

“Broken”

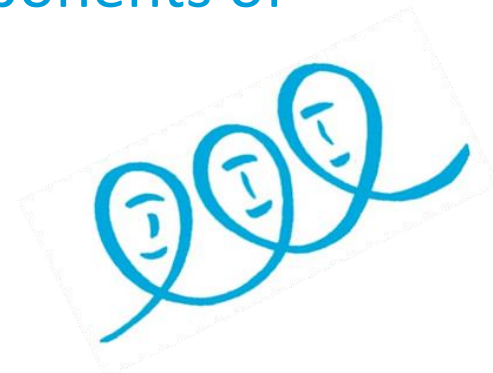
The psychological trauma suffered by family carers of children and adults with autism and/or learning disabilities & the support required



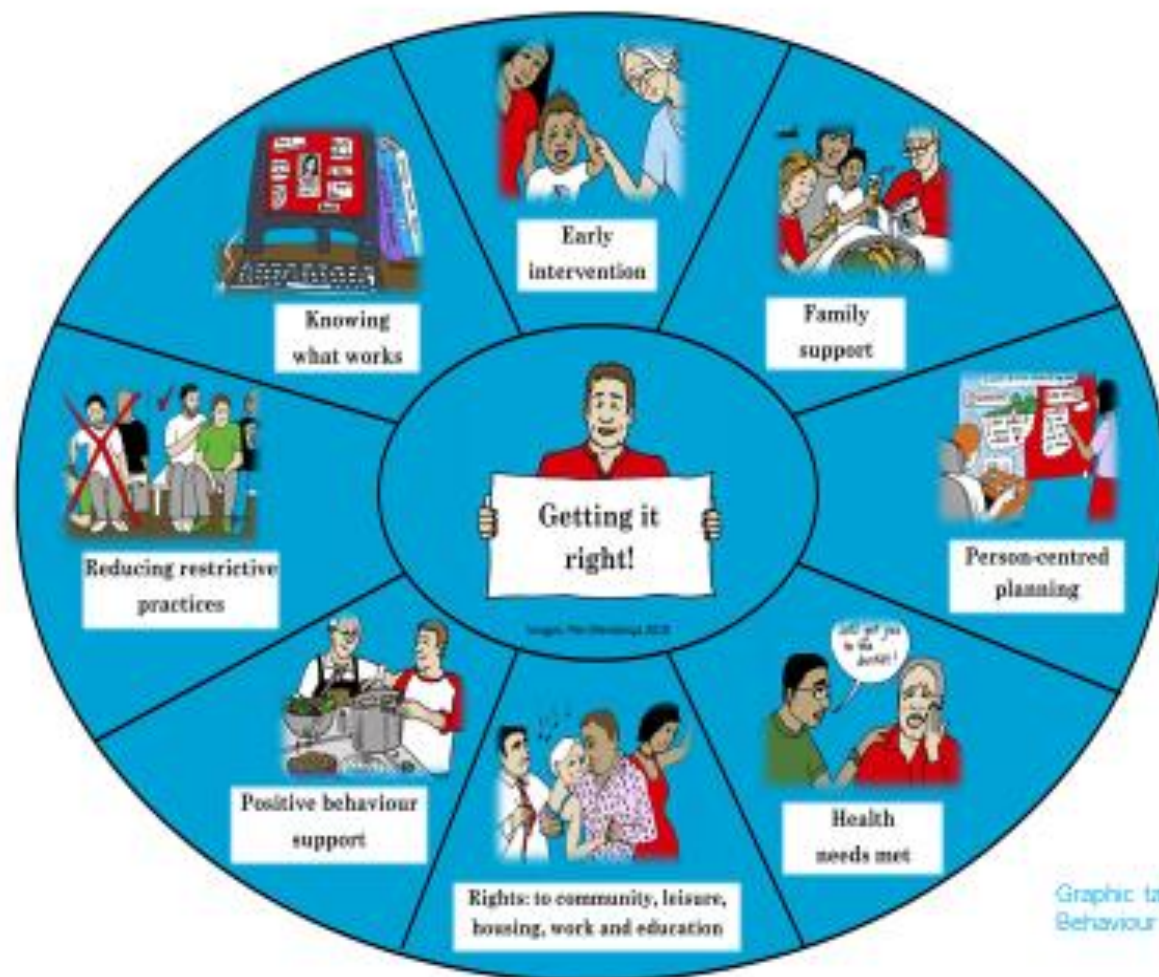
**The Challenging
Behaviour Foundation**
making a difference to the lives of people with severe learning disabilities

Background

- We know that families can describe a vision for their disabled relative...
 - “every individual, irrespective of their disabilities or difficulties, has a success story to live – they should be valued and respected equally with everyone else in the community and be provided with the same opportunities – and the support they need – to do this.”
- And CB NSG members have set out the components of the support that are needed.



Getting it right: what is needed?



Graphic taken from the Challenging Behaviour charter.

At the CBF we recognise that families are traumatised by what happens to their relative, and by the system that is meant to be there to support them:

- *“All of the parents involved with/supported by the CBF will be living in a state of chronic sorrow. ...Given that we are forced to look on helplessly as a fundamentally disjointed, all too often utterly unprofessional system damages or indeed all but destroys our children, it is surely to be expected that we end up traumatised as well.”*
- *“Trauma is totally overlooked and found not to be important but it affects everything. It’s false economy and prolongs agony.”*
- *“As a family we are traumatised- we wont ever recover. We are in a new phase - trying to deal with the trauma...”*



The Trauma Report

- In 2020, NHSE commissioned an investigation into this trauma experienced by families of children and adults with learning disabilities and/or autism
- Led to a collaboration with the Tizard Centre at the University of Kent and the Challenging Behaviour Foundation, with three interconnected strands:
 - Strand 1 – a literature review and a review of family carers' experiences
 - Strand 2 – a short intervention of therapy sessions for 6 family carers
 - Strand 3 – a review of professional experiences of supporting families who experienced trauma

“Broken” is the report of the family carer experience listed in Strand 1. A report of the whole project will be published shortly



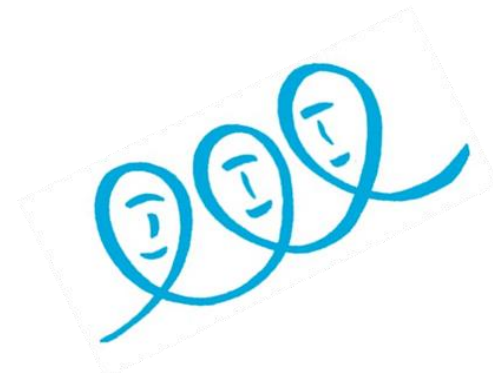
Broken

- Co-produced definition of trauma:
 - *“Trauma is how a person feels when he/she or someone they love is in a situation that could, or does, cause physical or emotional harm. As a result, the person feels helpless or overwhelmed and the world no longer feels like a safe place. They may find it harder to trust people, feel almost permanently on edge or anxious. It may be more difficult for them to concentrate or sleep, and they may have less patience on a daily basis.”*



Survey

- Co-produced survey to find:
 - Any evidence of the need to trauma-based support for families
 - Scope what is currently available and what works, including evidence-based approaches



Advisory Group

“...we .. realised that we were not unique in having to constantly fight the system for even the most basic help for looking after our disabled relative. It begins from the point when hopes and dreams of a life bringing up a child are shattered, often by a professional handing out a diagnosis, and continues forever. We, and our children are transformed instantly from being human beings into something lower, because of the way we are treated by the state, by professionals and by the general public. Our main problem is not our relative, but the response from others, especially those who have the power to help but seem unwilling to do so.”

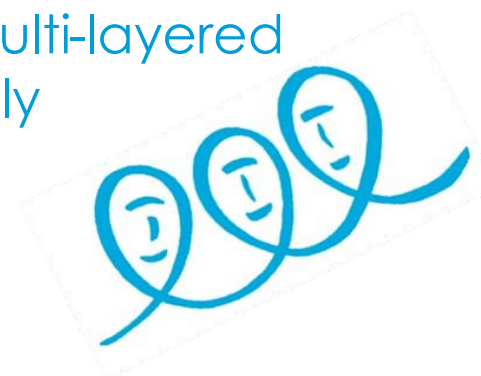


What we found

From 214 responses:

- Types of Traumatic Events & Their Impact
 - “Mainstream” and/or trauma relating to their relatives learning disability and/or autism
- Families described a wide range of issues that were traumatising- from out of area placements, to overmedication of their relative, restrictions on visiting / contact and abuse and crisis situations

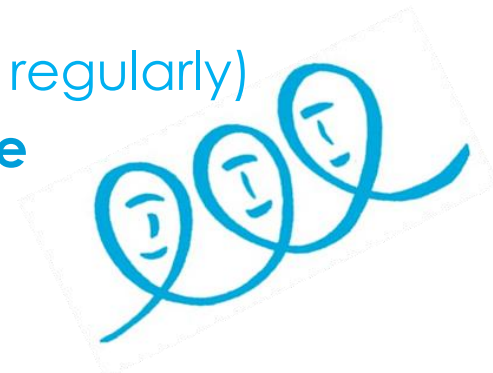
“....when we were allowed to see her she had multiple bruises and was so drugged that she didn't recognise me for about half an hour.”
- Survey showed that trauma for family carers is multi-layered and has a significant impact on them emotionally



The Impact on families

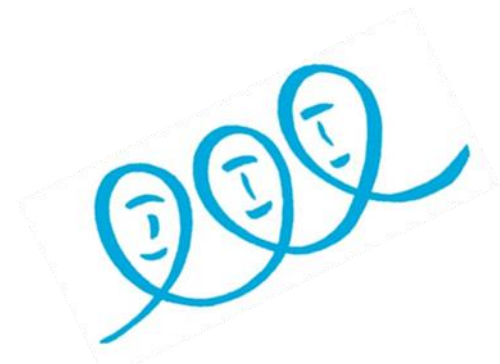
- Panic Attacks
- Insomnia/disturbed sleep pattern
- Unable to work, job loss
- Disagreement with friends/family members
- Family members leaving home
- Relationship breakdown
- Depression
- Anxiety and fearfulness
- Personality change
- Difficulty trusting others
- Guilt (59% of families said they experienced guilt regularly)

Over 72% of participants had experienced all of the above at least once



Impact

“Unable to function - panic when the phone rings. panic when the doorbell rings. Can't focus. Can't trust anyone ever. Find it extremely difficult to keep calm with 'professionals' who are utterly ignorant of Autism, (and most of them are). I overthink everything, relive it every day.”



What causes trauma?

Families can identify the causes- often they relate to “the system” which is meant to be there to support them:

“Exhaustion and a sense of complete isolation and hopelessness at the constant fight to get child’s needs met while no one listens and often hints at parent blame or exaggeration. Loss of friends, social life, a breathing space (child mostly out of school as schools couldn’t meet needs) plus at the same time trying to understand a very opaque system and do hundreds of hours of paperwork without guidance. Trauma from seeing your child in extreme distress and not always being able to help or get them help as CAMHS knock back referrals”



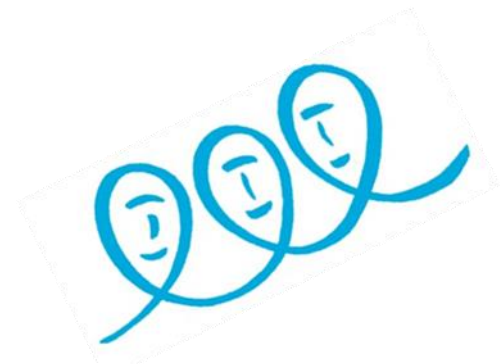
Trauma “risk factors”

- As identified by families:
 - • Lack of services and support to meet my relative’s individual needs (81%)
 - • Lack of early intervention services and support (77%)
 - • Lack of specialist support i.e. trained staff/support workers with learning disability experience (76%)
 - • Finding a way through the education, health and social care system (71%)



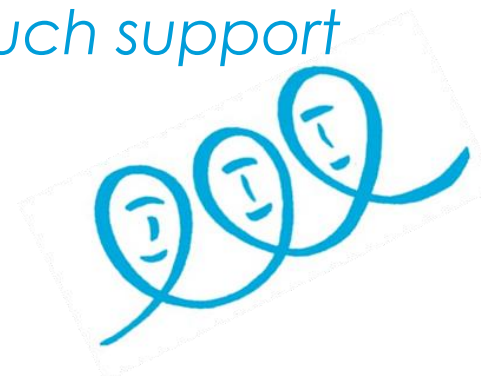
Causes

Family carers of children and adults with a learning disability and/or autism can clearly identify exactly what in the system is causing and is likely to cause them trauma. If families are able to do this, then it should be possible for commissioners, local authorities, clinicians and other professionals to do the same.



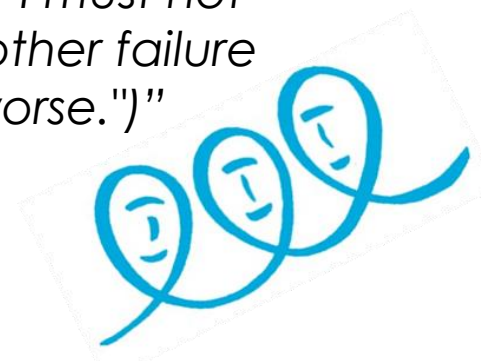
Support Available for Families

- *“We were not supported - we were expected to carry on despite my child suffering so much trauma. I personally feel they forgot we were human and had feelings and that we had no right to expect humane treatment.”*
- *“Requests for support vigorously rejected by local authority”*
- *“I am aware that there appears to be no such support whatsoever in my area”*



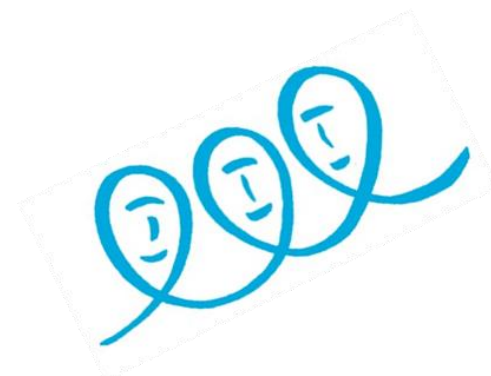
Support Available for Families

- Some families described looking for support – and how this created an additional layer of stress and burden:
 - *“The therapy I got was not offered to me by anyone. I had to refer myself for therapy. They give 6 sessions and then leave you whether it's helped or not. None of those therapies worked and I'm still suffering from PTSD and depression.”*
 - *“Time-limited support not helpful when problems are long-standing and ongoing. CBT model of therapy, with emphasis on 'fixing the person' when sometimes it's the situation that needs [to be] fixed, was experienced as deeply unhelpful – presenting the parent as culpable solved nothing and created new problems (“I must not be trying hard enough if I still feel bad about this - another failure to add to the others. Now I don't just feel bad, I feel worse.”)”*



What can we do?

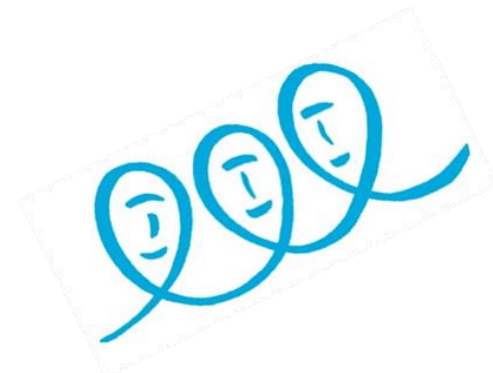
- The survey responses show that trauma experienced by family carers is a result of a combination of many challenges to overcome that are caused by the system - in addition to dealing with the trauma that we all have to manage in life.
- We agreed 3 key recommendations.



Recommendation 1

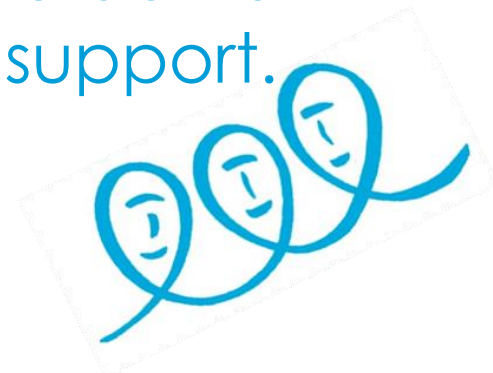
- The system should not traumatise families in the first place.

The system, (including commissioners, local authorities, clinicians, support staff, professionals and senior officials) must recognise and address the risk factors for trauma that families have identified in this survey.



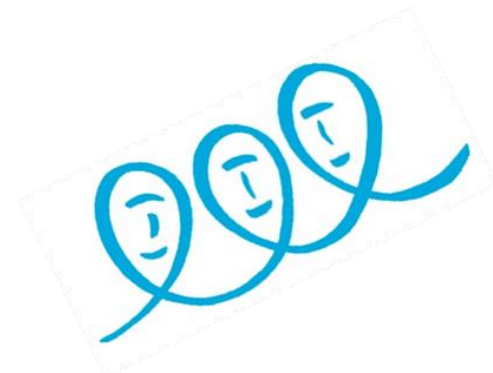
Recommendation 2

- When trauma does occur, there needs to be a **pathway in place to offer individuals and their families a person-centred trauma support package**. This should not be at a financial cost to the families. This package should allow individuals and families to access the range of support types that they need whenever they need it and should not increase the burden on families to look for or provide trauma support.



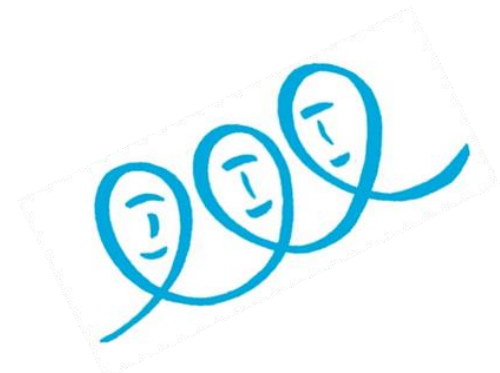
Recommendation 3

- Develop more widely available **specialist trauma support** for immediate effect to help those families who are already traumatised.



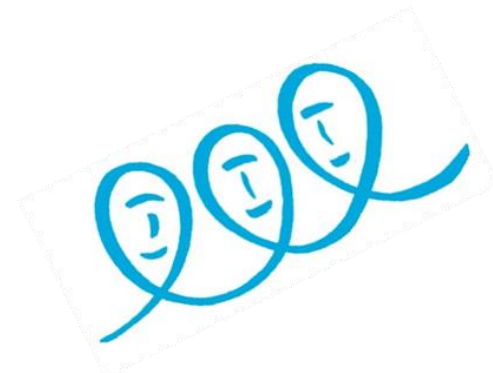
A “New Normal” Opportunity?

- Our “new normal” needs to acknowledge the causes, impact and cost of traumatising individuals and their families



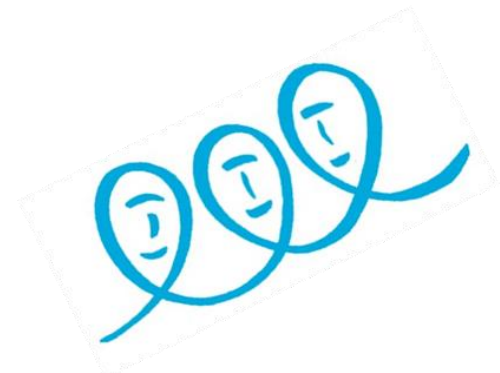
Last Word

- “We feel powerless to prevent some ill-informed decisions, which might have potentially enduring and seriously damaging consequences, being made about our son’s care. This is always a risk because funding is always being reduced. We live with such concerns each and every day and particularly in the early hours of the morning.”



“Broken”

- The report will be available shortly on our website
 - www.challengingbehaviour.org.uk
- The full report will be published in the next few weeks



Today's Discussions

- How do we break the vicious circle?

Families are in conflict with local authorities because of the cumulative impact of struggle since birth of child.

- How we get the message about trauma out to services/ parts of the system?
- What are we expecting people/ services/ the system to do with this message?
- **The problem is huge so the solution needs to be huge!**



Challenging
BEHAVIOUR
foundation



making a difference

THANK YOU!

