

Bright Futures School is concerned about PBS (and any other behaviour-based approach) being used as an approach for anyone with autism, and especially those who have experienced trauma. This is because:

a) Recent research does not support the use of PBS with autistic people

A recent multicentre, cluster randomised controlled trial conducted by Hassiotis et al. (2018) however found no 'treatment effects' in terms of reductions in 'challenging behaviour' between those being cared for by staff trained in PBS compared to those who were not, and that further research should: "...endeavour to identify other interventions that can reduce challenging behaviour." (Hassiotis et al., 2018:1).

b) Adult autistics who have experienced PBS/behaviourist interventions tell us that these approaches were at best unhelpful and at worst, abusive in themselves.

https://autisticadvocacy.org/wp-content/uploads/2017/07/First-Hand-Perspectives-on-Behavioral-Interventions-for-Autistic-People-and-People-with-other-Developmental-Disabilities.pdf

An autistic woman called Alexis made this video to explain her experience of behavioural support (specifically, PBS) being used with her when she was in hospital to address what was termed 'challenging behaviour'.

Rightful Live Investigates Behavioural Analysis and Support



She describes herself as 'constantly in a state of discomfort' and when she became exhausted from 'masking' (trying to make herself conform to the behaviour that was desired), she would have 'an almighty meltdown' and would end up performing self-injurious behaviour because she was 'out of control'. She describes the impact of these cycles as making her feel 'absolutely hopeless' and 'like a beast, a caged animal'.

Alexis states that the behaviourist strategies caused 'a fracturing of identity' and mental health problems, which culminated in her making an attempt on her own life.

Recommendation

We have heard from other parents and from some practitioners that a trauma-informed relationship-based approach is the best approach to use with an autistic person who is presenting with challenging/distressed behaviour.

NICE guidelines CG170 recommends consideration of a 'social-communication intervention for the core features of autism in children and young people that includes play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person.'

In older young people and adults, we are told that this has been achieved using the person's special interests instead of play-based strategies.

Adult autistics like Alexis who have experienced PBS tell us that what would have helped them is an approach that 'mirrors back' their experiences and validates them.