

# Challenge

Winter 2013

The newsletter of the Challenging Behaviour Foundation

## Facing Challenges Together

The governance of an organisation not only agrees its strategy and way of working but also, perhaps most importantly, its culture. As chair of the Voluntary Organisations Disability Group I have to admit to a certain bias: in my view a provider that has family members and people with disabilities with real governance

authority is one step ahead of those whose boards are primarily formed for commercial gain. That said there are good, bad and indifferent organisations regardless of size or legal status.

I think the key concern for families on a day-to-day basis is the quality of the service for their own loved one: the attitudes and behaviours of the staff, their confidence in the first-line manager, how receptive they are to families' views and concerns, how transparent and honest they are about issues and, most importantly, that they are doing what they promised.

***It is fundamentally important for all providers, regardless of their governance arrangements, to properly engage with families.*** It is in the best interests of the individuals to help keep them connected with their heritage and wider networks, and to improve decision making and accountability.

Sadly I hear too many stories from families and care providers



Bill Mumford

about antagonistic relationships and I find that nearly all of these spring from poor communication - often about the small things. Very occasionally there may be real fundamental disagreement and in such circumstances it is best to take a "best interests" approach involving trusted and

expert external parties to find a resolution.

Personally I like to see families and individuals involved in the recruiting, inducting and training of the staff, in building up local contacts and even, if appropriate, a bit of fundraising for the "extras". Regular family contact with the link worker and local manager is essential and occasional family days are to be encouraged. I love visiting services which have organised an event of some sort and to see everyone from toddlers to grandparents mixing in with everything that is going on. We need to bear in mind that we all have different tolerance levels for family involvement in our lives and these might be different among people sharing the same house or local day service but a bit of common sense and sensitivity is usually all that is required to ensure everyone is happy.

***The important thing is to build and sustain good relationships - it is in everyone's interests.***

• **Bill Mumford**  
Chairs the Voluntary  
Organisations Disability Group

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***A new film from the Challenging Behaviour Foundation***

'Challenge' is the newsletter of the Challenging Behaviour Foundation, supporting those caring for individuals with severe learning disabilities whose behaviour is described as challenging

## Your Comments

*Challenge* is changing and we want to make sure your views are included too. We'll be asking what you think about the latest newsletter on Facebook and Twitter and doing our best to print as many comments as possible.

This time we asked you how providers could work better with family carers.

It's so very important for the providers to work with parents/carers and listen to them, as lack of communication can cause so much unnecessary stress and anxiety for all concerned. (Malgosia, on Facebook)

I am my son's greatest ally and resource as I am the only constant in his life. Working together with professionals can save a lot of unavoidable behaviour that can challenge as I know his history and personality. Since working like this with my son's provider his quality of life and that of his staff has dramatically improved. (Jen, on Facebook)

Mums and Dads are professionals too, maybe not on paper but in experiencing the whole condition (Sharon, on Facebook)

I've learnt a lot in 17 years yet no one ever asks my advice (Virginia, on Facebook)

To believe what us parents say is the truth, instead of undermining us all the time by saying 'film it' (Kerry, on Facebook)

Heather also sent us a great link to a video on Youtube called 'Parents of disabled children – their Today' about all the things parents wish providers knew about life as a family carer.

A big thank you to everyone who commented this time.

If you have any thoughts on Facing Challenges Together and would like to feature in our next newsletter look out for our posts on

facebook.com/thecbf and

@cbfdn,

or send your comments to communications@thecbf.org.uk

## Valuing Families

### Working with families has to be the way forward

Along with over 60 other people I recently listened to a young woman describe the experiences of her brother who has a learning disability and displays behaviour described as challenging. She spoke passionately and her love, admiration and respect for her brother was plain. She described his journey through services, how he had been abused, and the enduring and terrible impact it had on him - and the immense impact on her and all of their family. Recovery will be gradual, trust has to be rebuilt.



Vivien Cooper

#### **The human price paid for getting it wrong is too high:**

we need to make sure people get the right support in the right place at the right time, in a society that is inclusive, supportive and understanding. Most people were moved to tears.

Valuing families as partners has to be the way forward. Most families provide a lifetime of love and support, regardless of where their family member lives.

#### **We need to get better at listening to families,**

recognising their expertise and knowledge, supporting them in their role and learning from them.

In this edition of *Challenge* we describe a range of ways to support and work in partnership with families, from Bill's provider perspective to individual support workers – and there is a common message throughout: better outcomes result through working together, through listening to each other and from having common goals.

Of course, we know there are challenges. The true test is when things

don't go according to plan - will everyone stick with it. It is hard sometimes to listen when you are told something is wrong. It is tempting to busy yourself with processes, distance yourself from blame and respond defensively. But the ultimate test is being able to focus on what needs to happen in order to get it right for

the person and to take responsibility for that.

Recently I have raised serious concerns about individuals being supported in totally inappropriate ways, and have been astonished at some of the responses of very senior people. They have examined their "quality assurance" processes and found them to be in order, or undertaken a lot of activity, lots of meetings, but nothing has changed.

They have missed the point that the purpose and real test of these processes is to ensure that people are safe, well cared for, happy and supported. Family carers are natural quality assessors! They are not distracted by policy documents, systems and processes – they ask a simple but powerful question: "would this be OK for you or your loved one?"

#### **We will know when we get it right –**

the sister sharing her experiences to a roomful of people will not have to be brave and wonderful. She will be able to simply be her brother's sister.

#### • Vivien Cooper OBE

Chief Executive and Founder of the Challenging Behaviour Foundation

# Working in Partnership

Welcome to the Autumn Edition of Challenge, the Newsletter from the Challenging Behaviour Foundation (CBF).

As one of a few changes in this edition we are introducing this new article to let you know what is going on at CBF and how we offer support around the issues discussed in each edition.

This edition focuses on Families and Care Providers working in partnership, something which we believe to be a crucial but often challenging part of providing good support.

The CBF is focussed on working in partnership. We want to support families and professionals not only to build good relationships but also enable families and individuals with learning disabilities to have a real input into how services are planned and provided. We also aim to support professionals to engage with families, help to build understanding between provider and family perspectives and support best practice.

We provide a range of information resources which can be helpful in enabling families and professionals to develop a common understanding of strategies for supporting someone who displays challenging behaviour. Our advocacy guide is designed to help both professionals and families to help an individual to voice their needs and wishes in developing their care plan. An extract from the guide can be read on page 5 and all our information and resources are available to download from our website [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) or you can order them using the form at the back of this newsletter.

We also encourage partnership working to develop behaviour support plans; this approach helps to ensure that a fuller picture is given of an individual's history, needs and preferences to develop support that works to reduce challenging behaviour. The CBF provide workshops with both paid and unpaid carers to understand the reasons behind challenging behaviour and start the process of building a behaviour support plan. To find out more about our workshops please see our website or email [workshops@theCBF.org.uk](mailto:workshops@theCBF.org.uk).

As part of our consultancy services we also work with providers to support the development of their own plans for engaging with families. We do this through providing specialist advice and input to specific projects or by providing speakers and facilitators for staff meetings and away days. If you would like to know more please email [info@theCBF.org.uk](mailto:info@theCBF.org.uk).

## About Us

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Coordinating peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops to reduce challenging behaviour
- Promoting best practice and supporting research
- Speaking up for families on a local and national level

Our vision is for all people with severe learning disabilities who display challenging behaviour to have the same life opportunities as everyone else and, with the right support, to live full and active lives in their community.

Our mission is to improve understanding of challenging behaviour, empower families with information and support, and help others to provide better services and more opportunities to people with severe learning disabilities who display challenging behaviour.

To access our information and support, or find out more about what we do, call 01634 838739, email [info@theCBF.org.uk](mailto:info@theCBF.org.uk), or visit our website: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk).

## Russell



*From left to right: Fiona (Sister), John (Father), Russell, Nigel (Brother) and Gwyneth (Mother), deceased.*

Our third child, Russell, was diagnosed with Down Syndrome in the 60's. His development and our family life would have both been much better if we had known where to obtain information and support especially when his behaviour became aggressive and destructive.

In the early days there was little support available and social services were unhelpful. One harassed social worker even said he should be locked up out of harm's way! Eventually we, not social services, located and obtained a few weeks respite care and later long term care.

As time passed we learnt that one must be calmly assertive and persistent when dealing with officialdom. My years of experience have taught me to ask for help not demand it, ask for justification of a negative response, make notes of conversations, if they cannot help ask who can, always thank them for their time even if you would rather throttle them! Never be aggressive or threatening.

Nowadays we have wonderful charities such as the Challenging Behaviour Foundation who have always given unstinting support over the years. Everyone at the Foundation is always ready to listen and offer support, obtain information, make suggestions and help in contacting independent psychologists, solicitors etc.

Other parent's experiences are helpful in providing answers and showing we are not alone. We cannot thank them all enough.

Nowadays thanks to CBF, psychologists and much improved social services, incidents of challenging behaviour are rare and when calm Russell has a likeable personality.

In spite of the difficulties, he has been a gift not a burden.

- *John Barker, Family carer.*

## Improving partnerships

As parents of a young adult with autism and challenging behaviour we have used many care providers over the years. They have generally been very supportive but sometimes haven't really understood what they need to do to provide a good service for our son. Nowadays our son benefits from very good support from his residential care provider, helping me to see what 'good' partnership working looks like.

Nearly everyone who supported our son did so with commitment and zeal. For the 'lucky' ones it seemed to be a natural skill but for the rest I think their success relied upon proper training, experience and support from their co-workers. Some of his support workers have struggled to build a relationship. We did try to help; I once gave a support worker some information about my son in the hope that it would help him understand him. "Thank you," he said, "I will put it in the file", and didn't even read it. It is important to be willing to engage with us parents in order to learn and develop strategies that have some chance of success.

**Care workers:** ask questions, read the notes, ask parents and colleagues to tell you as much as possible about your client. Until you have known your client for several years we parents are the experts so please treat us as such and all work together.

**Providers:** it is really important that you are fair and honest and understand that this is a partnership between you and us. When providing community support, families need your staff to be competent, punctual and reliable. Support must be person-centred and activities safe, appropriate and agreed with parents beforehand. Life is tough; please don't make it more complicated for us.

• *Ian Penfold is a CBF local champion and a keen disability advocate.*

## Q: My 25 year old son enjoys watching videos but keeps breaking his television/video combo.

### Does anyone have any ideas?

**A1:** What we have done is bought furniture that encloses the TV etc., which is not cheap but does the job. You can have locks put on which we did and can use remotes through the screens.

This does take away some of our daughter's independence and we found it a little frustrating at first but in time we have now been able to let her do more herself with supervision.

**A2:** My daughter has a large flat screen TV attached securely to the wall. The DVD player, Sky box and all electrical equipment are kept in a locked built in cupboard under the TV. The wires are in trunking, attached to the wall. All her favourite DVD's have been copied to her iPad, which has

a protective casing. We have a new purpose bungalow planned and the media system will all be built into the walls and ceiling with the DVD player locked in a metal case.

**A3:** I know independence is so important but I think supervised access may be the best compromise. By using a locked cabinet he would still have control with close supervision and yet the equipment would be safe when you are out of reach.

**A4:** Have a look at Tough Furniture Ltd. They manufacture furniture including TV/DVD cabinets that enable our son to watch television without being able to break it. We are currently researching watching films via the computer/iTunes. This would mean selecting a film from a list and not having an actual DVD to scratch or break. Obviously, this won't help with the videos but there are programs out there that allow you to transfer videos or companies that will do this for you for a fee.

## Q: We are having difficulty bathing our son. Do we have any chance of getting a grant for a wet room?

**A1:** We have just had a bathroom adaptation done so would say you may very well be able to get it done under the Disabled Facilities Grant. I would say make the call as soon as possible because it took us years to get it sorted. Just keep on their case and hopefully your area will be better than ours.

**A2:** We had similar difficulties bathing our daughter. The problem was she just refused to step into the bath and she would not sit down. As she was getting heavier and as she got older we couldn't lift her in any longer.

We applied to the occupational therapist (ask your social worker, or in our case the most important person was the community nurse) who

assessed our daughters need (and ours) and installed a full wet room for her. She adores standing under the shower (dancing most of the time). We have nothing within arm's reach that she could trash and we can get close to give her the wash she needs.

**A3:** Our social worker arranged for an occupational therapy assessment to be done and we qualified for a grant.

It took a while because her disabilities are behavioural rather than physical, but eventually a company who also supply care home facilities came and re-fitted the bathroom. You have just got to keep on at them. It does wear you down and I really feel for you, but this made a huge difference for all of us as a family.

Please start with your social worker, mine was fantastic. We also had a disabled children's community nurse and she also got things moving.

*These questions and answers are taken from our email networks.*

***Want to join the debate? Membership of the networks is free to both families & professionals supporting children or adults with severe learning disabilities.***

***Application forms from [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) or [email\\_network@theCBF.org.uk](mailto:email_network@theCBF.org.uk)***

## A Guide for Advocates

Advocacy can empower and protect people described as having challenging behaviour. The Guide for Advocates is a great practical resource for professional advocates but is also suitable for anyone in an informal advocacy role, including family carers.

The Guide covers the use of medication, physical intervention, seclusion and sectioning. It describes good support and contains questions, key ideas and information to keep in mind. The guide also includes case studies and a checklist.

A Guide for Advocates is free to families/unpaid carers in the UK and costs £16 for professionals and registered charities. To order a copy, you can call the CBF office on 01634 838 739, email [info@thecbf.org.uk](mailto:info@thecbf.org.uk) or send us the resource order form at the back of this newsletter.

## An Extract from a Guide for Advocates

### Working with families

It is important to note that many of the people this pack focuses on will lack the capacity to consent to having an advocate. It is very likely that the person's family members, until your appointment, have been the only people 'advocating' on behalf of the person.

" Families are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case for people with complex needs. Even when people leave home, they do not leave the family. Families continue to offer a lifetime of involvement, support and advocacy. "

### Valuing People Now, 2009

- Families often feel they know their relative very well. They may be the only source of background or historical information about the individual.
- It is good practice to ensure the family is involved in the individual's person-centred plan (PCP).
- Families may vary in the amount and kind of involvement they wish to have in their relatives' lives.
- A good service will ensure the individual is supported to maintain contact with their family. However, the service provider may have a view about the family and their role. Families likewise may not have positive experiences of support and service provision.
- Whatever the relationship between the family and service provider it is important to be honest with families and to treat family members with respect.
- Families may be suspicious about the appointment of an advocate because they may not have had good experiences of working with professionals in the past and they may not have been involved in the appointment process.
- Families may need advocacy support themselves, and the advocate should be able to signpost them to local organisations that could provide this support.

### Questions to consider:

1. Has the family been involved in the appointment of an advocate?
2. How is the person supported to engage positively to maintain relationships with their family?
3. How is the family involved in the individual's person-centred plan?
4. How will the relationship between the family and the advocate be managed in a positive and constructive way?
5. Have you agreed with the family how, what and when you will share information with them?

## The new Driving Up Quality Code

The Driving up Quality Code developed by the Housing and Support Alliance aims to make sure that what happened at Winterbourne View never happens again.

The code hopes to create and build a passion in the learning disability sector for high quality support. It plans to celebrate good work that's already happening and make clear what is and what is not acceptable practice.

The code focuses on 5 key ideas:

1. Support focuses on the person, involving them and their family in making decisions and plans for their care.
2. People are supported to have an ordinary and meaningful life.
3. Care and support focuses on people being happy and having a good quality of life. Care and support workers are trained and supported to offer high quality support.
4. A good culture is important to the organisation.
5. The organisation is well-led. Managers demonstrate that getting it right for people who use their service is their most important job.

Providers and commissioners will be encouraged to sign up to the code, and share evidence of what they are doing to meet its aims online. They will also be encouraged to use Experts by Experience to independently verify their self-assessments. To see who's signed up and how they are working towards meeting the the Code, go to: [www.drivingupquality.org.uk](http://www.drivingupquality.org.uk).

## A Winterbourne View Helpline

UK-based charity Respond supports people with learning disabilities and their families who have been affected by trauma and abuse.

In the wake of Winterbourne they've set up a helpline for former patients and their families, support sessions for families and are offering individual assessments for former patients affected by the abuse.

For more information call the Winterbourne View Helpline: Freephone 0808 808 0700 (Thursdays only) Email: [Annette.crump@respond.org.uk](mailto:Annette.crump@respond.org.uk) or go to [www.respond.org.uk](http://www.respond.org.uk).

# Support from a p

*Niamh is 9 and lives in Gloucester with her mum Carly, her dad Nick and her brother Finlay. She needs extra support and her family regularly need short breaks due to the challenging behaviour she displays, so Niamh is supported by Personal Assistants (PAs), including Laura. Laura and Carly tell us about working together to support Niamh.*

## **Carly, how did you come to employ Laura to support Niamh?**

We were given Direct Payments as Niamh's behaviour was so extreme that we got little rest as a family. Later when one of our existing PAs left we needed someone to take their place. After a school multi-agency meeting we mentioned we needed another PA and the school told us about Laura. We then set up a meeting and Laura came to our house to see us and she was employed from then on.

## **Laura, how did you come to work with Niamh?**

I was a Learning Support Worker in Niamh's class and after a review meeting Niamh's teacher said that Carly was looking for a PA so I went and met Carly and Nick and it went from there.

## **Carly, can you tell us what it's like employing a PA through direct payments?**

It's quite simple. Within Gloucester you are given a payroll

agency. One of their Independent Living Advisers comes to your house and tells you how much each PA gets and you get a handbook detailing holidays, getting employer liability insurance etc. As an employer you fill in the PA's time sheet, send it to payroll and they send you the PA's payslip detailing how much you need to pay. You can then pay the PA by cheque or by online banking. Niamh's Grandma is one of her PAs!



*Niamh and Laura*



*Jackie, Rhys and Wayne*

## Building Trust

I made the decision to become a support worker a few years ago because I wanted to contribute something of value to people that needed support. I didn't want just another "job", I wanted a change of lifestyle and to try to have a positive impact. I have good work experience and I know I have the potential to earn a lot of money in another profession but doing support work has made me a far richer person than any commission I could have ever made elsewhere.

The most important thing to me in my role in supporting Rhys is that Rhys feels comfortable and that he can rely on me. I am with Rhys for a significant amount of time during the week and I want him to feel safe and secure in the community and in his home.

Rhys is a 24 year old guy who enjoys life and knows what makes him happy. He knows what he wants and he lives very much in the now. I love that about him and it's an admirable quality. I just want to help him feel accepted for who he is and for him to feel included into everyday life.

The foundations of mine and Rhys' relationship are no different to any other relationships I have in my life, it is essential that there is trust between us and that I show him consistency. I really like Rhys' personality and I enjoy spending time with him which inspires me to go the extra mile in my work.

Rhys' family are an ocean of knowledge. They know Rhys better than anyone and without their input our support team would not be able to give Rhys the fantastic support he is getting. It is so important that I build a good relationship with his family as they need to feel assured in my ability to support Rhys positively and I need to also feel reassurance that I am doing what's best for Rhys. There must be an equal amount of trust and consistency between me and Rhys' family as there is between me and Rhys himself. His family are a constant source of knowledge, inspiration and support.

If care providers and support workers fail to recognise the importance of working with the families then I would expect them to fail in giving the people who use their services the best possible level of support. By working as a team, building trust and communicating effectively with the families of people being supported we can help and support each other to give people like Rhys a fantastic quality of life and in turn we can get the most out of our individual roles.

- *Wayne Pavey, Support Worker*  
(To read more stories visit [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk))

# Personal assistant

## How was the 'getting to know you process'?

*Carly:* Fortunately we already had experience of a PA and luckily Laura already knew Niamh because she was one of her support workers at school so really it was us getting to know Laura, but we want the PA to feel at home as much as possible so we ensure they have access to everything they need, e.g. Tea, coffee.

*Laura:* Well it was easier for me as I already got to know Niamh at school working in her class, and Carly and Nick were very welcoming and very helpful.

## Carly, what do you think is the most important thing to remember when working in partnership with a PA?

To be flexible. We have set Niamh up with her own email so I can put in all the shifts for each PA (we currently have 3) in the calendar so they all know when they are working. Plus, remember that although the PA is getting paid they are providing the family with a valuable service.

## Laura, what has been difficult and enjoyable about being Niamh's PA?

I wouldn't say anything has been difficult; the hardest thing is letting them down if I can't make a shift or if I'm sick. I have mostly enjoyed seeing Niamh progress through school and then seeing it at home too!

## Carly, what is the difference for your family between employing a PA and agency support?

With a PA through direct payments you can choose the PA and the start times and days they work. With an agency it is generally set days & hours and you don't get to choose the agency staff.

## Laura, what do you think is the most important thing to remember when working with a family?

Being respectful of the family's privacy especially as you are in their home.

## Would you offer any advice to families or support workers thinking of doing the same?

*Carly:* Just do it! Without the direct payments we would not get any time to spend with our son Finlay. It allows us time to be a 'normal' family. It gives us additional help if we want to take Niamh out as we have extra support. It also gives Niamh one-to-one time and gets her used to other people looking after her.

*Laura:* I love working with Niamh and her family. By giving the family a break from their caring duties I can see the benefit of what I do, e.g. they can spend time with Finlay and they get to go out as a family without the pressure of caring for Niamh.

*If a family carer has any questions for Carly then you can contact her via the CBF and she will be happy to answer them.*



*Priti, independent advocate*

## Partnerships in advocacy

Advocating for Claire\* has been an interesting experience for me. Communication, I believe, is the key to making it work – communication with the advocacy partner I have been paired with, communication with the staff at the home where Claire lives, communication with other professionals involved in Claire's care, communication with her family and with the Challenging Behaviour Foundation (CBF) at advocacy meetings.

The advocate needs to remember that we are the voice of the person we advocate for and therefore building a relationship with them is fundamental to the success of the partnership, as it will inform our understanding of their wishes and voicing these is our responsibility.

I think the most important thing that I've never veered away from is that Claire is, like any other person, entitled to have a preference and a choice, and some days she may not want to be disturbed, visited or do things she may have enjoyed in the past. A respect for this is very important; it is about valuing her and that she has a mind of her own, then speaking up on behalf of one's advocacy partner comes easily.

Working with a variety of professionals is an important part of the advocacy role. Sometimes this may be intimidating and challenging. Intimidating: because there may be a great deal of professional knowledge and practical experience within the staff team and personal experience within the family. Challenging: because each person may come at the same issue from a different angle and may face very different hurdles within their organisations and in their roles. However, each of these is like a different piece needed to complete the jigsaw; each one is relevant and necessary to make the whole. Working together in partnership is all about an appreciation of this. After all, we are all meant to be working towards better outcomes for the person we work with.

It is not always understood by all team members that the advocate is not watching and waiting to catch them out. Quite the contrary in fact; the advocate may be able to provide an objective opinion, certainly a different perspective and may well help resolve a challenge or a persistent issue. It takes very secure team members to incorporate the opinions and recommendations of advocates and very confident and patient advocates to communicate assertively, accurately and in a non-judgemental manner.

But it is a role I cherish personally. As well as contributing to Claire's well-being, I have gained from the role in the form of personal growth. I have gained knowledge of the challenges faced by professionals, an understanding of challenging behaviours, their causes and purposes, and skills like mediation and negotiation.

\*name changed to protect identity

• Priti is an independent advocate for the Medway Advocacy Project

# Everybody Matters

Everybody Matters is a powerful new film due to be launched later this year. It stars Colleen and Shaun, who have learning disabilities and enjoy fantastic lives in their communities. They have both been described as displaying challenging behaviour, but their stories show that with the right support, everyone can live happy and fulfilling lives.

Colleen's sisters describe her as "fun, mischievous, cheeky, full of laughter and sunshine". Shaun's mum told us "The bit that strikes most people when they first meet Shaun is his sense of humour. His personality comes across to everybody, and he makes me feel good."

In Everybody Matters, you meet Shaun and Colleen and see them enjoying their daily lives. You hear their stories and discover how they are supported to live life to the full. Their families and support workers explain what makes them happy and how their support helps them to thrive. Two leading academics, Tony Osgood and the late Jim Mansell, explain that everyone with severe learning disabilities and challenging behaviour can be supported to live good lives.

We hope that Everybody Matters will show families how to access good, local, personalised support for their loved ones. There's lots of information in the film, and if you want to find out more about anything, the CBF will be happy to help.

Everybody Matters is being produced by the CBF, with support from MacIntyre, United Response, Dimensions and the Milestone Trust.



Colleen with her sister Felicity

## Making it happen

*Everybody Matters shows the benefits of personalised, local support, but you may be wondering how this support can be achieved in practice. The CBF has lots of resources that might be able to help – such as our "Planning for the Future" information sheet. Take a look at the summary version here:*

### Planning for the future

We all think about the future, some of us more than others. When a child or adult has severe learning disabilities and challenging behaviour their needs will be more complex. Because of this it is a good idea to plan ahead and to think of all possibilities, especially if a house or flat and staff will be needed.

#### Person Centred Planning

A Person Centred Plan is one way to do this. It is a positive "vision" of what life should look like for the person and the support needed to achieve this. A range of people including family should help make the plan. It should focus on the person's strengths, abilities and the things they enjoy. The plan is only considered best practice and is not a legal requirement. Therefore, the key parts of it must also be in the person's Community Care Assessment and Care Plan. These must be carried out by law.

#### What are the options?

The options for a person with severe learning disabilities should be the same as for everyone else. Government policy states that people with severe learning disabilities and challenging behaviour have the right to:

- live in their local area
- access family life
- access community facilities e.g. leisure centres
- access learning opportunities e.g. college

However, the person will need help and support to achieve these rights. Other people may also need to adapt which is why careful planning is important.

A good service or support package should let a person with severe learning disabilities and challenging behaviour live an 'ordinary' life. With the support of a person advocating on their behalf they should have choice and control over their life.

The Challenging Behaviour Foundation information pack 'Planning for the Future' gives more information on:

- Rights
- Your options
- The processes
- Who can help
- The challenges
- Understanding the funding
- Keeping the individual safe

The full version of the information sheet can be downloaded from our website [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk), or ordered using our order form on the back page of the newsletter.

**Everybody Matters will be launched later this year and will be available free to family carers. Sign up for the Everybody Matters mailing list to hear Colleen's full story and find out how to get your DVD by emailing [everybodymatters@theCBF.org.uk](mailto:everybodymatters@theCBF.org.uk).**

## Hopes for the film

Putting together Everybody Matters would not have been possible without the involvement of Colleen and Shaun's families. Their dedication and commitment to the project has been inspiring. Here, they talk about why they got involved with the film.

By targeting commissioners, service providers and all those involved in inspections of services, I hope that the film will see the end of the horrors of the Winterbourne Views of this world. (Sue, Shaun's mum)

The families watching the film will see that there are providers out there that strive to work in partnership to provide truly person centred services. I hope that it will help Shaun's good quality of life to be sustained in the future and he will not be failed by services again like he has in the past. (Sue, Shaun's mum)

We hoped to show what life is really like from a family's perspective when trying to support a loved one. (Felicity and Fiona, Colleen's sisters)

We want to tell other families that their life experiences should never be underestimated. Their knowledge and the understanding gained over years of natural family support is of value and utmost importance. This can play a major part in achieving the right life, care and support for their loved one (Felicity and Fiona, Colleen's sisters)

We felt it was important to show that, even after a considerable time spent in campaigning and in pursuit of the right path for Colleen, that with polite, persistent, patient, dedicated work, we all survived the dreadful situations, moved on and are happy for our and Colleen's success. What may seem the impossible is really achievable and possible! (Felicity and Fiona, Colleen's sisters)

You can sign up to the Everybody Matters mailing list to hear more messages from these families, and to share their insights about how good lives can be achieved for people with severe learning disabilities whose behaviour challenges, email [everybodymatters@theCBF.org.uk](mailto:everybodymatters@theCBF.org.uk).

## Our sister, Colleen

*Colleen's story is a big part of the film. Colleen has learning disabilities and has been described as displaying challenging behaviour. Here, her sisters introduce Colleen's story and write about the good life she now enjoys.*

In the past, Colleen was living in a one-size fits all placement, which she was expected to endure and be grateful for. She had to live in difficult, unsafe and unpredictable placements, which we had no control over. She was with staff who were sometimes cruel, and she was bullied and abused.

Now, everything has changed. The correct systems and the right staff are in place, and the best way to describe Colleen's life is that it is simply a normal, everyday life. She can exercise choice and have control over everyday decisions. She can be sad and happy, she has input, and her communication is understood and responded to. Best of all is Colleen totally 'owns' her life and there is no doubt she is our (and everyone's) equal.

Colleen loves her home. She is happy when cooking, making greetings cards, watching the soaps, having a party, or hosting gatherings in her home. She also enjoys relaxing in her garden in the sunshine. Outside of her home she goes to her local church and is part of her church community. Every week, she goes horse-riding and is quite an accomplished rider. She loves meeting up with her drama group and a regular 'ladies group'. She enjoys going on outings and short holidays, and she loves planning these trips and saving up for them – for example, she thoroughly enjoyed attending last summer's Paralympics experience. She values one to one home time with her staff team: she is good at making, building and maintaining new relationships.

One of last year's highlights for Colleen was getting involved with a Christmas drama production called A Christmas Cracker. We were so proud to see her perform in this. She has now been involved with the drama group for just over 12 months and we were both blown away by how much Colleen had developed in that time. We were amazed at the depth of her contribution to the production - it was obvious that Colleen was proud of her acting role. She was delighted in our reaction and took pleasure in demonstrating how capable she is in her own right.

Colleen is at her happiest when she is the centre of attention – she's the perfect Queen Bee – she loves being the hostess with the people she loves – she has a wicked sense of humour and a charming laugh. She can be calm and presents a self-assured, confident poise when she knows she is in control - Colleen now shows us that being happy is good.



Colleen (centre) with her sisters Fiona (left) and Felicity.

***This year has definitely been the year of the challenge. Twenty CBF supporters have raised over £6,000 so far, with this amount still rising. With marathons, dinner parties, mountain climbing and everything else in between, our supporters have been doing it all. Thank you!***



*From left to right: The magnificent seven, Lynn James-Jenkinson, Kirk Wells, Chris and Tori Parsons.*

Seven of our bravest supporters got together for a team skydive at Headcorn in Kent. CBF's Holly and Becky were joined by Jen, Chris, Tori, Lynn and Kirk for the 12,000ft skydive on Sunday 29th September.

"Perched on the edge of the tiny plane you are suddenly launched into orbit! Tumbling disorientated your brain and heart freak out!! But only for a split second. Your body levels with gravity and you go ohhh WOW! Falling with style! Words and thoughts fail as adrenalin and acceleration take over. You are in awe. Life takes on perspective. You can do anything".

• *Jen Fookes, family carer.*

The Magnificent Seven all landed safely with huge smiles on their faces. Congratulations to all of the team!

The skydivers are family carers and professionals, all passionately supporting the CBF, and determined to raise as much money as possible. They have a team fundraising page, and are still collecting sponsorship money: [www.uk.virginmoneygiving.com/team/CBFJumpTeam](http://www.uk.virginmoneygiving.com/team/CBFJumpTeam)

Inspired? We're organising a second skydive in the spring! Email [fundraising@thecbf.org.uk](mailto:fundraising@thecbf.org.uk) to join the team.



*Last year's competitors outside Battersea Power Station*

Not content with just running a marathon this year, Dr Nick Gore from the Tizard Centre has put together a team for 'Survival of the Fittest' at Battersea Power Station in London. The team of eight, calling themselves 'Challenging Behaviour Champions' will be running through mud, climbing walls and crawling through ice plus whatever else the gruelling 10km assault course has in store for them on 16th November. Good luck Champions!

***We always welcome challenge fundraisers, so if you fancy taking on a personal challenge, please let us know. Big or small, we can help you with your fundraising efforts.***

With Christmas fast approaching, we know this is an expensive time of the year for most. There are still ways you can financially support the CBF without any cost to you. We highly recommend using Give as you Live [www.giveasyoulive.com/join/challengingbehaviourfoundation](http://www.giveasyoulive.com/join/challengingbehaviourfoundation)

When you shop online each retailer you shop with will donate a percentage of your spend to us at no extra cost to you.

In addition to raising money through shopping, you can also donate through recycling. Please find enclosed with our newsletter a freepost envelope – stuff this full of old, broken jewellery and old and unwanted foreign currency (notes and coins) that you may have lying around, and we will receive a cash donation.



The Challenging Behaviour Foundation is a registered charity and relies completely on grants, donations and fundraising to continue operating. We provide all support, information and training services free of charge to family carers, and low cost to professionals. Please consider supporting the CBF with a donation.

## The Early Intervention Project

This joint project from the Challenging Behaviour Foundation and the Council for Disabled Children is now underway. Activity in the next few months will involve a series of workshops with young people, family carers, professionals and commissioners to:

- Develop a vision of what good early intervention should look like from the perspective of children, young people and their families
- Understand the barriers to early intervention
- Discuss how we can overcome those barriers

We are also working hard to link up with related areas of work and to find out about good practice across the country.

If you know of any resources, training or good practice in relation to early intervention for children with learning disabilities whose behaviour challenges, or if you would like more information about the project, please contact Jacqui Shurlock on 07436 102778 or jacqui@theCBF.org.uk

## 100 Club Winners

Recent winners of the CBF 100 Club, winning £25 each, were:

### May 2013:

Jackie Cheeseman,  
West Norwood (London)

### June 2013 :

Mr SJ Corner, Maidstone, (Kent)

### July 2013:

Jane Crisp, Maidstone (Kent)

### August 2013:

Dawn Martin, Gillingham (Kent)

## 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 that all of these resources can be downloaded free of charge on our website: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

All our information and resources relate to the care of individuals with **severe learning disabilities** who are described as having challenging behaviour. We are happy to send resources **free of charge to parents/ unpaid carers**.

	Cost	Number	Total £
<b>CHALLENGING BEHAVIOUR DVD RESOURCES</b>			
The DVDs provide practical support from professionals and family carers. Academics or learning disability professionals give expert guidance while family carers share their experiences. The DVDs introduce each topic clearly, explaining the key ideas and offering a wealth of practical information.			
<b>An introduction to challenging behaviour: DVD</b>	£31.50*		
<b>Self-injurious behaviour: DVD</b>	£31.50*		
<b>Communication &amp; challenging behaviour: DVD</b>	£31.50*		
<b>Challenging behaviour – supporting change: DVD</b>	£63.00*		
Learn about the causes of challenging behaviour, and how to use a functional assessment to put appropriate positive behavior support strategies in place. (Two disc set)			
*Free to parents/unpaid carers. Registered charities: DVDs £16.50 (or £33.00 for Challenging Behaviour – Supporting Change). Price includes postage & packing in the UK only. Outside UK p&p £7.50 per item.			
<b>CHALLENGING BEHAVIOUR INFORMATION SHEETS</b>			
The information sheets are written by experts and provide practical support on a wide range of topics. Each information sheet contains a one-page summary, as well as a longer document providing more detailed information. The information sheets are suitable for both family carers and professionals.			
<b>Understanding challenging behaviour</b>	All information sheets are available free of charge on the CBF website.  To order by post please add £1.00 per sheet*		
<b>Communication and challenging behaviour</b>			
<b>Health and challenging behaviour</b>			
<b>Challenging behaviour – supporting change (functional assessment)</b>			
<b>The use of medication</b>			
<b>The Use of Physical Interventions</b>			
<b>Specialist equipment and safety adaptations</b>			
<b>Impact of caring on families</b>			
<b>Planning for the future: introduction</b>			
<b>Further information for family carers</b>			
<b>Ten top tips</b>			
<b>BASIC INFORMATION PACK (consisting of the 12 information sheets listed above)</b>	£12.00*		
The following additional information sheets are not contained in the basic information pack but may be downloaded from the Challenging Behaviour Foundation website or ordered separately:			
<b>Booklist for professionals</b>	£1.00*		
<b>Difficult sexual behaviour amongst men and boys with learning disabilities</b>	£1.00*		
<b>Getting a statement</b>	£1.00*		
<b>SUB TOTAL CARRIED FORWARD</b>			

\*All resources are free to parents/unpaid carers. Prices include postage and packing in the UK only.

/ Continued overleaf...

SUB TOTAL CARRIED FORWARD			
	Cost	Number	Total £
<b>Getting legal authority to make decisions about money, property &amp; welfare</b>	£1.00*		
<b>List of specialist 52-week schools and colleges</b>	£1.00*		
<b>Pica (eating inedible objects)</b>	£1.00*		
<b>Mental health problems in people with learning disability</b>	£1.00*		
<b>Self-injurious behaviour</b>	£1.00*		
IN-DEPTH RESOURCES			
<b>A guide for advocates (England and Wales)</b>	£16.00*		
A comprehensive and practical guide for professional advocates, as well as family carers advocating on behalf of their family member. Includes information on challenging behaviour, advocacy, and the key issues which are likely to arise.			
<b>PBS study pack for schools and colleges</b>	£45.00		
An interactive introduction to Positive Behaviour Support. The study pack is designed to be used by teachers to increase understanding of behaviour and develop a support plan for a student whose behaviour is challenging. Note: This resource is only available for schools and colleges.			
<b>Planning for the future: information pack</b> England / Scotland / N Ireland / Wales	£10.00*		
Written for people planning for the future of children aged 12 and upwards (transition), and those concerned about the support needs of adult sons and daughters. Contents include: Know your rights; Know the processes; Know your options; Case studies; Understanding the funding; Safeguarding & protecting the individual.			
<b>DONATION - please consider a donation to support our work. All proceeds go towards helping families caring for individuals with severe learning disabilities whose behaviour challenges. Thank you.</b>			
			TOTAL
*All resources are free to parents/unpaid carers. Prices include postage & packaging in the UK only. Outside UK p&p £7.50 per item.			

Please consider making a donation to help us support more families. If you would like to donate regularly, please tick here  to receive a standing order form.

Gift Aid means we can claim back the tax on your gift (25p for every £1 you give) at no extra cost to you. Please tick here  to confirm that you would like CBF to claim tax paid on this gift and any eligible past or future gifts.

Please note that to be eligible for gift aid you must pay at least as much UK income tax as the amount that will be claimed by all charities you donate to within the tax year.

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

Email (please print)

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

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

Alternatively, go to [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk) to order online.

# The CBF – how you can help

*Did you know.....?*

- **We are a registered charity and completely rely on donations, grants and fundraising to finance our work.**
- **We do not charge family carers for our services or resources.**
- **To keep costs down much of our work is carried out by volunteers.**
- **Regular giving by standing order makes your money go further by keeping down administrative costs.**
- **You can 'Gift Aid' your donation if you are a UK tax payer, this allows us to receive 25% extra on top of your donation without any further cost to you.**
- **You can fundraise for free! There are a number of ways to donate and raise money for us without spending any extra money. See our website for details.**

Your support really does make a big difference to us. So, thank you!

For more information please email [fundraising@theCBF.org.uk](mailto:fundraising@theCBF.org.uk)

## The Challenging Behaviour Foundation

Registered charity number 1060714 (England and Wales)

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