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Challenge

Challenging
BEHAVIOUR
foundation



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

Summer 2009

The newsletter of The Challenging Behaviour Foundation

Education matters

When my son was diagnosed with a disability, it felt as if I was entering a whole new world.

PAGE 2

Comment

There have been a plethora of television programmes extolling various approaches to dealing with problem behaviour

PAGE 3

What parents say

When my son was small I could only take him to playgrounds in the rain

PAGE 6

Scandal or solution?

Approximately 2,000 children and young people with learning disabilities attend a residential school

PAGE 8

Further Education – fact or fiction?

In theory, all disabled young people aged 18 to 25 are entitled to access Further Education

'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

I believed that others had the knowledge and expertise that I lacked and that they would work together in a co-ordinated way to do their absolute best for my son to enable him to have a good life. It soon became apparent that I was sadly mistaken. There are good, hard-working dedicated and skilled people, but 'co-ordinated', 'seamless' and 'best practice' are certainly not terms that can be used to describe our experiences in accessing support for Daniel.



Vivien Cooper

In this newsletter we are focussing on education. Education equips us for life and is a fundamental right of all our children, but we need to look carefully at what we provide, how we provide it, and most importantly what it delivers for individuals who have severe learning disabilities and behaviour described as challenging.

Education equips us for life and is a fundamental right of all our children

We have enough strategy and policy that says the right things. It is translating this into real outcomes for individuals and families that we have yet to achieve. It can seem overwhelming for families at times – I know from personal experience how difficult it is to achieve even what seems basic: good information, practical support, living locally, access to healthcare, etc.

The new Employment Strategy for people with learning disabilities, due out as we go to print, will link to education and be ambitious to provide opportunities to change attitudes and experiences. Sadly, for most families with children and adults who have severe learning disabilities and behaviour described as challenging, supporting them into employment seems so far from reality that it is not even a goal.

I know from personal experience how difficult it is to achieve even what seems basic

But we do have families demonstrating a person-centred, individualised approach and who are enabling their relatives to experience work opportunities, and a future edition of Challenge will focus on how.

We have to continue to challenge the systems, attitudes and processes that get in the way of our relatives living happy, interesting and varied lives. My son is a person, an individual – as we all are - and has the same rights to everyday life opportunities as we do. He just needs the right support, at the right time, in the right place to make it work for him.

• **Vivien Cooper**

Chair of Trustees and Founder of the Challenging Behaviour Foundation

Time out or time in?

Someone (I forget who, I'm afraid) once observed that if a kid can't read we teach them to read, if they can't swim we teach them to swim, but if a kid doesn't know how to behave we... discipline? ...punish?

There have been a plethora of television programmes extolling various approaches to dealing with problem behaviour. You've got fifty minutes tops, so you have to just present the basics – and because you're selling advertising, you need to get the ratings, which means you tend to make it somewhat sensational...

So we've got boot camps, we've got pigeon experts (these people who fly in and fly out of people's lives and leave an awful mess...), we've got naughty chairs, we've got intensive intrusive approaches ("Tell me why you're angry – and the eight million viewers at home..."). And we sit and watch. But don't think all the stuff transmitted is good or right or correct. Now lots of people will speak about "time out" from positive reinforcement without understanding the science behind it. "Time out" use and effectiveness is determined by why the person seems to

"Tell me why you're angry – and the eight million viewers at home..."

engage in the behaviour. It's only of help if the context is right and as a very small part of wider, more positive approaches.

"Time out" has its place, but by focusing on a naughty chair we forget the underpinning stuff: communication, respect, teaching, clear fair boundaries, understanding, listening, routines, fairness, dare one say – love, even. So the next time you watch someone advocate for "time out", ask yourself how often they speak of "time in"? What about belonging and inclusion? What about teaching new ways of getting something, new ways of avoiding something?

Punishment is very reinforcing for the person punishing and controlling access to good stuff and attention. Be wary. We might get so caught up in responding to the behaviour once it has occurred we forget other things. It can teach the person being punished what? That there are limits, that there are rules, that it's okay to punish people you have control over? That love is contingent?

Many people whose behaviour



challenges have a lot to be upset about. Many children who challenge have good reason.

"Time in" means teaching and sharing, learning together, being clear, often being less verbal and more doing. My favourite quote is attributed to St. Francis: preach the Gospel at all times and when necessary use words. "Time in" means belonging and being welcomed, not given ultimatums all the time and having hoops to jump through in order to earn a star to stick on a chart. An extra twenty minutes of your time a week? Gee, I thought you were my parents...

We wouldn't buy sugar-laden foods for people with diabetes; we don't buy wholemeal bread for people with a wheat intolerance. Despite bread being good for many, it's not good for all. And we all like a little sugar, but for some it's deadly. There is no behavioural supermarket parents can walk through, selecting off-the-shelf techniques. If an approach works for one it doesn't follow it works for all.

Warning: just because a couple of headache tablets reduce pain it doesn't follow a whole pack will do you any good.

• **Tony Osgood**

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

NEWS

CBF News

At the time of going to print we are delighted to be welcoming two new staff members to join the CBF team.

Hiromi Umizawa, who has just completed her MSc in Analysis and Intervention in Intellectual & Developmental Disabilities at the University of Kent Tizard Centre will be our new Training and Resource Co-ordinator. This new post has been made possible through funding from the Department for Children, Schools and Families.

Charlie Clay, who is currently completing a Graduate Diploma in Applied Behaviour Analysis (also at the Tizard Centre), will be our new Family Support Worker. Gemma Honeyman, who previously held this position, is now working alongside Vivien Cooper as CBF's Family Support Policy Officer.

Q: My 9 year old son has severe learning disabilities and is extremely noisy, both in the house and out and about. Has anyone experienced this?

A1: My son who is also 9 years old and is autistic has very noisy phases every few weeks. This has been much better since having a Sensory Profile completed by our school Occupational Therapist (OT), as it identified that when my son was noisy he was hyposensitive (under sensitive) to sensory input, physically as well as auditory. He was trying to adjust this lack of stimulation by making lots of noise banging on radiators, windows and walls, as well as high pitched shrieking. The OT developed a Sensory Diet Programme, which gave a list of activities I could offer him when this behaviour occurred, e.g. jumping on a

trampoline. This doesn't always work, but by using these activities at regular times throughout the day, even when he isn't very noisy, I have found a big difference in the level and frequency of noise that he makes.

A2: My 8yr old son has the same issues as your son. Does your son have speech? If he has limited speech then he will have frustration and this is the only way he will be able to communicate. Have you tried giving him one to one attention? My son plays the Wii and this amuses him but he has to have constant things to do.

A3: My autistic daughter makes a lot of noise, and when she was younger I had problems dealing with it. As she has got older I've learnt that the noises have different tones and levels which indicate her mood and humour. Other people don't matter – listen to the sound and you may find they are a form of communication, possibly the only one he has to offer.

Q: I am working with a teenage male with Autism. He is repetitively laughing at the top of his voice for extended periods of time both at school and at home. I have tried an aversion technique of blowing a whistle each time it occurs but he went and got his own whistle and began blowing it back at his parents. Any ideas?

A1: Most Health Trusts and service providers in the adult sector have policies that prohibit the use of aversive techniques. Simply trying to eradicate a behaviour because others find it difficult to manage without looking at the function of the behaviour is not a good idea.

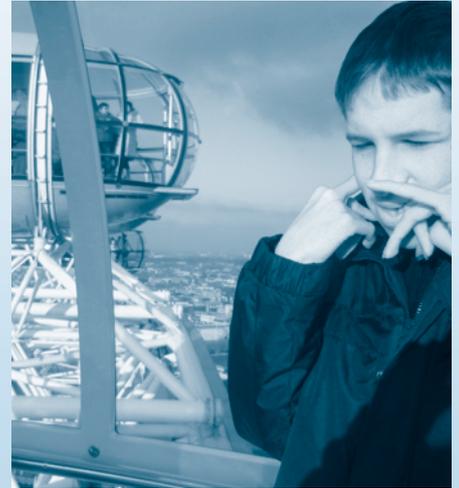
A3: I don't know what kind of analysis you have done but it doesn't sound like you have done a Functional Analysis

yet. This should question whether 'education' is pitched at the right level and highlight the person's tolerance of certain 'education' activities so that expectations are realistic. We often get obsessed with the idea that education can only occur in buildings or at desks. It may then be a matter of making sure the person has the right level of enablement to succeed.

A3: There are major ethical issues in using a technique because you think that it will be aversive: that is, you hope that it will technically be a punishment. This is particularly the case with using loud noises with people with autism, given that such people can be particularly sensitive to loud noises. However, using a whistle as a (non-aversive) distracter can be helpful with some people.

A4: Possibly this young man needs to have his hearing checked and a full physical in case the laughing is masking something else. I also wonder if he does this for sensory means? A sensory assessment may be the best course of action, but also a focused health review around his ears.

What parents say



Enjoying a ride on the London Eye

When my son was small I could only take him to playgrounds in the rain as I knew they would be empty.

Shopping was a nightmare and going to different places was out of the question. My son's challenging behaviour shaped everything that we did. For years we went to the same places following the same routines. We could not even walk down the other side of the road for my fear of him self-injuring.

But over time little by little I would change our routines. And over time my persistence has paid off. Now we both enjoy our new found freedom of doing new things and experiencing new places, giving us both confidence.

Our first breakthrough was going on the London Eye. We had walked past it for years but as my son's preferred medium for head banging is glass, being encased in a pod dangling over London with no means of escape seemed an impossibility. But one rainy day as we walked past it was empty. I took my courage in my hands and bought 2 tickets and on we went. He absolutely loved it!

From that day we have not looked back. Our relationship has strengthened as he trusts me and I have more faith in him. We have both gained a much better quality of life.

Gone are the days of empty parks in the rain. He is still not keen on shopping (but then again he is a man!). But taking that risk opened up our world.

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

New safeguards

The Deprivation of Liberty Safeguards (DoLS) became law in April 2009. They are an addition to the Mental Capacity Act, providing a legal safeguard for adults over 18 who lack the capacity to consent to their care and treatment, where their freedom of movement has to be significantly restricted in their own best interests.

The European Convention on Human Rights states that no one can be deprived of their liberty without a legal process to authorise the deprivation and the right to appeal against it. DoLS were introduced to give these rights to people who can't consent to the restrictions that might be necessary to give them the care and treatment that they need. There is no clear definition of how many restrictions there have to be in order for them to amount to a deprivation of liberty, but deprivation may be occurring if the person is being regularly restrained, their contacts and social activities are decided by staff, they are under constant supervision or observation, or staff refuse requests by carers for the person to be discharged to their care. It is not necessary for all of these to be happening, and each case is judged on its own merits.

DoLS only apply to hospitals and registered care homes (i.e. not to people living with their families or foster carers). If the hospital or care home thinks they are depriving someone of their liberty, they have to apply to their local authority or PCT for an authorisation. An assessment will be arranged and, if the decision is that it is in the person's best interests to be deprived of their liberty in order to be cared for properly, then the authorisation will be granted.

Authorisation can last up to one year, and conditions may be attached. The hospital or care home has to comply with these conditions.

• **Dr Theresa Joyce**

Mental Capacity Act Lead & Head of Psychology Services for Adults with Learning Disabilities, South London & Maudsley NHS Foundation Trust



The new Challenging Behaviour National Strategy Group at work

NEW SAFEGUARDS

Can you justify it?

The new Deprivation of Liberty (DoLS) safeguards should have a positive impact on people described as having challenging behaviour. Their care will be open to external scrutiny from the DoLS assessors, and any restrictive care practises will have to be justified as being in the person's best interests. Care plans will have to be reviewed to ensure that restrictive practises are justified. There must be at least two assessors, and one is required to assess whether the deprivation is in the person's best interests, including contacting the family to ask their views.

restrictive care practises will have to be justified as being in the person's best interests

If the person is being deprived of their liberty, and the supervisory body authorises it, then they are entitled to have a representative appointed to monitor and review what is happening to them. Where people have a family, this is likely to be a family member, and means that the family can be more involved in discussions about the need for any restrictions and in monitoring any conditions attached to the authorisation.

If they have no family, then the supervisory body has to appoint someone independent to take on this role. This provides an additional safeguard for people with challenging behaviour.

Want to find out more? See page 11

Working together

November 7th 2008 saw the launch of the Challenging Behaviour National Strategy Group (CB-NSG); a new key national group 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 will be to develop a co-ordinated and strategic approach that will offer lasting solutions for individuals whose behaviour challenges our present services.

The Challenging Behaviour Foundation is aware of many important initiatives and policy opportunities around individuals who challenge. We know that much better support and services could be provided – including evidence from the individual families who contact us, research and policy reports. However, the current situation is that organisations/ stakeholders initiate work, commission research or reports or carry out pilots around specific themes or groups. What is missing is a group which has an overview of this work, its impact and the policy opportunities available in order to develop a co-ordinated and coherent strategy across child and adult provision to ensure that every individual benefits. We believe that now is an opportune time to bring all key stakeholders together.

The Challenging Behaviour Foundation has instigated this action-focused group as we believe we are uniquely positioned to do this, building on our work of the last eleven years with children, adults, families, and with a wide range of organisations and groups.

A second meeting of the CB-NSG was held on 24th April 2009 to develop a work plan and identify priorities for the group. The Challenging Behaviour Foundation would like to thank all the organisations and individuals who have supported this initiative so far.

For further information about the CB-NSG please contact Gemma: Tel: 01634 838739 or email gemma@theCBF.org.uk

Preview our DVDs online!

You can now preview all five of the Challenging Behaviour Foundation's DVDs online:

- An Introduction to Challenging Behaviour
- Self-injurious Behaviour
- Communication and Challenging Behaviour
- Challenging Behaviour – Supporting Change, and
- A New Pathway.

A short clip of each DVD is available to view on the Challenging Behaviour Foundation website, free of charge. A written outline accompanies the clip to provide an overview of the content of each DVD.

"As a parent who has spent the last ten years trying to understand my child's challenging behaviour, and have searched for information, this new DVD 'Supporting Change' is the light at the end of what has been a very dark tunnel. Well done to the three families who allowed us into their lives. The DVD will enable parents and professionals to bring about much needed changes towards a better understanding as to why our children use their behaviour to get their needs met. This DVD has given me the courage to now make sure these changes are put in place."

WWW.CHALLENGINGBEHAVIOUR.ORG.UK

The screenshot shows the website's navigation menu with options like Home, About Us, How we can help, Challenging Behaviour, Support Options, Resources, and Campaigns. The main content area is titled 'DVD Resources' and includes a 'Click Here to DONATE' button. Below this, there is a section for 'Self-injurious Behaviour DVD' with a video player showing a woman, Roz Erskine-Gray, and text describing the DVD's content.

You can now view DVD clips on the Challenging Behaviour Foundation website

"Very well put together, very positive and easy to watch. Well done"
(Community Nurse)

Please see pages 11 and 12 to make an order. All DVDs are free of charge to family/unpaid carers (donations welcome). Proceeds from the sale of our DVDs go towards our work to improve the lives of people with severe learning disabilities.

If you would like to support our work with a donation you can also go to www.challengingbehaviour.org.uk and make a donation by credit card using the 'Donate' button on our home page. Thank you for your support.

Solution

As an independent provider of special needs education and care, at SENAD we are constantly developing our services to meet both legislation and the changing needs of those using our services.

The need for residential placements is not purely the result of there being a lack of local provision, which, if it were available, would enable individuals to remain day students and live at home. There may be difficult family circumstances, for example there may be an elderly carer or a single parent with other younger children.

Local provision may be available but located across several bases e.g. school, parental home (sometimes two parental homes) and a respite placement. People with severe learning disabilities, especially those with Autistic Spectrum Conditions, may find this particularly difficult: routines are more likely to be disrupted; staff changes more likely and there may be a lack of consistency in management programmes and communication.

In contrast, well thought out professional residential placements can allow individuals to develop and flourish, and maintain family links. Residential provision gives the benefits of a 24 hour curriculum, often with a high level of therapy input and expert support.

Providers should be able to provide flexible education and care packages to meet specific individual needs. At one SENAD school we have a young person who is placed for 42 weeks. She goes home for all holidays except the long summer break when she goes home for two weeks and stays at the school for the other four weeks.

The residential option should be seen as the best solution for all at that particular moment in time following assessment and consultation with all those involved. Placement arrangements that are established at the start are not necessarily forever

• **Jennifer Fearn**, SENAD group

Home or away?

Policy and practice regarding children with learning disabilities have changed radically in the past 40 years. Peter McGill examines recent research and issues for future provision.

Before the 1971 Education Act, children with severe learning disabilities (SLD) were legally ineducable; now all have a legal entitlement to education and over a quarter attend mainstream schools.

Inclusion is not without its casualties, however. Schools often struggle to cope, and it is estimated that about 35 children move from local SLD schools to residential provision each year. Children who, forty years ago, would have lived in long-stay hospitals now live with their families and attend local schools. Yet support services for families often remain poor, so it is not surprising that a significant number of parents still want or would consider residential care for their child. Despite the focus of policy being inclusion, some young people are being excluded from mainstream social and educational opportunities.

Asked why their child had gone to residential school, parents' reasons included breakdown of local support ("excluded from the two schools identified by the council") and family breakdown ("we couldn't cope anymore...I had a breakdown"). As one Mum in a recent study put it: "The SLD School were phoning saying 'can you come and pick him up? We can't

It is estimated that about 35 children move from local SLD schools to residential provision each year



Children who, forty years ago, would have lived in long-stay hospitals now live with their families and attend local schools

cope.' I just think – yeah, it's me on my own here - you've got a whole team of people". It is not surprising if the combination of inadequate support and their child's complex needs is too much for some families to cope with and, in desperation, they seek a residential placement.

Today approximately 2,000 children and young people with learning disabilities attend a residential school, almost 700 of them 52 weeks of the year. Including social care and health placements the number of children living away from their families rises to approximately 3,000. These figures suggest a surprising conclusion. Despite the move away from long-stay hospitals and policies of inclusion we now exclude from their local communities nearly as many children with learning disabilities as we did in the 1970s. These are mainly teenagers with a range of complex needs, particularly perhaps the combination of severe learning disability, autistic spectrum disorder and challenging behaviour.



Photograph courtesy of SENAD. Used with permission

Despite the move away from long-stay hospitals and policies of inclusion we now exclude from their local communities nearly as many children with learning disabilities as we did in the 1970s

suggest we should do the following:

1. Substantially increase and improve the quality of family support.
2. Substantially improve the competence, coverage and inclusiveness of local services for children with the most complex needs.
3. Substantially improve local authority planning.

Finally, however, it is important to say something about the strengths of residential schools both to avoid an interpretation that they are in any sense the “baddies” of this story but also because we can learn a great deal from these strengths. The existence and growth over time of residential schools reflects the demand for their services. These services include the capacity to meet the needs of most of the children that local services and families cannot support. This capacity reflects the degree of expertise and specialism developed by many schools particularly in the areas of challenging behaviour and autism. We should do everything we can not to lose this knowledge and experience.

We know very little about their experiences in residential schools but enough to be at least concerned about the benefits of such placements. We certainly know that residential school placement, especially distant to the family home, will likely lead to reductions in family contact. Such reductions leave children, already vulnerable because of their severe disabilities, at great risk. The continuing failure to ensure that all children in such placements have the protections of the Children’s Act is of great concern.

I conclude with three recommendations for change.

It would clearly be much better if far fewer children and young people had to leave their families and travel halfway round the country in order to access specialist knowledge and experience. If we are to reduce the need for residential school (and other residential) placements I would

It is not surprising if the combination of inadequate support and their child’s complex needs is too much for some families to cope with



• **Peter McGill**,
Tizard Centre,
University of
Kent

For the full article and references please refer to the Tizard Learning Disability Review, Vol 13, issue 4 (December 2008): Residential schools in England: recent research and issues for future provision

Scandal

When my son was very young the consultant told me that I was ‘going to have my work cut out’ caring for him. But although the need was identified, no early intervention took place.

It is paramount that families get support, but most families say that they don’t receive help until they reach crisis point, by which time it’s too late. I was fortunate to receive respite, but at every annual review I was told that I wouldn’t be able to manage him at home for very much longer. However, although it was relentless I knew how to meet his needs. I knew that keeping him busy was key, and that to enable him to take an after-lunch siesta made an enormous difference to his ability to cope with the day. However, the school could not meet this need and he was excluded at the age of 14, spending the next four years in an out of county residential special school.

When a child is placed out of county (or in our case, quite a few counties – 200 miles) contact is certainly not daily as it should be in a child’s life. I visited at least once in six weeks, but my son was fortunate because his siblings were older. Had he had younger brothers and sisters it would have been much more difficult to maintain contact.

It disappoints me that an article needs to be written in 2008 about the widespread use of residential schools. All children should have the opportunity to live ordinary lives with their families in their own communities. It is a fundamental need and right. It is a scandal that we take children with learning disabilities away from their families instead of providing the support that families need at home. It is a violation of their human rights to family life and it is discriminatory.

• **Jan Seamer**, parent

Read more of Jan Seamer’s viewpoint in the Tizard Learning Disability Review, Vol 13, issue 4, December 2008.

Moving On

In March 2004 the Learning and Skills Council (LSC) National Council endorsed the need for a strategic review of its funding and planning of provision for learners with learning disabilities. The concept of working in partnership was considered central to the notion of provision that is person centred and appropriate to the needs of such learners. Mid Kent College entered into a partnership in Medway to provide an educational programme to young people who in addition to learning disabilities also had challenging behaviour.

The programme was based on a person centred approach and necessitated care and education providers working together to provide an integrated 24 hour curriculum. For Mid Kent College a number of resource issues had to be taken into consideration and adaptations to the environment had to be made. Specialist staff were recruited to support the learners, with a ratio of 2:1 needed at all times.

The Moving On programme started in November 2006. Four students were enrolled on to an Essential Skills qualification which it was hoped could provide them with further support towards independent living. The curriculum included skills that were transferable and was planned so that any student could access regardless of disability. The pilot programme was structured to cover two years.

Lessons learned from this project will help similar future projects. It is essential for partners involved to be absolutely sure at the outset of their roles and responsibilities and to be committed to work together. Continued and constant liaison between staff at the residential home and staff at the education establishment is vital if a personalised curriculum is going to be effective.

The project provides an outline for fulfilling an essential need for the provision of educational access for these vulnerable learners.

• **Daphne Rowlands**

Director for Business General and Higher Education, Mid Kent College

Worth the wait?

Westgate College in Kent is a leading national specialist college for deaf people and those with additional complex needs. Here Ros Facey, Director of Projects and Partnerships, talks about a new initiative to provide individually tailored Further Education opportunities for a group of students with severe learning disabilities and challenging behaviour.

Current national strategies have ensured Further Education (FE) Colleges have been working hard to embrace the principles of inclusive learning and placed them within the context of an expanded learning and skills sector, with a new focus on employability and employment.

Everyone in the sector is clear that mainstreaming brings enormous benefits to learners, as long as their involvement and success is monitored specifically.

However the following issues, fundamental to equality and diversity, require consideration in order to achieve a shared vision for young people and adults with learning disabilities:

- Provision of improved opportunities and choices, including employability and employment
- Joint strategies for learners with profound and complex needs
- Strategies for those learners who also have mental health difficulties
- Increased local capacity to meet a wider range of needs
- Increased flexibility between providers
- Professional development to support these strategies

The landscape for FE is clearly changing. Amongst these changes is

Further Education – fact or fiction?

In theory, all disabled young people aged 18 to 25 are entitled to access Further Education. Two current national strategies *'Through Inclusion to Excellence'* and *'Learning for Living and Work: Improving Education and Training Opportunities for People with Learning Difficulties and/or Disabilities'* set out this entitlement.

In practice, most young people with severe learning disabilities and challenging behaviour are unlikely to access Further Education - unless through a specialist residential college, which may or may not enable them to retain contact with their family.

The Challenging Behaviour Foundation promotes the rights of all young people with severe learning disabilities and challenging behaviour able to access individually tailored learning programmes through their local Further Education college, and has been piloting this approach in the Medway area, initially via a mainstream provider and recently working with a specialist provider.

On these pages we hear from some of the partners involved in the CBF pilot FE project, and hear a family's perspective of the opportunities available post 18.



Photo: Anne Lord

Seth Jorgensen

the need for creativity and innovation. We rely on the Learning and Skills Council (LSC) to be a supportive partner in any initiative and we need to be able to find ways round systemic barriers erected by inflexible funding mechanisms.

As an individual provider, we aim to be the right partner to increase flexibility and contribute to local capacity. We know it takes time to develop strategic partnerships. We recognise that getting the services and providers working together and to agree joint strategies won't happen overnight.

Westgate College has been working with local partners to develop what we think is an exciting model of education tailored to meet the individual needs of four very different young people, each with severe learning disabilities and challenging behaviour. It will provide a blended programme of home, community and

The landscape for FE is clearly changing. Amongst these changes is the need for creativity and innovation

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college for each young person.

The journey to get to this point has been a long one. The struggle to get the right match, to tailor a successful learning programme depends on many factors such as health, choice, aspirations, available resources, staff skills, expertise and environment, to name but a few.

There is a clear message that we must continue to send to the LSC: there needs to be confidence in the partnership to continue to move forward whilst all these key elements are brought together.

At the time of writing this article we are still waiting for confirmation of funding from the LSC.

And four young people are still waiting to access their Further Education entitlement.

• **Ros Facey**

Director of Projects and Partnerships,
Westgate College

Smoke & Mirrors

Society has not planned for the fact that, through medical intervention, a chronically sick child will live longer than in other decades. A lot longer.

And whilst everyone applauds the fight for life of a sick child, there is a resounding silence when this child continues this fight into adulthood.

Social, health, educational and leisure support, whilst meagre in childhood, vanish in young adulthood. And whereas the act of becoming eighteen changes access to resources, on the basis that there is access to work opportunities, we all know that is all smoke and mirrors. Hey, we are told, watch this hand, while I move the thing that you want and need with the other hand. And you don't know it is gone until it is gone.

Perhaps it is easy to take my son's silence for acceptance, but it is because he cannot speak. If he could speak he would tell you that he too wants to have gym and sport facilities that cater to his needs. He too would like to go to the seaside and have the use of civic amenities. He too wants to be kept well and safe. He too wants a life beyond the home. He too wants lifelong learning opportunities.

But the work opportunities do not exist; the leisure opportunities do not exist; the educational opportunities do not exist.

But my son exists, and will continue to exist.

His grandfather lived until he was ninety years old, and I do not think this society has prepared for the possibility that my son might, just, do the same.

• **Solveig Jörgensen**

From the CBF: We need to ensure that we work with families as valued partners. Together we can turn policy into practice, ensuring that individuals who are perceived as challenging are not excluded from Further Education and other opportunities.



Helping hands at the CBF office

With our newsletter 'Challenge' now going to over 3,000 families and professionals three times a year, we are very grateful to volunteers from Greatfield Lodge, Kent, for their fantastic help with our newsletter mailings. Thank you everyone; we couldn't manage without you!

Thank you

While we cannot mention all our donors by name we would like to say a big thank you at this time to **Trinity School, Nottingham**, whose sixth form raised £200 for us through various fundraising activities last year, also to **Waitrose Allington Park** (£390) and to the Waitrose customers who nominated and voted for the Challenging Behaviour Foundation, and finally to the **NPA Team at Lloyds City Office**: £160 raised through a sponsored 'giving things up for Lent' fundraising appeal.



Fundraising opportunities

If you live in Kent do get in touch to find out about our regular fundraising events (quiz nights, sponsored walk, dragonboat race). If you live outside Kent but would like to raise money for us do let us know – or perhaps you would like to sponsor our dragonboat team?

The CBF has no regular guaranteed income; we rely on people like YOU to help keep our work going. Please get in touch if you would like to help. Thank you.

Deprivation of Liberty Safeguards

Want to know more? (From page 4)

"Mental Capacity Act 2005 Deprivation of Liberty Safeguards: A guide for family, friends and unpaid carers"

"Deprivation of Liberty Safeguards: A guide for hospitals and care homes"

Both are available to download free of charge from:

www.dh.gov.uk/publications or Tel: 0300 123 1002

Mental Capacity Act 2005: Deprivation of liberty safeguards – Code of practice to supplement the main Mental Capacity Act 2005 Code of Practice

Free to download from:

www.dh.gov.uk/publications or £12.50 from TSO: 0870 600 5522

100 Club Winners

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

February 2009: Mrs N Leggat, Bexhill on Sea

March 2009: Mrs T Bigham, Cranbrook

April 2009: Mrs S Catford, Canterbury

May 2009: Miss P Croft, 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. To order by post please add £1.00 per sheet*		
Communication and challenging behaviour			
Health and challenging behaviour			
Challenging behaviour – supporting change (functional assessment)			
The use of medication			
The use of physical interventions			
Specialist equipment and safety adaptations			
Parents' perspectives			
Planning for the future: introduction			
Further information for parents			
Booklist for professionals			
BASIC INFORMATION PACK	£10.00*		
The following additional information sheets are not contained in the basic information pack but may be downloaded from the CBF website or ordered separately:			
Getting a statement	£1.00*		
Self-injurious behaviour	£1.00*		
Pica (eating inedible objects)	£1.00*		
Psychiatric disorders in people with learning disability	£1.00*		
Difficult sexual behaviour amongst men and boys with learning disabilities	£1.00*		
List of specialist 52-week schools and colleges	£1.00*		
SUB TOTAL CARRIED FORWARD			

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

/ Continued overleaf...

SUB TOTAL CARRIED FORWARD			
	Cost	Number	Total £
SUPPORT OPTIONS			
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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Tel: 01634 838739;

www.challengingbehaviour.org.uk