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Challenge



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

Winter 2007

The newsletter of The Challenging Behaviour Foundation

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Communication and Challenging Behaviour

We sometimes think that these children are being naughty, when actually it's their only means of communicating...

'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

Choices, choices

Rhys is seventeen years old, with severe learning disabilities, severe autism and at times severely challenging behaviour.

In our new DVD resource: 'Communication and Challenging Behaviour' (page 5), Rhys's mum explains how communication issues are often the root cause of Rhys's behaviour – and how important it is for Rhys to be able to communicate his choices and preferences.

"One day last summer when the community care team were due to take him out for a walk, he wouldn't get into the car. He became very agitated – just walking round in circles. I ran in and got his little board with "yes" and "no" and asked him: "Do you want to go out for a walk today?", and he clearly pointed to "no"...

We did it three times just to show them he really doesn't want to go. That doesn't mean he doesn't need community care to take him out for a walk, it was just that particular day he didn't really want to. So he was able to express his views. We were able to communicate with him and he calmed right down."

my son's carers now have a duty to consult with me

In this issue of 'Challenge' we are looking at the new Mental Capacity Act (pages 2 and 4) and how this both empowers individuals with learning disabilities to make their own choices as far as possible, while at the same



time ensuring their protection in situations where they lack the capacity to make a decision. As the parent of a young man with severe learning disabilities I welcome this new legislation – particularly as my son's carers now have a duty to consult with me on any important decision that has to be taken on his behalf.

The new Act will protect my son's rights – the right to make his own decisions and choices as far as possible, and the right for his best interests to be clearly central to any decision that is made on his behalf.

Isn't that exactly what you or I would expect for ourselves?

• **Vivien Cooper**

Chair of Trustees and Founder of the Challenging Behaviour Foundation

WE HAVE MOVED!

Please note our new postal address:
**The Challenging Behaviour Foundation
The Old Courthouse
New Road Avenue
Chatham
ME4 6BE**

Tel: 01634 838739

Email: info@theCBF.org.uk

ANALYSIS

Presumed capable

When we consider capacity of individuals with disabilities to make decisions, beware inadvertently excluding people by setting the bar of capacity too high.

Have you ever made any bad decisions? From having one too many drinks, too much cake, turning the wrong way onto the M25? Even, perhaps, in terms of relationships? Having the capacity to make decisions is not the same thing as making good decisions. Think foreign policy and you get my drift.

Choices, dumb decisions, uninformed decisions, are a part of our lives. The Mental Capacity Act (2005) knows this and declares every adult should be presumed to have capacity to make decisions, unless proven otherwise.

But not all decisions are equal: there is a difference between choosing between a chocolate digestive or a rich tea, and choosing your partner. There are quantifiable differences between choosing to take your medicine to help control your epilepsy or not. The reason I know this is because I have (to

some degree, my wife might suggest) capacity to make decisions on quite serious topics. I can understand what my options are, I can retain that information, and I can make a decision, all in a non-coercive situation.

And so to people with learning disabilities. Some decisions are easy and don't involve much risk. These issues seldom raise the capacity question. But not taking medicines? Not leaving the house alone? Not speaking to strangers? Not choosing the out of area residential placement offered?

No one can give consent on behalf of another adult, but that doesn't mean we cannot act in the person's best interests. But saying we are acting in a person's best interest is not an excuse for us to do whatever we want to do. Just because we think something is the best course of action, doesn't

mean we should not involve the person in the process, nor listen to their apparent decisions, be they considered wise or not, informed or not. Just because the person appears to lack the capacity to make decisions doesn't mean their opinions and wishes should not be considered.

And just because someone appears to lack the capacity now does not mean they will forever be thus. How can we build the understanding of the person? Can we make the information more accessible? Can we build capacity over time?

Capacity fluctuates with the decision at hand, with how we're feeling, with what we've just experienced. We ourselves too often fail to act in an informed manner. The reinforcement for eating rubbish is immediate: the stuff tastes so satisfying. Distant health dangers are no match for immediate satisfaction.

Unless we can see the consequences immediately and clearly, many of us opt for the quicker fix, which is so often also, sadly, the poor choice. So even though most of us would be deemed to have capacity, the idea of an informed, independent choice might be a little too easy to deconstruct.

With the dawning of the Mental Capacity Act (2005) we have a pathway to follow, we have safe guards. But the key to its successful implementation is that we recognise the humanity and abilities of the people labelled as disabled.

We are all human, and we all make mistakes, yet our humanity, and our expectations that people will listen to our points of view, are not diminished.

Lord, grant us the capacity to understand the implications of the Mental Capacity Act. Amen to that!

• **Tony Osgood**

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



BACKGROUND

The Mental Capacity Act 2005

The Mental Capacity Act (MCA), which is introduced fully in England and Wales from 1st October 2007, formalises and develops existing law in order to empower and protect adults (with a chronological age of 16 years or more), such as men and women with severe learning disabilities who may lack the ability or capacity to make one or more of their own decisions about their health, welfare, or money. It also places a duty on those who make decisions on behalf of others to consult with families.

To find out more, visit the website of the Ministry of Justice (www.justice.gov.uk) or the Office of the Public Guardian (www.guardianship.gov.uk) and then search under Mental Capacity Act. This provides access to the Mental Capacity Code of Practice which provides more details about the MCA in everyday language, and other useful guidance, such as Making Decisions: A guide for family, friends and other unpaid carers.

The Code of Practice can be downloaded from the websites or ordered from The Stationery Office, PO Box 29, Norwich, NR3 1GN (tel: 0870 600 5522 or email customerservices@tso.co.uk). Making Decisions can also be downloaded or ordered (tel: 023 8087 8036 or email reorder@inprintlitho.com).

With thanks to Isabel Clare and Tony Holland – more on page 4...

YOUR QUESTIONS

Q: My daughter (age 9) has just got a diagnosis of autism after several years and still the LA are not amending her statement and not allowing my request for a residential school. We do have respite but it's not enough. I'm on my last legs, can't cope anymore. What can I do?

A1: Have you had a Carers' Assessment? This should help you get the support you need. Get your councillor involved, make a complaint. I have made three successful complaints over this type of thing; it's hard work to complain alongside living with the stresses of a challenging young person but our children have rights and we have rights. Don't give up!

A2: A new statement for your daughter must be the first job. With a revised

statement it's easier to get everything else. The system is designed to accommodate the line of least resistance and lowest cost. You have to assert your child's rights - no one else will.

A3: Have you formally asked for your daughter's statement to be amended or for residential school to be considered? That would be the first step. If you have and been refused then there are procedures to follow to challenge the decisions which the LA should inform you of. We found that our son's paediatrician, school and respite staff were all supportive, so get as many people involved as possible. Sometimes just making it clear that you will challenge everything will get things moving.

A4: Regarding respite care, ask for a reassessment from Social Services and stress that it is urgent. My own experience is that Social Services do not respond until the situation reaches crisis point and this has to be spelled out to them clearly and repeatedly.

Q: Can a harness be used for safety on a buggy, or is this perceived as restraint?

A1: If you have a harness on a wheelchair or sides on a bed to prevent someone falling out, then this really shouldn't be considered as restraint. If the cot sides are to prevent someone from getting out of bed in the morning because that's more convenient for staff, or the harness is to stop the client pottering about in the house, then this is restraint. Clear guidelines concerning when and where the harness can be used, and a robust monitoring and review process to ensure that the guidelines are being followed are essential.

A2: I think it is important to risk assess the situation. If a child is at risk of injury if not kept safe then it maybe necessary to look at a harness, especially if parents are out on their own or have other children. I would

also look at reasons why they are fidgeting, for example, are they bored or hungry?

A3: I was once given a group of pupils who had been used to being strapped into buggies but it was very clear that they didn't want to be in them. I spent two years trying to get them into structured teaching routines where they would sit on a chair for increasing periods of time. We did get there in the end, but it would have been easier if they didn't have to unlearn that 'I only sit when I'm strapped in'.

A4: Read the 'Guidance for Restrictive Physical Interventions' published by the Dept of Health. It is very clear that physical restraints are illegal if they are used without being in the best interests of the person. It mentions multidisciplinary approaches, best interests, no other more suitable means available and being proportionate to the behaviour of the individual.

What parents say



Our son Elliot contracted encephalitis in December 2001 aged three and a half. He was left with a mental age of a 1-2 year old although he's now nine.

Elliot hates shopping and I was in our local supermarket with him a month or so ago. He was sat in his wheelchair screaming and shouting and just generally protesting, when a man in his sixties came up to me and said:

"Do you realize, I can hear you all around the store!"

Overcoming my embarrassment and annoyed at what I perceived as a lack of understanding from this man, I was just about to educate him with a lesson on children with learning disabilities and challenging behaviour when he then carried on to say....

"And do you know what, I don't blame him. I often feel like screaming. I hate it in here too!"

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

THE MENTAL CAPACITY ACT (2005)

Support for decision-making

The involvement of families is very important in supporting the Mental Capacity Act. Families can provide important support for decision-making.

Families can provide opportunities in childhood and young adulthood for their relative to develop skills and confidence in making her own decisions, as far as this is possible, and participate as fully as possible in decisions that need to be made on her behalf. This kind of support makes it more likely that she is more likely to develop an understanding that:

- there is a decision to be made, involving a choice between two or more options
- choosing one option rather than another has different outcomes
- the option chosen controls, or at least has a significant influence on, the outcome.

Families can provide information for others (in writing, or on tape, or DVD) about the decisions (health, welfare, finances) that their relative is able to make for herself and the kinds of support that is most likely to help her make her own decisions.

Anticipating that there may be one or more decisions that the person is unable to make for herself, they can also provide information about her wishes, values, and preferences (and what she does not like). This will not be legally binding but anyone making a decision on her behalf when she is an adult must take this information into account.

The involvement of families is also very important in supporting the balance between empowerment and protection.

For more information about the Mental Capacity Act, please see page 2.

With thanks to Isabel Clare (Clinical Psychologist) & Tony Holland (Psychiatrist), Cambridgeshire & Peterborough Mental Health NHS Trust, and the Learning Disabilities Research Group, Department of Psychiatry, University of Cambridge (www.ldr.org.uk).

Challenging decision-making

On some occasions, families may feel that:

- their relative is not being permitted to make one or more decisions that she is able to make for herself, or could make for herself with support, or
- there are 'reasonable grounds' for believing that their relative lacks the capacity to make one or more decisions she is making for herself and that her 'choices' are not valid, or
- they have not been consulted about one or more decisions made on their relative's behalf, or
- one or more decisions made on their relative's behalf are not in her 'best interests' because they are for the convenience of others, or unnecessarily restrictive.

In any of these situations, families should, first, make an informal

approach to those responsible. Staff supporting the person should be able to justify the approach they have taken.

Where there is disagreement about whether or not someone is able to make a particular decision, it may be helpful to ask for an assessment of capacity (for example, by a member of the local community team for people with learning disabilities), and to involve an independent advocate. If a disagreement proceeds to a formal complaint, the Office of the Public Guardian can give advice and information.

If other methods do not resolve the issue, the Court of Protection, which deals with health, welfare, and financial decisions by men and women whose decision-making may be compromised, may become involved. Families may want to get help from a solicitor or Citizens' Advice about this.

THE MENTAL CAPACITY ACT (2005)

Empowerment and protection

The Mental Capacity Act attempts to balance the right of adults to make personal decisions for themselves, as far as possible, and their right to protection from hardship, exploitation, abuse or neglect.

| EMPOWERMENT | PROTECTION |
|--|---|
| The starting point is that every adult has the right to make her own decisions, provided she has the ability, or capacity, to do so. | Any decisions made on behalf of someone who is unable to make decisions for herself must be in her best interests. Decisions must not be made to suit others. |
| Everyone should receive support to help them make their own decisions, as far as practicable. This may mean breaking the decision down into parts, or making it simpler (for example, presenting the possible options rather than offering them in words), or thinking about the timing of the presentation of the decision. | In considering 'best interests' the values and preferences of the person on whose behalf the decision is to be made must be taken into account. As far as possible, families and others must be consulted so that her values and preferences are represented. |
| Any decision made on behalf of someone, in her 'best interests', should involve as few restrictions as possible. | There are two new criminal offences to protect those who are neglected or ill-treated by staff (or family members) with a responsibility ('duty of care') towards them. |

PARENT PERSPECTIVES

Getting away

Before we won our appeal for our son to attend a specialist 52-week residential school, things at home had been at a critical stage for years.

We were all totally exhausted. Michael only needed two hours sleep per night – so every night we suffered from broken sleep.

If we dared to remain asleep when he woke up, the house would be turned upside down. The dining table, chairs, sofa, TV, video would be piled in the middle of the room like a bonfire. Or the fitted carpets would be completely pulled up, bathroom flooded, radiators ripped off the wall, water everywhere. This was the norm. We started to take it in turns sleeping on the hall floor outside his room.

Michael's special school freely admitted they didn't know how to deal with his behaviour. Daytimes were spent just waiting for them to telephone. I would go for long walks or rides on my bike. I just needed to get away where nobody could contact me.

Once education stopped funding Michael's residential placement our son wanted to move back to the village to be near his family.

Social services wanted him on the edge of a run down council estate where vulnerable adults were often victimised. We refused.

After a long hard struggle, we eventually found a housing association which assists adults with challenging behaviour and learning disabilities to live in their local community, in their own property, with support.

Support during pre school years had been erratic and I didn't think that things could get worse - but they did. Michael is 22 now and life has been just one long struggle.

To get away from it all I used to go to my allotment to do some digging with the small amount of energy that I had left. In the afternoons, once the sun was up, I would just lie on the ground. And sleep.

NEW RESOURCES FROM THE CBF

Communication and Challenging Behaviour

Communication is one of the most important ways in which we control our environment and influence other people. However, many people with learning disabilities may have difficulties with communication, and challenging behaviour can sometimes become their only effective means of communicating.

Our new 40 minute DVD profiles Rhys, Laura, Sean and Isobel to examine the link between communication and behaviour. Interviews with family carers and a speech and language therapist highlight some common

communication difficulties, illustrate different communication approaches available and demonstrate the importance of all carers working together.

Produced primarily for family carers, the DVD 'Communication and Challenging Behaviour' will also provide a useful introduction for health, social care or teaching staff who may encounter challenging behaviour

To order your copy of the DVD 'Communication and Challenging Behaviour', please see page 7.

EXTRACT FROM OUR NEW DVD

"We sometimes think that these children are being naughty, when actually it's their only means of communicating..."

And until we find a different way they've got no choice, really..."



Clare Pierce and daughter Isobel, from our new DVD 'Communication and Challenging Behaviour'. See order form on page 7.

Thank you, Debra

By the time you get this newsletter we should be installed in our new office – thanks largely to Debra Pratt, CBF volunteer. Debra has volunteered at the CBF office over the last three years, mailing out information, organising our resources, keeping on top of our filing, helping at fundraising events, and now managing our office relocation. Thank you, Debra!

Our new address: The Old Courthouse, New Road Avenue, Chatham, ME4 6BE

Debra Pratt, CBF volunteer



As the last resort: reducing the use of restrictive physical interventions

This study by Roy Deveau and Peter McGill, the Tizard Centre, University of Kent, examines the attitudes and practice of 137 adult residential services with respect to the use of restrictive physical interventions. The findings show that 15% of services using physical interventions do not have physical intervention policies or provide physical intervention training.

The report offers three core strategies for services serious about reducing the use of restrictive physical interventions. For more information visit

www.kent.ac.uk/tizard/research/projects

A BIG THANK YOU to all who supported us during 2007

"I have found so much support and advice via the CBF, your help has been invaluable....I think without help from your Foundation I would not have known where to turn....."

This, our 10th anniversary year, has been an exiting time for us, with the appointment of Gemma Honeyman as a full time Family Support Worker. Gemma is currently responding to around six crisis calls a week from families, as well as running our growing support network and developing new resources for carers.

As we are now reaching more families (currently in regular contact with over 800) so our costs have also risen – and we are indebted to our faithful supporters without whom we could not continue – our 100 club members, quiz night supporters, and those who give regularly by standing order.

While we cannot mention everyone by name we would like to say a special thank you at this time to the following groups:

- Bradfield FE Centre, Gillingham, for help with this mailing
- Greenside School, Hertfordshire: £30 donation following a musical morning
- St Peter & St Paul PCC, Leybourne - £225 donation
- Sir Joseph Willamson's Mathematical School, Rochester: £100 donation and £570 raised at their summer charity fete
- The Napier Community Primary & Nursery School, Gillingham: £97.64 raised at their performance of 'Daniel'
- Wycombe Abbey School - £625 donation, proceeds from the school bus service

Thanks also to the Motley Crew dragon boat team – a great performance and sponsorship money still being collected!

Challenging Behaviour: A Unified Approach

This report, by a joint working group of the learning disability faculties of the British Psychological Society and the Royal College of Psychiatrists, in consultation with the Royal College of Speech and Language Therapists, looks at standards of clinical practice in supporting people with learning disabilities who present behavioural challenges.

The report aims to provide a unified framework for good practice, to inform and empower service users and carers, and to provide a set of standards of good practice against which service provision can be benchmarked and audited.

Cost: £12.50. Available from the Royal College of Psychiatrists, tel: 020 7235 2351 or visit www.rcpsych.ac.uk/publications/collegereports

Help To Move On: Transition pathways

This report examines the experiences of twenty young people with learning disabilities leaving residential school or college and looks at what support and information was available for them and for their families. The report makes recommendations concerning the transition from residential school or college.

For more information contact: Pauline Heslop, the Norah Fry Research Centre, tel. 0117 331 0980 or email pauline.heslop@bristol.ac.uk

Calling parents of children with Smith-Magenis syndrome: we need you!

The University of Kent at Canterbury Tizard Centre is conducting a study examining challenging behaviour displayed by children with Smith-Magenis syndrome.

The study aims to look at why children with Smith-Magenis syndrome display such behaviours. In return for participating you will be offered a brief assessment of your child's behaviour. Please contact Paul Langthorne if you are interested in finding out more, telephone: 01227 827269 or e-mail P.Langthorne@kent.ac.uk

100 Club 2008: now's the time to join!

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

February 2007: Mrs J Evans, Hawshurst

March 2007: Dr S Judd, Chester

April 2007: Mrs F Ingarfield, Loose

May 2007: Mrs M Judd, Wickhambreux

June 2007: Mr G Foster, Marshside

July 2007: Mrs M Matthews, Isleworth

August 2007: Mrs P Mosley, Lyme Regis

All proceeds from the 100 Club help towards our office running costs. Shares cost just £1 per month. To join in 2008 please see back page.

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

All our resources relate to the care of individuals with severe learning disabilities who are described as having challenging behaviour.

Parents/ family carers please note: While we are happy to send our resources free of charge to parents/ unpaid carers in the UK, if you send a donation this will help us to provide free resources to other families. Thank you.

| | Cost | Number | Total £ |
|--|---------|--------|---------|
| Challenging Behaviour (Information pack) | £10.00 | | |
| Communication and Challenging Behaviour (DVD) | £31.50 | | |
| An Introduction to Challenging Behaviour (DVD) | £31.50* | | |
| An Introduction to Challenging Behaviour (VIDEO) | £35.00* | | |
| Self injurious Behaviour (DVD) | £31.50* | | |
| Self injurious Behaviour (VIDEO) | £35.00* | | |
| A new pathway for young people with severe learning disabilities (DVD) | £10.00 | | |
| Transition: what are the options? (Information pack: England only) | £10.00 | | |
| Adult services: what are the options? (Information pack: England only) | £10.00 | | |
| Postage & Packing | | | |
| <small>All prices include postage. For orders outside the UK please add £7.50 per item</small> | | | |
| Donation | | | |
| <small>* Registered charities: DVDs £16.50 or videos £20. Price includes postage & packing in the UK only.</small> | | | |
| Total | | | |

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

Gift Aid means we can claim back the tax on your gift (28p for every £1 you give) at no extra cost to you. If you are a UK tax payer and would like to Gift Aid your donation, please sign here:

Please indicate if you are a parent or unpaid carer. If you are a registered charity please give 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.

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

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

Please support the Challenging Behaviour Foundation

YES I would like to support the work of the CBF

Please tick as appropriate:

- I would like to support the CBF regularly. Please send a standing order form
- I enclose a donation to help you to reach more families in 2008
- I would like to Gift Aid my donation*

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

Signed

Date

Name

Address

Postcode

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

- I would like to join the CBF 100 Club 2008. Each share entitles me to a chance to win a monthly prize of £25. All proceeds help with CBF running costs. I enclose a cheque for £ (£12 per share)
- I would like to help you reach more families. Please send me brochures to distribute to families/ professionals.
- I would like to fundraise for the CBF. Please send me information on how I can help.
- Please remove me from your mailing list.

Please 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.....?

- *The CBF does not charge parents for services or resources*
- *To keep costs down much of our work is carried out by volunteers*
- *If everyone reading 'Challenge' gave just £15 a year we would have a guaranteed income of over £25,000, which would enable us to take forward a number of important projects*
- *Regular giving by standing order makes your money go further by helping keep down administrative costs.*
- *Your support really would make a big difference to us!*

Please help us to 'Find the Families'.

Please consider how you could support our work

The Challenging Behaviour

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