

Resilience

To read Challenge online, please see: <https://www.challengingbehaviour.org.uk/information/cbf-newsletters.html>

What's in this Newsletter?

Welcome to this edition of "Challenge" which is focussed on "Resilience". Resilience is being able to adapt to unplanned changes and having the capacity to recover quickly from difficulties. We all do this in our everyday lives, but when you are supporting a child or adult whose behaviour challenges, as well as trying to navigate through a complex system for support, there are additional challenges which can seem overwhelming. It is important to recognise this, because building and sustaining resilience is essential - we need to pay attention to and invest in building our resilience. This newsletter includes a powerful account from a mum who reflects on her personal responses to the challenges she faces, which many families will identify with and share. In this newsletter we provide some information on resources, practical techniques and research evidence which we hope will be helpful. Building resilience is not about being able to put up with bad practice, it is strengthening our ability to manage unexpected changes or challenges that arise so that quality of life is improved for all.



Vivien Cooper
Family carer and CEO of the CBF

Family Based Positive Support

Clinical Psychologist and Senior Lecturer, Steve Noone has worked with other Newcastle based researchers and family carers to develop an innovative series of workshops to help family carers of adult family members, who have learning disabilities and behaviours that challenge, cope better with stress. It ran on three separate occasions, with family carers being interviewed throughout the sessions. Starting with evidence-based ideas, the family carers helped edit the content, how it should be delivered and decided on how to judge its effectiveness.

The workshops ran over five weekly sessions for a couple of hours. Small groups of 8-10 people met with a trained facilitator and a researcher. It was important that the atmosphere of the sessions never resembled a classroom and were set up like a kitchen table conversation to enable everyone to contribute.

The role of the facilitator was to gently direct the conversation around key ideas without lecturing. The first session explored the inevitability of stress and how it shows up in the body. Using an ancient Buddhist metaphor of the two darts, a central idea is that no one can do anything about the initial impact of a stressful event. It is like being hit by a dart. Yet how we respond to the event; getting lost in unhelpful habits and becoming embroiled in thoughts about the event, can make the distress last longer. It is effectively like being hit again by a second dart. Yet this time the dart is self-inflicted.



You may not be able to stop the waves but you can learn to surf

Throughout the five sessions, ways of dealing with this second dart are explored. Simple mindfulness exercises are practiced so they can be used at times of feeling overwhelmed and unable to cope. But to be effective, everyone is encouraged to practice as often as possible.

To counteract how stress takes away the inclination to invest in things that nourish us, time is spent to help identify valued activities and the group encourage everyone to try and find ways to reinvest in themselves.

The study has produced a fresh and exciting contribution to how we might support family carers in the future. The project has taught us that how we set up and run the workshops is as essential as the content. The psychological theory by itself would have little impact without the warmth and wisdom of the other family carers who offer compassion to each other's stories and celebration to each other's success.

For more information on the study please see:

<https://www.onlinelibrary.wiley.com/doi/10.1111/hex.12914>

New Wellbeing Guidance

Researchers at the University of Warwick, taking forward research about the links between parental and child wellbeing, were conscious that families did not have access to the findings. Parents were also asking for guidance on positive ways to support their children at home. So, in 2018 the researchers worked in collaboration with family carers, The Challenging Behaviour Foundation, Mencap, and Cerebra, to co-create *A Parent's Guide: Improving the Wellbeing of Young Children with Learning Disabilities*.

A Parent's Guide:
Improving the well-being of young
children with learning disabilities



A collaboration between the University of
Warwick, Cerebra, Mencap, the
Challenging Behaviour Foundation, and
parents of children with learning disabilities

The guide includes relatively small and practical things parents can do to nurture the wellbeing of their child such as play dates, flexible routines, spending focused time together (little but often) and including siblings but a significant portion of the guidance is also about the wellbeing of parents/carers.

Parents often have to cope with high stress levels- twice as high as parents of children without learning disabilities which affects their mental health and ability to practice positive wellbeing.

However, the guide points out that being kind to yourself is the most important thing, even when this can often feel like something you do not have the luxury to do .

The guidance opens with the following statement from the parents who took part in the research:

'raising a child with a learning disability is a learning curve, and that it is OK to not know everything [...] [the parents] thought that it was really important to let other parents know that they shouldn't feel guilty for finding things difficult, and that it won't be this way forever'

Families helped to shape the guide which (at parents' suggestion) has a 'reflection section' at the end of each chapter, for parents to think about what would help and how to achieve this.

One of the most important pieces of advice in the guidance to parents on their own wellbeing is that it is ok to have positive experiences even when you are stressed; it is important that parents give themselves permission to have positive moments in spite of whatever else is going on, and to not feel guilty about it. Feelings of isolation are very common amongst the families that contact the CBF and the guidance reflects this by suggesting that parents create a support network of friends, family and other parents so that they know they are not alone.

For the full guide, please see: https://warwick.ac.uk/fac/soc/cedar/parentsguide/a_parents_guide_improving_the_well-being_of_young_children_with_learning_disabilities.pdf

Newsflash

TED X Talk:

Family Carer Elly Chapple gave a powerful and inspiring TED talk about the importance of hope and working with individuals with learning disabilities.

You can watch the full TED X talk at the following link:
https://www.youtube.com/watch?v=DXBdiGUQ8Lw&feature=youtu.be&fbclid=IwAR2IfBAMPFmrT8P4zRPvrOELUc2STCflmY79r7Bjdboy7y1a1pxYnrr_f-0

Baby News:



We are delighted to announce that Holly, our Family Support Lead, has given birth to a baby boy. Both mother and baby are doing well. Holly is now on maternity leave until next year.

New Staff:

We are very pleased to introduce you to our new staff

Charlie Clay and Beverley Dawkins are both working part-time in family support to cover Holly's maternity leave. Some of you will remember Charlie who was our Family Support Worker from 2009 – 2014. Beverley has a wealth of experience working in the field of learning disabilities and supporting families, including Mencap's Death by Indifference work.

We are very grateful to the National Lottery Community Fund for enabling us to have 2 new posts as part of a new 3-year project. Mary Spence, who was our Policy and Information Intern for the past year, has now taken up the new Policy Officer Post and Kate Mawbey has joined us as a Communications Officer.

Interns – we are very happy to have received funding for an additional intern post this year. Eirini Symeonidou is our Policy and Information Intern focussing on Children's Policy and Emma Corris is our Policy and Information Intern focussing on Adult's Policy.

Your Questions From the Email Network

Q: My son is 11, non verbal and has Down syndrome and Autism. He had problems getting into the school bus with head banging and refusing to get in. We got a school car and he has been good until last week. He will not get in even when he is calm the hour before and distractions don't help either.

It could be the smallest thing which is distressing, maybe try taking a photo see if you can see anything, could be a smell, person's clothes etc. Good luck

Hi, you need a PBS plan to analyse sensory issues, people he might be afraid of or anything at school that he's not looking forward to. I'd have a reward for him for getting in the car - of course I don't know him, but you need a meeting with school to plan a better morning.

My son used to do the same, trying to identify what he was trying to tell me was so difficult. Looking back now I see it was all about communication and being able to try to prepare in advance what he might want to know. My son has two carers in the car, one driving and the other to sit in the back seat with him and talk to him about where he is going and generally about his day. The carer also has a laminated strip of pictures, symbols showing him now and next, what will be happening.

We had a similar experience. And it turned out that she got highly anxious at school and her behaviours worsened. You could visit the school, observe and see it from your son's eyes- the environment he is in, peer group etc.

I am sorry to hear this. My first question would be is he in a harness? and are they using it correctly? I have found in my experience you have to physically go and look and check as we had a situation where we found on more than one occasion that the harness was being used incorrectly.

Want to ask your own questions or share your experience? Join the Family Carer Email Network at:
www.challengingbehaviour.org.uk/supporting-you/for-families/family-carers-email-network.html

Helpful Resources

The CBF has a wide range of practical resources that might be able to help you if you are feeling like you are running out of the energy to always be resilient.

Aside from our Family Carer Network where you can ask other carers of a loved one with a severe learning disability whose behaviour challenges for recommendations and support, you may also find the following useful:

The Challenging Behaviour Foundation Website

FAQs on being a family carer

This page answers questions on circles of support, exclusion from short breaks services, reaching crisis point, and 'what will happen when I'm gone'?

<https://www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/faqs.html>

Services directory information sheet

This resource may be able to help you identify other organisations who might be able to help you. Our Family Support Line is also open Monday to Thursday 9am-5pm and Fridays until 3pm should you need to speak to someone directly.

<https://www.challengingbehaviour.org.uk/being-family-carer/further-information-families.html>

The Paving the Way website

FRIENDS for life: promoting emotional resilience

FRIENDS stands for : Feelings, Remember to relax, I can do it, I can try, Explore solutions and coping step-plans, Now reward yourself you've done your best, Do practice, Smile stay calm and use your support networks.

A useful way to focus on keeping a positive feeling and 'can do' attitude for children.

<https://pavingtheway.works/whats-new/friendsforlife/>

Where do we go for help poster and presentation

This resource details other support and information services that may be able to help you. It is also available in a user-friendly format.

<https://pavingtheway.works/whats-new/where-do-we-go-for-help/>

PBS- Updated—Resource for Family Carers

The Positive Behaviour Support (PBS) resource for families has now been updated. PBS provides support for a person, their family and friends to help people lead a meaningful life and learn new skills without unnecessary and harmful restrictions. You can find the resource here: <https://pavingtheway.works/whats-new/pbs-resource-family-carers/>



Download our free resources

We have a wide range of resources for family carers and professionals at: www.challengingbehaviour.org.uk/information/information-sheets-and-dvds/info-sheets-and-dvds.html

Family Story – I Really Gotta Use My Imagination

I am a visual thinker, but my heart lives through music. I've entitled this article in gratitude to Gladys Knight, her Pips and this song, which I've channelled in my numerous and various hours of need. If 70's funk soul is also your thing, here's the link. [<https://www.youtube.com/watch?v=jLKSZ0ehHNA>]



My child is a much-loved person with a severe learning disability and autism, whose behaviour can challenge others, mostly (if not always) as a result of unmet need. Like too many families like ours, getting our child's needs met has been a constant up-mountain struggle.

We families can feel that we are constantly crisis-managing, challenged far less by our loved one's behaviour and far more from the behaviour of services that are by law required to meet our loved ones' needs. The barriers preventing our children's needs from being met can seem insurmountable. They can leave us feeling powerless. Sometimes being a parent of a child with a learning disability and behaviour that challenges can be a very lonely place.



Recently, after a particularly difficult period for our family, I've done some hard thinking about the things I can change to help me, as Gladys sings, '*keep on keeping on*'. I've reflected a great deal on what I've learnt from other families like mine and what I've learnt about myself, as a person and as a parent.

I've come to realise that there's a big factor affecting my behaviour, and my actions. It's something that saps my energy, erodes my self-confidence, health and well-being. It's something families like ours don't often talk about, but I suspect I'm not alone in experiencing. It's a big thing that over the years (for me at least) has become normalised. However, I've recently realised that it doesn't need to be a big thing. I've realised I've let it get out of proportion. That thing is guilt.

There's a guilt list I imagine many (if not most) parents have in their heads, whether or not their child has a learning disability and behaviour that challenges. That list could include (gender specificity mine but other options available):

- guilt that I'm not a good enough mother to my children
- guilt that I'm not a good enough wife for my husband
- guilt that I'm not as good as #OtherMums



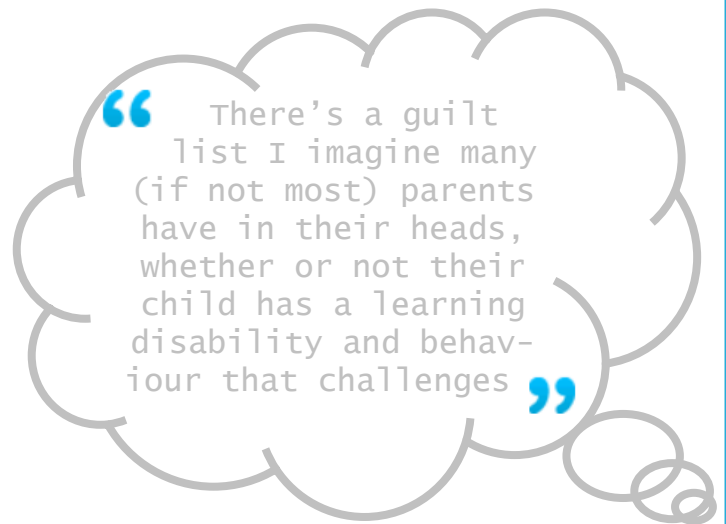
But for us extra-ordinary parents, the guilt is not about the one or two things we might have done wrong. If only it were! Instead, the guilt pervades everything. It's about what we think we should have done. It's about what we wish we could have done. It's about the opinions of people (peers and professionals) who haven't walked in our – and our family's – shoes. It's about feeling that the love we have for our children is not enough to protect them.

Our guilt list is so much longer than the typical. In no particular order and non-exhaustively, it might include:

- guilt that I caused my child's autism and/or learning disability (#TestosteroneSurgeInWomb, #OtherTheoriesAbound);
- guilt that my child's 'complex' needs aren't being met; guilt that I'm not fighting hard enough to get them met;
- guilt that I'm letting down my other children because I'm on constant alert and crisis managing my 'complex' child's needs;
- guilt that what the school/social worker/psychiatrist says about me is somehow true;
- guilt that the lady in the supermarket who says, "Can't you control your child?" may have a point;
- guilt when the teacher says "he's disrupted the whole class/ruined this display/is a nightmare for his TA to cope with" (delete as applicable)
- guilt that my child might have it better than equally 'complex' others because my husband hasn't left me yet;
- guilt that I trusted that psychiatrist when he said your child needs to be sectioned for 12 weeks so he can be assessed and treated;
- guilt that I've had to entrust my child's care to others, when I know they can't (and won't) care for him as I do;
- guilt that I haven't been able to protect my child from situations in which they have been exposed to neglect, restraint and overmedication;
- guilt that I'm not doing enough to stop what's happening to my child from happening to others;
- guilt when the professionals tell me yet again how expensive my child is, when other services are being cut;



- guilt that I feel angry at the friends I used to have, before my child appeared so different from their children; before my child's godparents screened their 'inconvenient' godchild out of their lives;
- guilt that my husband is the last one on the list of people I should feel guilty about; and
- guilt that I'm not looking after myself and perhaps I'm going mad and it's all my fault.



An enormous, colossal and ever-expanding mountain of guilt. And then there's the biggies. The ones no-one dares to talk about. Perhaps the biggest of them all:

- guilt that some days I struggle with my much-loved child's challenging behaviour;
- guilt that I'm letting my child – and myself – down because today I'm not coping; and
- guilt that sometimes I think – why me?

So, in the words of Gladys and her Pips, "*I've really gotta use my imagination*". I'm going "*to think of good reason to keep on keeping on*". I now know that, if I'm going "*to make the best of a bad situation*", I have to be kind and fair to myself, before I can be kind and fair to the people I love and who matter most to me. I'll need to keep a handle on what is typical for most people. I'll need to hold on strong to what I know is real and true for my family – and for me. And most of all, I'm going to put that guilt back in its rightful place.

#Anonymum

CQC State of Care Report

The Care Quality Commission (CQC) registers, regulates and inspects health and care services. A service can be rated as Outstanding, Good, Inadequate or Requires Improvement.



On the 15th October the CQC released its annual State of Care report with a focus on care for people with learning disabilities and/or autism. The report describes care for these individuals as 'unacceptable' and pushes for a more joined up approach across health and social care and government. The report confirms an increase in the number of services being rated inadequate and placed into special measures. The CBF has released the following statement about the report:

"This report from CQC, which has a welcome focus on services for people with a learning disability and/or autism, simply confirms what is widely known. Families who contact the CBF continue to report a lack of appropriate community support, a lack of access to the right support in the right place at the right time - and poor quality services, including issues around staffing levels, and staff skills and knowledge.

Every inadequate service has people in it, and poor quality support results in harm to those individuals. We have asked the Department of Health and Social Care what they are doing to keep those individuals safe and ensure they have the support they need and have a right to.

These issues are well known and documented – the "perfect storm" CQC describes for people with learning disability and/or autism is the result of the lack of a strategic, joined up plan for support and services across education, health and social care that Transforming Care has failed to deliver.

We know it is possible to deliver the right support in the right place at the right time – in some areas this happens – but it is not happening enough. CQC must use its influence to address key parts of the system, including better commissioning, by pressing for a coherent and resourced cross Government approach with people with lived experience at its heart that delivers good outcomes for children and adults with learning disabilities and their families, rather than the current scattergun approach to activities, groups and reviews."

To read the full report please see: <https://bit.ly/2pzbuRq>

Supporters' News

New Local Champion Training

The CBF is once again organising training for Local Champions, this time in the North of England. Local Champions are valued members of the wider CBF Team who volunteer to attend relevant learning disability events in their local area and tell them about the CBF and the support we offer. Local Champions help us to access parts of the country that we would otherwise be unable to.

Local Champions are family carers who attend coffee mornings to talk to parents, man stalls at conferences, organise fundraising events and share information about the CBF when they meet someone who could benefit from our help.

This year Local Champions have: spoken at events and conferences to carer groups, university students and others about their experiences of caring for a relative with severe learning disabilities; and raised over £1000 for the CBF through sponsored events and equipment donations.

In November, the new recruits spent three days learning more about the CBF and our values. They completed our core training programme and took part in our Understanding Challenging Behaviour and Supporting Behaviour Change workshops. Then they explored carers' rights and talk about safeguarding. The training finished with workshops to help volunteers feel confident when speaking about the CBF, getting to know our resources, recommending them and developing their presenting skills.

These three days were also a chance for family carers to meet each other, meet us, have fun and even enjoy a well-deserved soak in the bath in their hotel room at the end of the day.

If you are interested in becoming a CBF Volunteer Local Champion, please email Gemma at volunteering@theCBF.org.uk for more information.



Are you a family carer of someone with a severe learning disability? ✓

Are you involved in carer networks in your area or would you like to be? ✓

Are you looking for a new way to support the CBF? ✓

The CBF are recruiting new volunteer Local Champions.

For more information please email volunteering@theCBF.org.uk for a role description and application form

No experience necessary, training will be given, free travel and accommodation

Fundraising Events

In July, Local Champions Balwinder Sandhu and Pat Nekati attended an event at a local Gurdwara to promote a walk. The Sri Guru Singh Sabha Southall would be doing in the autumn to raise funds for the CBF. The walk took place on 22nd September and raised £750 for CBF – a big thank you to everyone who was involved!

Balwinder Sandhu and Andy Fenwick also represented the CBF in the Spring and received a new projector donated by the Southall Lions on behalf of the CBF. The CBF sends its thanks to the Southall lions, the projector having most recently been used for a presentation to social work visitors from South Korea in recruitment of new Local Champions as

well as workshops for family carers.



Balwinder and Andy receiving the CBF's new projector donated by the Southall Lions

Family Carer, James Carty has raised £500 for the CBF by running two marathons in two days. Sheryl Carty, James' wife, said

'Thank you to the CBF for always being there'.

A big thank you to both James and Sheryl for all your fundraising efforts.

James Carty
with his medal



QUIZ NIGHT

The CBF runs a local quiz night three times a year on Friday nights, our latest quiz raised over £400. All the money raised goes towards supporting the CBF running costs.

If you would like to attend or host a quiz night for the CBF then please get in touch, info@thecbf.org.uk.



Ways to help CBF this Christmas

CBF relies on grants and donations to provide vital support to families of children, young people and adults with severe learning disabilities whose behaviour challenges.

Here are some of the ways you can support the CBF this Christmas:

- * For £12 a year you can Join our 100 Club and be in with a chance to win £25 a month – why not give it as a Christmas gift?



<https://www.challengingbehaviour.org.uk/support-us/donate.html>

- * Make a donation to the CBF instead of sending Christmas Cards
- * Nominate CBF for 'Charity of the Year' at a workplace
- * Nominate CBF as a charity in participating Banks & Supermarkets such as Asda, Waitrose, John Lewis or Sainsbury's
- * Raise free funds for us every time you shop online with Amazon Smile, Give as you Live and Easy Fundraising



- * Regular donations are especially valuable to us as we can plan in advance what we spend and donating online reduces our admin costs. You can set up regular donations or make a one-off donation through Virgin Money Giving
https://uk.virginmoneygiving.com/donation-web/charity?charityId=1002370&frequencyType=M&stop_mobi=yes



- * Text:

CBFDN 05 (to donate £5) or

CBFDN 10 (to donate £10) or

CBFDN 20 (to donate £20)

to 70085



THANK YOU FOR YOUR SUPPORT

Can you help us?

We rely on donations, grants and fundraising to continue our work helping families. Find out how you can help us at:
www.challengingbehaviour.org.uk/support-us/support-us.html

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The Challenging Behaviour Foundation. Registered Charity No. 1060714 (England and Wales). Address: The Old Courthouse, New Road Avenue, Chatham, Kent, ME4 5BN. Email: info@thecbf.org.uk. Tel. 01634 838739.
www.challengingbehaviour.org.uk