

Challenge

Winter 2016



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

The newsletter of the Challenging Behaviour Foundation

Challenges for Transforming Care

Challenges for Transforming Care

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Getting it right for children

Introduction to our new Keeping in Touch with Home resource, PBS resources for family carers and a look at pathways and early interventions for children.

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Your questions to the email network, and a look at the CBF's Family Linking Scheme.

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News updates

A round up of what's been happening, and what's new on the web.

My family and I have recently moved from London to South Manchester as I have started a new, exciting, professional challenge - that of Chief Officer of the Greater Manchester Health and Social Care (GMHSC) Partnership.

GMHSC Partnership is the body made up of the 37 NHS organisations and councils in the city region, which is overseeing devolution and taking charge of the £6bn health and social care budget for Greater Manchester. I am sad to leave behind so many great colleagues at the Department of Health but I now have an excellent opportunity to tackle the challenge of improving the health outcomes of 2.8million people in Greater Manchester.

As many of you are aware, learning disabilities is a major passion of mine and in this new role I have already begun to see how I can help make a real difference to people with learning disabilities in Greater Manchester. There is no question that over recent years the reliance on in-patient care for people with learning disabilities and / or autism has significantly reduced. However for a small number of people we are still relying on hospital based care, which can sometimes be away from family and friends.

Public service organisations should be looking at new ways of supporting people with learning disabilities and their families to encourage independence, develop new skills and relationships within their communities and access employment opportunities. This requires a whole public sector response to supporting people that stretches further than a traditional health and social care based model.



Jon Rouse

In Greater Manchester work had already started when in October last year a three-year £3million Greater Manchester plan to increase community-based care with a family focus was announced. This allowed Greater Manchester to use the opportunities of devolution and being a 'fast track pilot' to take a new look at how things can be done differently. With the person at the heart, Greater Manchester has developed intensive community based support that has enabled a reduction on a reliance on inpatient beds. Work done by the Manchester Learning Disability partnership and the Oldham Living Outcomes group has been a signpost to others in this respect.

However our ambition is now to go further and we are currently undertaking a whole system review of learning disability services, working with people to produce new models of care that meet their needs while encouraging independence.

• Jon Rouse

Chief Officer of the Greater Manchester Health and Social Care Partnership

'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

As the CBF looks to construct its strategy for the future, we wanted to know what your vision is for the coming years. We asked our Facebook and Twitter followers: "What changes would you like to see for your relative in the next five years?"

These are some of the comments we received:

Future? Like many other mums & dads of my age my big worry is who'll carry on the fight when I'm gone? Even when things are working well we feel unable to trust those 'in power' to carry on what's working.

We must be vigilant, stand up, kick up a fuss, go public until standards improve enabling the many fabulous care givers an opportunity to deliver that care safely, humanely, with dignity, respect and enthusiasm

I am very privileged as my son has a care award that I fought for since birth.. but even with the funding, there are just not the qualified or committed carers out there to help. The government needs to put funding into training so that there are the carers out there in the first place. Not just carers, invaluable therapists, equipment and housing!

Too many carers are in distress and not supported to care for their relatives. On top of this why does it always mean a long "fight" to obtain the care, support & dignity for all?

Thank you for all your comments!

If you'd like to feature in this column we'd love to hear from you. Look out for our posts on

[facebook.com/thecbf](https://www.facebook.com/thecbf) and
@cbfdn,

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

Change-for better and for worse?



Vivien Cooper

Change is inevitable, and we all want positive change – to improve, to develop, to move forward. These changes for good can't come quick enough. They are opportunities and we are impatient for things to get better. But some types of change are unwanted or disruptive. They can feel like a step backwards, like starting again, going over old ground or round in a circle.

When we started the CBF charity, I naively thought the change that was needed would be straightforward (in simple terms - providing families with good information, understanding behaviour, and putting the support around a person that they needed instead of trying to fit them into something that made things worse). I did not appreciate the extent to which "the system", which should be there to provide and deliver support, was set up in a way that not only didn't make this easy, but actively made it difficult.

Whilst policy says all the right things and is focussed on personalisation, in practice, the systems that should be there to facilitate it are yet to deliver for families of children, young people and adults with severe learning disabilities who display behaviour described as challenging. The change we want to see is a move away from the crisis management approach which I experienced when my son was younger ("go home, and if you get to a point where you can't cope, get in touch") – an approach families still experience today – to a situation whereby good

information, advice, support and services are offered early and proactively to prevent and minimise behaviour described as challenging and to enable children, young people and adults to experience what most of us take for granted - ordinary life opportunities, such as a family life and good health.

Progress is being made for some people, but these changes seem painfully slow. They are not helped by constant changes within the system – reorganisations take place on a regular basis, which often means that just as you begin to feel confident that someone understands the issues and you will see some progress, they move on and you have to start again. These challenges happen at an individual and a strategic level.

My son does not have an allocated care manager, and a recent emergency meant that one was hastily named. He clearly had not even met my son or me, and told me that he could not confirm whether he will remain involved after the immediate crisis. This constant change is not helpful - it would actually be really helpful to have a professional in this role that knew my son well and understood all the complexities of his support needs.

In the five years since abuse at Winterbourne View was exposed the national Transforming Care team and its leadership have changed regularly. Four different Government Ministers have had responsibility for the work and there has been a completely new Department of Health team. The result is little organisational memory and lots of re-starts.

Some change can't come quick enough, whilst other changes hinder it. But throughout it all, the lifelong support, advocacy and commitment families provide for their loved ones, as well as their determination to enable them to have a good life, remains constant – there's no change there.

Vivien Cooper OBE

Chief Executive and Founder of the Challenging Behaviour Foundation

Looking to the Future

Next year, the CBF is turning twenty - many birthdays more than we hoped would be necessary to bring about change. It is our ambition that within the next twenty, the CBF will no longer have to exist at all. Cogs are finally slipping into gear. There have been commitments from NHS England to close down inpatient beds across the country, policy reviews into overmedication, and the formation of forty-eight Transforming Care Partnerships (TCPs) promising to bring change for local areas. These developments create a huge opportunity for children and adults with severe learning disabilities who display behaviour described as challenging, but also bring big responsibilities for ensuring promises don't fall on deaf ears. That's why this issue of *Challenge* is "Looking to the Future", taking stock of where we are and planting a vision for the next few years.

Our lead article features Jon Rouse, Chief Officer of Greater Manchester Health and Social Care Partnership, as he discusses challenges the Government will face as it moves to deliver on its commitments. He explains the reform that is currently underway in Manchester and the strategies he hopes will lead to more people with learning disability having an independent and active life.

The best evidence-based approach for preventing challenging behaviour is to deliver Positive Behaviour Support (PBS) early. On pages 4&5 we look at ways this can be achieved. Jacqui Shurlock, CBF lead for Children and Young People, begins with a detailed introduction to the common care pathways for children and how they could be improved. We then review our new resources explaining how PBS works and how it can be used by family carers. Finally, we summarise the results of a report we co-produced on the importance of maintaining family contact when children and young people are living away from home.

Actioning promises will be a challenge and we need to make sure authorities don't fail to deliver. Pages 6&7 set-out what you can do if you feel change is too slow or heading in the wrong direction. Take a look at the recently released "Making it Happen" resource empowering families to raise issues in their local area, and see a preview of our new FAQ for making complaints. Finally, we have an early introduction to the large medication consultation the CBF has been running to gather family carer perspectives on the use of medication for their loved one.

We hope you find the content of this newsletter useful. If you have any comments or other feedback, please email us at communications@thecbf.org.uk. If you would like to suggest a topic, or contribute an article to a future edition of 'Challenge', we would love to hear from you.

About us

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



Information



Supporting You



Workshops



Driving Change

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**, or visit our website: **www.challengingbehaviour.org.uk**.

Transition Time

My son, Henry, was almost 18, due to leave residential school and had no transition plan in place. All options suggested by social services were inappropriate – places that were too noisy, shared with others displaying aggressive or self-injurious behaviour, or with no positive behaviour support. Making things worse, the local authority also planned to axe his support team down from two or three staff at all times, to only one or two, despite the fact Henry's needs had not changed. We were told this was because 'adult services didn't have as much money as children's services'.

We contacted the CBF not knowing our options or how we could proceed. They helped us, providing us with information and support to plan Henry's future and ensure his needs were properly assessed. They researched sections from the Care Act and Mental Capacity Act relevant to Henry's case and helped us use them effectively in complaint letters and at meetings. We were also referred to much-needed legal support.

With the CBF's backing, Henry moved into a single occupancy flat specially adapted for his needs. He doesn't have to worry about noise, and loves watching aeroplanes flying overhead. There's only been one incident of self-injurious behaviour since then, and I was very happy with how it was managed, recorded and learnt from. The new staff really like and care about Henry, and have a very person-centred approach. One afternoon, he went into the bathroom and took off his clothes. Staff followed his lead and ran him an early bath. They said 'it's his home and if he wants to take a bath at 4pm, of course he can'.

Henry smiles all the time now; he loves having his own place and his own team. In contrast to residential school, he goes out every day and is engaged in a full activity programme. Whereas previously Henry wouldn't let us visit him – he would push us out, saying we were in the 'wrong place' – we now get to visit him whenever we like.

Judith
Family carer

Pathways



CBF's Jacqui Shurlock and family carer Olive Fallows discussing early intervention for children

Local Pathways for Children

For the Transforming Care Programme to succeed, local areas will need to develop effective pathways for children with learning disabilities who display behaviours that challenge. These local pathways will need to be child and family centred, lifelong and linked to adult pathways, and they will need to be developed in partnership with families.

Many things should feature in an effective pathway for children, but here are five of the most crucial:

1. Family information, support and training on challenging behaviour – this would include families being given peer & sibling support, a social care assessment and support (including short breaks), as well as the offer of direct payments/ a personal budget.
2. Behavioural support and skills development in education.
3. Positive Behavioural Support (PBS) – this would begin with referral to a PBS early intervention team to assess whether a PBS service is required, followed by a functional assessment of behaviour, and behaviour support plan.

4. Coordinated and proactive healthcare – this would include support for additional needs when very young (e.g. sleeping, feeding, toileting); continued monitoring and support including annual GP health checks from age 14; assessment for continuing healthcare funding and offer of personal health budget if eligible; and input from relevant health professionals to an Educational Health and Care Plan.

5. Support for mental health and wellbeing – risk factors and early signs of mental health problems in the child or his/her main care givers should be identified and acted upon.

A strategic approach local authorities could adopt when developing a local pathway might include:

- Assessing current service provision in partnership with families, identifying gaps and strengths
- Looking at Care and Treatment Reviews of children from the local area to identify common barriers to effective local support
- Reducing spending on out-of-area placements and crisis interventions, whilst increasing spending on effective, evidence-based local support
- Using the least restrictive methods possible and planning for a reduction in restrictive interventions within all services

Over the coming years, it will be crucial that families and campaigners hold Transforming Care Partnerships to account, and make sure these pathways form an important part of the 'local offer' for children with learning disabilities.

Keeping in Touch with Home



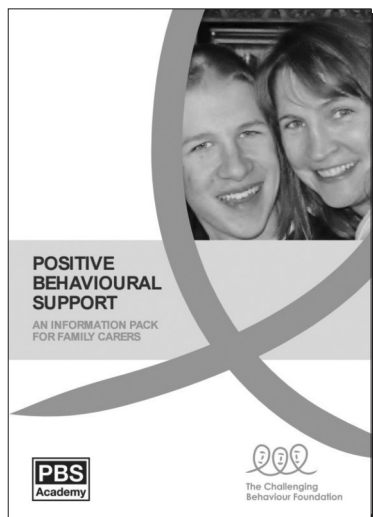
Keeping in Touch with Home

Thousands of children and young people with learning disabilities live away from home for much of their childhood and adolescence in specialist residential placements. Residential placements may be a positive choice, but for children with the most complex needs they are often far from home, on a full-time basis and maintained for years. These placements could include residential special schools or colleges, mental health assessment and treatment units, and children's homes.

In July this year, the CBF launched a new report, co-written with Mencap, called 'Keeping in Touch with Home.' This report reveals the significant barriers families can face when trying to keep in touch. The report is also the first time that guidance has been issued on how residential settings should ensure parents can keep in touch with their children.

The central message of 'Keeping in Touch with Home' is simple: children have a right to family life and to know and be cared for by their parents. The presumption should always be that families want to keep in touch and, with the right attitudes and the right support, this can happen.

PBS Resources for Family Carers



PBSResource

Earlier this year, the CBF launched 5 brand new Positive Behaviour Support (PBS) resources for family carers which we created in collaboration with the PBS Academy. PBS is an effective and ethical way of supporting people with learning disabilities who are at risk of developing challenging behaviours. An essential part of PBS is understanding the causes of a person's behaviour. PBS also involves families, professionals, schools and services working together in order to create a consistent approach across every setting..

A guide to the 5 new resources:

1. **What is PBS?** This resource explains what PBS is, and has links to other sources of information.

2. **What should PBS look like?** This resource gives more detail, and explains what you might see happening in a service/school where PBS is used. This information may be helpful for family carers who are visiting a service/school they are thinking of using for their relative, or for family carers who are preparing for a home visit for a professional and want to assess whether the professional has a good understanding of PBS. This resource also gives examples of good practice, and explains a number of key terms (e.g. visual timetable, social story etc.)

3. **Questions to check whether PBS is being used well.** This resource provides a list of detailed questions you can ask a professional or service to assess the quality of the PBS they are offering.

The resource also gives examples of good answers to the questions about PBS, versus answers which might set alarm bells ringing, as well as some follow-up questions which you can use if you don't get a satisfactory answer to one of the questions. These questions and sample answers may be useful to family carers about to choose a provider, or family carers who are preparing for an assessment of their relative's needs. Finally, the resource also includes information about what you can do if you are unhappy with the service being offered to or provided for your relative.

4. **Family carers using PBS.** This resource gives suggestions about how to find out more about PBS, and get further training. The resources lists the statutory organisations (e.g. your Local Authority) from which you can request support, as well as some information about independent training providers, and how to access funding.

5. **Practical tools.** This last resource gives examples of Behaviour Support Plans, and a template letter which family carers can use to raise concerns about the quality of a service.

The new PBS Family Carer resource pack is available to download, free, from the Paving the Way website: www.pavingtheway.works. We welcome your feedback on these new resources as we are aiming to improve on their format, please email: earlyinterventionproject@thebcf.org.uk

With Home Resource

Here are a few of the key recommendations for residential placements:

- Be sensitive to the grief families may feel when their child moves away from home
- Arrange visits to familiarize the child/young person with the setting
- Visit the family home to start to build relationships
- Involve families in planning how to ease the transition
- Explore how families want to be kept in touch with their child, and use audio-visual technologies to facilitate day-to-day contact with home
- Have an 'open door' policy for visits and provide family-friendly visiting areas.
- Invite families to join in activity days, information sessions and training
- For young people who have no-one to visit them, find a suitable befriender and advocate
- Use secure websites to facilitate information-sharing and an on-going dialogue between staff and families
- Use social media to enable families to get to know each other and to provide an informal feedback channel
- Seek feedback from families about how to improve

To download the full resource, or the executive summary, please visit the Paving the Way website: www.pavingtheway.works/whats-new/keeping-touch-home

Making it Happen – New Joint Resource

Forty-eight new Transforming Care Partnerships (TCPs) are mobilizing across England. Their aim is simple; to support the closure of inappropriate inpatient facilities and replace them with high-quality support services in the local community. The partnerships, which should include people with learning disabilities, family carers and clinicians as well as local authorities and NHS commissioners, were expected to draw up plans for the future by July of this year. However, it is still unclear what state these plans are in and how they will be delivered. Pressure is now needed from all sides to ensure that TCPs are held to account on their promises and that the long-awaited changes are brought to effect. With our new resource, “Making it Happen”, we hope to support you to get involved.

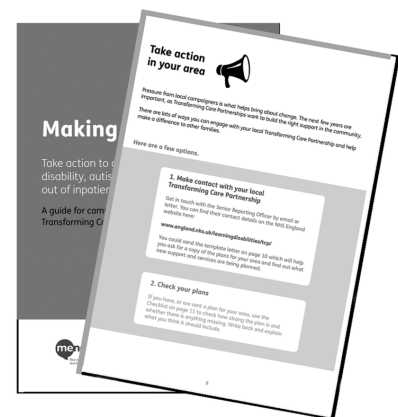
Strategy plans produced by TCPs are public documents and can be viewed on request to the Senior Reporting Officer; this is the person in charge of overseeing the TCP. They have a responsibility to make sure that everyone likely to be affected has their views reflected in the development and delivery of those plans. This means that by submitting opinions and feedback on the proposed changes, individuals with learning disabilities and their family carers are in a position to make a big difference to local policy and practice

We understand that, for many families, the prospect of getting involved in campaigning for the first time can be daunting. That's why we've been working with Mencap and the National Autistic Society to produce “Making it Happen”, a brand new resource aiming to support individuals and small local campaign groups who want to be a part of this change. This practical resource will equip you with the tools necessary to find out what TCPs have

planned for your local area and help you contribute your voice to the development of those plans. Included in the pack are step-by-step instructions for identifying and contacting your local Senior Reporting Officer, template letters which you can send to request a copy of the TCP plans, or to express your interest in joining the partnership, and a handy checklist which you can tick off to evaluate the quality of the plans so far.

With the introduction of TCPs and an ever-stronger spotlight on care for children, young people and adults with learning disabilities, this is an exciting time to get involved in shaping the future for new and better support services, and we hope that many of you will take up the challenge.

To download the Making it Happen resource visit <https://goo.gl/gXYNw6>



The new Making it Happen Resource

CBF Complaints FAQ



The CBF family support team hears from family members worried about the care being delivered to their family members in care homes, hospitals, schools or other services. The concerns vary from low levels of staff on duty to provide care, their family member not being given a choice in what they would like to do, eat or activities to take part in, dilapidated living accommodation and many others. Raising these concerns with

staff is often challenging for family members as they do not want to change the family's relationship with the service or they are unsure how to raise a complaint. We have written a new Frequently Asked Question (FAQ) to suggest what families can do when unhappy about their family member's care. This is an extract from the FAQ:

FAQ: I am unhappy about my daughter's care. What can I do?

A: Family carers often find themselves taking on the role of an advocate while supporting their family members to ensure they have a voice when making everyday life decisions. However, knowing how and when to raise a complaint can be complicated. What effect might raising a formal complaint have on the relationships you would like to develop between yourself and professionals, or on the care your family member receives? If you raise the issue informally, are you speaking to right person who can help make the changes needed? What is the best way to introduce the subject?

The FAQ includes information on how to raise your concern informally with the manager or person in charge, how to raise the concern formally, useful tips for writing a complaint letter along with links to other useful websites, and what to do if the concern is not resolved.

To read this FAQ in its entirety, visit the CBF website: www.challengingbehaviour.org.uk

CBF Medication Survey

Everyone takes medication from time to time; medication can stop heart palpitations or relieve an irritable bowel. We normally trust our doctor has thought of alternatives (counselling, diet change, or a well-needed break) before reaching for the prescription pad, and we would certainly be concerned if prescribed a strong drug like insulin without a thorough diagnostic test. Similarly, it is unacceptable that people with learning disabilities are prescribed strong psychotropic drugs (e.g. anti-depressants or antipsychotics), without thorough rationale of the need. But this often happens. Of 33,000 people with learning disabilities tracked in a recent University College London study, 63% were found to have taken some form of psychiatric drug - despite only 34% actually having any mental health diagnosis. In such cases, not only is medication entirely inappropriate, it can also produce unnecessary and life-threatening side-effects, including weight gain, sedation and rapid heart-rate.

Long-term use of a so-called "chemical cosh" to allay challenging behaviour often results from a lack of understanding about causes of behaviour and an absence of any alternative strategy. When staff have little knowledge or experience with positive behaviour support (PBS) or person-centred care approaches, it is common for them to see challenging behaviour as a symptom that can be treated with medication, regardless of mental health status. When this medication then either fails or makes things worse, staff have nothing else to fall back on, and so a cycle typically commences where existing medication dose is increased or another medication is prescribed, continuing unsatisfactory results.

But the problem is not limited to those without a mental health diagnosis. Often inadequate support means even those with a mental health condition receive more medication than otherwise needed. In depression, for example, it is well known loneliness, boredom and long-term physical pain can both trigger and

exacerbate symptoms. Care packages emphasising community networking, diverse activities and immediate response to physical health problems, in addition to medication, therefore, might not only reduce depression severity, but even prevent it.

Following concern around this issue, NHS England has launched a major policy review, opening its doors to consultation from patients and families. The CBF is one of those asked to gather these views. Response to our consultation has been fantastic with over 100 families getting involved through our online survey, phone conversations, email narratives or face-to-face interviews. We have collected a wealth of data on various subjects including availability of psychological therapies, effectiveness of medication, and how the current system could be improved. With family carers often the best authority on how medication affects their relative's behaviour, listening to these views is a crucial step in driving reform.

Analysis is ongoing, but an emerging concern seems to be considering over-medication an isolated problem. With medication often a "quick fix" for challenging behaviour, there is worry, when it is removed as an option, other potentially harmful solutions, e.g. seclusion and restraint, will become more common. This can only be solved by investing in PBS strategies, teaching carers about the importance of understanding challenging behaviour and factors that can underlie and trigger it.

Medication itself is not taboo. For every three people with learning disabilities who don't need medication, there is one that may. The challenge for the future will be ensuring that when people are prescribed medication it is appropriate.

Look out for the results of our survey to be published later this year.

Some Family Perspectives on Medication

It's imperative that we stop over-medicating people with learning disabilities, but we need to make sure the pendulum does not swing the other way, making professionals reluctant to prescribe such medication at all. The oft-quoted figure of 1 in 4 people in the general population having mental health problems at some point in their lives applies to people with learning disabilities too - in fact, prevalence may be even higher. Trying to address a mental health problem solely by behavioural or environmental manipulation will mean our loved ones missing out on the treatment they need. The term "pill-shaming" has been coined to describe the belief that mental health 'ought' to be managed without medication. We must be careful not to depict appropriately prescribed medication as stigmatizing for users or an admission of failure by carers just as much as we fight inappropriate over-medication. As with everything, balance is the key.

Andrea, family carer

Failure of clinicians to appreciate my daughter Chrissy's complex needs, combined with a reluctance to listen to our experiences, resulted in Chrissy suffering unpredictable and distressing side-effects from a range of medications. We saw this first in the treatment of her epilepsy, where a number of drugs had dramatic, paradoxical effects on her seizures and personality, and again when antipsychotics were prescribed. We raised our concerns with doctors but they were often ignored. Meanwhile, Chrissy's fluctuating reactions became so extreme and violent

that, eventually, we had to resort to sedation. It was only when Chrissy was admitted to a children's ward and her medication regime completely overhauled and restarted that her sociable personality re-emerged. Unfortunately, it was not monitored effectively, later culminating in a life-threatening reaction and another crisis. She moved into an ATU where she stayed for four years, receiving extensive and coordinated medical input. The result was another treatment plan which transformed her life again. Chrissy is now stable and happy, and her medication is under frequent review, but I can't help thinking that if this had been started right from the beginning we could have avoided a lot of the suffering.

Jane,
family carer



Chrissy celebrating her 30th birthday.

Joining the CBF Family Linking Scheme

My son, Ian, has autism and severe learning disabilities. For nine years, he was an inpatient in a hospital, which was very tough on him – and I ended up feeling like I needed counselling myself.

Until I first contacted the CBF, over a year ago, I hadn't even realised that "family support" of any kind existed. When you've got all kind of problems going on, there's nothing worse than feeling on your own – but for many years that is how I had felt.

The CBF had been supporting me for several months before they recommended that I consider also joining their Family Linking Scheme. I was nervous at first, but I agreed to give it a go. The CBF linked me up with another family carer, whose child was also living away from home. Once a week I get a phone call from her, and we talk. Or sometimes we catch up by email instead.

Neither of us knew quite what to say at first. I wondered – 'maybe our situations aren't that similar after all?' Over time, however, it became clear that there were lots of similarities in our situations, and she really understood how I felt. Now I feel very comfortable talking to her; during some stressful periods, having that link with another family carer has more or less kept me sane! I still use the CBF support line when I have a specific issue or question, but knowing that I also have someone there to talk to on a regular basis has been an enormous help.

Now Ian is in a residential home, and is doing much better (in July he had his first home visit in 5 years). However, I still hope to keep using the Linking Scheme in future, as it has been so helpful. I would recommend it to anyone.

Janet, a family carer

For more information about the CBF's Family Linking Scheme, please visit our website: www.challengingbehaviour.org.uk/supporting-you/families/linking-scheme.html

Q: I recently had a best interest meeting where we failed to reach an agreement. Has anyone else had this experience? Also, has anyone experienced the next step, the Court of Protection?

A1: I am headed for a Best Interest meeting to decide my son's future residence. I am likely to disagree with the Local Authority's decision as they want to keep him in an unsuitable care home.

The solicitor helping me with the Best Interests process advised me to say at the meeting that I disagree with the decision and wait for the minutes of the meeting as a record of the 'disagreement'. Once we have evidence of the disagreement, an application can be made to the Court of Protection and a legal aid solicitor will manage the case. They will ask advice about my son from all 'interested parties' (his mum, dad and any other relatives) as part of investigating the case.

Q: I'm a lone parent to a wonderful son of 15 with challenging behaviour. Can dating and having a love life be compatible with loving & caring for a challenging loved one?

A1: I too felt cautious about having a relationship and fitting it into my chaotic lifestyle supporting my son.

I got lucky though and found someone great for me on an online dating site. He is open to learning about special needs, caring and kind to my son. The first time my son met him he was fascinated and checking him out favourably.

It can be nice for your relative with challenging behaviour to see you with a supportive partner and get to know them. My partner built a swing for my son in the garden of his care home. We had to shut the curtains and do it all in secret so the cement set well before my

A2: Thanks for replying.

I have experienced delays in getting to the Best Interest meeting - in fact it took a year to get there. I asked staff from the day centre to attend as they had worked with my daughter for many years, but they were not allowed. My eldest daughter's typed statement was ignored. I also tried to apply for deputyship but this was held back by social services.

A3: Your deputyship shouldn't be held back by anyone, unless there was a good reason.

The delays you mention are unforgivable - they stop real, person-centred work from ever happening. I've had this happen myself - if people are too 'busy', they're not acting in anyone's best interests. It is in your daughter's best interests to be listened to now, not a year later.

Your eldest daughter's typed letter is very important, and she could be a co-Deputy or alternative choice Deputy. I've got my husband and daughter named as potential deputies if anything ever happened to me.

son used his swing. His face when he eventually peeped from behind the curtains was a picture of sheer joy and gratitude!!

Go for your dreams, no harm dating someone to find out if it would work or not. When we are happy don't our children feel the impact, learning difficulties of not?

A2: We should be able to form relationships outside of our parenting but I don't think it's easy to balance the level of caring we do with another relationship. I've found that moving to adult services has meant that we now get to do exciting things like go to our local night club on the special needs evenings, so my daughter and I have a lot of fun and meet lots of people, so that could be a way for you to meet other people in a similar situation.

I've always thought that if I did meet someone, it would probably be another carer/parent in the same situation - perhaps we need to start a carer dating site?!

Recommendations for specific products in this article are made by people on our Email Network; inclusion doesn't constitute endorsement by the CBF. Readers are encouraged to evaluate the benefits and risks of each product before purchase

These questions and answers are taken from our email networks. Want to join the debate? Membership of the networks is free to both families and professionals supporting children or adults with severe learning disabilities. Application forms are available to download at www.challengingbehaviour.org.uk or email network@thecbf.org.uk.

News

A round-up of what's been happening

Stopping Over-Medication of People with Learning Disabilities: NHS England Produces New Guide



A new toolkit for NHS doctors was released this summer which aims to tackle the over-medication of people with learning disabilities. It has been estimated that around 35,000 people with learning disabilities are prescribed strong psychiatric medication. This is despite the vast majority not having a mental health diagnosis. Inappropriate drug prescription can have a range of severe side-effects and is often counterproductive in treating challenging

behaviour in the long-term. The toolkit sets out a comprehensive review strategy to ensure people only receive the medication they should. Professor Sir Bruce Keogh, NHS England's National Medical Director said "We have managed this successfully in dementia; it's now time to bring similar benefits to patients who have learning disabilities".

Read more and download the resource here:

<https://www.england.nhs.uk/2016/06/over-medication-pledge>

7 Days of Action Returns



The grassroots campaign network, 7 Days of Action, coordinated another week of UK-wide pressure this October to raise awareness for the 3000 people with learning disabilities still housed in inappropriate inpatient facilities. Following the outcry after abuse at Winterbourne View was revealed, NHS England promised to move the majority of people into community-based care, but progress has been slow and the plans are still unclear. As part of the 7 Days of Action campaign, hundreds of the families affected have been spreading their message, online, in the media and through their local MPs.

Resignations at Southern Health

Several high-profile resignations have taken place at Southern Health, the NHS Foundation Trust that was shamed early this year over allegations it failed to investigate hundreds of unexpected deaths across its hospitals. After mounting criticism of its management, Katrina Percy, head of Southern Health at the time of the scandal, resigned after claiming her position had become untenable, but attracted scorn after it was suggested she had been automatically side-stepped into a similar highly-paid role outside of the public eye. One month later, the chairman who appointed her to this position, Tim Smart, stepped down citing "personal reasons" after facing a fierce media backlash. Shortly after, Percy announced she was abandoning her new role.

BBC Radio 4 Broadcasts "Homes Not Hospitals"

In September, BBC Radio 4 broadcast a special documentary "Homes Not Hospitals" which shone a spotlight on the future for people with a learning disability still trapped in assessment and treatment units. It heard from families across the country with direct experience of the countless difficulties trying to bring their relatives home. Many were increasingly worried by NHS England's apparent lack of commitment and willingness to invest in the vital community services required to support transition, with several family members already re-united with their loved ones reporting a life on the brink of crisis. NHS England claim they are making progress towards these goals, but they continue to face criticism from families and professionals who believe they are working too slowly and with a frustrating lack of transparency

Care Quality Commission Responds to Care Home Visitor Bans

A BBC investigation has recently revealed that hundreds of care providers prevent visitors who complain from seeing their relatives. But this practice is unlawful, as stipulated by the Care Quality Commission (CQC) in their visitor rights information sheet brought out in response to these worrying trends. People both have a right to visit their relatives and a right to have their complaints heard. Read the guidance in more detail here: <http://bit.ly/2ehVVCv>

Innovative, interesting or useful resources available free online.

Independence Pack: Help for Moving Home

CHANGE's Independence Pack is a new Easy Read and interactive resource aiming to break down the process of leaving an inpatient unit and returning home. It has sections covering what to expect from discharge planning, options available for independent living, and a guide for what to do when things go wrong. You can download the Independence Pack here:

<http://bit.ly/1qJHeio>

"Stuck in the System: Care in Crisis"

"Stuck in the System: Care in Crisis" is a 30 minute YouTube documentary made in collaboration with the 7 Days of Action campaign. It describes how families struggles to move their relatives out of inappropriate inpatient units and back into the community. Watch the video here: <https://www.youtube.com/watch?v=n3hqZ2jvns>

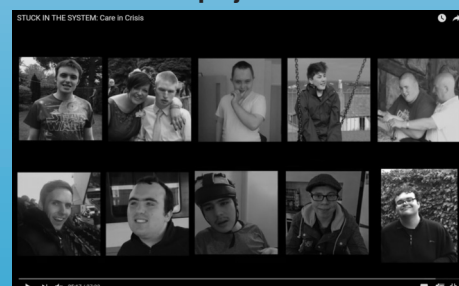


BILD Webinar Series

The Centre for Advancement of Positive Behaviour Support has been running a series of interactive online seminars at the British Institute for Learning Disabilities aiming to promote understanding of positive behaviour support amongst healthcare professionals. Each seminar draws on international experience to present a new strategy for good practice, and have covered topics including the Prevent-Teach-Reinforcement schooling model, identifying and defining restrictive practices, active support engagement, and practice leadership. The next webinar will be on "Applying Positive Psychology Principles to PBS" and will take place at 10am on 30th November.

You can sign-up to the event or watch the previous broadcasts here: <http://bit.ly/2dGJmlb>

Fundraising Success

CBF supporter Lawrence Nasralla cycled from Manchester to Blackpool earlier this month to raise funds to support our work. Lawrence raised a fantastic £2,510 – thanks from all of us at the CBF!

Lawrence's account of the day:



Lawrence and his supportive wife Jill

Sunday 10th July 2016, 06:30 am: the rope was dropped, the horn hooted and we were off, as the first wave of the Manchester-Blackpool cycle started. It was a dry day with light wind.

"This is for you, my boy," I shouted, as I started following the route that the organisers had chosen. The route was well marked, with marshals on junctions throughout. As my legs were doing all the work, I had been worried the previous night that I would get a puncture. The last thing I wanted to do was let down the people who had kindly sponsored me.

I had left the city behind me and, not before long, I was in the country. Before I knew it, there was a big sign which welcomed me to Lancashire.

What kept me going was the thought of my son and all he has suffered; all those our family have met through the CBF, and their special children; and all the team at the CBF who, very quietly, do an amazing job.

After 3 hours and 27 minutes I had covered 62 miles. I made it to Blackpool, arriving to the cheers of my wife Jill and all those at the finish line, where I shouted again: "This is for you, my boy." I was very emotional but delighted that I had completed the ride – and the cup of tea that I had with Jill was the best ever.

Support the CBF through a team-building day!



We are pleased to announce a new collaboration with the Grain Store Studio, a creative studio, exhibition and teaching space in the heart of the Kent countryside. The Grain Store studio has kindly agreed to donate the use of their beautiful teaching room so we can offer you and your colleagues unique team-building days. So...how does it work?

You and your team come and spend the day at the Grain Store Studio, in Faversham, Kent. You will learn the art of screen-printing from a resident artist and then set about printing our beautiful selection of fundraising merchandise! You will also have the opportunity to take a selection of products away with you - to run an in-house competition to see who can sell the most...whilst raising funds for us of course! Lunch and mid-morning or afternoon tea can also be provided.

What could be better...? You get to team-build, have fun, and learn something new in a wonderful environment, whilst also raising funds to help family carers in desperate need of support and advice. It's win-win!

To find out more, please email: laura.brown@theCBF.org.uk

Christmas Fundraising Do!

This year's Christmas fundraising event promises to be a feast of entertainment, glorious food and frivolity! With a stand-up comedy medley (including acts from the London comedy scene), music, dancing, a buffet dinner, and a cash bar, all set in a beautiful historic building in the heart of Rochester, Kent – this is one not to be missed!

For ticket information contact Laura on 01634 838739 / laura.brown@theCBF.org.uk.

Need a little inspiration for Christmas?



Don't forget you can order our beautiful fundraising merchandise directly from Red-Bubble. There are various designs and products to choose from. Place your order early for delivery straight to your door!

www.redbubble.com/people/theCBF

Thank You

We'd like to thank Jackie Clarke, a family carer from Bristol, who has given invaluable support to another mum at a court case of a care provider accused of falsely imprisoning her son. Jackie attended court many times over several weeks this Summer throughout the trial and again this Autumn for sentencing of the accused. The CBF and the mum who Jackie spent time with in court are very grateful to her for giving up her time and for her compassion.



Jackie Clarke

100 Club Winners

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

May 2016:

Hillary Hawkins (Ayelsford, Kent)

June 2016:

Carol Lowe (Greenford, London)

July 2016:

Vivien Birchall (Wigan, Lancashire)

All proceeds from the 100 Club help towards CBF running costs. Please get in touch if you would like to join for just £12

Have your say

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

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			
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.			
Everybody Matters: DVD Getting the right person-centred support for adults	£31.50*		
An Introduction to Challenging Behaviour: DVD	£31.50*		
Self-Injurious Behaviour: DVD	£31.50*		
Communication & Challenging Behaviour: DVD	£31.50*		
Challenging Behaviour - Supporting Change: DVD Learn about the causes of challenging behaviour and how to use a functional assessment to put appropriate positive behaviour support strategies in place. (Two disc set)	£63.00*		
*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.			
CHALLENGING BEHAVIOUR INFORMATION SHEETS			
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.			
Understanding Challenging Behaviour: Part 1	£12.00*		
Finding the Causes of Challenging Behaviour: Part 2			
Positive Behaviour Support Planning: Part 3			
Communication and Challenging Behaviour			
Health and Challenging Behaviour			
Impact of Caring on Families			
BASIC INFORMATION PACK (consisting of the 6 information sheets listed above)			
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:			
Teaching New Skills	£1.00*		
The use of Medication	£1.00*		
The use of Physical Interventions	£1.00*		
Specialist Equipment and Safety Adaptations	£1.00*		
Planning for the Future	£1.00*		
Further Information for Family Carers	£1.00*		
Booklist for Professionals	£1.00*		
Difficult sexual behaviour amongst men and boys with learning disabilities	£1.00*		
Getting a Statement (Wales & Northern Ireland)	£1.00*		
SUB TOTAL CARRIED FORWARD			

*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 £
For Families: Getting an EHC Plan (England)	£1.00*		
For Professionals: Developing an Education, Health and Care Plan (England)	£1.00*		
Getting Legal Authority to Make Decisions	£1.00*		
Pica (eating inedible objects)	£1.00*		
Mental Health Problems in People with Learning Disabilities	£1.00*		
Ten Top Tips	£1.00*		
Self-Injurious Behaviour	£1.00*		
IN-DEPTH RESOURCES			
Paving the Way A guide for commissioners on how to develop effective local services for children with learning disabilities whose behaviours challenge			
8 Ways to Get a House A guide to help families think about the different types of accommodation and how they are funded.			
A Guide for advocates (England and Wales) A comprehensive, practical guide for professional advocates; or family carers advocating for their family member.			
PSB Study Pack for Schools and Colleges The Positive Behaviour Support study pack is designed for teachers to increase understanding of behaviour. Note: This resource is only available for schools and colleges.			
Planning for the Future: Information Pack England / N Ireland / Wales			
For anyone planning for the future of children aged 12 and upwards (transition), or concerned about the support needs of adult family members.			
Read more about all our in-depth resources online at www.challengingbehaviour.org.uk			
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.			
*All resources are free to parents/unpaid carers. Price include Postage & packaging in the UK only. Outside UK p&p £7.50 per item.		TOTAL	

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
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Name	<input type="text"/>
Organisation	<input type="text"/>
Address	<input type="text"/>
	<input type="text"/>
	<input type="text"/>
Postcode	<input type="text"/>
Telephone	<input type="text"/>
Email (please print)	<input type="text"/>

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

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

Alternatively, go to www.challengingbehaviour.org.uk to order online

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 do not charge family carers for 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 costs 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

The Challenging Behaviour Foundation

Registered charity number 1060714 (England and Wales)

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

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Tel. 01634 838739

www.challengingbehaviour.org.uk