

Challenge



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

Summer 2011

The newsletter of the Challenging Behaviour Foundation

Partners or Opponents?

Partnership is a term often used and widely promoted as a positive way of working.

PAGE 2

Howdy Partners?

Courage is being scared to death...and saddling up anyway

PAGE 3

Your questions

My worst nightmare is my son being hospitalised

PAGE 4

Families and the workforce

Why families have such an important contribution to make in developing the workforce

PAGE 6

Improving lives?

The key proposal in the long awaited Green Paper is to introduce a single statutory assessment

PAGE 8

Paid work!

For Ben the impact upon his life of moving into work has been very significant.

'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

It is an example of "the whole being greater than the sum of the parts". It makes sense – working together to achieve common goals or outcomes – and it is a founding principle of the Challenging Behaviour Foundation.



Vivien Cooper

But although it sounds so simple and sensible, it can be difficult to achieve. Working together as partners requires effort, commitment and honesty. It means listening and understanding different perspectives, considering views other than your own and jointly agreeing how to move forward.

Working together as partners requires effort, commitment and honesty.

Families make attractive partners – they are long term, committed and dedicated. They can be persistent, determined and creative, and are unhindered by bureaucracies and constraints that many professionals are required to negotiate. But these are the very qualities that can be used against families. A senior manager of a large provider organisation (unaware I was a family carer) unwisely announced to a large meeting "I find it best to keep families very firmly at arm's length". In contrast, thankfully, other providers recognise the importance of working with families.

Families make attractive partners – they are long term, committed and dedicated

Partnerships are built on trust. For my son to be able to live a good life, I need to be able to trust all the

people involved in providing his care and support. This includes his direct support staff, their managers, the senior management of the organisation, the local authority social care staff and those who assess, commission and fund his support. To maintain that trust we must all continue to work with shared values to agreed outcomes – and this can be jeopardised by any of these individuals. One person who does not understand, or does not subscribe to the values of rights, independence, choice and control can be hugely damaging. Trust can be easily shaken.

Partnerships are built on trust.

The recent Panorama programme showed completely unacceptable treatment of vulnerable people, and the complexities of how this dreadful situation arose are huge. But being truly person centred, developing local, individualised packages of support and working as partners to meet all the needs of the individual has to be altogether better.

• Vivien Cooper

Chair of Trustees and Founder of the Challenging Behaviour Foundation

Howdy Partners?

One of my guilty secrets, growing up, was enjoying Westerns. You know the sort of thing...

A stranger rides into town. Friendships are struck. Partnerships are formed. Then the newcomer raises the sticky topic of the corrupt sheriff. There's a shoot out. Things get messy. Eventually, though, justice is done. The new pals ride off into the sunset.

Today, social care is replete with promises of aspiring to high ideals. Not a week goes by without fancy new words for ancient principles being adopted by organisations. A common phrase heard across the badlands today is partnership. Partnership means working constructively together. It implies an equality of influence and control. Between 'service user' and professional, between professionals, between all involved parties. We work together. We do not shoot first. We establish a dialogue and explore what we all need to get us through the badlands.

Partnership means working constructively together. It implies an equality of influence and control

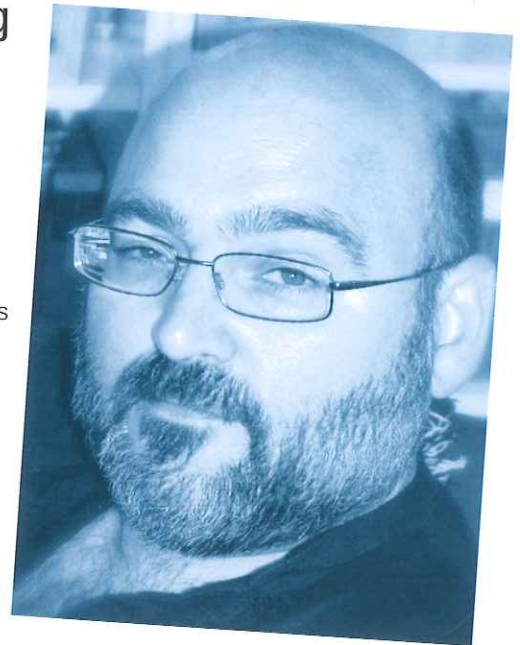
Partnership is logical because if everyone feels involved, that their voice is worthy of being heard, then things can happen more smoothly.

Partnership means being involved in decision options. Partnership isn't a vacuous phrase but is based upon measurable behaviours, such as listening and responding and delivering. It's not partnership if a professional says I'm listening but fails to deliver anything of substance. (Not that that ever happens, of course.)

For me partnership is demonstrating good communication. That through my behaviour, I'm showing the person I'm spending time with they are worthy of being taken seriously and heard. So I turn up, I shut up, I listen. That's a good start for partnership. I don't try to twist the person's words by inane comments or professional translations. It's not just good practice to involve people, it is common politeness. John Wayne knew this.

You see, we operate services. The clue is in the titles of our organisations. Trusts. Social Services. The titles are a bit of a pointer.

If we as professionals work in partnership with families, we're building our own competencies. If we are known to work in partnership with people, people will want to work with us. Partnership working is particularly important when working with vulnerable or excluded groups.



Partnership working is particularly important when working with vulnerable or excluded groups.

We know partnerships are working well when families feel involved, when they don't feel judged or stigmatised, when professionals show commitment and authenticity to family concerns. Life is hard enough without being ignored. Families report a sense of partnership when professionals are empathic, trustworthy and encouraging, when disagreements are negotiated (even the Apostles fell out at times.) Whatever the issues, whatever the difficulties, at no point in the rocky road should partners start shooting one another.

At no point in the rocky road should partners start shooting one another

It is scary giving time and a bit of ourselves to fellow humans in difficult situations. It takes courage. Go ask John Wayne. As he said: "Courage is being scared to death... and saddling up anyway."

• **Tony Osgood**

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

HOW YOU CAN HELP

Demand for our work is increasing and we need to fundraise harder to meet that demand. Here are some easy ways that you can help:

HOLD A DINNER4GOOD:

Just invite some friends round for dinner and have a great time. Go to www.dinner4good.com/thecbf (More on page 10)

DONATE IN CELEBRATION:

Do you have a special birthday this year or know someone who is getting married? Would you consider donations for the CBF instead of (or as well as) presents? Go to www.virginmoneygiving.com and search for Challenging Behaviour Foundation, then click on 'start fundraising' and follow the instructions for giving for a special occasion.

MAKE A DONATION:

We can accept donations online, by post or by credit card over the phone. Simply call the office on 01634 838739.

THANK YOU FOR YOUR SUPPORT

Q: What do others think of training for all NHS staff around challenging behaviour? My worst nightmare is my son being hospitalised.

A1: I can entirely relate to your concerns as our 22-year old son has SLD, severe autism and he presents with life-threatening challenging behaviour. Teeth extractions due to abscesses caused us immense stress when our son was nine. I am terrified of our son needing hospital treatment in the future as he's an adult now and, with the build of a muscular rugby player, his strength is immense. Very few environments would be safe for him and I have no confidence that hospital staff could ensure his safety.

A2: I feel very strongly about this and have had good and bad experiences with my son. In one hospital they were willing to listen to suggestions in advance and were flexible about

waiting times, who can be with him and where consultations took place (one lovely consultant found a pleasant quiet space without loads of medical equipment around as this freaked my son out), but this has been the exception. We need to have all NHS providers on board with clear helpful guidelines, and personal plans in place before treatment or interventions are required in hospital.

A3: In my local children's hospital challenging behaviour would be discussed with the parent and the best strategies implemented to cope. I couldn't fault them. My son spent 6 ½ months in the cardiac ward. Everything was addressed in consultation with the parents. I found what best worked was the child passport / personal profile, and a willingness for parents to work with the ward manager. If your son has really challenging behaviour, I would try and work in partnership with your GP / Paediatrician to introduce a behavioural management plan in case of emergencies.

Q: Where can I purchase splints to prevent self-harming?

A1: Before ordering any splints you need to make sure that you've examined the behaviour in detail, including input from a specialist clinical psychologist or behavioural nurse. Using splints to control self-injury is restrictive and can make the self-injury worse unless you find out and address the function(s) of the behaviour.

A2: Splints are fundamentally restraints and all other avenues need to be exhausted beforehand and then you need to provide an evidence based argument as to why they're needed and get it ethically approved. We had a similar request and this went before our Trust board's Ethics Committee. Our lady finished up not needing them. A medication review and low arousal approach, productive engagement, communication package and functional risk assessment proved sufficient.

A3: All interventions with respect to self-injurious behaviour (SIB) are an ethical issue, not just those that use restraints. Where there is significant SIB and an intervention is going to be undertaken then there is always a balance to be maintained. If two different interventions have a reasonable likelihood of being effective, then if one is less restrictive than the other but will take a much longer time to reduce the frequency and intensity of the behaviour then the risk is that with the client will then be exposed to a much longer period of self-injuring. So which do you choose - the least restrictive or the one that will work more quickly?

A4: I am personally not in favour of using such types of mechanical restraint but understand their application. What is key is that the use of such a restraint may be justified only where it can be demonstrated that this is the only alternative available at the time and furthermore, that strategies are in place to eventually reduce/abolish their use through other proactive strategies being tried.

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

What Parents Say



Debby and Simon

Simon is a fantastic six year old boy with Fragile X syndrome, but as is no doubt true of many other parents, we have found it hard to enjoy Simon and have felt our hearts sink when he comes home.

We can only do our best, and we need to know that this is the best we can do for our beautiful children. I wanted to write this to illustrate that we are all in the same boat, and that no one should feel guilty about having a disabled child. So that we can see the positive side of our child, we now sit with him each night and write down three positive things which he has done, even if it is as simple as good talking or signing.

We still try to fit our life around him instead of fitting him around us and inform friend and foe before we go out! We keep to a routine so he goes to bed by himself, which does help to keep some of the behaviour under control.

We wish that the wider world would instantly understand when our children 'inexplicably' (to them) have a meltdown in the middle of the supermarket. Severe learning disability is such an unknown to most people, that even though they would actually like to help, they shy away. Education is the key here. Remember the person you were before having a child with a learning disability, they are all around you now. Think about it.....

• **Debby Cocks, family carer**

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

Families as Partners



Jackie with son Rhys

As the parent of a 21 year old with severe learning disabilities and behaviour that challenges, I have found that when we are able to work in partnership pooling all our combined knowledge and many ways of knowing, this has led to better outcomes for Rhys and us as a family. When professionals explain what their role is and how they can help Rhys, it helps me to understand my role in supporting them. For example, family carers often know an individual's particular way of communicating their preferences and the best approach to use. Sharing our understanding of what needs to be in place helps ensure that Rhys doesn't need to be challenging to be heard. Working with the professionals as equal partners has led to tailored person-centred support that meets Rhys' needs more effectively - and it costs less too!

Rhys has a Person-Centred Plan that was compiled with contributions from school, the respite unit and a circle of support (family and friends who knew Rhys well), which gives the fine details of what works for Rhys. It includes how he communicates and how to communicate with him. We have found that the staff team needs to be person-centred, open minded and comfortable asking for help. Family carers provide consistency when other agencies may change, for example from school to adult services. Sharing what works and what does not enables effective communication and a better understanding of how we can work together.

• **Jackie Edwards**, family carer

Families and workforce development

A new guide: 'Good practice in involving families in your workforce development: the what, why and how' features the CBF as one of seven examples of good practice from organisations across the country. The guide explains why families have such an important contribution to make in developing the workforce....

Back in 2009 a scoping study commissioned by the Valuing People workforce lead looked at how people with a learning disability and family carers were involved in workforce development. The study identified lots of examples of people with a learning disability being involved in recruiting and interviewing staff, in training during the induction process and in reviews and appraisals, but fewer examples of family carers being involved in workforce development.

As the Strategy for the Participation of Carers in Skills for Care Work highlighted: 'Carers represent an essential and largely unrecognised part of the social care workforce...provide assistance that cannot be offered by commissioned services and...can offer a valuable insight into working with people who use services and the gaps in the social care system'.

Families have, more than anyone, a vested interest in getting the best possible workforce to support people with a learning disability.

Families have, more than anyone, a vested interest in getting the best possible workforce to support people with a learning disability. Being involved in training and workforce planning makes for better working relationships. It can break down barriers and establish greater trust between families and workers.

The Valuing People Now team and the National Workforce task group then commissioned a piece of work that sought to establish what good practice in involving families in workforce development looked like, highlighting examples from local authorities, health care and social care providers and training organisations. Mencap led this work with support from the National Valuing Families Forum. The aim of the report has been to give organisations looking to improve their approach to engaging families in workforce development some practical suggestions and tools that can help them. Taking these steps can help organisations achieve the Care Quality Commission outcomes that providers should be working to for the people who use their service.

At the beginning of February this year, Kate Sanger from the CBF helped Mencap lead a workshop at the Skills for Care "Excellence out of Adversity - developing the workforce" conference. The impact of Kate's message was powerful - and highlighted to the professionals present the important role that families can play.

• **Lucy Virgo**

Families and Communities Project Manager, Mencap

To download a copy of the report visit www.mencap.org.uk/workforce or contact Lucy at lucy.virgo@mencap.org.uk, telephone 07796 948 733



Top Tips for Families

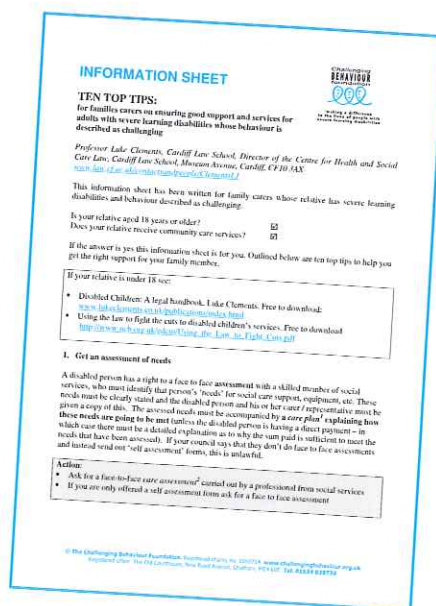
In the current economic climate the Challenging Behaviour Foundation is increasingly hearing from family carers who have had vital services and support cut, or have been told cuts are planned in the near future.

If you are in this position or your relative is receiving poor quality support you may find the new Challenging Behaviour Foundation information sheet helpful: "Ten top tips: for family carers on ensuring good support and services for adults with severe learning disabilities whose behaviour is described as challenging".

Written by Professor Luke Clements, an expert in Community Care Law, this information sheet provides basic legal information including getting an assessment of needs and a care plan, and the role of allocation panels.

It has been written for family carers whose relative is aged 18 years or above and has severe learning disabilities and behaviour described as challenging. Each "top tip" is accompanied by action points which family carers can take to ensure their relative receives good support and services.

To order a copy of the new information sheet please see page 11. The information sheet is free to download from the CBF website: www.challengingbehaviour.org.uk



EXTRACT FROM OUR NEW RESOURCE

Ensuring good support

Your local authority will formally decide what level of need it will meet and fund under Fair Access to Care criteria - this is known as the eligibility criteria. When it has set this level, the law says that a disabled person's **assessed needs which meet the local authority's eligibility criteria must be met.**

NB: Throughout this information sheet "meeting assessed needs" will refer to needs which meet the local authority's eligibility criteria for funding.

Range and amount of support available

Councils can't have blanket policies that they don't do certain types of social care support services (e.g. 'we don't provide help with bathing unless this need is verified by a doctor's note' or 'we don't provide travel support anymore' or 'we don't provide evening (or weekend) services' and so on). **The law requires that a person's assessed needs have to be met.** Personal budgets cannot be used to impose limitations of this nature - so councils cannot have 'upper limits' on the amount of financial support that can be provided: **a person's assessed needs must be met, regardless of their cost.**

Action:

- If your relative is denied access to a particular type of support or a cap is placed on the amount of support they can get, check that 1.) Your relative's needs are clearly described in their care assessment 2.) That their care plan states how their needs will be met.
- Challenge any blanket bans or upper limits on the amount of financial support that is provided. The council has a legal duty to meet your relative's assessed needs.

Investigation into abuse at Winterbourne View

The Panorama programme showed systematic, pervasive and planned physical and emotional abuse of people with learning disabilities who were placed in the care of Castlebeck. What the programme documented was criminal activity.

The fact that this was perpetrated on people with learning disabilities at one level should be irrelevant, such criminal activity is a fundamental violation of the rights of any individual to be free from harm, abuse, exploitation, humiliation and degradation. People with learning disabilities, and in particular those who are labelled as challenging, are less able to stand up for themselves and to be listened to when they cry out for help.

We are concerned not just about the immediacy of the welfare of the individuals with learning disabilities shown in the programme but also for the longer term impact on them of being subject to such trauma. We must not forget the families who entrusted the care of their relatives not only to a private care provider but also to a wider health and social care system that at many levels has failed them all.

We strongly support Professor Jim Mansell's assertion that institutional care is not the answer for people with learning disabilities and that with commitment, vision and drive it is possible to provide support and care to enable people with learning disabilities who are also challenging, to live fulfilling lives integrated within the community.

We continue to work with individuals and organisations and government throughout the UK to highlight the need for continued commitment, investment, promulgation of good practice, research and safeguarding for a group of people who are so often vulnerable to restrictive and abusive practices perpetrated in the name of 'care' and 'treatment'.

Further information about the work of the National Strategy Group is on the CBF website: www.challengingbehaviour.org.uk

• **Dr Roger Banks**, on behalf of the National Strategy Group for Challenging Behaviour

Welcome news!



Sam

Our son Sam is sixteen and our journey started when he had health issues aged six months. The green paper talks about identifying needs early; Sam had the signs for autism from an early age but no one was willing to correctly diagnose him until later.

The paper proposes that schools be more open and frank with parents with a focus on transparency and accountability. If this had been the case, Sam would never have been excluded from a special unit which resulted in a long struggle to find a placement that met all his needs.

Our journey now continues with the joys (!!!) of transition into adult care. It has been a bumpy ride so far. The service is supposed to be seamless but there are great chasms in it. The proposals identify the need for a continuation from birth to 25 with all the agencies working together without a hand over from one agency to another.

The green paper describes a journey that has less stresses and strains on the family of those caring for someone with special needs and a focus on the individual at the centre of this process. If the Government can make this work and remove some of the extra pressure currently put on families like ours, spending less time fighting to get what our children need would mean we had more time and energy to invest in a better quality of life for our whole family.

Richard and Helen Dando

Improv

Green papers are consultation documents which outline work. Matthew Dodd and Philippa Stobbs from the Council Green Paper on Special Education Needs (SEN) and Disa

The key proposal in the long awaited Green Paper is to introduce a single statutory assessment process across all services and replace statements of SEN with 'Education, Health and Social Care Plans'. The purpose behind these changes is to streamline the process by which families can access the support they need and radically improve the way services work together to support disabled children and young people. CDC knows that parents and children face multiple assessments and that these are not sufficiently coordinated across health education and social care services. We also know that different agencies don't work together as well as they could when delivering services. In principle, therefore, a single statutory assessment process and plan is to be welcomed. In practice, however, there are a number of barriers that will make this difficult to achieve.

A single statutory assessment process

There are major challenges which need to be addressed if a single assessment process is to work. First, there needs to be a recognition that a single assessment process will not stop the need for multiple assessments – as disabled children often have complex needs which require a range of interventions – but rather that these assessments need to be much better coordinated. There are also different thresholds for being assessed in different services – for example, the threshold for getting a statutory assessment in education is when a school 'cannot reasonably be expected to have the resources to be able to provide for the needs of the child' whereas the threshold for a social care assessment is if you are a 'child in need'. How these multiple thresholds could be streamlined is a major challenge for Government and the sector.

Second, some individual or agency must be the key point of contact for communicating with parents, children and young people involved in the single assessment process. Without a single point of contact, parents, children and young people will still have to communicate with many different agencies and will not experience the more joined up assessment process which the Green Paper envisages.

Education, Health and Social Care Plans

The green paper recognises that there are different duties on different agencies to provide services to disabled children and children with SEN. For example, a statement of SEN currently gives a legal entitlement to educational services needed by a child.



g lives?

Government intentions and seek views on making them for Disabled Children comment on the recently published *Support and Aspiration*.

A statement also includes an agreement from health and social care services to provide services, but these are not binding and the local authority is the default provider.

The green paper states that single plans will provide the same statutory protection to parents as the statement of SEN and will include "a commitment" from all parties to provide their services. In order to ensure all agencies deliver services set out in the plan, the commitments made in an Education, Health and Care Plan by social care and health services will clearly need to be more binding than is currently the case. Without this, there may be no improvement on the current system

It is the Government's intention that by 2014, all children who would currently have a statement of SEN would be entitled to this new single assessment process and plan.

What would be needed to make this work?

The idea of a single assessment and plan is just that: an idea. If this idea can be developed in a way that improves the current system, who would not want to contribute to that endeavour? So, what would be needed to turn this idea into practical reality?

First, all the evidence on multi-agency working indicates that bringing agencies together to meet individual needs is unlikely to work unless there is a wider strategy securing their commitment. Such a strategy would need to involve a joint approach to assessing needs across an area, shared accountability and joint funding. Bringing this kind of approach together locally will take significant input in terms of commitment, time and effort.

So, secondly, there needs to be plenty of time: time to try out innovative ideas, time to identify the practical barriers and ways of overcoming those barriers. If these ideas are going to work this needs to be seen as the start of a long term change programme. The risk is that otherwise we finish up changing the name of a statement into an education health and care plan. Not in itself an objectionable idea, but it significantly limits the ambitions of the Green Paper. Where more important to make them work than in relation to challenging behaviour?

• **Matthew Dodd and Philippa Stobbs**
Council for Disabled Children



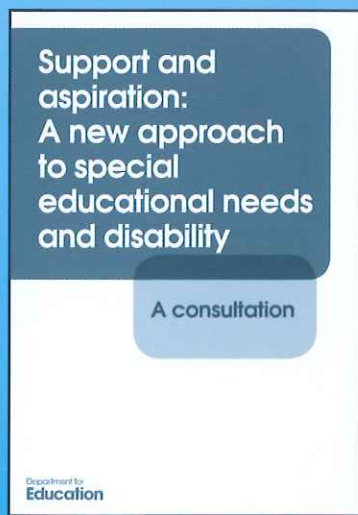
Message of Support

The Challenging Behaviour Foundation has been in correspondence with Sarah Teather MP, Minister of State for Children and Families, about the SEN Green Paper 'Support and aspiration: A new approach to special educational needs and disability' who said:

"Ensuring that the most vulnerable get the best support is a priority for the Government. I recognise that, for some children, their special educational needs or disability includes very challenging behaviour. The Challenging Behaviour Foundation does tremendous work in raising awareness and improving the skills of families and professionals in how best to understand and support behaviour change. I am pleased that the Department for Education has been able to fund the Foundation's development of information and training materials through the Children and Young People grant programme. This is now being taken forward on a larger scale through our new Improving Outcomes for Children and Young People grant programme. It will mean that up to 1500 children and families and staff in up to 150 special schools with nursery classes will be able to benefit from the training at this important stage of their development."

She goes on to say "I wish the Challenging Behaviour Foundation and its dedicated staff every success in the future."

The Challenging Behaviour Foundation will be sending a detailed response to the SEN consultation 'Support and aspiration: A new approach to special educational needs and disability'.



Raising aspirations

The Sustainable Hub of Innovative Employment for people with Complex Needs (SHIEC) project aims to support genuine paid employment for people with learning disabilities who have additional complex needs. This includes people with profound and multiple learning disabilities, those with severe learning disabilities and challenging behaviour and people with learning disabilities and histories of mental health problems or offending behaviour. SHIEC is a hub of individuals and organisations who are working together to achieve this.

The project aims to identify and support a range of employers to employ adults with learning disabilities and additional complex needs and to utilise existing employment support and pathways and make these work for everyone.

To date, SHIEC are working with 31 people across the UK, all of whom now have completed vocational profiles. Of these, 4 people are in paid employment and 6 people have engaged in voluntary placements.

A supportive network comprising of provider organisations, educational services, family carers, policy makers and academics meet on a regular basis to develop and share materials and to discuss progress, barriers and solutions regarding pathways to employment for people with complex needs.

Major barriers regarding getting people with complex needs into work have been firstly, engaging with employers and secondly, changing cultural expectations and raising aspirations for these people.

Next steps for the project will include further training to frontline staff and senior managers. SHIEC need to continue in changing hearts and minds and improving expectations for people with complex needs. Enhancing outcomes and celebrating individual's achievements will be key to the success of the project.

SHIEC aims to use the learning from the project, developing materials and resources which can be used in future to ensure sustainability of the pathways to employment for people with complex needs.

• **Frank Proctor**
SHIEC Project Manager

Paid work!

Ben is aged 36 years old. He has severe learning disabilities, severe communication difficulties and epilepsy. These difficulties contribute to him presenting some behaviours which others find challenging.

Upon joining the SHIEC project, people working with Ben recognised that simply by restructuring the support package they could help him gain paid work by providing one to one support in the workplace.

Various employers were approached and three were found who were prepared to realign tasks within their businesses to create meaningful paid employment for Ben. A programme of careful induction to each position was organised.

Ben has been in paid employment since July 2010 beginning on 3.5 hours with one employer increasing by a further 3 hours per week and then gaining a further 10 hours paid work with another employer. His tasks are primarily general gardening, mowing, weeding, planting and digging.

For Ben the impact upon his life of moving into work has been very significant.

Objectively, incidents of challenging behaviour have reduced, his epilepsy appears more controlled and his relationships with others, both staff and service users have matured. Subjectively, he appears happier, more relaxed, more able and willing to communicate and more in charge of his life.

"Starting out at college and moving to residential care and now moving into his one bedroom bungalow has built Ben's self esteem beyond recognition. Now he has moved into paid employment with support from the staff and the team at SHIEC. The quality of that support is quite outstanding. You can see how proud he is of this achievement and a spin off is that his challenging behaviour has reduced. I believe he is much happier and fulfilled."

• Ben's Sister

Key achievements of the SHIEC project

- 4 people are in paid employment
- 6 people have engaged in voluntary placements
- Positive effects in terms of the well being of individuals placed in work
- Noticeable reductions in challenging behaviour of individuals involved
- Knock on effects on ideas and aspirations for other people with learning disabilities with whom service providers work.
- Employer engagement training for frontline staff
- Breakfast forum to engage local employers
- Individual targeting of large employers

For more information contact frank.proctor@theCBF.org.uk



Ben at work

First of its kind?

Dr Nick Gore, from the University of Kent Tizard Centre, reports on the recent evaluation of CBF's Training Workshops for Family Carers and School Staff

There have been several research studies that have shown the benefits of training in challenging behaviour. These have included training for either groups of paid staff or family carers. These studies have found positive changes for the people who have received training (i.e. increased knowledge, better emotional coping) and people with learning disabilities who they support (i.e. reductions in challenging behaviour).

The CBF training workshops are, however, unique in that they provide sessions for both family carers and paid staff simultaneously. There could be extra benefits to running training in this way such as creating more consistency of approach and strengthening communication between families and professionals.

The current evaluation took part in 2010. We aimed to find out whether the CBF training workshops helped bring about positive changes for people who took part. School staff and family carers from five special needs schools in Kent filled out three questionnaires before the workshops began and again after they were completed. The questionnaires were:

- the Checklist of Challenging Behaviour (this asks people to make ratings about different challenging behaviours a child displays)
- the Challenging Behaviour Attributions Scale (this asks people about why they think challenging behaviours occur)
- the Emotional Reactions to Challenging Behaviour Scale (this asks people about how experiencing challenging behaviour makes them feel)

Some very positive changes were found when we compared people's questionnaire answers from before and after the training. Family carers and school staff reported slightly different changes on the measures but all of these were positive. Changes reported included:

- People showed a change in their understanding of the causes of challenging behaviour.
- People reported feeling less depressed and angry and/or less fearful and anxious when experiencing challenging behaviour.
- People rated incidents of challenging behaviour displayed by children they supported as happening less often and when they did happen being less severe and easier to manage.

People who have taken part have previously described these benefits but the evaluation helps to provide even more evidence. The CBF training appears to be a very useful resource for both families and professionals.

• **Dr Nick Gore**, Tizard Centre, University of Kent

For a full copy of Nick's report contact info@theCBF.org.uk

We are delighted to report that we are now able to offer schools and families **FREE CHALLENGING BEHAVIOUR TRAINING** for a time limited period (subject to availability), thanks to grant funding from the Department of Education. If you are interested in receiving challenging behaviour training at your school please contact info@theCBF.org.uk for a schools information pack. For general information about our training please visit www.challengingbehaviour.org.uk

Please note the training is only relevant to carers of individuals with severe learning disabilities (ie. limited speech, often non verbal, and needing help with daily living skills such as eating and dressing).

CBF training – we need YOU!



Sarah Roberts

Sarah Roberts, one of our family carers, writes: "I initially had no clear idea of what volunteering might entail. I needn't have worried. I received a lovely warm e-mail thanking me for my interest and inviting me to find out more about the CBF and what opportunities there were to get involved.

All my travel and accommodation arrangements were taken care of for me and I soon found myself in Kent with a whole bunch of potential new recruits.

We received two days of 'core training' from professional and family carer trainers which I thoroughly enjoyed and met some truly inspirational people. I knew then that I wanted to be part of it.

I signed up to become a family carer trainer and after some further training I delivered my first workshop alongside a professional trainer in March. I was a little nervous at the start but Andy, the professional trainer, put me at ease and I knew that I wouldn't be left floundering. I thoroughly enjoyed delivering the training and can't wait until the next one. It was great to be able to share my story with other family carers knowing that this would be helping them to get the right support plans for their sons and daughters."

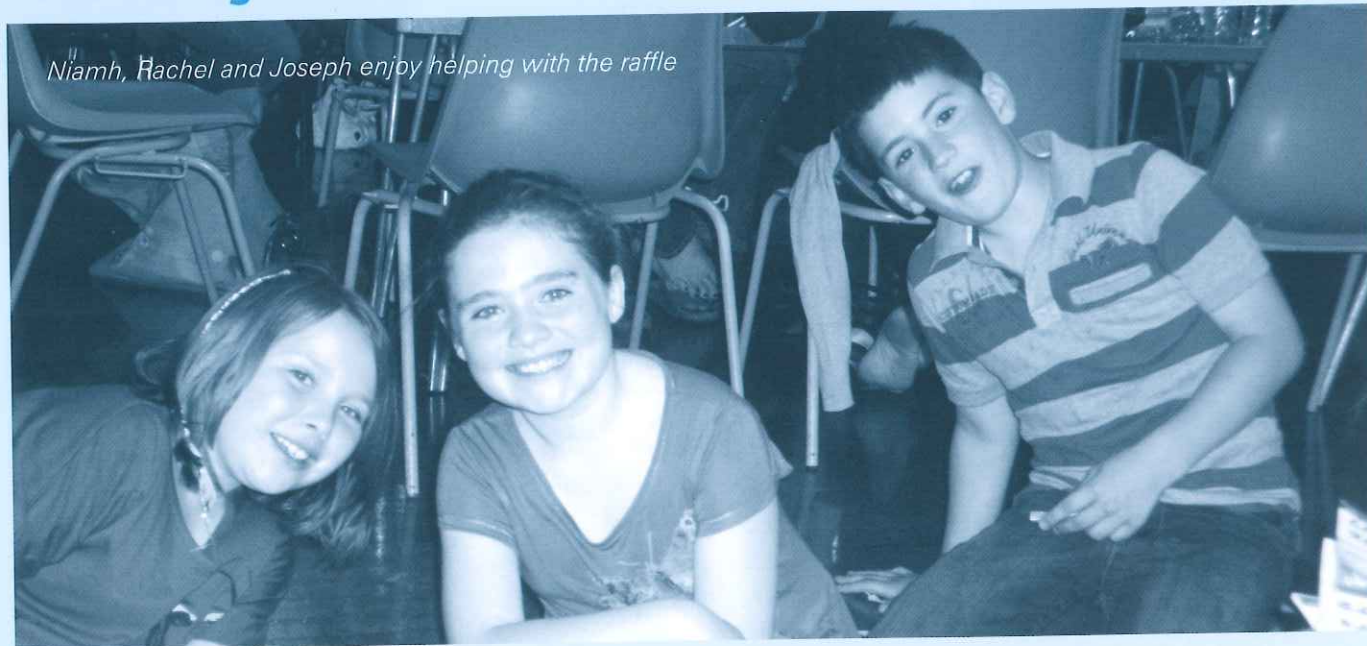
As demand for CBF training increases we are looking to recruit more positive behaviour support trainers and more family carer co-trainers. Some trainers work on a casual or self-employed basis, others may be seconded by their organisation for a day or so each month, and others work as volunteers. Please contact helen@theCBF.org.uk to register your interest.

Thank you to all those who have donated to the CBF recently including:

A big thank you to **Anne Martin** who gave a £20 donation in memory of her friend Ruby Gadd. Ruby sadly died earlier this year, but had spent her early years working with children with special needs. The staff and customers of **J Dowle Fencing & Garden Services Ltd** have raised £96 via a collection box in their shop – thank you all!

If you know of anyone who would be willing to have a collection box for the CBF please let us know.

Fundraising Events



Niamh, Rachel and Joseph enjoy helping with the raffle

Our hardworking Fundraising Committee arranged another Quiz night on 6th May - we even recruited some young volunteers to help on the night. We had a great night and the total amount raised was £547.70. Look out for further quiz dates later on this year.

If you would like to arrange your own quiz night please let us know and we can supply you with the questions and tips for running a good event. Alternatively you could consider having Dinner4Good.....



For those of you that are unable to attend a fundraising event in Kent

we are looking at new ways for you to raise money for the Challenging Behaviour Foundation. We have started the ball rolling by signing up to Dinner4Good, which allows you to raise money for us simply by doing something you enjoy - having friends round for dinner! To see how it works just go to www.dinner4good.com/theCBF

From here you can create and send personalised email invitations (takes less than 5 minutes). Your guests can then accept and donate online, so there's no awkwardness over asking for money or hassle of collecting cash.



Coming Soon...

We have asked some of our supporters to help us by filling in a survey about our planned Friends of CBF scheme, which we hope to launch later this year. We wanted to thank all those people who have taken the time to fill in our survey both online and in paper format. We've had a really good response and we are now incorporating your comments into our plans – thank you. If you would like to take part in the survey do get in touch – all your comments and ideas are valuable to us.

Keep an eye on our website, it will have a new look later this year and will include lots of ideas for fundraising.

CBF on Twitter

The Challenging Behaviour Foundation is now on Twitter. You can follow us at <https://twitter.com/CBFdn>

Everybody's Business

With the help of carers and professionals working with carers, Skills for Care and Skills for Health have produced 'Carers Matter - Everybody's Business', guidance to help employers and organisations support carers better through learning and development of staff. It is based on a set of Common Core Principles for Working with Carers.

The resource is currently free to download. Visit www.skillsforcare.org.uk/carers or www.skillsforhealth/carersmatter for more information.

100 Club Winners

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

February 2011: Sarah Down (Kent)

March 2011: Mark Lawrence (Lincolnshire)

April 2011: Carol Lowe (Middlesex)

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

Have your say

We welcome articles from parents and professionals. Please get in touch if there is something you would like to write about.

Disclaimer

While every care is taken in the compilation of this newsletter, the Challenging Behaviour Foundation cannot be held responsible for any errors or omissions, nor accept responsibility for any goods or services mentioned.

© The Challenging Behaviour Foundation. All rights reserved.

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 & 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 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*		
Getting legal authority to make decisions about money, property & welfare	£1.00*		
Difficult sexual behaviour amongst men and boys with learning disabilities	£1.00*		
NEW ***Ten Top Tips for Families***	£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			
Planning your House	Web Only**		
Provides family carers with practical help with planning for future housing needs.			
8 Ways to get a house	Web Only**		
Explains the different ways to get a house and how they are funded			
**Due to anticipated changes in funding, these new resources will initially only be available to view on our website www.challengingbehaviour.org.uk . Family carers who would like a printed copy should contact the CBF. Final copies will be available by the end of the year.			
Planning for the Future: Information Pack England/ Scotland/ N Ireland/ Wales (please specify)	£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 & report	£10.00*		
This 20 minute DVD provides an overview of a specialist transition service developed to bring four young people back to their local area from out of county residential schools. An accompanying 40-page report reviews how the service was developed.			
OTHER RESOURCES			
A guide for advocates (England and Wales)	£16.00*		
Key 'at a glance' bullet points identify 'what you may encounter' and 'what you should know' – a very practical tool for both professional advocates and family carers advocating on behalf of their family member.			
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 provide your charity registration number

Name

Organisation

Address

Postcode

Telephone

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

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

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

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

To pay by credit/debit card please telephone us on 01634 838739 (3% card handling fee applies)

Thank you for your support

The CBF – how you can help

Did you know.....?

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

Please consider how you could support our work.

The Challenging Behaviour Foundation

Registered charity number 1060714

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

Email: info@thecbf.org.uk
Tel. 01634 838739
www.challengingbehaviour.org.uk