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Challenge

Winter 2009

Challenging
BEHAVIOUR
foundation



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

The newsletter of The Challenging Behaviour Foundation

Breaking news

Common sense tells us that caring for a child or adult with behaviour that challenges is difficult.

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Comment

No more crumbs, thank you

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What parents say

I like eating fish – not looking at them!

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Resources

Help to improve safety and protect the living environment

SPECIAL REPORT

Getting a break

Families are expected to cope without support and on a long term basis with a situation which qualified professionals say they are unable to manage, is too difficult for them or beyond their expertise

In this issue the Challenging Behaviour Foundation and the Tizard Centre, University of Kent, report on findings from a survey of families' experiences of short break provision

'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

To expect families to do this day in day out without a break is unreasonable. We don't expect paid staff to do this – we provide them with training and support, set hours, holidays and sick leave. But most families who are in contact with the CBF don't get anywhere near the support they could or should be offered. The systems operate with little planning or co-ordination, and services are mostly allocated on a crisis management approach.

This has to change. The emotional, health and quality of life costs to individuals and families is completely unacceptable – and the financial cost when compared to the outcomes delivered is hard to justify. It simply doesn't make sense.

Services are mostly allocated on a crisis management approach

I know what it's like to live with a child whose behaviour is constantly challenging, who sleeps very little and who has to be watched constantly for his own safety and that of others. And that's in addition to trying to get the support you need. It's hard. If it was described as a job, no-one would apply! But the absolute worst thing is – it needn't be like that.

We have an opportunity now to make



Vivien Cooper

If it was described as a job, no-one would apply!

some changes – all the policies say the right thing but they have yet to translate into positive practice. In this issue of Challenge we report on new research into the

availability of short breaks. The day to day reality for many families is unacceptable.

We have an opportunity now to make some changes

I started the Challenging Behaviour Foundation because it simply didn't make sense to me that the knowledge, information and expertise available about supporting people with behaviour that challenges failed to get through to those who would benefit from it.

Our approach is simple – we aim to empower families with information, and engage with others (through our national strategy group) to campaign for - and deliver - strategic change so that quality support is delivered when, where and how people need it.

Not rocket science – common sense.

• Vivien Cooper

Chair of Trustees and Founder of the Challenging Behaviour Foundation

Getting a break

If you are caring for a disabled child or adult, getting a break can be likened to searching for a low-lying island whilst treading water in a shark infested ocean.

If you are caring for someone whose behaviour is challenging, getting a break is like trying to do the same but with someone standing on your head.

A break means a rest, breathing space, interlude, lull or pause, depending who you ask. For me a break means a change in my usual often *imposed* routines, a time to do things I want, a pause to step outside the everyday and gain a little space to think, to remember who I once was, and still, deep down, remain.

I'm not talking a monastery here (4am starts seem a little beyond me. And gardening is something that happens to other people). But a time to reflect. (No, not in a mirror- that way lies horror, and probably, seven years bad luck). A break, for me, is like an island on my journey through an ocean of the everyday. It's an essential, not a luxury.

For families of those whose behaviour challenges, a break might have the same value as, say, a snorkel to a diver. A break isn't about having a holiday or

'a well earned rest', but often about merely surviving.

But getting a break has been equated, in terms of difficulty, to asking in Welsh, after six pints of Old Peculiar, for directions to the nearest all night avocado merchant.

And for too many families fortunate enough to have secured (with superglue?) some form of short breaks, and without placing their children at risk, there exists, sometimes, the temptation to overlook matters that might sour their relationship with the organisation providing the break. This is a little like being determinedly satisfied with crumbs from the captain's table; families feel they have to appear grateful to the powers that be for small mercies. *Don't rock the boat too much,*

A break isn't about having a holiday or 'a well earned rest', but often about merely surviving.



else they might leave us to swim.

One of the services I managed, some time ago now, provided short breaks. We went out of our way to make sure parents knew they could let us know when we let them or their children down (no provision is ever perfect). My confident "You can pop in anytime, day or night, just to make sure" was in hindsight an invitation to do just that. So we had families "just popping in" at eleven at night. At seven in the morning. And, on one famous occasion, the day before Christmas Eve, accompanied by a Salvation Army Brass Band.

There are some great short break providers. And there are some who provide the minimum. It illustrates the dearth of breaks that for many families, anything even remotely safe is better than nothing and will be seized upon.

We need more. We need better. And, for those of us in the business of providing, we must be prepared to work with families – at eleven at night, at seven in the morning, accompanied by Brass Bands if necessary – to ensure what we are providing is actually what families need.

No more crumbs, thank you.

• **Tony Osgood**

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

NEWS

Are we making a difference?

We want to improve the lives of individuals with severe learning disabilities. If our resources or support have helped make a difference

PLEASE LET US KNOW.

The CBF has no regular guaranteed income and we constantly need to provide evidence to our funders and potential funders that our work does make a difference...

YOU CAN HELP US

by providing stories, anecdotes, or examples (anonymously if you prefer)

Please email, write or telephone:

The Challenging Behaviour Foundation,

Freepost RRRH-GCJS-BRZJ

The Old Courthouse, New Road Avenue, Chatham, ME4 6BE

Tel. 01634 838739 Email: info@theCBF.org.uk

THANK YOU FOR YOUR SUPPORT

Q: My daughter (24 years old) has autism, severe behavioural problems and learning disabilities. She attends a day centre and caused some damage during an "outburst" which I have been informed I must pay £150 for – is this right?

A1: I would refuse to pay and ask for the people running the day centre to give a written explanation for their request, stating clearly when and where they had previously given notice that clients are held personally responsible for damages. Did you or your daughter sign any agreement that you would cover damages?

There is an insurance policy available via the National Autistic Society that gives cover against such damage; that

would not help in this case but might be useful in the future.

A2: It sounds unbelievable that a parent should be charged when the local authority and the day centre has a duty of care to the daughter, plus the fact that at the age of 24 she is an adult in her own right and any action should be against her – which of course would be a crazy approach! I would suggest you contact the free advice service 'disability law' (020 7791 9800) for an opinion, also the disability rights commission...

A3: That seems incredibly unjust. What can you do about it when you are not there? Is that not a staffing issue and an insurance issue (they must be insured – surely they can claim under their own insurance?). Can you approach someone higher up the food chain of the organisation? Maybe you are worried that she will be banned from attending if you complain but perhaps you will need to.

Q: We are working with a young non-verbal man with ASD who spends much of his time spitting. Over the years many approaches have been tried, but to little effect. His family is concerned that this may lead to exclusion. Any ideas?

A1: What about social stories? Write a story in pictures (unless he can read then use words as well) about how we should behave outdoors/in a specific location and where it is ok to spit. What you don't do is talk about what behaviours we don't want, only behaviours we do. This has worked in the past for different issues. The story should be read regularly (e.g. before going out) and becomes part of the routine.

A2: You need support from a specialist clinical psychologist or behavioural nurse. This person should carry out a functional analysis to distinguish the different reasons for the behaviour and then guide you on how to respond to the behaviour depending upon the reason(s).

A3: Does he not like saliva in his mouth? Is it an oral tactile issue? Not just a visual stimulation? If it is oral there are other things that might be useful to try.

A4: Clients with autism may spit (or do other repetitive behaviours) to add predictability in situations that they feel are unstructured, as part of superstitious learning (e.g. they believe it causes something that it doesn't), etc. It's worth having a look at any other repetitive behaviours that the client engages in to see when and where they might be using them, and what for.

What parents say



Dominic on a seaside visit from the Thomas Centre, Lincolnshire

We first went to the Thomas Centre (holiday accommodation for the whole family, specialising in autism and severe learning disabilities) to escape the builders and our son Dominic had such a good time we went back again in August to celebrate his 21st birthday! We are already thinking about when we might visit again.

It is evident from the layout of the centre and the onsite facilities that the owners (Jan and Richard) have firsthand knowledge of disability. On arrival, after a 3½ hour journey listening to the same song, we were ready for a swim. Each family is allowed sole use of the indoor pool on a daily basis. The welcome pack provided was amazing, containing scrummy local produce and on our second visit Jan had remembered Dominic was on a gluten free diet. We enjoyed playing skittles, snooker, table football and our own version of giant chess in the huge play barn. There is a small wood which was ideal for Dominic's favourite game – hide and seek. On our second visit a mini assault course had been built. There is a trampoline (dug into the ground – much less worrying) and a football pitch. Cleethorpes and Skegness are nearby and we had a trip to the Deep – although Dominic signed "I like eating fish – not looking at them!" Fish and chips on the way home sorted that! The accommodation was spotless, well furnished and equipped. The Thomas Centre got the thumbs up from Dominic and he is not an easy young man to please.

• **Audrey Giles, parent**

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

Note: the CBF does not endorse or accept responsibility for any goods or services mentioned.

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

Working together

In our last issue we reported on the new Challenging Behaviour - National Strategy Group (CB-NSG), founded by the Challenging Behaviour Foundation to bring key stakeholders together to address the needs of children, young people and adults with learning disabilities whose behaviour is perceived as challenging. The long-term objective of the CB-NSG is to develop a co-ordinated and strategic approach that will offer lasting solutions for individuals whose behaviour challenges our present services.

The group has now developed a charter which sets out the rights of people with learning disabilities who are perceived as challenging to services, as well as highlighting the action which needs to be taken to achieve this. This is the starting point of the work of the group and we look forward to working together to achieve better lives for people with learning disabilities whose behaviour challenges.

We will bring updates on developments and specific actions in future issues of 'Challenge', and you can now read more about the work of the CB-NSG on the Challenging Behaviour Foundation Website.



Visit www.challengingbehaviour.org.uk and click on 'Campaigns' to read about how the group started, view the charter, download a sign up form, see who has already signed-up, apply to become a member and view meeting dates.

To contact the group e-mail: nationalstrategygroup@theCBF.org.uk or Tel: 01634 838739

Specialist Equipment & Safety Adaptations

Need practical information? Then look no further! The Challenging Behaviour Foundation has updated the information sheet "Specialist Equipment and Safety Adaptations" with new products and suppliers. This information sheet contains information about specialist equipment for children and adults with severe learning disabilities who are described as having challenging behaviour and provides details of some of the considerations which can help to improve safety and protect the living environment. Suppliers' contact details are listed at

the end of the information sheet.

New products described include magnetic shower and towel rails, curtains with Velcro tab tops and virtually unbreakable windows, television cabinets and mirrors.

The updated 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 by post, please see page 11.

EXTRACT

Extract from our updated information sheet

Note: Inclusion in this information sheet does not constitute an endorsement from the CBF. Readers are encouraged to evaluate the benefits and risks of each product before purchase.

Beds & Bedding

- Virtually indestructible mattresses are available from Endura, Link Design and Solk Furniture (but are expensive!). One parent contacted the local hospital to purchase a plastic covered mattress after her daughter constantly ripped mattress covers and waterproof sheeting, and this was also easier to clean. Bedding should be made from cotton, to withstand high temperature washes. Tough Furniture and Endura produce beds which can be fixed to the floor if required.

apart under pressure and can be re-attached are available from Primera. Lockable wooden shutters are another alternative, or using a plastic stick-on covering (available from most DIY stores) to give privacy whilst still letting in the light.

Bathroom

- If shower or towel rails are pulled down, magnetic versions (which pull apart from the brackets under pressure and can be re-attached) are available from Primera.

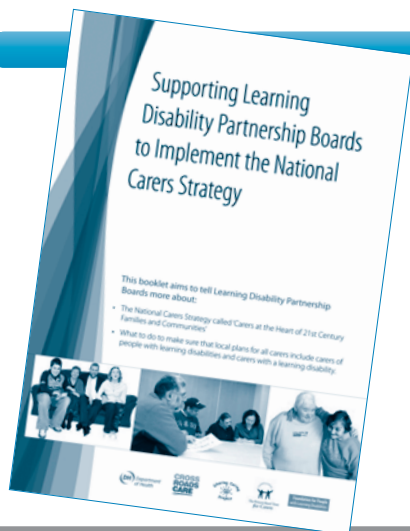
Still can't find what you need?

- Fledglings is a charity which aims to help parents find the equipment they need for their disabled child. Website: www.fledglings.org.uk Tel: 0845 458 1124.

Curtains

- If curtain rails are pulled down curtains with a Velcro tab top are available from Colourways. Magnetic curtain rails which pull

The full information sheet "Specialist Equipment and Safety Adaptations" can be downloaded free of charge from the CBF website, www.challengingbehaviour.org.uk. To order a copy by post please see page (11)



Implementing the National Carers Strategy

The National Carers Strategy ('Carers at the Heart of 21st Century Families and Communities') says that family carers should be supported in their caring role and that they also have a right to a good quality life of their own. For family carers of people with learning disabilities to benefit from this mainstream carers' initiative it is essential that Learning Disability Partnership Boards link up with the implementation of the National Carers Strategy in their local area.

A new guide commissioned by the Office of the National Director for Learning Disabilities, families work programme, 'Supporting Learning Disability Partnership Boards to Implement the National Carers Strategy' aims to inform Learning Disability Partnership Boards about the National Carers Strategy and what to do to make sure that local plans for all carers include carers of people with learning disabilities (and carers with learning disabilities).

The guide gives an overview of Government legislation with respect to carers, an overview of the National Carers Strategy, and sets out to show how the National Carers Strategy ties in with Valuing People Now, concluding with 'questions to ask to make the National Carers Strategy happen'.

Written primarily for Learning Disability Partnership Boards, the guide provides useful information for any carers wanting to know what is happening (or what should be happening!) for carers of people with learning disabilities in their local area.

To obtain a copy of the guide visit the Valuing People Now website: www.valuingpeople.gov.uk

Commissioning for Carers

A new best practice guide, "Commissioning for Carers" has been produced, developed by a range of organisations including Carers organisations, the Association of Directors of Adult Social Services and the Local Government Agency.

Although aimed at NHS and council commissioners, this contains useful information about providing comprehensive carer support, including key questions for commissioners to discuss with carers.



The guide recommends the following actions for local commissioners:

- Think "carer" in all commissioning and area needs assessments
- Improve outcomes, independence and choice for carers, and those they care for
- Involve carers of all groups and communities in decision making and planning
- Strengthen the provider market
- Meet new NHS & social care inspection requirements

Copies are available from: www.idea.gov.uk

Workshop

Kith & Kids are holding an afternoon Workshop on Wednesday 24th February 2010 at the Directory of Social Change, London, with a full programme of information for both

carers and professionals.

Luke Clements and Dame Philippa Russell will speak and answer questions on all aspects of Community Care Law concerning all people with a learning disability.

The afternoon will cover such topics as 'Personalisation', 'Eligibility Criteria' and the 'Equality Bill' and what it will mean for family carers and people with learning disabilities.

Cost is £55 for professionals; £20 for family carers, voluntary advocates and self-advocates. Email: sandra@kithandkids.org.uk or telephone 0208 885 1517 for more information and a booking form

This workshop is part of Kith & Kids 40th Anniversary programme, and is endorsed by BILD, MENCAP, the National Family Carer Network and the Challenging Behaviour Foundation.

Top Tips

The PMLD Network has produced a 'Top Tips' guide to encourage partnership boards to include people with profound and multiple learning disabilities (PMLD).

People with PMLD have very complex needs and most don't use words, signs or symbols. Because of this they are unable to 'speak up' for themselves on Partnership Boards in the way many other people with a learning disability can. Because of this their needs can often be ignored.

Help change this by getting your partnership board to follow the 'Top Tips'!

The guide can be downloaded from the PMLD Network website: http://www.pmldnetwork.org/resources/Top_tips_guide.pdf

The PMLD Network would very much like your feedback about how you have used the top tips guide. Please email them at pmldnetwork@mencap.org.uk



In Memoriam

Our sympathy to Maureen, Christine, Catherine and Alexandra Molloy, following the sudden death of Jim Molloy, long time supporter of the CBF. Jim was tragically killed in a road traffic incident on his way home from work.

"Jim was a devoted family man who is sorely missed by us all. He was born in Belfast, but moved to London at the age of 19 to work for British Telecom. He was a senior manager there until his early forties. Through voluntary work he discovered his love of working with people with learning disabilities, especially those with challenging behavioural needs. At the time of his death Jim was a highly respected challenging needs specialist with the South London and Maudsley NHS Trust. The tributes that we have received from colleagues past and present and relatives of service users have highlighted his dedication and excellence in this field. Although we feel great sorrow at the loss of our beloved Jim, it has given us great comfort to know that in his short life he had achieved so much in helping those with learning disabilities and challenging behaviour."

Thank you to Jim's family, friends and colleagues who have generously donated £3,523 in Jim's memory through www.justgiving.com/Jim-Molloy. This will be used to support the work of the Challenging Behaviour National Strategy Group.



Jim Molloy, 26th November 1950 to 31st July 2009



Just Giving

If you would like to help raise money for the CBF, fundraising has been made very much easier now through 'Just Giving' – you can register with 'Just Giving' (www.justgiving.com) to raise money for the Challenging Behaviour Foundation. Simply email all your friends telling them what you are doing (eg. a sponsored event or other activity), and 'Just Giving' will provide you with a link to the 'just giving' website so that they can make a donation on line.

Thank you

The CBF does not have any regular guaranteed income and we rely on grants and donations to continue our work.

While we cannot mention all our donors by name we would like to say thank you at this time to everyone who took part in the **North Downs Sponsored Walk** (£200), **J Dowle Fencing & Garden Services Ltd** (£300), **Wycombe Abbey School Bus** (£500), CBF's very own fantastic Team Administrator, **Helen Marron**

(£120 raised through a sponsored 10km run), **Tawny Engineering** (free PAT testing) and the 2009 **Dragonboat team** (pictured), who are aiming to raise at least £2,000 for us.

If you would like to sponsor the CBF Dragonboat team you can make a donation through www.justgiving.com/Challenging-Behaviour-Foundation

Personalisation

The Social Care Institute of Excellence (SCIE) www.scie.org.uk (tel: 0207 089 6840) has a range of free publications that you may find helpful, including:

- A rough guide to personalisation
- Personalisation briefing- implications for carers

Non accidental injury

A new report, 'Understanding parents' information needs and experiences where professional concerns of non-accidental injury were not substantiated', is available on the Royal College of Paediatrics and Child Health website: <http://www.rcpch.ac.uk/Policy/Child-Protection/Child-Protection-Publications>

The executive summary was published on DCSF website in April 2009.

100 Club Winners

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

June 2009: Linda Smith, Norwich

July 2009: Mr & Mrs Nurse, Rainham

August 2009: Mr D Cheeseman, London

September 2009: Alison Stickles, Gillingham

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). 40 minutes			
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. 40 minutes			
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. 40 minutes.			
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. (Approx 70 mins)			
CHALLENGING BEHAVIOUR INFORMATION SHEETS			
Basic information about challenging behaviour	All information sheets are available free of charge on the CBF website.		
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	To order by post please add £1.00 per sheet*		
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			
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 have no regular guaranteed income**
- **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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