Positive Behaviour Support (PBS)

December 2021

Introduction

PBS is being widely promoted as an approach to be used on people who are disabled and/or neurodivergent and display behaviours others do not wish to see. Often the disabled person has significant sensory, communication, trauma or medical needs and rights that are not met. Despite a broad buy-in, PBS is not actually supported by Disabled People's Organisations and allies. This is because PBS does not meet human rights, has a poor quality evidence base and its risks and harms are not understood.

This paper has been prepared to set out evidence for these issues in order to aid discussions at all levels. Section 1 starts by providing evidence that PBS is akin to a brand of Applied Behaviour Analysis (ABA) as claims are often made that "PBS is not ABA". Section 2 sets out ways in which PBS goes against human rights, despite claims by the field that PBS is a rights based approach. Section 3 looks at the lack of an evidence base in the face of PBS claims that "PBS is the most evidence based….". The extent to which concerns are shared is widespread and this is evidenced in Section 4. Section 5 explores the ways in which behaviourist interventions such as ABA and PBS can harm, an area the field seems to not have looked into.

- 1. PBS is a brand of ABA (Page 1)
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- 5. Harms and risks of behaviourist interventions (page 11)

1. PBS is a brand of ABA

1. Positive Behaviour Support and Applied Behaviour Analysis (Johnston et al 2006)

Paper published in ABA International journal about the relationship of ABA and PBS.

2. PBS and ABA: A Familial Alliance (2008)

"Recently, there has been some confusion regarding the definition of PBS and, in particular, its relationship to ABA. In this article, it was noted that the practice of PBS and ABA, in some instances, can be indistinguishable but that important differences in definitions and emphases mandate an explicit distinction."

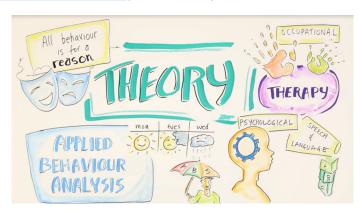
3. UK Society for Behaviour Analysis - About Behaviour Analysis

Scroll to the bottom of the page where it confirms PBS is based on behaviour analysis and that "it should be overseen by a qualified Behaviour Analyst."

4. PBS Academy UK competency framework (2015)

Page 7 sets out the PBS framework. Point 5 "Primary use of principles and procedures from behaviour analysis", point 6 "The secondary use of other complementary, evidence-based approaches to support behaviour change".

5. BiLD Introduction to PBS video (at 4:45 mins)



6. Autism, ABA and PBS some questions (2017)

Article looking at the relationship between ABA and PBS.

2. PBS does not support human rights

 Care Quality Commission review of PBS plans in "Out of Sight - Who Cares?" report (Oct 2020)

Findings included PBS plans omitting diagnosis and inadequate consideration of sensory needs.

British Institute of Human Rights noted dignity concerns with PBS plans as "people were seen not as individuals but as a condition or a collection of negative behaviours".

2. PBS also "others" and dehumanises in its use of language that is discriminatory and stereotyping which is in direct contravention of the <u>UN Convention of Rights of People with Disabilities</u> eg "complex needs", "non-compliance", severe "challenging behaviour", "aberrant behaviour".

3. Ethical Concerns with ABA for Autism, Kennedy Institute of Ethics Journal 2020

Written by a philosopher and ethicist this paper concludes that "ABA manifests systematic violations of the fundamental tenets of bioethics. Moreover, the supposed benefits of the treatment not only fail to mitigate these violations, but often exacerbate them. Warnings of the perils of ABA are not original to us — autism advocates have been ringing this bell for some years. However, their pleas have been largely unheeded...Specifically, we will argue that employing ABA violates the principles of justice and nonmaleficence and, most critically, infringes on the autonomy of children and (when pushed aggressively) of parents as well."ABA lacks social validity

- 4. Flagship <u>Journal of ABA was reviewed over 50 years</u> (Pritchett et al 2020) and findings concluded that ABA is not used collaboratively, contributes to oppressive and commodified structures, lacks informed consent, addresses problems that were rarely initiated/voiced by community and there was little indication of improved lives of the "person at the centre".
- 5. Autistic Self Advocacy Network looks at the ethical concerns of behaviourist interventions such as ABA PBS in their paper "For Whose Benefit: Evidence, Ethics and Effectiveness of Autism Interventions?"
- 6. United Nations Human Rights Special Rapporteurs (2015)

"In many countries, autistic persons lack access to services which would support, on an equal basis with others, their right to health, education, employment, and living in the community. When available, services are too often far from human rights friendly or evidence-based....

Autistic persons are particularly exposed to professional approaches and medical practices which are unacceptable from a human rights point of view. Such practices – justified many times as treatment or protection measures – violate their basic rights, undermine their dignity, and go against scientific evidence....

Autistics persons should be recognized as the main experts on autism and on their own needs, and funding should be allocated to peer-support projects run by and for autistic persons.."

7. New Jersey Centre of Excellence for Autism hosts experts on child development and neuroscience who confirm there is no ok type of ABA and that all ABA is inherently harmful:

(511) The Effects of Behavior-Based Models on Neurodevelopment and Learning with Alfie Kohn & Prof. Torres - YouTube

8. How behaviourism fails when it comes to understanding behaviours

<u>An autistic human rights campaigner shares her experience</u> of behavioural analysis and support, highlighting how stressed autistic behaviours were inappropriately viewed and treated and led to long term restraint and seclusion.

In <u>one of ten videos</u> linked to the National Autistic Taskforce's <u>Independent Guide</u> to <u>Quality Care for Autistic People</u> we see another example of how behaviours were inappropriately viewed leading to restraint and seclusion.

9. Autonomously Autistic: Exposing the Locus of Autistic Pathology (2018)

Paper discussing how ABA goes against rights, such as autonomy and agency.

10. Distorting Psychology at the Expense of Joy (2018)

Human Rights violations against autistic people via ABA.

11. Scottish Human Rights Commission

Human Rights Based Approaches: "Everyone has the right to participate in decisions which affect them. Participation must be active, accessible and meaningful"

PBS was developed and is being mandated without meaningful say by disabled people. PBS is routinely used on disabled people without consent and without values, wishes or preferences that reflect those of the "person at the centre".

12. The Misbehaviour of Behaviourists (Dawson 2004)

Extensive paper about "Ethical Challenges to the Autism-ABA Industry"

13. Review of 2020 ABA textbook (900 pages, known as the "white bible")

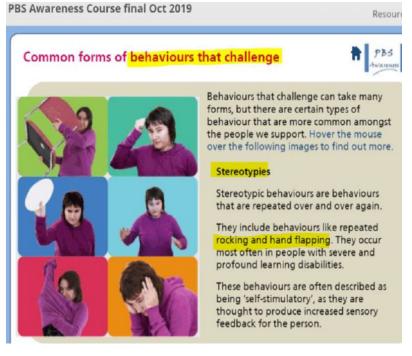
Concerns include omission of discussion of ethics, consent, human rights, risks/harms, and protecting autonomy and promotes harmful practices discussed such as ignoring a person in distress, putting children in aversive situations, removing favourite things for noncompliance.

14. PBS Values and quality of life - BiLD online training course 2020

These reflect those of typical society and those around the person, rather than the goals of those of the "person at the centre"

The PBS training on Values creates harmful mindsets, power imbalances and fuels ableist and "saviour" mentalities. Extracts from the BiLD PBS training course (prerequisite for PBS accredited courses):







PBS normative approach targets behaviours that look odd and devalues normal autistic behaviours, such as stimming or other ways of self regulation, often treating autonomic brain responses e.g. behaviours from fight/flight, trauma or dysregulation, as purposeful and learned.

Such stress responses can manifest in external challenging behaviour, or can be contained as the individual becomes passive and disassociates. A focus on unwanted external behaviour is flawed and goes against development of regulation, current understanding of autism, neuroscience and child development.

The <u>Challenging Behaviour Foundation guidance on PBS</u> reinforces the idea that behaviours are learned/purposeful. "in general, many cases of challenging behaviour appear to be effective ways for a person with learning disability to control what is going on around them. This may reflect their lack of more usual methods of control or making choices, such as communication skills or daily living skills."

The <u>PBS Academy Competency Framework (2015)</u> states the first step in PBS is to define a person by their external behaviours which is over simplistic and dehumanising:

"The PBS process begins with a systematic assessment of when, where, how and why an individual displays behaviour that challenges, a process known as functional assessment or functional analysis. The primary outcomes of this process are:

1. A clear description of the behaviours of concern (including classes or sequences of behaviour that occur together).

- 2. The identification of the events, times, and situations that predict when the behaviour will and will not occur across the person's full range of typical daily routines.
- 3. Identification of the consequences that maintain the behaviour (that is, the purposes or functions that the behaviour appears to serve for the person)
- 4. The development of one or more summary statements or hypotheses that describe specific behaviours, the situations in which it occurs, and the consequences that may maintain it.
- 5. The collection of direct observational data that support the summary statements that have been developed.

3. PBS is not supported by quality evidence

1. An investigation into Positive Behaviour Support and Quality of Life (2019)

Systematic review "Although the Challenging Behaviour Foundation (2019) attest to their being "strong evidence that PBS is effective in producing positive outcomes, such as increasing the person's skills and positive life opportunities", this was not substantiated for adult service users in this review. The main output of this review for service users, their families, clinicians, services and policymakers, is that there is a lack of scientific knowledge on the extent to which PBS is effective for adult service users. This is consistent with the evidence review undertaken by NICE (2015) who did not explicate PBS in clinical guidance due to the scarcity of evidence."

2. <u>Clinical outcomes of staff training in PBS to reduce challenging behaviour in adults with intellectual disability</u> (March 2018)

"Staff training in PBS, as applied in this study, did not reduce challenging behaviour. Further research should tackle implementation issues and endeavour to identify other interventions that can reduce challenging behaviour."

3. <u>Process evaluation of a randomised controlled trial of PBS-based staff training for challenging behaviour in adults with intellectual disability</u> (Aug 2019)

"Therapists found it difficult to undertake all the elements of the intervention in routine care. Implementing a workforce training strategy is important to better define the active components of PBS, and resource implications if the intervention is no better than usual care". Can PBS be done with fidelity?

4. <u>Clinical and cost effectiveness of staff training in the delivery of PBS for adults</u> with intellectual disabilities, autism and challenging behaviour (April 2020)

"Results suggest lack of clinical effectiveness for PBS delivered by specialist ID clinical teams. Further evidence is needed from larger trials, and development of improved interventions."

- 5. Pervasive failure to disclose Conflict of Interest in ABA Autism Literature (2021) https://www.frontiersin.org/articles/10.3389/fpsyg.2021.676303/full
- 6. Addressing the wicked problem of behaviour in schools Armstrong (2019)

Review of PBS in schools in Australia, Canada, England, New Zealand and US concludes "Students with disabilities affecting their behavioural development or who have mental health difficulties (MH) frequently face disadvantage, suspension or exclusion as a result of the application of this model in practice. ... Evidence-based, initiatives designed to address this dilemma in the US since the late 1990s, using PBS (Positive Behaviour Support) and also SWPBS (School-Wide Positive Behaviour Support) are outlined but the conclusion is reached that these efforts do not appear to have been successful. Recommendations are made for progress in tackling this wicked problem and include: wholehearted rejection of the manage and discipline model by practitioners....Finally, this article advocates radical change in attitudes by teachers toward student conduct in schools and argues that educational practice should align with insights about human behaviour arising from research in developmental psychology."

7. US Dept of Defense 2020 Annual TRICARE Autism Report on ABA

This concluded (page 30) "there is no way to know if the relatively small change observed here is the result of ABA services, other services received, or if this simply a result of maturation.... This finding strongly suggests that the small changes noted are not related to ABA services"

8. Autistic People's Organisation A4A Ontario Summary ABA evidence 2020

4. The extent to which PBS is not supported is widespread

- 1. <u>US National Council for Independent Living</u> (2021) Resolution passed against all forms of ABA, considered to be abuse.
- 2. Critique of ABA and PBS: Labour Party Neurodiversity Manifesto Appendix (2018)
- 3. Autistic UK <u>Does ABA therapy harm autistic people?</u> (2018)
- Autistic people should be listened to and autistic communities do not support ABA (2017)

Evidence that autistic people should be listened to and the extent to which autistic communities do not support ABA, including the Autistic Self Advocacy Network, the largest Autistic People's Organisation.

5. Therapist Neurodiversity Collective: organisation consisting of multidisciplinary therapists and educators:

Why the TNC does not support PBS

ABA goes against supporting neurodiversity

Why TNC do not support social skills training (with evidence)

"PBS, PBIS and Positive Reinforcement are all forms of ABA. Despite some industry changes in ABA and therapy models, ABA practices will always be based upon a foundation of compliance, coercion and behaviourist principles. It is impossible to practice ABA even gently or playfully, without attempting to control and manipulate a persons behaviour. The fundamental goal of ABA is compliance with the will of the person in position of authority. This is completely counter-intuitive to self advocacy, self-determination and upholding human rights and dignity".

6. Dr Damian Milton – ABA and The Autistic Community: Time to Listen

Webinar delivered in 2020 about the normative approaches of ABA PBS, nature of issues and alternatives.

7. New Jersey Autism Centre for Excellence

Has various resources and webinars discussing the issues of behaviourist approaches, how they are outdated and do not reflect current understanding of neuroscience and development, eg why-positive-reinforcement is not so positive-reinforcement is not so <a href="https://www.neuroscience.com/positive-reinforcement.com/positive-reinforcement.com/positive-reinforcement.com/positive-reinforcement.com/positive-reinforcement.com/positive-reinforcement.com/positive-reinforcement.com/positive-reinforcement.com/positive-reinforcement.com/positive-reinforcement.com/positive-reinforcement.com/positive-reinforcement.com/positiv

8. American Speech and Hearing Association article (2020)

Mentions harms of behavioural therapies and collaborative approaches with autistic people to support emotional regulation and energy levels.

9. Alliance Against Seclusion and Restraint (2019)

Hold panel discussions with other experts in neuroscience, child development and educational psychologists. Their 2019 paper on <u>"The Problem with Behaviourism"</u> sets out why it goes against current understanding and asks where is the evidence that it reduces restraint and seclusions?

10. Studio 3 Prof Andy McDonnell: The Recovering Behaviourist

Paper setting a journey from 1980s as an ABA user through the decades with lessons learned from supporting people with distress behaviours, including the problem of focusing on behaviours.

11. Polls of autistic people's views:

Bonello (2018) on ABA – "Generally speaking, I support ABA for autistic children?"

(n=3,431, agree 5%, disagree 52.5%, n/a or no answer 41.2%)

Memmott (2020) on PBS – "Should teams use PBS methods on autistic people?" (n=649, yes 7%, No 75%)

12. <u>AutCollab</u> international effort to ban autistic conversion therapy/all forms of ABA.

ABA in all its forms is considered autistic conversion therapy as it targets natural ways of being for not being typical or looking odd. This international collaboration includes a number of panel discussions about this.

13. Trauma informed care and intellectual disability 2021

Article in Learning Disability today raises issues of behaviourism

14. Physical and petition protest against the BiLD PBS International Conference 2021

https://www.change.org/p/hilton-worldwide-stop-pro-abuse-conference-at-doubletree-by-hilton-glasgow

https://m.facebook.com/events/doubletree-by-hilton-glasgow-central/protest-the-bild-international-pbs-conference/553535232625187/

5. Harms and Risks of behaviourist interventions

1. The National Autism Dividend report (2017)

An extensive review into autism interventions noted on page 93 "There are also concerns strongly expressed by some autistic people and their families and carers that some behavioural therapies (and this would include ABA and PBS) are unethical, trying to force people to adopt (or stop) certain behaviours, even when it causes considerable discomfort or even pain, and therefore can cause harm."

2. The psychological risks of behaviourist methods have not been looked at in ABA literature

Dawson & Fletcher Watson 2021 research paper, When Autism Researchers Disregards Harms, "Failures in addressing harms have proliferated across autism research...for reasons such as the embrace of low standard by journals, and the omnipresence of unchecked conflicts of interest. Disregard of harms has in turn wrongly been interpreted as evidence of no harms, with consequences rippling out to other areas (e.g. early detection and screening), distorting research and practice. Despite a large literature spanning decades, accumulated knowledge about potential or actual harms to autistics from interventions that may occupy many of their waking hours, for years, is negligible. Indeed, conflicts of interest entangled with low standards in research and practice would undermine future efforts to accurately capture harms via routinely collected data. Nothing justifies these multiple failures on the part of autism researchers.

We welcome the attention to harm. But this attention is as rare as it is terribly overdue. We are left with an influential literature lacking fair tests of the benefits versus harms of autism interventions that have been widely implemented for decades. Autism researchers should be deeply troubled by this comprehensive failure to apply fundamental standards. We must recognize, understand, take responsibility for, and reduce the unacceptable biases that have led to autistics being considered unharmable, such that anything can be done to them."

3. PBS focus on stress, trauma and regulation is inadequate

Functional assessments (avoidance, access to something, social attention, other (feels good), Antecedents, Behaviours and Consequences (ABCs), documentation of immediate triggers etc are an oversimplification and reductionist approach to understanding autistic (and human) behaviour generally, going against what we understand about stress and neuroscience and what is needed for autistic learning and regulation.

Research showing clear links between role of the sensory environment and resulting anxiety and stress, especially for those with higher levels of autistic traits (behaviours).

This tweet about a PBS manual shows how the role of trauma (more common amongst autistic people) takes a back, rather than front seat:

Concerns around PBS: Trauma

In the bizarre world of autism ABA and PBS, there is no more worrying sentence than this one. Hidden on a back page of the standard training manual for behaviourists, the acknowledgement that "...it is possible that many of the [behaviours] may be...trauma based responses".



1:07 pm · 12 Sep 2019 · Twitter Web Client

<u>April 2020 research paper</u> looking at autism and trauma, concluded that autistic people are more likely to have PTSD from traumatic life events and noted few service providers consider this.

Autistic people are more likely to <u>be victims of traumatic events</u>, due to treatment by others in society. Targeting the victim for their behaviours is the wrong target.

Need to move beyond "trauma-informed" approaches to "trauma-focused" (<u>FULD 2018</u>). Too many are applying behaviourist interventions before understanding mental health co-occuring conditions.

"Mounting evidence for stress and trauma as a risk factor for comorbidity and the worsening of core ASD symptoms may intimate a shift in the way clinical social workers and other clinical practitioners conceptualize and approach work with this population to include trauma-focused assessment strategies and clinical interventions".

4. Link of ABA to PTSD

Study suggesting behaviour therapies may lead to an increase in trauma/PTSD symptoms (<u>kupferstein 2018</u>) and response to the ABA field who dismissed the study (<u>Chown et al 2019</u>)

- 5. Using Functional Analysis (ABA) to treat Self-injurious behaviours is unethical and beyond scope (Scheldy 2019)
- 6. Masking/camouflaging costs to mental health

Behavioural interventions reward/reinforce individuals to act in ways that are considered culturally more appropriate, including how stress is manifested, repetitive and stereotypical behaviours, engaging in activities mainstream society values. There are significant costs to mental health from camouflaging/masking and not being accepted for natural ways of being:

<u>Cassidy, Baron-Cohen et al 2018 research</u> concluded "camouflaging and unmet support needs appear to be risk markers for suicidality unique to ASC"

<u>2021 research paper on poor mental health outcomes</u> and burnout from living in authentic lives, including links between masking and suicide

<u>2021 Journal American Medical Association Article</u> discussing problem of autistic individuals masking to conform with societal expectations, "....Quantitative and qualitative research studies show that such camouflaging is exhausting and is associated with poor mental health, including suicidal thoughts and behavior. This has important implications for many interventions" with a "risk of exacerbating a disconnect between the true self and performing self, potentially increasing anxiety and decreasing self-esteem."

7. ADR: Anti-Ableism 101 Facebook group (1,800 members)

A basics/beginner Facebook group set up in the last year to learn about the harms that ABA can cause clients, particularly autistics. This group educates about anti-ableism, pro-neurodiversity, autistic experiences and voices.

- 8. McGill & Robinson research 2018 into Experiences of Applied Behaviour Analysis - emerging themes: 'removal of autistic self', 'increased vulnerability', 'missed empathic response' and 'autistic led alternatives', a clear antithesis between ABA practices and perceived wellbeing in comparison to experienced quality of life. "
- 9. Autistic Science Person why ABA is harmful to autistic people.

10. Dr Beurkens podcast, US (2020)

"The serious problem with behavior management approaches". Interview wiith OT expert in neurologically supportive approaches. Discuss "how many approaches used for challenging behaviours are outdated, not supported by current research, and there are many adults on the autism spectrum and with related kinds of issues who have started to speak out about the trauma they experienced during these kinds of therapies when they were kids. Unfortunately, these types of approaches continue to be recommended in schools, in some therapy settings, and at home"

11. Harmful mindsets

As set out in A (6) above, the values in PBS training are normative and create unhealthy mindsets.

A 2019 thesis review of ABA research showed the existence of oppression violence within ABA research articles reviewed in one month of the Journal of ABA, and that autistic people resisting ABA highlights agency and dignity.

12. Behaviour analysis links to gay conversion therapy

<u>Disturbing behaviours: Ole Lovaas and the queer history of autism science</u> (2018)

<u>Treating autism as a problem the connection between gay conversion therapy and ABA</u> (2018)

The main behind ex-gay conversion therapy started out trying to make autistic children "normal" (2021)

<u>Building a person legal and clinical personhood for autistic and trans childrenin</u> <u>Ontario</u> (2020)

LGBTQ+ conversion therapy and applied behavior analysis: A call to action (2021)

Societal changes and expression of concern (2020)

Autistic Conversion Therapy (2016)

13. How ABA methods go against autistic learning

The problem with PECS (ABA communication tool)

<u>Hyperlexia: a systematic review, neurocognitive modeling and outcome</u> (2017) – why many assumptions about autistic learning are not supported by current understanding.

Should we change methods and targets of early intervention in autism in favour of a strengths based education? (Mottron 2017) how ABA methods have been called into question in the last decade due to poor standards, and evolution of ethical and societal standards, illustrating various areas where assumptions ABA makes about autistic learning are not supported.

<u>Perceptual learning in autism: overspecificity and possible remedies</u> (Oct 2015) repetition (a key ABA feature) hinders ability to apply learning to new situations.

<u>Learning in autism</u> (Section 2.38.5) sets out history and incorrect assumption what lead behaviour analysts to believe ABA methods are a good way of learning for autistic people, inconsistent with more up to date research

Alfie Kohn – child development expert speaks out against the use of reinforcements (punished by rewards) and behaviourism and autism.