Children and young people with learning disabilities whose behaviours challenge

**Good practice examples:**

- Halton- Positive Behaviour Support Service
- Tizard Centre – Early - Positive Approaches to Support
- Kent – Multi-agency local offer
- East Sussex – Family Intensive Support Service
- Ealing - Intensive Therapeutic and Short Break Service (ITSBS)
- South Gloucestershire - iPBS
Positive Behaviour Support Service:

HALTON BOROUGH COUNCIL:

• Halton Borough Council alongside St Helen’s and Halton NHS commissioned a specialist peripatetic, life span Positive Behaviour Support Service.

• Neighbouring authorities Knowsley and St Helens also commission the service.

• It is the first Local Authority service in the UK to be staffed and led by Board Certified Behaviour Analysts (BCBA)
# Visions of the PBSS

<table>
<thead>
<tr>
<th>For the individuals…</th>
<th>For those caring and supporting individuals…</th>
<th>Reduction of risk</th>
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| Improved quality of life | Reduced stress | • To health and social well being.  
• Personal injury  
• Placement breakdown  
• Out of borough/restricted placement  
• Reaching crisis point  
• Damaged relations  
• Preceded by one’s case history  
• Intrusive support levels  
• Normal life opportunity limited by over zealous risk assessment  
• High cost placement/support packages |
| Increased opportunity for meaningful engagement | Increased knowledge of behaviour function, environmental and stimulation effects | |
| More opportunity for education/cognitive development | An increased efficiency during times of problem behaviour occurrence | |
| Increased opportunity for community participation | Improved relationships with service user | |
| Greater access to a less restrictive environment | A feeling of being supported. | |
| Improved relationships | An increased confidence in ability to cope | |
Eligibility:

Who Accesses the Service?

• Core service for individuals with a moderate to severe Learning Disability and/or diagnosis of Autism who are engaging in behaviour that challenges services

• Some new service development for older people with a diagnosis of Dementia (no Learning Disability)
Staffing Structure:

**POSITIVE BEHAVIOUR SUPPORT SERVICE**

**Operational Director:** Paul McWade  
**BCBA-D:** (Clinical supervisor)

**Principal Manager:** Marta Saville

**TEAM 1:**  
**HALTON**  
Practice Managers x 2 (Behaviour Analysts)  
Care Managers (Assistant Behaviour Analyst level)  
Support workers x 2  

**ADDITIONAL HALTON:**  
Practice Manager (Behaviour Analyst): Dementia Lead  
Practice Manager (Behaviour Analyst): Safeguarding lead, sits in Integrated Adult Safeguarding Unit  
Care Manager (Assistant Behaviour Analyst level): Education  

**TEAM 2:**  
**KNOWSLEY**  
Practice Managers x 2 (Behaviour Analysts)  
Care Managers (Assistant Behaviour Analyst level)  
Support workers x 2  

**TEAM 3:**  
**ST HELENS**  
Practice Manager (Behaviour Analyst)  
Care Manager (Assistant Behaviour Analyst level)  
Support worker  

**FUNDING:** Core Team  
Team 1: Halton Adults, Halton CCG and Halton Children and Enterprise  
Team 2: Knowsley  
Team 3: St Helens LA and St Helens CCG  

**FUNDING:** Additional Halton  
Dementia Practice Manager: Halton Adults  
Safeguarding Practice Manager: Halton Adults  
Care Manager Education: Children and Enterprise
Service Specification:

FOUR KEY FUNCTIONS
The service aims to work collaboratively in four related areas
The Key Functions:

Technical Support: So far…

- PBSS have worked with 82 people so far (across children and adult services and stakeholders)
- Age range of 4-96
- Cluster of 14-19 year olds (transition-crossing children and adults services)
- Over 60% of people have a diagnosis of Autism
- 1 re-referral to date
Case Vignette: Lucas

- Aged 9, diagnosis of Autism and Learning Disability
- Home placement in jeopardy due to high risk behaviours
- High frequency absconding
- High frequency, high intensity self-injury, medium frequency aggression
- Limited activity, restricted environment, limited communication
Case Vignette: Lucas

- PBSS aim- stabilise placement, increase activity and communication, change restrictive environment, reduce behaviours
- FA completed, intervention supported
- Absconding has ceased altogether
- Other behaviours have reduced (particularly in intensity)
- Functional Communication skills and activity have increased
- Lucas freely moves around the house…
- Stabilising a home placement avoided the cost of a specialist residential school, a cost of £150,000-£250,000 per year
Not all Plain Sailing…

Staff availability
High staff turnover
Weak management
Cancellations
Safeguarding complexities
Tired parents
Carer mental health
Perseverance…

Agency staff
Recruitment
Burnt out staff
Medication
Fear
‘Been there done that’ attitude

Capacity
Data refusal
Conflicting advice
‘Know it all’ attitude
Conclusions:

Going well…

- The ‘four armed’ pragmatic approach of the PBSS is proving successful
- Quality of lives are improving (significantly)
- Commissioners are impressed (and wanting to invest more)
- Cost effectiveness is being shown
- More Behaviour Analysts are being trained
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Tizard centre - Early - Positive Approaches to Support (E-PAtS)

• The aim of E-PAtS is to reduce the risks of behaviour that challenges before a crisis is reached and to limit the impact of such behaviour on children, families and professionals.

• E-PAtS will deliver a package of best practice supports to families with children who have a learning disability and are at high risk of developing behaviour that challenges.

• Identified children will be under 5-years old and present with a combination of risk factors supported by the research literature. The central aim is to help better meet the needs of these children and their families at an early stage.

• A range of outcomes that reflect the experiences of both children and families will be evaluated over time.

• The E-PAtS team will aim to identify other examples where early support for behaviour that challenges has been put into practice.

• E-PAtS will create a professionals’ network to disseminate and sustain all learning.

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Multi-agency Local Offer for Children and Young People with Challenging Behaviour and their Families

• Winterbourne View
• Co-production of parent carers
• Evidence based commissioning linked to Positive Behaviour Support framework
• New whole system approach focused on early intervention and prevention as well as intensive support
• Children’s Continuing Care Packages
• Shared outcomes and KPIs

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Sussex: CAMHS Learning Disability/The Family Intensive Support Service

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The team

CAMHS LD/ FISS is a multi-disciplinary team working with children with moderate to severe learning disabilities and emotional, behavioural and communication difficulties and their families. comprising:

• team leader
• clinical psychologists
• child and adolescent psychiatrist
• assistant psychologist
• speech and language therapists
• mental health nurse
• family support workers
• administration staff
Aims

• To work in partnership with families to provide high quality assessment and intervention and promote needs of learning disabled children.

• To support children to live valued lives & participate in community activities wherever possible.

• Focussing on the prevention of difficulties by supporting and enhancing parents’ confidence to handle current problems, and enabling them to anticipate future problems that may arise.
What does this mean in practice?

- Provide emotional support/relationship work with families & others
- Work with siblings
- Undertake detailed functional analysis of behaviour & communication
- Develop specific communication resources
- Individual therapeutic work with children
- Parents groups:
  - Positive Behaviour Support Course
  - All About Me group – focussed on resilience
- Facilitate multi-agency meetings and parent consultation sessions
- Provision of consultation, support and training to staff and parents across settings
- Contribute to CAMHS policy and strategy
Preventing Residential Placements for Young People with Learning Disabilities and Challenging Behaviours

Dr Caroline Reid, Clinical Psychologist
Ealing Intensive Therapeutic and Short Break Service (ITSBS)
South Gloucestershire Intensive Positive Behaviour Support (iPBS) Service
What is the Ealing ITSBS?

- **Intensive** Therapeutic and **Short Breaks** Service

- Collaboration of
  - Clinical Psychology
  - Social Services
  - Short breaks services for children with disabilities

- Based within Ealing Services for Children with Additional Needs (ESCAN) - multi-agency.
- Aims - enable young people with LD and behaviours which challenge to remain within their family/community
- Provides - intensive clinical psychology input to the young person, family and frontline workers, including an extended short break
- Named as a Good Practice Example (Winterbourne View Review, DoH 2012)
Policy and Legislative Background

• Aiming High for Disabled Children (2007)
• Valuing People: A Strategy for Learning Disability for the 21st Century
• Mansell report revised (2007)
• Between 5 and 15% of people with a learning disability present with challenging behaviours whereby the safety of them or others is compromised (Borthwick-Duffy, 1994; Quereshi & Alborz, 1992)
• Once young people go into residential placements they tend to remain in them as adults (from clinical experience & Mansell, 2007)
• Risks of residential care – Winterbourne View
Early service development

- **July 2008** survey of characteristics of those in Ealing entering residential – male, 11+, moderate/severe LD, ASD, C/B

- **Sept-Dec 2008** – Service successfully piloted with one young person using existing resources from CAMHS-LD within ESCAN.

- **Dec 08** - Presented to senior managers for children with LD who agreed to fund the service for 2 years initially.
Service development

• **Year 1** (2009-2010): 0.5 clinical psychologist & additional short breaks as required for those receiving the service – allowed us to offer a service to 4 young people/families.

• **Year 2** (2010-2011): 0.5 clinical psychologist, 1 wte assistant psychologist, additional funding for short breaks as required for those receiving the service – aiming to offer a service to 6-8 young people/families.

• **Year 3 and 4** (2011-2013): 0.8 clinical psychologist, 1 wte assistant psychologist, additional funding for short breaks as required for those receiving the service – aiming to offer a service to 8 young people/families.

• **Year 5** (2013 onwards): 1wte clinical psychologist, 1wte assistant psychologist, 1wte social worker. Same additional funding for short breaks for 8 families.
Key partners involved

• Clinical Psychologists for Children with Disabilities
• Short Breaks Services – managers and frontline workers
• Social Services for Children with Disabilities
• Joint Assistant Directors for ESCAN
• Special Schools in Ealing
• Other members of the multi-agency service as needed e.g. Paediatricians, OT, SALT, Educational Psychology.
Key Components of the ITSBS Model:

- Short Breaks
- Positive Behavioural Support (PBS)
  - System Support
    - Network training with video modelling
    - Staff training and consultation
  - Therapeutic Interventions
    - ACT and Mindfulness (parent group interventions)
    - Family therapy/Narrative Therapy
    - Adapted CBT
Demographics Oct 2008 – April 2014

28 young people referred & assessed (6 inappropriate)
22 young people/families offered intervention:
• 20 male, 2 female
• Mean age - 12 years (range from 7-17)
• Ethnicity – 9 Asian British,
  – 7 Mixed Race British,
  – 4 Black African British,
  – 1 White British/Irish,
  – 1 White British
• 13 single parent families, 9 both parents
• 16 had siblings (5 siblings with diagnosis of ASD)
• 5 have been re-referred
Referral Information

- All 22 young people:
  - diagnosis of mod/sev LD
  - referred due to high levels of challenging behaviour at home and in other settings (e.g. school, short break services)
  - families/other professionals were concerned about home placement breakdown
- 20/22 - diagnosis of ASD
- 20/22 cases already accessing short break services and/or professional support
- 5/22 - diagnosis of Epilepsy
A Typical Referral

- Physical aggression at home and school including punching, scratching, hair pulling and kicking family, staff and other students
- Destructive behaviours; damaging property, throwing furniture, smashing windows, fire setting
- Absconding and risky behaviours in public
- Self-injurious behaviour
- Obsessions, compulsions and rituals
- Sleep difficulties
- Soiling and smearing
- High anxiety levels
- Low mood
The Process of Intervention

• Engaging and bringing together the network
• Extended Clinical Psychology Assessment and Formulation (first 4-8 weeks)
• Planning and preparation for short break
• Extended short break stay (up to 3 weeks) or additional short breaks in the home (length varies)
• Intensive Clinical Psychology intervention 1-3 months (plus bringing in of other agencies where needed)
• Network trainings
• Evaluation
• Follow-up Clinical Psychology support (as long as needed)
Psychology Assessment (4-8 weeks)

- Initial network meeting requested
- Psychometric Tools given to parents pre- and post-:
  - DBC*
  - Three Concerns / Goal-based assessment *
  - Family Quality of Life Scale
  - Emotional Reactions to Challenging Behaviour
  - Attributions to Challenging Behaviour Scale
  - General Health Questionnaire
*also given to staff in school and short break settings
- Clinical interviewing
- Direct observations across all settings with use of video
- Leading to the development of a PBS plan
Extended Short Break

• Can be for **up to 3 weeks** at local short break facility – Heller House

• Prior to the stay:
  – PBS plan
  – Preparation (e.g. social stories)
  – Staff training in PBS plan

• During the stay:
  – Family visit to observe and practice PBS
  – Young person is given a visual timetable countdown

• Clinical psychology visit regularly to monitor and support implementation of the plan and offer staff consultation

• Adapted model of short break – if Heller House not appropriate.
Parent Quotes

“It has helped me to find positive solutions to my child’s problems…and made me look at my son’s problems in a different way. I no longer feel at the mercy of his temper and he doesn’t feel the need to lash out because he knows I’m on his side and I’m trying my best to understand him.”

“The way the psychologist looked into every aspect of our child’s difficulties and worked out plans to help with each one, and getting other agencies involved e.g. short breaks, OT and SLT. She was very pro-active in helping us e.g. doing home visits and going out in the community with our child.”

“I used to cry every day and dread Joseph coming home, but now I cry less and sometimes even miss Joseph when he is out, and look forward to him coming home.”
South Gloucestershire – iPBS

- New service based on Ealing ITSBS model
- Aim to prevent social exclusion – young people who are at risk of home and/or school placement breakdown
- 0.5 wte Band 8B Clinical Psychologist
- 4.09 wte Band 5 Clinical Nurse Specialists, previously worked within a health-commissioned overnight respite unit.
- BTEC PBS Training in South Wales
- 8 young people to be seen each year
- Working in a locality where there is a residential unit in Bristol
Financial Impact

• Approx cost of out-of-borough residential placement = minimum £200,000.

• Brief annual cost comparison demonstrates the service (2 x psychologists plus short break package) can be run for less than what it costs for one child to be placed in residential care.

• Current collaboration with London School of Economics for a more robust cost analysis of this type of service provision.
Advantages of Service Model

• Cost comparisons
• Proof to parents that ‘they’ can do what is needed
• Intensive input allows for a more thorough assessment formulation and intervention
• Support systems remain after the crisis
• A short break gives the family a break from the norm and time to:
  – sleep and recover
  – think about their child and their wishes for their future
  – attend Clinical Psychology appointments
  – consider new ways of supporting their child
  – re-organise the home and make changes to the environment.
Challenges

- Timing of different agencies and MDT work
- Working with VERY large networks
- Managing risk / shouldering responsibility
- Staff burnout – importance of consultation, supervision and informal support
- Boundaries?
- Coordinating and motivating ‘stuck’ / problem saturated systems
- Engendering hope
- Restrictions around physical resources e.g. space in schools, housing, financial
- High levels of creativity required!
For more information, please contact:

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