THESE ARE OUR CHILDREN

13 March 2018

JACQUI SHURLOCK

THE CHALLENGING BEHAVIOUR FOUNDATION

jacqui@thecbf.org.uk

Challenging BEHAVIOUR foundation

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

1. Which children?

2. The Early Intervention project

3. The Lenehan review

4. What works?

6. Any questions?

Challenging BEHAVIOUR foundation

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

NHS England

Which children and young people?

Children and young people with learning disability, autism or both with behaviours that challenge and / or a mental health condition

CHALLENGING BEHAVIOUR

Children with learning disabilities or autism are much more likely to behave in a way that other people find difficult.

Challenging behaviour is behaviour which puts the child or others at risk, makes it hard for them to go to ordinary places such as shops or playgrounds or stops them having a normal home life.

Why do children challenge?

- It works!
- to gain choice & control
- to communicate something:
  - personal reasons – hunger, pain
  - environmental reasons – noise, people
  - specific purpose – get something, attention, escape, sensory

HOW MIGHT THE CHILD OR YOUNG PERSON BE FEELING?

- Scared
- Upset
- Anxious
- Frustrated
- Helpless
- Sad
- Confused

WE MAY FEEL SIMILAR EMOTIONS WHEN SUPPORTING SOMEONE WHOSE BEHAVIOUR CHALLENGES.

Daniel's mum, Viv, didn't know what to do when Daniel started head-banging aged one. Daniel was sent far away to a school which used PBS to help Daniel communicate. Viv thought, 'why didn't we know this earlier?'

20 YEARS

LATER

12-year-old Josh was sent to a unit 6 hours from home because his self-harming was so severe. Cornwall said they had no facilities to help him. His family spent years campaigning for his return. He returned home at the age of 15.

Josie was excluded from her school and respite centre because of aggression, even though it was known her behaviour was due to anxiety. She was at home for 8 months then sent to a school 200 miles away.

“Children without learning disabilities display challenging behaviour during the “terrible twos,” but then develop communication and social skills which enable them to get what they want and need. Many children with learning disabilities do not develop these skills and are left with the same needs as other children but are much less able to get them met.”

Professor Peter McGill

THE WELL-TRODDEN PATH

- No local behaviour support when children are small
- Professionals with little or no training or expertise in challenging behaviour
- Continued stress and emotional challenge for families over many years
- Children at risk of poor outcomes, bullying and abuse
- High cost services, often far from home, leading to restricted adult lives

£171,176

Cost per year for a 52 week placement in a residential special school.

Average cost per year for an inpatient (17 or under) in an ATU.

£250,000

£89,335-
£358,415

Cost per year for an adult service catering for adults with severely challenging behaviour.

EVIDENCE PAPERS

Evidence papers were written in collaboration with leading LD professionals including doctors, professors and representatives from national charities. Contributing authors included experts from their fields with strong backgrounds working in the area of learning disability

A VISION FOR OUR CHILDREN

A SUMMARY OF MESSAGES FROM FAMILY CARERS OF CHILDREN WITH LEARNING DISABILITIES WHOSE BEHAVIOURS CHALLENGE

OUR CHILDREN Should have the same opportunities & experiences as other children

OUR CHILDREN Are trying to tell us things

OUR CHILDREN Should be valued, Should be understood, feel safe & secure

AT EVERY AGE OUR CHILDREN NEED:

1. A keyworker to help us through the system
2. Everyone to use Positive Behavioural Support pro-actively
3. Proper Reasonable Adjustments to ensure access to healthcare & community

AT EVERY STAGE WE NEED:

1. Information & training so we understand causes of behaviour & how to support change
2. Support for the practical & emotional difficulties we face (Support from parents/professionals)

WHEN THEY ARE LITTLE (0-5)

- Early identification by experts!
- The right information & support, at the right time, in a form that is right for us

WHEN THEY ARE AT SCHOOL (5-16)

- Schools/services to work with us
- Local schools to rise to the challenge of supporting our children
- Professionals to help us access local mainstream & specialist support

AS OUR CHILDREN GROW UP (14-25)

- A keyworker, one-stop-shop for planning & delivery
- Appropriate housing options
- activities - real choice including positive risk
- lifelong learning
- Skilled support workers/carers

BETTER OUTCOMES FOR CHILDREN, FAMILIES & COMMUNITIES

WE NEED GOVERNMENT, LOCAL AUTHORITIES & HEALTH TO:

- Show that you value disabled children
- Think & talk about people not processes
- Have a named Challenging Behaviour Co-ordinator
- Deliver long-term planning & clear pathways
- Employ keyworkers
- Commission Positive Behavioural Support
- Include specialist support within the "Local Offer" to respond to needs identified in Education, Health & Care Plans
- Ensure access to responsive schools near home which work with parents to provide effective education
- Develop a national strategy
- Ensure a joined up approach

Early Intervention Project, Challenging Behaviour Foundation 2014

Mendonça 2014

Graphic by Pen Mendonça

The Lenehan Review, January 2017

1. Children's Rights
2. Residential Special Schools and Colleges
3. 18-25s in inpatient settings
4. Model of Care
5. Professional Responsibility
6. Local Authority role
7. Keyworker/named worker
8. National and local coherence
9. Local Implementation
10. Workforce
11. Financial Incentives

What works?

Evidence based interventions

CBF academic expert group recommended:

- **Early behavioural interventions;**
- **Training and emotional support for families;**
- **Systematic early identification and a family-centred rapid response;**
- **Positive behavioural support (PBS), based on a functional assessment
and applied consistently across home and school settings.**

PAVING THE WAY – best practice

Establish a person centred approach, right from the start, supported by a key-worker and a team around the child

1

Wolverhampton Special Needs Early Years Service

Identify problems early and respond rapidly using an integrated, multi-disciplinary approach to ensure all needs are met

2

Coventry and Warwickshire Community Learning Disability Team

Provide evidence-based parenting programmes to help parents to support their child in the best possible way

3

Stepping Stones in Brighton and Hove

Establish a local positive behavioural support service, working across homes and school

4

Bristol Positive Behavioural Support Service

Develop a local approach to crisis prevention so children can stay nearby if there is a crisis

5

Ealing Intensive Therapeutic Short Break Service

Andrew

Supported by Bristol Positive Behaviour Support Service

Andrew is 11, and has a severe learning disability. He likes watching videos, and DIY with his Dad. Placing demands on Andrew could lead to aggressive incidents. As these increased, Andrew was excluded from school. A functional analysis of Andrew's behaviour was carried out and a Positive Behaviour Support programme was used to help Andrew label his emotions so he could express his feelings through Makaton signs rather than aggression. Andrew's family learnt new skills so they could help Andrew with his emotional literacy and communication skills. Andrew was described as a 'joy' by the time he left the service, and was much calmer and happier.

> There is strong evidence that some of the key factors causing challenging behaviour can be changed, and when changed can lead to marked reductions in challenging behaviour.

Professor Eric Emerson

> We've fallen back in love with our child.

Parent carer

Any questions?

The Challenging Behaviour Foundation

- **Enquiries: 01634 838739 or info@thecbf.org.uk**
- **Family Support Worker: 0300 666 0126 or support@thecbf.org.uk**
- **Websites:**
- **www.challengingbehaviour.org.uk www.pavingtheway.works**
- **Facebook:**
- **www.facebook.com/thecbf**
- **Twitter:**
- **@CBFdn**