



# Finely balanced.

By Debbie Austin.

Parent/Carer.

# HELP !



## Behaviours that challenge.

- ▶ Can begin very early.
- ▶ It is a way of communicating a need.
- ▶ This increases risk of poor outcomes.
- ▶ Physical health
- ▶ Mental health
- ▶ Isolation/social exclusion.
- ▶ Institutionalisation
- ▶ Poverty



Lucy.  
Our story  
of  
success.

## Lucy's strengths

- ▶ Sense of humour and love of slapstick.
- ▶ Resilience
- ▶ A brilliant memory
- ▶ Musical
- ▶ Self reliance
- ▶ Determination
- ▶ Apart from a very serious illness at 18 months old, good health.

## Challenges that Lucy's disability brings.

- ▶ A severe learning disability.
- ▶ High levels of anxiety.
- ▶ A concrete understanding of the world.
- ▶ Very limited danger awareness.
- ▶ Communication skills that require support of people who know her well, **especially in social situations.**
- ▶ Fine motor skills that require support eg. dressing, toileting.
- ▶ In social settings Lucy will sometimes use behaviors that challenge to communicate her needs.

## A PBS success story. With luck and good timing.

Introduced to Positive Behavioural Support early. Though could have been earlier.

5 days of training from Tizard Centre.

3 days training from CBF.

Friends and colleagues who work in the field.


A personal interest.


It all fell into place recently, Lucy has well managed needs and doesn't often need to use behaviours to express herself.

Lucy has increased confidence in us, as parents, to provide the support she needs. She can tolerate, even enjoy, situations she previously found impossible.



## Why do I need resilience?

- ▶ To meet Lucy's needs.
  - ▶ To meet my families needs.
  - ▶ To survive in the system
  - ▶ To survive in the community.
- 



## Challenges in the system.

- ▶ Interventions are not reaching enough families *in time*.
- ▶ Families in need do not know who to ask, and what to ask for.
- ▶ They are often not believed when they do.



## Systemic problems as identified by family carers.

- ▶ **It's a lottery.**
- ▶ **Lack of reporting of unmet need.**
- ▶ **Parents are denied the opportunity to be an expert on panels.**
- ▶ **Support is often not offered.**
- ▶ **EHCP's are used as ieps.**
- ▶ **A lack of understanding about learning disability and autism.**





## Challenges in the wider world.

- ▶ Parenting through a magnifying glass.
- ▶ With a very thick skin and utmost
- ▶ Patience
- ▶ Sympathy
- ▶ Gratitude
- ▶ Understanding
- ▶ Positivity.

## My strategies.



A new language of calm reasoned logic. I talk of her needs **not** my wants.



*Can you meet her needs?*



I use parallels with physical disability.



Understanding the limitations of her disability.



“You must learn to let go”.

- ▶ Not over, but appropriately, protective.
- ▶ Not overanxious but appropriately concerned.
- ▶ Not high, but appropriate, expectations.
- ▶ Not excessive, but appropriate, support.

# HELP !



We need **everyone** to understand that behaviour is a communication of unmet need(s).

Training for families.

Training into schools, respite settings, to health professionals and social care staff.

PBS Competencies.

## Co-production or more.



- ▶ Parents as **paid** partners.
- ▶ Parents as colleagues.
- ▶ Parents as service leaders.
- ▶ Parents as commissioners.
- ▶ Parents as quality control.
- ▶ Parents as trainers.
- ▶ Not as unpaid volunteers.

The slide features a white background with decorative elements. On the left, there is a vertical strip of light green with several question marks in various colors (blue, purple, green) and sizes, some with soft shadows. On the right, there are large, overlapping geometric shapes in various shades of green, creating a modern, abstract design.

# Questions and discussion!

Thank you.

Debbie Austin