At the CBF we try to address this for individual families through our family support work. But it requires a bigger,

more strategic solution.

At the CBF we had a radical idea: to identify all the people and organisations who have a role to play in supporting children and adults with learning disabilities and behaviour described as challenging, to bring them all together, and to agree how to work in a

co-ordinated way to make sure that the right support is delivered in the right place at the right time.

### **The right support in the right place at the right time**

This edition of Challenge focuses on the work of the Challenging Behaviour National Strategy Group (CB-NSG). True partnership working requires time and effort and a willingness to change. But it makes sense to do it, however hard it may be at times.

### **True partnership working requires time and effort and a willingness to change**

Members of the CB-NSG are working together to a common aim – to enable people to live good lives with the right support. Together we can facilitate real change.

#### **• Vivien Cooper**

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

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##### **Resources**

***A truly excellent practical resource...***

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##### **A Charter for Change**

***As many as 27,000 people in the UK may have been given a label of challenging behaviour – a label that has become misused over time...***

#### **PAGE 8**

##### **Sign up now**

***Show your support and commitment to working together to improve the lives of individuals with learning disabilities described as challenging...***

#### **PAGE 9**

##### **Invite your MP**

***On 1st December 2010, the All-Party Group on Autism and the All-Party Group on Learning Disability will hold a joint meeting in Parliament to discuss 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

# Pulling together

Professionals hold powerful roles and have opportunities to influence people's lives for the better or for worse.

Through the heaps of assessments and explanatory models flying around, never forget our purpose is to serve and understand a fellow human in acute distress. Seek to remain humane and open. This is a challenge to us all, regardless of profession: to be human and responsive to our companions in distress on this small pale blue-green dot of a planet.

Expert? Alternative translation: Ex - past it. Spurt - an unexpected poorly aimed drip.

Meyer & Evans, in their 2006 New Zealand analysis on what works in terms of intervening constructively with children who challenge, note that all the intervention approaches (and there are a heap of ideas out there, from pills to programmes, from cuddles to curses) can be enriched by working together. Different disciplines, families, services, solving problems by working together...

Mmm. You know, sometimes the blindingly obvious isn't seen.

Meyers & Evans' is a great report. Bit short on laughs, but hey, so much of

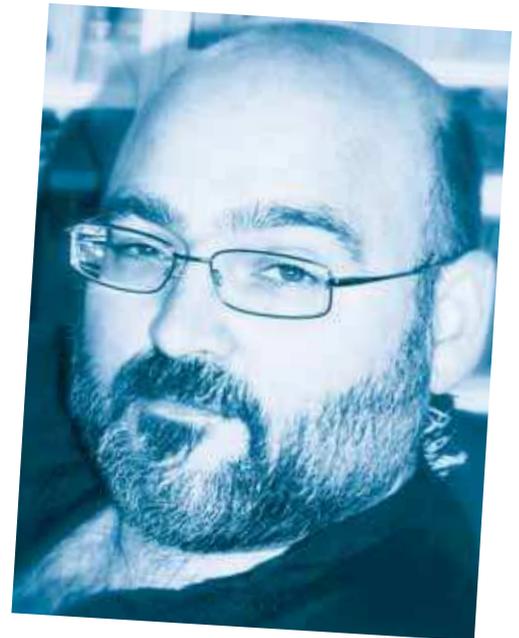
academia is like that. This is a serious issue and they're keen to note we're wasting people's lives while we debate what works and get ourselves organised. These two were amongst the first to argue against prescriptive interventions, to consider why the child did what they did, to consider communication, to help the kids learn, to start with the child. So they have my vote, being something akin to Heroes with a capital 'H' to me.

Alas, all of us moving Down Under isn't an option. It's time for change here, now.

The word, folks, is collaboration. Collaboration enriches understanding of contexts. It enables professionals to learn a lot, to contribute to family and child-specific solutions.

## *Collaboration enriches understanding*

One family I worked with had numerous kids (more kept appearing from behind sofas, under the stairs, making us spill our teas) with numerous issues and these parents



were, well, the word is knackered. One child (and they showed me the letters as proof) had no less than twenty agencies and services involved. And here's the truly shocking bit: most of these professionals disagreed with one another in the advice they gave.

So the family tried to sail a sensible course for their situation - and reaped the whirlwind abuse of spurned professionals.

Working together, sharing ideas, will mean breaking down professional boundaries and that dreaded 'professional distance' theme. Listen. It's simple.

I wish the Challenging Behaviour National Strategy Group every success as it seeks to bring about change. One task is to work out why things don't work so well currently. When it can be worked out why services, different professionals, parents and children and adults who challenge are pulled apart from one another, then perhaps solutions can be tried, good practice examples of working together can be celebrated and shared, and grown. The knack is this: to pull together, not pull apart.

• **Tony Osgood**

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

## HOW YOU CAN HELP

### Please support the work of the National Strategy Group (see pages 5 - 9)

***"The Challenging Behaviour National Strategy Group is playing a critical role in sharing information and good practice from around the UK. It's also forging partnerships and developing initiatives that will help improve the quality of support received by some of our most vulnerable citizens"***

*(Prof. David Allen, Abertawe Bro Morgannwg University Health Board & Cardiff University)*

***"As a family carer I have long felt that what was needed for my son was a joined-up approach – with my son's needs kept central at all times. The CB-NSG is committed to action that will make a real difference – for my son and for others with similar needs across the UK."***

*(Viv Cooper, Chair of Trustees, The Challenging Behaviour Foundation)*

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

If you would like to support the work of the Challenging Behaviour Foundation in leading the work of the Challenging Behaviour National Strategy Group,

**PLEASE SEND A DONATION TODAY.**

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

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

**THANK YOU FOR YOUR SUPPORT**

**Q: Our 30 year old daughter has severe learning disabilities and Prader-Willi Syndrome. Her placement has begun to break down and her psychiatrist feels her house is too busy (she lives with nine people) and has put her on medication. Any suggestions?**

**A1:** Have you ever thought of a one-to-one placement in a home rented just for your daughter? I was horrified when this was suggested to me for my son but it has worked out very well. He is 25 and lives in a lovely flat, with one-to-one care by a team of carers.

**A2:** My main stream sons would not

want to live with nine people they hadn't chosen to live with, so why should a person with a disability wish to spend their life with nine strangers? Try to get funding to house her on her own with care built around her? Might take a long time but in the long term it will build a life for her surely that is better for her.

**A3:** A home for your daughter should not be too difficult to achieve under the Inclusion Policy. Does she have a social worker/advocate who might be able to help? My son was assessed for Continuing Care at the age of 18. The psychiatrist admitted that his challenging behaviour would entail medication and restraint. Having fought for services, he lives in his purpose-built bungalow with us. I asked that the Local Health Board provide support for our son, when we can no longer manage his behaviour due to age etc. Plans are now in place for a transition in nine years time.

**Q: I am working with a girl whose outbursts are triggered by communication, light and noise. Should I focus on communication or all target areas at once? The school wants to employ time-out, but I don't think this should be the first action.**

**A1:** You are right to resist 'time out' as a punitive strategy as it does not seem to have any evidence base. I would probably start with the area associated with the highest frequency/severity of behaviour. Functional Communication Training (FCT) is an important part of any change coupled with a Total Communication strategy. A Speech and Language Therapist (SLT) will support your work.

**A2:** I suggest assessments for Autism Spectrum Disorder or communication disorder. There is

perhaps some need for a more appropriate communication with the girl. The outbursts may be due to lack of understanding what is expected of her. There may also be far too much sensory information around (sounds, smells, other people, etc.) that makes it impossible to focus on the task required.

**A3:** I would recommend involving Speech and Language Therapy for a communication programme, and one intervention at a time with measurements compared with baseline data in order to monitor the impact of the intervention.

**A4:** It sounds like you know how to support the person to adapt her behaviour but you need to change the behaviours of her support system to enable this to happen. It is often better to focus on one thing at a time unless risk and real life demand otherwise. Joint working can take time to coordinate which may dictate your implementation schedule. Early successes are very motivating if teams are reluctant to follow implementation plans.

## What parents say



Sol and Seth Jørgensen

This is a heavy planet for my son. The consultant said that walking for him is like running for us, so how many people run through a day, never mind a life?

I have come to think of it more as this is a heavy planet, when it comes to my son and others like him. A bit like the astronauts when they try to walk, where every move is costly, each movement takes immense effort and we watch them and see the sweat shine.

I wish there was a way that I could teach others who see or work with my son the reality of his life. Perhaps I could send them underwater, with weights, and then get them to try to do everyday things and see then, the slowness of response, the moving through heavy water. The inability to move or even turn quickly.

I wonder? What would people think of me if this became a necessary training requirement of working with my exceedingly patient, quiet, and gentle giant of a son - when they ask him to do yet another impossible task, and do not see that he is walking through heavy water, on a heavy planet.

• Sol, mother to Seth

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

**Want to join the debate? Membership of our email networks is free to both parents and professionals. Application forms from [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) or email [info@theCBF.org.uk](mailto:info@theCBF.org.uk)**

## Josie's story



Josie Sharp

Josie is 16 years old and has severe learning disabilities, epilepsy and challenging behaviour. Initially she went to our local special needs school, but she was taken out of her classroom due to aggression.

A behavioural specialist carried out an assessment which concluded that Josie's behaviour was due to increased anxiety. The Deputy Head then told me that my daughter could no longer attend the school and that she felt Josie should go to a residential school. Infuriated, I suggested that there was a behavioural plan in place, drawn up by the behaviour specialist and asked why it was not being adhered to at school when it was working very well at home. But Josie was permanently excluded from school, which also caused her to be denied any access to her respite centre. As a consequence this led to Josie having to stay at home for 8 months. Much to my dismay I then had to come to the conclusion that Josie had to go to a residential school, as she could not get the education or help she deserved.

Josie has now been at residential school for three years, about 200 miles away. The school provides consistency and enthusiasm, which is all that Josie really needed to help her progress. It angers me that this support was not available in our local borough, not only for myself but for all the mothers and fathers who are still in the same situation. Something needs to be done!

• **Ann Sharp**, family carer

## Now available

A guide for advocates in England and Wales supporting people with learning disabilities who are described as having challenging behaviour is now available from the Challenging Behaviour Foundation.

Characteristics of good support are identified, with suggested questions for advocates to ask around personalisation, activities and opportunities, staff training and communication skills.

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

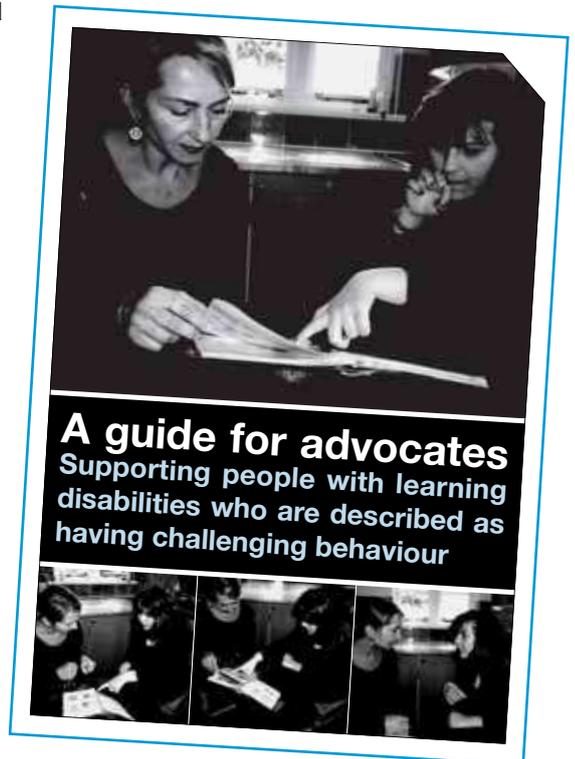
Key 'at a glance' bullet points identify 'what you may encounter' and 'what you should know' – a very practical tool for both professional advocates and family carers advocating on behalf of their family member.

"a truly excellent practical resource" (advocate)

"very, very good" (Rick Henderson, Chief Executive, Action for Advocacy)

Cost: £16.00 (includes postage and packing in the UK only). Free to family carers. To order please see back page.

Visit [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) to preview a sample chapter.



### HOW YOU CAN HELP

## Get involved

Thank you to all those of you who registered your interest in working or volunteering with us following our feature article last issue.

We are still looking for more family carers and professionals interested in supporting the work of the Challenging Behaviour Foundation in very practical ways, eg. fundraising, attending events or conferences on our behalf, speaking or training on behalf of the CBF, offering emotional support to other families – and more!

Please get in touch if you would like to find out more. Training and support will be provided, and by registering your interest you can help us to plan future training events – either at the CBF office in Chatham, Kent, or local to you if we get sufficient interest.

The CBF Trustees are also looking for volunteers to act in an advisory capacity to the Trustee Board. If you have professional experience in finance (investments), PR, Media or marketing please contact [Karen@theCBF.org.uk](mailto:Karen@theCBF.org.uk) (telephone 01634 838739) to discuss how you could help.

**THANK YOU FOR YOUR SUPPORT**

# A Charter for Change



Dr Roger Banks

As many as 27,000 people in the UK may have been given a label of challenging behaviour – a label that has become misused over time. Rather than being used as a term to encourage carers and professionals to understand the underlying reasons for a person's behaviour, 'challenging behaviour' has been used as a diagnostic label, viewed as being intrinsic to the person. Used in this way, this group of individuals has become stigmatised and socially excluded, denied the right to ordinary lives in the community, to education, recreation and employment, and frequently placed in institutional settings a long way from home and families.

It is with this in mind that the Challenging Behaviour Foundation has brought together a group of organisations and individuals to form the Challenging Behaviour National Strategy Group (CB-NSG). The main concerns of the CB-NSG are the risks to the human rights of individuals, the need for better support and services, and for campaigning and advocacy on behalf of individuals and their families. The work of the CB-NSG falls within three main spheres of activity:

- **The gathering of evidence** about current service provision and development
- Establishing and promulgating examples of **best practice**
- **Raising awareness** at all levels including individual and families, statutory health and social care organisations, regional and national governments, the third sector.

The great asset of the CB-NSG lies in its ability to have brought together a wide range of people and organisations; to have families and carers, health and social care professionals, service providers, commissioners and advocates all working to a shared set of aspirations set out in the CB-NSG charter (see over the page). This group is reviving the expectations of those who first promoted the term 'challenging behaviour', encouraging the systems around the individual to find ever more creative, responsive and person centred ways of rising to the challenge.

- **Dr Roger Banks** FRCPsych FRCGP(hon)

*Consultant in the Psychiatry of Learning Disability; Betsi Cadwaladr University Local Health Board, Wales;  
Honorary Senior Lecturer, Bangor University*

## Working Together



Jackie Edwards

As the parent of a 20 year old young man who has behaviour that challenges I have felt it very important to support the work of the CBF and in particular the Challenging Behaviour National Strategy Group (CB-NSG).

My son's behaviour has made it difficult for him to be supported in his local community and has meant that he was out of area for quite a few years. With the right support he has now been able to move back into his own home within a few miles of where he grew up.

The CB-NSG is a group of parents and professionals working together to achieve the best outcomes for individuals with learning disabilities who are described as challenging.

I have personally found it very helpful to be able to learn and work alongside professionals through the CBF and I am now in the process of writing an information sheet for family carers on how to raise complaints effectively - an idea that arose at a CB-NSG meeting.

- **Jackie Edwards**

*Parent and Family Carer Coordinator for the Valuing people Support Team in the South West.*

## An important development



Bob Tindall

Amongst the many strengths of the CB-NSG is its capacity to engage in dialogue with a broad array of people who can bring about improvement nationally. Crucially, the contribution of family members keeps us grounded in determining practical steps forward. Personally, I have found it a source of inspiration and renewal. Those of us tasked with leadership responsibilities need to listen, but we also need to be open

to being taught. These opportunities should be taken when they are presented.

As personalisation develops, the organisations which will thrive are those willing to engage with people and their families, and to find ways through difficulties which inevitably will occur. There also needs to be a real commitment within organisations to recognise and encourage creative action by staff in front line support roles. Colleagues in these roles will need to be trained in finding person centred – as opposed to beaurocratic, repressive and timid – solutions to the potential difficulties arising from someone's challenging behaviour.

The Challenging Behaviour National Strategy Group is an important development for providers and United Response is delighted to be taking part.

- **Bob Tindall**

*Managing Director  
United Response*

# Rights and Values



1. People will be supported to know about and make use of Human Rights. They will get help to stay healthy and to be an important part of the community where they live. They will be helped in ways that make sure other people give them respect. The person's age, sex, race, beliefs, sexuality or disability will not be a reason for discriminating against them.

2. People will find out everything they can about a child who has behaviour problems. They will help and support them and their family as soon as possible. So when they grow up they will not have as many problems.



3. Families will be helped to be healthy and happy together.

4. People will have person-centred planning and support that is just for them. Plans and services will know all about how people communicate. Their support will change if it needs to. People will get help from the services where they live.



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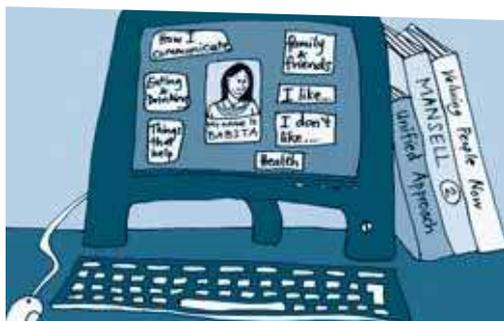
**5. People should have the best help to be as well and healthy as they can be.**

**6. People have the same rights as everyone else to a family and social life, relationships, housing, education, work and leisure.**



**7. Care and support should be given by people who are properly trained. They should be able to support the person with whatever they need and whatever problems they have. They should support people in ways that have been shown to work best. They should be able to get extra help from specialists when they need it.**

**8. Everyone must do everything that they can to make sure that people will not be hurt or made to feel bad by the things that are done to cope with difficult behaviour.**



**9. Carers, supporters and staff must make sure that they find out what are the best ways to help people who have problems. They must find out what is up to date and what works from people who study these things.**

## Support the Charter

The Challenging Behaviour National Strategy Group (CB-NSG) charter (see pages 5 - 7) was developed to set out the shared aims and aspirations of members. It was felt to be important to emphasise the human rights of children and adults with learning disabilities perceived as challenging who are often excluded from their local communities and managed in restrictive ways.

To show your support and commitment to working together to improve the lives of individuals with learning disabilities described as challenging, please sign and return the slip below.

We welcome sign-up from both organisations and individuals.

## Sign up now

I/We .....  
(name of individual/ organisation)  
endorse the rights of individuals as set out in the Challenging Behaviour Charter and commit to working with the National Strategy Group to influence change.

All who sign up to the charter may be listed on the CBF website (contact details will not be listed). I/we give our permission to be added to this list.

Signed.....

Print name.....

Name of organisation & job title  
(if applicable)  
.....

Contact details:

E-mail  
.....

Tel no.....

Address.....  
.....  
.....

Please return to: CB-NSG Charter, Challenging Behaviour Foundation, The Old Courthouse, New Road Avenue, Chatham, Kent, ME4 6BE

# Promoting best practice and raising awareness

The work described on these pages provides a taster of the actions CB-NSG members are taking to work towards better lives for individuals with learning disabilities perceived as challenging.

The Challenging Behaviour Charter was an important starting point for the Challenging Behaviour National Strategy Group (CB-NSG). In addition to the values (see pages 6 & 7), a second section of the charter lists the action to be taken. A comprehensive work plan is now being developed building on the actions set out in the charter.

To view the full charter, action plans, presentations from meetings and to find out how to become a CB-NSG member visit the CBF website  
[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)  
and click on the "Strategy Group" pages.

## Capable environments



Lisa Hopkins

What should commissioners and people with their own budget be looking for when purchasing support? Getting it right for people with a reputation for behaviour that challenges should involve a 'Capable Environment'. A Capable Environment refers to the technical competency of the support being provided; it includes a positive culture, organisational structure, professional guidance, and practice leadership.

Dimensions, with input from the CB-NSG, are writing a new resource guide describing Capable Environments and offering guidance on what to look for. The guide will be available later this summer.

• **Lisa Hopkins**  
*Director of Specialist Development, Dimensions*

## Services and support for family carers



Catriona Moore

The Social Care Institute for Excellence (SCIE) has been asked by the CB-NSG to produce a set of pamphlets for family carers, summarising the services and support they should expect at each life-stage. The aim is to help family carers understand what 'good practice' looks like, and to help them ask the right questions about services in their local area. The pamphlets will be based on current national policy on learning disability and challenging behaviour. A 'virtual advisory group' of CB-NSG members are providing input, with the final version expected later this year.

• **Catriona Moore**  
*Policy Development Manager, Social Care Institute for Excellence*

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## Influencing politicians

On 1st December 2010, the All-Party Group on Autism and the All-Party Group on Learning Disability will hold a joint meeting in Parliament to discuss challenging behaviour.

All-Party Groups are groups of MPs and Peers from all political parties who share an interest in the same topic. The All-Party Group on Learning Disabilities was set up in 2005 and has around 40 members. The All-Party Group on Autism was set up in 2000 and has over 90 members. Both groups campaign in Parliament and lobby the Government for greater awareness and better services for people with learning disabilities and autism.

The December meeting aims to raise the awareness of challenging behaviour with MPs and Peers, giving them an opportunity to understand why individuals may behave in ways perceived as challenging and how this can be addressed via personalised support. It

will also discuss what steps the government can take to improve the lives of people with challenging behaviour.

We will hear from a wide range of people at the meeting, including parliamentarians, family carers and professionals. The speakers will share their experiences and insights. We have also invited the minister and shadow minister to listen and learn from the discussion.

Please contact your local MP asking them to attend the meeting, as this is often an effective way to ensure their participation. If you are not sure who your MP is you can find out at [www.parliament.uk/mps-lords-and-offices/mps](http://www.parliament.uk/mps-lords-and-offices/mps).

We also hope to see many of you there at the meeting!

• **Ellen Broome**  
*Public Affairs Officer, National Autistic Society*

## Influencing decision makers

The CB-NSG will raise awareness of the needs of children and adults with learning disabilities who are perceived as challenging at the National Children and Adult Services (NCAS) Conference in Manchester on Wednesday 3rd November 2010.

This event is attended by councillors, senior officers, policymakers and service managers with responsibilities for children's services and adult social care in the statutory, voluntary and private sector. Attendees discuss and debate the latest issues affecting children and adult services.

This year these important decision makers will hear from the CB-NSG represented by Dr Roger Banks (Royal College of Psychiatrists), Dr Theresa Joyce (British Psychological Society) and Sally Meadows (an individual with an autism spectrum condition) who will explain the key issues in identifying the needs of individuals whose behaviour is perceived as challenging and in developing, co-ordinating and delivering effective supports that can result in the best outcomes for the individual.

The CB-NSG will make information available for every local authority regarding their population, financial and other costs, and key actions to take.

**To find out more about any of the work described on these pages and to get involved, contact [nationalstrategygroup@thebcf.org.uk](mailto:nationalstrategygroup@thebcf.org.uk) or telephone 01634 838739**

## Invite your MP!

Dear .....  
(insert name of MP),

I am writing to ask you to attend an all party group on challenging behaviour, associated with learning disabilities or autism.

**Date:**  
Wednesday 1st December 2010

**Time:**  
4.30pm-6pm

People with learning disabilities or autism and behaviour perceived as challenging are amongst the most vulnerable in our society; please show them and their families your support by attending this meeting to find out more.

### Message to your MP:

Name.....

Address.....

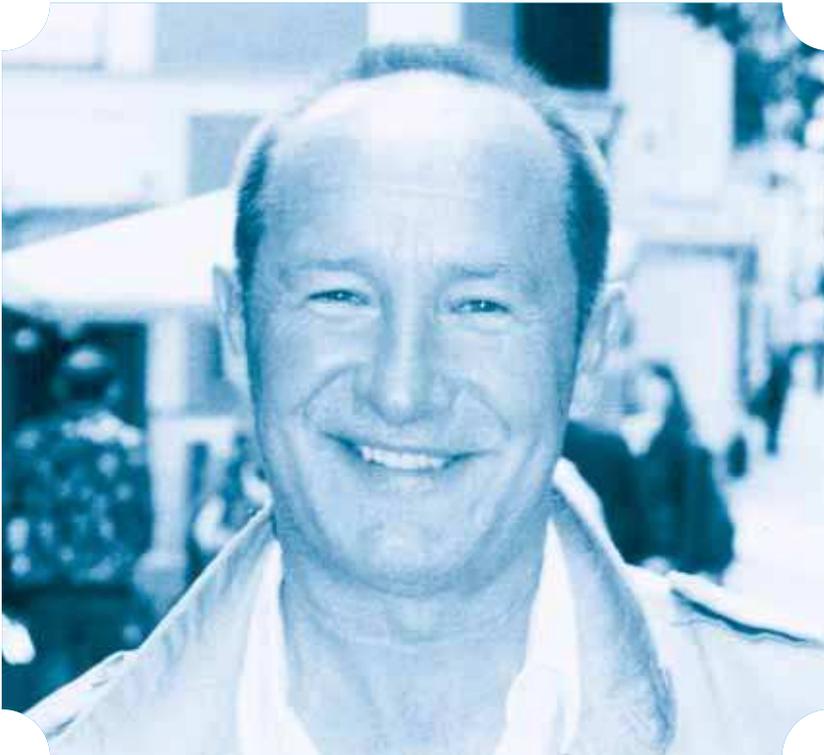
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To find the postal address of your MP visit: [www.parliament.uk/mps-lords-and-offices/mps](http://www.parliament.uk/mps-lords-and-offices/mps)

## IN SYMPATHY



We were sorry to hear of the sudden passing of

### **Graham Boulden**

on 2nd April 2010 from a heart attack  
while on holiday in Egypt.

Many 'Challenge' readers will know Graham, his wife Jayne and son Oliver who all feature in the CBF DVD 'Challenging Behaviour – Supporting Change'. Our sympathy to Jayne, Ollie and Alex at this very difficult time and our thanks to Graham's friends, family and colleagues who together have donated £775 in Graham's memory to the Challenging Behaviour Foundation.

## Wanted: adult siblings of people with autism and high support needs

Adult siblings often find themselves taking on increasing responsibilities and advocating for a disabled brother or sister as their parents get older, even though they may no longer live nearby. Support services can overlook the contribution or concerns of adult siblings who may be important figures in the lives of people with autism, whatever their level of disability.

The Economic and Social Research Council (ESRC) is funding an 18 month study at the Department of Health Sciences, University of York, to find out what kind of information, advice and support might help siblings feel more confident to play the role they wish in the lives of their brothers or sisters in the future.

For more information, with a view to taking part in this research, please contact  
Rosemary Tozer,  
e-mail [rjt102@york.ac.uk](mailto:rjt102@york.ac.uk) or  
telephone 01904 321908

## Carers' Credits

Introduced in April 2010, the Carer's Credit is a National Insurance credit which helps to protect an individual's National Insurance record to ensure there are no gaps from having to undertake caring responsibilities.

Carer's Credit is available to people who provide care for one or more disabled person(s) for a total of 20 hours or more each week, where they do not currently receive Carer's Allowance. Each person you care for must receive: Disability Living Allowance care component at the middle or highest rate; or Attendance Allowance at any rate; or Constant Attendance Allowance at any rate. If the person being cared for does not receive one of these benefits, you must provide a Care Certificate signed by a health or social care professional (HSCP).

For more information and for a Carer's Credit application pack telephone 0845 608 4321, visit [www.direct.gov.uk/carers](http://www.direct.gov.uk/carers) or write to: Carer's Credit, Palatine House, Lancaster Road, Preston, PR1 1HB

## SUPPORTERS' NEWS

### Pass it on!

With no guaranteed regular income the CBF needs volunteers to help raise funds to continue our work. Did you know you can raise funds for the CBF and have fun at the same time? Over the years CBF supporters have taken part in a range of activities on behalf of CBF, ranging from quizzes and sponsored walks to mud-racing and sponsored leg waxing for the more adventurous!

If you are not in a position to be able to raise funds for us yourself, please consider whether any of your friends, family or colleagues may be

able to help. Would they like to join the CBF 100 Club? Many companies offer matched giving incentives to encourage employees to raise funds for charities, others choose a 'charity of the year' to support – why not nominate the CBF?

Friends, colleagues, professionals or family members are all potential supporters. One easy way to help is to pass this newsletter on to someone else and to ask them to consider supporting the CBF.

For more information about how you can support the CBF contact [info@thecbf.org.uk](mailto:info@thecbf.org.uk) or visit [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

## Thinking about the future?

'Prepared for the future' is a new resource from the Foundation for People with Learning Disabilities, designed to help families to prepare for when a young person with learning disabilities is leaving school or college.

'My kind of a future' is a workbook to help young people with learning disabilities prepare for adult life. With practical exercises and tasks, the workbook has been produced to help young people think about what they want and to provide the information they need when they leave school or college. 'What kind of a future?' focuses on supporting young people with Down's syndrome prepare for life beyond school.

All resources can be downloaded free of charge from the Foundation for People with Learning Disabilities website: [www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

## 100 Club Winners

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

February 2010: Mrs A Stickles, Gillingham

March 2010: Mrs K Dickens, Spalding

April 2010: Mr & Mrs Shaw, Rainham

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

## 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 £ |
|---|---|--------|---------|
| <b>CHALLENGING BEHAVIOUR DVD RESOURCES</b>  |   |        |         |
| <b>An Introduction to Challenging Behaviour: DVD</b>  | £31.50*   |        |         |
| What is challenging behaviour? Why does it happen? What can be done about it? Uses interviews with two parent carers, with specialist input from Peter McGill (University of Kent Tizard Centre). <i>40 minutes</i>   |   |        |         |
| <b>Self-injurious Behaviour: DVD</b>  | £31.50*   |        |         |
| What causes self-injurious behaviour? What action should parents and carers take? Professors Chris Oliver and Glynis Murphy join forces with two family carers to offer clear and practical information and advice to families. A useful introduction also for professionals. <i>40 minutes</i>   |   |        |         |
| <b>Communication and Challenging Behaviour: DVD</b>   | £31.50*   |        |         |
| Four family carers and a speech & language therapist explain the relationship between communication and behaviour and highlight practical approaches to improve communication and minimize challenging behaviour. <i>40 minutes</i>   |   |        |         |
| <b>Challenging Behaviour – Supporting Change: DVD</b>   | £63.00*   |        |         |
| In this 2-disc DVD set meet Oliver, Dougie and Dominic and hear the functional assessment process explained. Interviews with family carers highlight the range of causes of challenging behaviour, and how a functional assessment can help put in place appropriate behaviour management strategies for individuals with severe learning disabilities. <i>(Approx 70 mins)</i> |   |        |         |
| <b>CHALLENGING BEHAVIOUR INFORMATION SHEETS</b>   |   |        |         |
| <b>Basic information about challenging behaviour</b>  | All information sheets are available free of charge on the CBF website.<br><br>To order by post please add £1.00 per sheet* |        |         |
| <b>Communication and challenging behaviour</b>  |   |        |         |
| <b>Health and challenging behaviour</b>   |   |        |         |
| <b>Challenging behaviour – supporting change (functional assessment)</b>  |   |        |         |
| <b>The use of medication</b>  |   |        |         |
| <b>The use of physical interventions</b>  |   |        |         |
| <b>Specialist equipment and safety adaptations</b>  |   |        |         |
| <b>Parents' perspectives</b>  |   |        |         |
| <b>Planning for the future: introduction</b>  |   |        |         |
| <b>Further information for parents</b>  |   |        |         |
| <b>Booklist for professionals</b>   |   |        |         |
| <b>BASIC INFORMATION PACK</b>   | £10.00*   |        |         |
| The following additional information sheets are not contained in the basic information pack but may be downloaded from the CBF website or ordered separately:   |   |        |         |
| <b>Getting a statement</b>  | £1.00*  |        |         |
| <b>Self-injurious behaviour</b>   | £1.00*  |        |         |
| <b>Pica (eating inedible objects)</b>   | £1.00*  |        |         |
| <b>Psychiatric disorders in people with learning disability</b>   | £1.00*  |        |         |
| <b>Difficult sexual behaviour amongst men and boys with learning disabilities</b>   | £1.00*  |        |         |
| <b>List of specialist 52-week schools and colleges</b>  | £1.00*  |        |         |
| <b>SUB TOTAL CARRIED FORWARD</b>  |   |        |         |

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

/ Continued overleaf...

|  |         |        |              |
|--|---------|--------|--------------|
| SUB TOTAL CARRIED FORWARD  |         |        |              |
|  | Cost    | Number | Total £      |
| <b>OTHER RESOURCES</b>   |         |        |              |
| <b>A guide for advocates (England and Wales)</b>   | £16.00* |        |              |
| Key 'at a glance' bullet points identify 'what you may encounter' and 'what you should know' – a very practical tool for both professional advocates and family carers advocating on behalf of their family member.  |         |        |              |
| <b>Planning for the Future: Information Pack</b><br>England/ Scotland/ N Ireland/ Wales<br><i>(please specify)</i>   | £10.00* |        |              |
| Contents include: Know your rights; Know the processes; Know your options; Case studies; Understanding the funding; Safeguarding & protecting the individual. With information relevant both for those with children aged 12 and upwards (transition) and those concerned about the support needs of adult sons and daughters. |         |        |              |
| <b>A New Pathway: DVD &amp; report</b>   | £10.00* |        |              |
| This 20 minute DVD provides an overview of a specialist transition service developed to bring four young people back to their local area from out of county residential schools. An accompanying 40-page report reviews how the service was developed.   |         |        |              |
| <b>DONATION – please consider a donation to support our work.</b><br><b>Thank you</b>  |         |        |              |
|  |         |        | <b>TOTAL</b> |

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

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

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

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

|  |  |
|--|--|
| Please indicate if you are a parent or unpaid carer. If you are a registered charity please provide your charity registration number |  |
|--|--|

Name

Organisation

Address



Postcode

Telephone

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

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

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

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

**Thank you for your support**

# The CBF – how you can help

*Did you know.....?*

- ***We are a registered charity and rely on donations, grants and fundraising to finance our work.***
- ***We have no regular guaranteed income.***
- ***We do not charge family carers for services or resources.***
- ***To keep costs down much of our work is carried out by volunteers.***
- ***If everyone reading 'Challenge' gave just £30 a year the guaranteed income would enable us to take forward a number of important projects. (Please ask for details)***
- ***Regular giving by standing order makes your money go further by keeping down administrative costs.***
- ***Your support really would make a big difference to us!***

***Please consider how you could support our work.***

## **The Challenging Behaviour Foundation**

Registered charity number 1060714

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