Kent Academic Repository

Gore, Nick J., Sapiets, Suzi J., Denne, Louise D., Hastings, Richard P., Toogood, Sandy, MacDonald, Anne, Baker, Peter A., Allen, David, Apanasionok, Magdalena M., Austin, Debbie and others (2022) *Positive Behavioural Support in the UK: A State of the Nation Report.* International Journal of Positive Behavioural Support, 12 . ISSN 2047-0924.

Downloaded from

https://kar.kent.ac.uk/93504/ The University of Kent's Academic Repository KAR

The version of record is available from

https://www.ingentaconnect.com/contentone/bild/ijpbs/2022/00000012/a00101s1/art00001

This document version

Author's Accepted Manuscript

DOI for this version

Licence for this version

UNSPECIFIED

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal* , Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies).

Author Acepted Manuscript 08.12.21

Positive Behavioural Support in the UK: State of the Nation 2021

Authors

Nick J Gore[a], Suzi J Sapiets[ab], Louise D Denne[b], Richard P Hastings[b], Sandy Toogood[c], Anne MacDonald[d], Peter Baker[a] and the PBS Working Group[1] (in alphabetical order):

David Allen, Magdalena M Apanasionok, Debbie Austin, Darren L Bowring, Jill Bradshaw, Anne Corbett, Vivien Cooper, Roy Deveau, J Carl Hughes, Edwin Jones, Matt Lynch, Peter McGill, Michael Mullhall, Mark Murphy, Steve Noone, Rohit Shankar, & David Williams.

Acknowledgement for proof editing John Shephard

Affiliations

[a]Tizard Centre, University of Kent, Kent, CT2 7NF. UK

[b]Centre for Educational Development Appraisal and Research (CEDAR), University of Warwick, Coventry, CV4 7AL. UK

[c]College of Human Sciences, Bangor University, Bangor, Gwynedd, LL57 2DG. UK

[d]Institute of Health & Wellbeing, University of Glasgow, Glasgow, G12 8QQ. UK.

[1] Contributors to 'PBS for People with Learning Disabilities - A Refined and Updated Definition for the UK'

Corresponding author: Nick J Gore: N.J.Gore@Kent.ac.uk

What This "State of the Nation" Report Seeks to Address

The 2013 International Journal of Positive Behavioural Support (IJPBS) special edition acknowledged the evolving nature of Positive Behavioural Support (PBS). This "state of the nation" report seeks to provide clarity around the questions that have arisen in respect of "who PBS is for". It proposes an updated, refined definition of PBS and a guide to future PBS delivery for the UK that captures the developments and issues arising as described below. An overview of current and significant research provides a clear narrative about the evidence base "for" PBS, including what the research tells us about how "not to do" PBS. The themes that are explored in this state of the nation report are also pulled together in a proposed logic model for PBS in a UK context to guide future research and practice. As in 2013, the aim is to provide clarity around key issues in relation to PBS especially those that have arisen in the past eight years, to reflect on PBS in the 2020s in the UK, and to prompt debate about the direction of future service design and delivery models, research, and further thinking on PBS.

Keywords: Positive Behavioural Support (PBS), learning disabilities, behaviours that challenge, service delivery, United Kingdom (UK)

PBS in the UK 2013-2021

In 2013, the IJPBS special edition sought to "put a marker in the sand that makes sure that people are describing and implementing the same approach when nailing their colours to the PBS mast" (Allen and Baker, 2013, p4). There was an urgent need for this at the time; a

need that was specific to the UK context of supporting people with a learning disability[2] at risk of displaying behaviours that challenge[3]. Two years earlier a BBC investigation had uncovered the systematic abuse of residents at Winterbourne View, a care home for people with learning disabilities who presented with behaviours that challenge. Concerns about the quality of support provided to people with learning disabilities were not new, but "Winterbourne" was the catalyst for a series of actions by the then government including recommendations advocating the use of PBS. The problem, and this was acknowledged in the final report reviewing events at Winterbourne (Department of Health, 2012a), was a lack of guidance on best practice around PBS. Furthermore, there was little understanding that PBS is a service delivery model rather than a single 'intervention', or of the implications of this for people with a learning disability, and those who are important to them including their families, along with implications for service providers, support workers, and health, education, and social care professionals.

The 2013 IJPBS special edition was the first step in a series of initiatives that sought to address this set of inter-connected problems. There was a deliberate focus on the delivery of PBS in the UK with the expectation that much of the content was likely to be applicable to other countries. The special edition provided a conceptual framework for understanding the occurrence of behaviours that challenge in people with learning disabilities (Hastings et al., 2013). It also provided an up-to-date definition and scope of PBS (Gore et al., 2013) and outlined the social and organisational factors that impact on PBS delivery along with implications and opportunities for building capacity at an individual service user, organisational, and cultural level (Allen et al., 2013a). Finally, the special edition built a case for the development of a competence framework for those providing PBS services (Denne et

[2] Consistent with a UK context, throughout this report we use the term 'learning disability' rather 'intellectual disability' (Cluley, 2018).
[3] We use the term 'behaviours that challenge' rather than 'challenging behaviour' to reflect the most common language use in the UK at this time

al., 2013). These papers were well received. For example, the Gore et al. (2013) definition of PBS was described as the "go-to paper regarding what PBS is in a UK context" (Scott and Denne, 2017, p8).

Initiatives that followed largely focused on the identified lack of guidance around PBS practice. This included the development of the PBS competence framework (PBS Academy, 2015), acknowledged as "the nearest we have got to a Standard" in the final report of the post Winterbourne consultation published in February 2016 (Association of Chief Executives of Voluntary Organisations, 2016, p6). It also included resources to help key people[4] put the competence framework into practice, and establish PBS Standards for service providers, individual practitioners, and for PBS training. The PBS Academy (a collective of organisations and individuals in the UK committed to defining standards for the delivery of PBS), was established informally to deliver these initiatives. Members and resources from the PBS Academy supported local and national policy in relation to behaviours that challenge across the lifespan. This included contributing to work streams relating to the Transforming Care Programme and, significantly, the development of National Institute for Health and Care Excellence (NICE) guidelines for behaviours that challenge (NICE, 2015) and for service design and delivery in the support of people with learning disabilities and behaviours that challenge (NICE, 2018). In addition to the NICE guidelines, the Department of Health and Social Care in collaboration with Skills for Health, Skills for Care, and Health Education England commissioned and funded the development of the Learning Disabilities Core Skills Education and Training Framework (Skills for Health, Health Education England and Skills for Care, 2016, 2019). This framework is used (primarily in England) by employers, universities, and care providers in both health and social care to support workforce

[4] In this report we use the term 'key people' in place of the term 'stakeholders' to try and better reflect UK cultural context, and to better emphasise human relationships.

development. The framework builds specifically upon the PBS Academy competence framework, referenced in the document as one of three national guidance documents for communication and leadership and management in learning disability care and support. Skills for Care has additionally been instrumental in supporting PBS training in adult social care though the provision of funding (£557k) and by launching a PBS peer review pilot to improve PBS training. The PBS competence framework was used as one of the criterion for applications to the funding programme (169 grants were awarded to 65 organisations) and a peer review pilot is based on the PBS training and individual practitioner standards (Skills for Care, 2021).

It has now been eight years since the publication of the 2013 IJPBS special edition. Arguably, the aim outlined by the editors to provide a "common baseline" for further developments in PBS has been achieved to at least some degree. Moreover, the concerns that prompted the four articles and the initiatives that followed no longer applies – there is today a wealth of resources and guidance around best practice and, to an extent, a shared understanding of what "good" looks like in the support of people with learning disabilities (Denne et al., 2020). The examples of the evolution of PBS described above primarily relate to England, but are reflected across the four nations of the UK.

In Northern Ireland, it has been particularly encouraging to see an increasing number of posts advertised requiring applicants to have a background in or knowledge of PBS. At Ulster University, the core principles of PBS are taught as part of the Master of Science (MSc) in Applied Behaviour Analysis, and a module in PBS is being introduced into the undergraduate psychology degree, which will include direct input from partner PBS services in Northern Ireland. The aim is to allow students to become familiar with this service provision model at an earlier stage of their professional development before embarking on further postgraduate study or entering the workforce.

Within Scotland, the *Coming Home* report, which sought to address out-of-area placements and delayed discharge from hospital for people with learning disabilities and complex needs, recommended the use of PBS as part of the solution to help bring people back home to their local communities (Scottish Government, 2018). Following this, the new implementation framework for *The keys to life* (the Scottish Government's learning disability policy; Scottish Government, 2019) committed to investment in PBS via the establishing of a university-based post to deliver qualifications in PBS, and also to support development of a PBS Community of Practice (CoP) for Scotland. Since then, the Scottish PBS CoP has taken the lead role in setting the agenda for PBS in Scotland utilising many of the resources referred to in this paper.

The All Wales Challenging Behaviour Community of Practice (CBCoP) has helped drive the development of PBS good practice in Wales for over a decade (CBCoP, 2019). CBCoP members were instrumental in co-producing several resources that are shared free of cost, such as the PBS Standards for Wales (British Institute of Learning Disabilities, 2021). The CBCoP has acted as an expert reference group for Welsh Government for several years and this has established an important, critical feedback loop that has resulted in some key Welsh government policies that explicitly reference PBS, such as the "Learning Disabilities: Improving Lives Policy" (Welsh Government, 2018) and The Welsh Reducing Restrictive Practice Framework (Welsh Government, 2021). The PBS Business and Technology Education Council (BTEC) qualification blended e-learning qualifications delivered by Abertawe Bro Morgannwg University Health Board and more recently Swansea Bay Health Board have also driven positive change, in Wales and further afield.

There has also been a significant contribution to our understanding of the delivery of PBS (at various levels) from practitioners within the field. As articles in subsequent issues of the IJPBS attest, there are many positive examples of person-centred focused support

(Langdon et al., 2017; Paris et al., 2019), more rigorous use of data (McLennan et al., 2017; Hughes and Huerta, 2016), and good outcomes from practitioners working in increasingly systematic ways (Paley et al., 2020; Bowring, Totsika and Hastings, 2019a). The IJPBS continues to play an important role in shaping practice, encouraging contributions to the literature from all key people involved in the provision of PBS, and enhancing their involvement in the development of PBS.

PBS has largely been embraced with an enthusiasm that has exceeded the expectations of the authors of the 2013 IJPBS special edition. The field has, quite rightly, continued to evolve and, in so doing, has sometimes outpaced our capacity to respond to developments. Many of these developments, such as the publication of the NICE guidelines for service design and delivery noted above are extremely positive, and create high expectations around PBS implementation and delivery. Other developments have highlighted the need for specific clarification, for instance around the population for whom PBS is relevant, the settings in which PBS is delivered and with regard to the wider social context of such issues as equality, inclusion, and diversity.

The Current Landscape

One of the developments that we could not have anticipated was the adoption of PBS for a population that the original pieces of work in the IJPBS special issue and from the PBS Academy did not explicitly seek to include. Similarly, it was not anticipated that PBS would be adopted for behaviours that do not meet the Emerson and Einfeld (2011) definition of behaviours that challenge (which categorise behaviours that challenge in terms of the risks of harm to self, harm to others, or impact on life quality). For instance, there are multiple references to the use of PBS in the Mental Health Code of Practice (Department of Health, 2015). This includes discussion of PBS in relation to “all people receiving treatment for a mental disorder in a hospital and who are liable to present with behavioural disturbances,

regardless of their age and whether or not they are detained under the Act" (p281) irrespective of whether they have a learning disability. Of particular concern is the tendency to group together autism and learning disabilities. This is perhaps not surprising as much recent guidance has been based on the Transforming Care Programme that set out "to transform services for people with learning disabilities or autism and mental health conditions or behaviours described as challenging" (Department of Health, 2012a, p2). The recently published Care Quality Commission (CQC, 2020) review of restraint, seclusion, and segregation for autistic people[5], and people with a learning disability and/or mental health conditions, is a good example. However, given up to 70% of autistic people (Loomes et al., 2017) may not have a learning disability, this is problematic. The conceptual framework for understanding the occurrence of behaviours that challenge (Hastings et al., 2013), was also described very clearly in relation to people with learning disabilities. Whilst there may be some emerging evidence of the effectiveness of PBS for other populations, and whilst the underpinning mechanisms of change such as an understanding of the functions of behaviour are applicable to all behaviours, the indiscriminate use of PBS risks prompting a backlash against a perception that PBS is trying to be the answer to all things. Worse, it risks PBS being associated with attempts to deny neurodivergent people a part of their identify or to conform to "societal" or neurotypical preferences. For example, interventions to change behaviours that are important or helpful to the person but do not meet the definition of behaviour that challenge by Emerson and Einfeld (2011) described above.

This in turn leads to questions about what PBS is trying to achieve. The Gore et al. (2013) definition built upon previous iterations describing PBS as primarily concerned with enhancing quality of life for people with a learning disability and their families (Allen et al.,

[5] We use identity first language in relation to autistic people and person first language with respect to people with learning disabilities throughout this report, reflecting what is (typically) preferred language use within the UK

2005; Carr, 2007; Carr et al., 2002). Whilst this was described as "enhanced wellbeing and greater meaningful and valued participation in the community" (Gore et al., 2013, p16) quality of life outcomes have often been neglected in PBS research and pactice (Gore, Jones and Stafford, 2020) and many questions remain. Quality for whom? How is it measured and assessed? What other outcomes are associated with PBS?

Another development has been the increased use of PBS for individuals with learning disabilities across a range of settings such as schools, forensic services, and hospitals. There is also increasing evidence in the UK of service delivery models based on whole systems approaches – a focus that Allen et al. (2013a) suggested could be part of the solution to increasing capacity. Of particular interest is the notion of a tiered approach, often a key feature of whole systems PBS approaches. This potentially contributes to one of the issues highlighted above – the question of "who is PBS for?" In whole-systems applications, such as School-Wide Positive Behaviour Support, Tier 1 or "universal supports" are universally applicable across the whole school or service setting population but are not specific to people with learning disabilities (Sugai and Horner, 2002, 2006). The pursuit of quality of life outcomes is relevant across all populations, but increasingly focused supports, in a multi-component model, are likely to differ markedly according to individual or clinical need and evidence. There is, therefore, a need for increased clarity around models of service delivery which will vary from setting to setting, and further consideration of ways in which systems change, critical for any upscaling of provision, can be delivered to support implementation (Denne et al., 2020). Along with this comes considerations of resource availability and allocation – determining who needs what and when, and how individual needs are best met over the lifespan.

The recognition that all professionals from across a range of disciplines have a role to play in the delivery of PBS has been an important step forward in the recent development of

PBS in the UK. The British Psychological Society (2018) Committee and Working Group Position Statement on PBS acknowledges the role of clinical psychologists in the delivery of PBS, and the Royal College of Psychiatrists (2018) recommends PBS in their Reduction of the use of restrictive practice (physical restraint, seclusion, rapid tranquilisation) guidance. No one single profession has a monopoly on the skills needed for the delivery of PBS. Even so, there remain questions of "ownership" and calls for clarification around who is responsible for the delivery of PBS and, related to this, how other theoretical approaches and technologies are included in its multi-component framework.

Who is PBS for?

The question of who PBS is for may be addressed in several ways. In this section, we consider the historical perspective and context within which the PBS framework evolved, PBS as a multi-stakeholder model, neurodiversity, and scope for extending the PBS framework to other populations. The PBS framework is primarily for individuals with learning disabilities who are at risk of developing or engaging in behaviours that are complex and challenging, and those affected by such behaviour. A proportion of individuals with learning disabilities will additionally be autistic. It should be noted however, that PBS as defined here, and in the past, is not intended for persons identifying as neurodivergent who do not have a learning disability.

Behaviours that Challenge

Behaviour that challenges as defined by Emerson and Einfeld (2011) is behaviour likely to limit or deny access to ordinary freedoms and opportunities. This includes, but is not limited to, behaviour associated with restrictive practices, life-changing injury, severe trauma, and even premature death. It also includes less immediately impactful behaviour for which early intervention has the potential to improve an individual's quality of life and/or to

prevent more severe behavioural forms from being shaped over time in respect of their frequency, intensity or duration and their impacts.

Behaviours that challenge are neither transient nor trivial, affecting approximately 15% of the learning disability population, although some studies that look at specific settings, behaviours, or groups of people affected report a prevalence as high as 50–80% (Bowring, Painter and Hastings, 2019b). The human and economic costs of behaviours that challenge are substantial, touch the lives of many, and are, in the absence of focused effort, unlikely to change.

Historical Context

PBS emerged with a distinct identity (Horner et al., 1990) at a time when many of the world's developed nations were engaged in large-scale programmes of deinstitutionalisation in services for the "mentally handicapped or retarded" (i.e., people with learning disabilities). Concepts and practices that define PBS evolved in the UK during the mid-to-late 1980s as a way of addressing the support needs of a small but significant number of individuals who had been identified in the context of deinstitutionalisation as presenting a significant challenge to the re-provisioning of services (Towel, 1987). Opinion was sharply divided in services for people with learning disabilities between those favouring a values-led approach and those claiming an adherence to empiricism or behavioural approaches (Emerson and McGill, 1989). Advocates of a behavioural approach were further divided on the use of aversive stimuli to suppress the occurrence of damaging behaviour, such as severe self-injurious behaviour. Interventions characterised by critics as degrading and inhumane strengthened the desirability of non-aversive alternatives that could be effective for persons with learning disabilities.

Two other developments bolstered early models of non-aversive intervention with children (Evans and Meyer, 1985) and adults (LaVigna and Donnellan, 1986). First, a

conceptual re-grounding in behavioural analytic research reinstated the centrality of designing intervention according to the results of a prior functional analysis of behaviour-environment relations (Carr and Durand, 1985; Iwata et al., 1994) rather than matching topographical features of behaviour with a procedure or technique derived from research in Applied Behaviour Analysis (Carr, 1977). Second was the elaboration and dissemination of the Principle of Normalisation (Wolfensberger, 1972), which was influential in the field of learning disability services and the process of deinstitutionalisation. In two-and-a half decades normalisation evolved through Social Role Valorisation (Wolfensberger and Glenn, 1975) and multiple systems of Person-Centred Planning and support (O'Brien and O'Brien, 2002) before being cited by Carr et al. (2002) as a defining component of a PBS approach. Normalisation Theory had been widely misunderstood as attempting to "make people normal" and was re-named Social Role Valorisation for this reason. The ultimate goal of Normalisation has been the use of culturally valued means in the pursuit of culturally valued outcomes (i.e., that everyone has the same rights as anyone else to lead the life they choose to). It was not, as was (and is) sometimes believed, the slavish pursuit of a narrow stereotype of what was considered normal (Wolfensberger, 1983). Normalisation Theory continues to address societal reaction to negatively valued forms of diversity and difference and the symbolic representation of disability. It aims to improve the life chances of individuals by supporting culturally valued behaviour and appearances and competency enhancement. Essential components of Normalisation Theory are physical and social integration, autonomy and rights, development and growth, and personal identity.

Partnership Model

PBS has been described here and elsewhere as a multiple partnership (or stakeholder) model, involving persons with a learning disability and the key people, organisations, and systems that support them (see later). This means that a range of individuals is often involved

in deciding on a person-by-person basis what is worth changing and for whom, and how those goals should be pursued. Multiple partner involvement requires careful consideration of how benefits and costs of intervention are distributed between participants and how competing aspirations and interests are resolved where there are imbalances of power. Stakeholder perspectives may be ordered primary, secondary, and tertiary.

The primary participant in any PBS framework will be the person with a learning disability who is at risk of developing or engaging in behaviours that challenge. Severity of learning disability and associated impairments of communication are known risk markers for behaviours that challenge (Hastings et al., 2013) so that persons most likely to benefit from PBS will often be among those least able to select or consent to intervention components within the framework. This should not be a barrier to participation in decision making. In principle, informed consent is a basic requirement for the intervention components within a PBS framework and there are ethical and legal protections for individuals whose capacity may be impaired in some way that would enable interventions to be carried out under the auspices of a "best interest" principle where necessitated.

Secondary stakeholders are persons close to the individual who might be affected by behaviours that challenge. Examples of secondary stakeholders are family members, friends, paid staff, and professionals involved at a systems level. Such persons may participate in goal selection with or on behalf of an individual whose behaviour is challenging and/or for themselves, such as reducing the risk of exposure to injury or stress in families (McKenzie et al., 2018a) or among paid carers (Bromley and Emerson, 1995).

At the tertiary level is accountability for individual and system level decisions and for how symbolic representations of learning disability are influenced at a large group and societal level. Society maintains an interest in the quality of life and behaviour of its members and is responsible for protecting the rights, entitlements, dignity, and freedoms of

individuals (United Nations, 2021). Resources are distributed and behaviour regulated through policy, legal entitlements, education, and the provision of professional supports and services. There is an interest, therefore, in knowing what works, how it works, and what the underlying values are.

Neurodiversity

Neurodiversity reflects a shift in understanding of neurodevelopmental differences that moves away from medical models that view such differences as pathological abnormalities (deficits, disorders, diseases) that need to be cured or treated. Neurodiversity means understanding neurodevelopmental differences as a natural (and valuable) part of the diversity within the population (Dyck & Russell, 2020; Bottema-Beutel et al., 2021). The term has also been used by a section of the population that identifies as being neurodivergent (i.e, not neurotypical) including those who are labelled autistic. About a third of autistic people have a learning disability (Loomes et al., 2017) Many of those who do not have a learning disability embrace autism as a way of being and prefer to identify as autistic, rather than as someone with or having autism (Botha, Hanlon and Williams, 2021; Chapman and Bovell, 2020). Societal responses to autism are cited as a disabling force, rather than autism per se. According to this view, autism does not require treatment, which would amount to changing the person. In particular, the *wholesale* implementation of curriculum-based behavioural interventions has been criticised as damaging and inhumane. This criticism appears to refer to early work done in the field of Applied Behaviour Analysis. Whilst there continues to be, as with many fields, examples of poor practice, contemporary accounts within the field are characterised by their person-centred nature (Association for Behaviour Analysis International, 2021; Friman, 2021). The theoretical underpinnings of PBS are built upon concepts, principles, and practices from Applied Behaviour Analysis, but only those that are compatible with PBS core values and aims and that support learning or address

behaviours that are likely to cause harm or impact significantly on a person's life quality in other ways. PBS would never be used, for instance, to address self-stimulatory behaviours that serve the function of self-regulation for the person concerned unless those behaviours meet the definition of behaviours that challenge.

Scope for Extending PBS to Other Populations

Components of a PBS framework that address quality of life through a system of universal support might be reasonably expected to generalise perhaps with some modification. Supports that are universal apply to everyone and are available to all. Focused supports on the other hand might be expected to vary according to population needs and characteristics, what is relevant, and what is evidenced in a given field.

How similar or different the approaches are will depend on the extent to which those other populations share some key features with the learning disability population. So, for example, for autistic people with a learning disability, the model may be very similar. However, the PBS model may have little relevance without appropriate adaptation for autistic people with no learning disability . The framework, whilst sharing some core features, may also need to look different for those with dementia, and those with serious mental health. Extending PBS to other populations may turn out to be extending the defining qualities of the approach rather than the approach itself – qualities delineated in this "state of the nation" report.

PBS for People with Learning Disabilities - A Refined and Updated Definition for the UK

Background

The 2013 IJPBS special edition achieved notable early impact (Scott, Denne and Hastings, 2018a). In the eight years that followed, the four articles in this edition influenced policy, practice, and research focused on supporting the lives of people with learning

disabilities (e.g., Department of Health, Skills for Health and Skills for Care, 2014; Gerrard et al., 2019; Leitch et al., 2020; PBS Academy, 2015; Ridley and Leitch, 2019). The ten components described by Gore et al. (2013) provided a core foundation for defining PBS, referencing and building on academic literature and remains of fundamental importance for the field. PBS implementation in the UK has however, increased (in magnitude and scope) considerably in this time, and as an evolving framework, continued to grow and develop in exciting ways by:

1. Promoting discourse between people with lived experience and between disciplines to challenge and clarify assumptions and stimulate new possibilities;
2. Drawing on values and technologies that reflect service philosophies and practice in the UK;
3. Increasing the delivery and consideration of PBS in multi-professional contexts and communities of practice.

In this section, we have sought to update and refine (rather than re-create) the Gore et al. (2013) definition of PBS in ways that capture these developments and may further guide future PBS delivery. The updated definition remains consistent with both the 2013 definition and international literature, but is presented and discussed to reflect nuances of a UK context (i.e., we have attempted to adopt terminology that reflects UK culture and service models). Other countries will share some or all of these contextual issues, so while intended to have UK focus, we hope that the resulting re-formulation will be of use globally.

We have provided some academic referencing (where possible, citing UK research alongside that drawn from international sources) but have focused on providing descriptive detail. We appreciate that the PBS community will need to develop additional resources to support implementation (including resources and documents co-developed with and for

people with leraning disabilities and other key people, academic papers, and updates to competence frameworks) but hope that this definition provides a helpful starting point.

We recognise that there are many service examples or instances of poor practice that do not reflect the definition that follows (but may at times be referred to as 'PBS' or 'PBS services'). The 2021 definition is based on a synthesis of expertise and experience from professionals, academics and people with lived experience, to clarify and guide what is considered best PBS practice. We recognise that PBS is not owned by a single group or profession. What follows are the collective views and opinions of contributors. We welcome ongoing discussions focused on the rights, needs, and life quality of people with learning disabilities at risk of behaviours that challenge, and those key people who care, support, and advocate for them.

Methodology

A team of UK contributors with special interests and experience in PBS, from a range of (sometimes overlapping) groups, co-developed this definition. Contributors included people with lived experience (as a person with a learning disability; a person who is autistic; a person with a history of displaying behaviours that challenge; and/or as a family carer). Contributors also included researchers and people from a variety of professional and disciplinary backgrounds who together had experience of service delivery, commissioning, training, and practice across child, adult, health, education, and social care contexts. This included people with experience as front-line support staff; Speech and Language Therapists; Nurses; Psychiatrists; Occupational Therapists, Clinical Psychologists, Physiotherapists, and/or Behaviour Analysts. The group included people with some diversity in relation to different ethnicity groups and socio-cultural backgrounds (although we recognise that our representation in this domain was limited).

Gore and Sapiets coordinated creation of the definition during a series of group workshops, individual discussions, and writing rounds. These took place over a six-month period, with meetings tailored to meet the requirements of each contributor. This included an initial online group workshop, further online discussions with individual contributors, discussions via email, and/or revisions and comments to drafts between contributors. Key learning points and themes from discussions were synthesised and shared with group members for feedback and amendment, with drafts for the 2021 PBS definition and accompanying table of components shaped across a series of iterative rounds and collective edits. This reflective group process supported a meaningful and balanced integration of input from the group, whilst building a shared definition based on consensus opinion.

Scope of the definition

Scope of population. The 2021 PBS definition focuses on support for people (children, young people, adults, and older adults) with learning disabilities with a variety of needs (including people with learning disabilities who are autistic) across the lifespan. Whilst recognising the potential for some components of PBS to support people with other areas of need who do not have learning disabilities, the 2021 definition of PBS specifically focuses on support for people who have a learning disability in the context of behaviours that challenge.

Scope of behaviours that challenge. Within PBS, behaviour is defined as challenging when it has significant negative impact on the health, wellbeing, and life quality of people with learning disabilities and/or key people in their lives (see Emerson and Einfeld, 2011). Direct impacts can include considerable physical injury to the person and others. Behaviours that challenge can, for instance, result in people with learning disabilities losing their sight or motor coordination or dying from repeated self-injury; people damaging their bodies from ingesting inedible objects; and caregivers with cuts, bruises, and broken bones living in fear. Behaviours that challenge can also result in significant restricted opportunities for people

with learning disabilities and key people in their lives, and have effects on individual and family life quality. This can include behaviours that result in the exclusion of people with learning disabilities from schools, colleges, or other community settings and people with learning disabilities being prevented from accessing favoured activities and having contact with loved ones. For families, behaviours that challenge place considerable strain on relationships and can mean being unable to deviate from very set routines, go out or spend time together, or to maintain employment, amongst many other impacts.

In PBS, there is recognition that people with learning disabilities, parents, and siblings often become separated from one another in the context of behaviours that challenge or become increasingly isolated over time, and may experience trauma, stress, and other emotional difficulties. There is also recognition that people who display behaviours that challenge are at heightened risk of abuse and long-term incarceration in highly restrictive environments, being subject to seclusion, restraint, over medication, and/or may come to live in barren spaces with few opportunities for meaningful relationships or activity.

Behaviours that challenge may come in many different forms, but are only within the scope of PBS when defined in the context of the sort of impacts described above. PBS is not used to make changes to behaviours that reflect cultural differences, neurodiversity, individual interest, or idiosyncratic expression or functioning, where such behaviours do not impact negatively on health, wellbeing, and quality of life.

Scope of settings. We maintain, as described in 2013, the range of ways in which PBS might be implemented. PBS can be implemented effectively on a case-by-case basis by single practitioners and/or multi-professional teams, in collaboration with the person with a learning disability themselves and key people in their life (e.g., Toogood et al., 2015; Higgens, 2021; Allen et al., 2005; Hassiotis et al., 2009; Bowring, Totsika, Hastings and Toogood, 2020). In addition, system-wide approaches can be used to implement PBS at varying levels of

intensity, via tiered-models that cover an entire organisation or geographical area (e.g., McGill et al., 2018; Allen et al., 2012). We have attempted to better capture this range of applications in the components that follow.

We also maintain the view that PBS can be implemented in a wide range of settings, such as supported living and family homes, residential homes (e.g., Bowring et al., 2020), and in educational settings, such as schools (e.g., Sugai and Horner, 2009; Paris et al., 2019). In the case of the latter it is important to clarify, however, that although the components for PBS described in this report have application to an educational environment, School-Wide Positive Behavioural Support has some unique features, and is considered an overlapping, but distinct, model (see Beqiraj, Denne and Hastings, 2021). There is also emerging evidence for use of PBS within non-community, hospital and secure services, and forensic settings for people with learning disabilities (e.g., Barnoux, 2021 *IJPBS special issue*).

Those using PBS recognise the limits imposed on opportunities and life quality for people in institutionalised settings that may relate to buildings, location, staffing roles, practices, and expectations. Those using PBS, also recognise that complex organisational factors, other systems-level factors and perspectives, may mean individuals live in restricted service settings that are not capable of fully supporting the delivery of PBS. Major environmental and systems-wide changes that eliminate institutionalised practices in some settings are therefore essential for the implementation of PBS.

Goals of PBS

PBS is built on a premise that quality of support, quality of life, and behaviours that challenge are intertwined in complex ways (Carr et al., 2002; Bowring et al., 2019b; Denne et al., 2020). In the context of poor quality support and reduced quality of life, behaviours that challenge become more likely. At the same time, behaviours that challenge *by definition* have a considerable negative impact on life quality and restrict opportunities for people with

learning disabilities and other key people in their lives. The aim of PBS, therefore, is to ensure high quality support that combines goals of enhancing life quality and reducing the occurrence and impact of behaviours that challenge for people with learning disabilities and other key people in their lives (Carr et al., 2002; Carr 2007; Horner and Sugai, 2018). Figure 1 illustrates how PBS explicitly combines these focal goals and provides examples of approaches and strategies that do not explicitly do this. [INSERT FIGURE 1 ABOUT HERE]

In line with these goals, PBS provides high-quality, bespoke support environments and uses constructional approaches that both enhance individualised dimensions of life quality and mitigate factors associated with the risk of behaviours that challenge. The 2021 PBS definition highlights how proactive and early intervention can support good lives for all people with learning disabilities and those key people that care for and support them. The definition promotes cultures of support, empowerment, and developmental trajectories that result in high quality lifestyles and reduce the overall risk and occurrence of behaviours that challenge at an individual and population level. At the same time, the definition ensures focused support for people with learning disabilities and key people in their lives when behaviours that change have developed, to both maximise life quality and reduce the risk and occurrence of these.

The 2021 PBS Definition

Table 1 presents an updated and refined series of key components that, taken as an integrated framework (rather than a menu of choices), constitute the 2021 PBS framework for the UK. As in the 2013 definition, components are organised into three major categories (Figure 2), but with some changing emphasis reflected in titles used for the first (now entitled *Rights and Values*) and third categories (now *Process and Strategy*). Each of the major categories now also begins with an over-arching statement that summarises the significance

of components and the fundamental connection between these across the PBS framework.

[INSERT TABLE 1 AND FIGURE 2 ABOUT HERE]

Rights and values are fundamental to the definition of PBS. Whilst procedures help inform how to support behaviour change, rights and values inform the focus of this change and shape all other components (Carr et al., 2002; Gore et al., 2013). Rights and values determine the ultimate goals and outcomes for support and serve as an ethical compass to guide and govern which technologies are used in practice. Theory and evidence-based components then inform the means for ensuring rights and values are protected and actively promoted. Processes and strategies provide the practical steps and approaches to best achieve this within complex, real-world systems. All specific evidence-based procedures and processes must be consistent with rights and values and selected to ensure these become a lived reality.

A total of 12 components are included in the 2021 definition. Some of the components described have been developed in other contexts, are utilised as standalone supports or within other support packages, and often have their own evidence base. The value and use of these components in other contexts, to serve other aims, often remains. A defining feature of PBS, however, is the integration of components, which are sometimes otherwise quite separate, or even seen as conflicting. Synthesis of components within a framework definition, to serve the combined goals of PBS, mean that practices and supports are selected and organised in ways that may at times be different to how these are used singly or in other contexts. Integrating and implementing components within a PBS framework definition in this way, on a person-by-person or setting-by-setting basis, is a high-level skill requiring training and supervision.

Rights and Values

Above all else, PBS adopts as guiding principles international frameworks for human rights that started with the Universal Declaration of Human Rights and now include the United Nations Convention on the Rights of Persons with Disabilities and the United Nations Convention on the Rights of the Child (UNICEF, 2021). These rights-based frameworks, for example, mean that PBS rejects the use of pain, shame and fear inducing procedures in any interventions.

Alongside championing people's rights and understanding their support needs, PBS reflects a compassionate stance toward people with learning disabilities and key people in their lives. The primary focus of values is facilitating good lives, now and into the future, for people with learning disabilities who display and/or are at risk of behaviours that challenge and those who support, care for, or are important to them in other ways (e.g., Challenging Behaviour National Strategy Group, 2019). Doing this fully and effectively also reduces the development and maintenance of behaviours that challenge. There are some things that are generally important for most people to have a good life but also considerable variation in what this means for different people. There can also be challenges to understanding the needs and preferences of people who have additional communication needs, and to balance the priorities of different key people in a person's life. Those working within a PBS approach consider and support these factors carefully.

PBS rests on an understanding that many people with learning disabilities and key people in their lives experience adversity, and are often disempowered by systems that surround them. Together with unmet need and restricted personal repertoires for exerting control, these factors provide an important part of the context for the development and maintenance of behaviours that challenge and their further impacts on life quality. In direct response, those using PBS work in partnerships with people with learning disabilities and key

people in their lives to minimise adversity and ensure good lives, rich in opportunities for learning, development, growth, choice, and agency.

1. **Person-centred foundation**

Given that the focus of values in PBS is to support good lives, it is critical to determine what this means at an individual level. Person-centred approaches continue to have precedence within the 2021 PBS definition, to ensure needs, aspirations, and preferences of the person are at the heart of goals, methods, and individualised outcomes that are selected (Kincaid and Fox, 2002; Gore, McGill and Hastings, 2021). Quality of life research has identified some measures that can be helpful for identifying areas that are commonly important to and for people to live well (e.g., Schalock et al., 2002; Townsend-White, Pham and Vassos, 2012) and can be a helpful starting point. But there will always be variation for different people, and it is for this reason that there is no 'one size fits all' intervention or outcome in PBS. Packages of support must be bespoke, co-produced, personalised, and culturally sensitive, with the aim of maximising and celebrating individuality rather than driving conformity to a fixed social norm.

A range of person-centred methods (O'Brien and O'Brien, 2000) can help ascertain areas of priority for children and adults with learning disabilities (both through direct engagements and observations with the person with a learning disability and consultations with other key people), that support positive outcomes (e.g., Robertson et al, 2002), and should be utilised throughout a PBS pathway. There is increasing attention in PBS to ways in which people with learning disabilities can be consulted and engaged to co-design the support they receive. For instance, in recent work by Gore et al. (2021) and Bradshaw, Gore and Darvell (2018), children with a range of developmental needs were supported to identify priorities and personalised goals for future support using a Talking Mats® procedure (Murphy and Cameron, 2008).

Person-centred goal formation is a critical aspect of PBS Process and Strategy. Person-centred approaches should determine the focus of bespoke assessments and guide the development of behaviour support plans. These should reflect what an individual likes and dislikes (e.g., preferred activities), needs (e.g., things of importance to the person such as physical health support), wants (e.g., things that are important for the person such as where they live and who supports them), and aspires to (i.e., their dreams and goals for life). PBS should ensure support attends to these fundamental areas in the context of strategies to reduce the risk and impact of behaviours that challenge, but should also be ambitious by identifying, celebrating, and facilitating people's unique talents and qualities. A good life is one that is rich and vital, rather than adequate or simply devoid of problems.

2. Constructional approaches and self-determination

Many people with a learning disability, by definition, experience communication challenges and difficulties taking part in everyday activities associated with independence and decision-making (e.g., Grove et al., 1999; Tassé et al., 2012). With the right support, people with learning disabilities are more able to use and develop skills in all these areas to express their needs and wishes and engage in life in ways that are right for them and support their wellbeing (e.g., Ho, Perry and Koudys, 2021; Romski et al., 2015). It is commonly the case, however, that people with learning disabilities are not given the kind of support they need to develop fundamental skills and often live within systems of care that do not support them to be meaningfully engaged and stimulated, express themselves or make choices, or have their preferences recognised (e.g., Beadle-Brown et al., 2016; Kruger and Northway, 2019). At the same time, those who display behaviours that challenge are at heightened risk of exclusion and restriction, with those who need the most support often receiving the least (Bowring et al., 2019b; Hastings et al., 2013). These sort of unhelpful contexts influence the

development and maintenance of behaviours that challenge and are directly addressed as part of PBS process and practice.

PBS is consistent with a social model of disability, which argues that it is not individual deficits or limitations that directly cause problems for an individual and their family, but rather society's failure to provide appropriate services and adequately ensure people's needs and rights are considered fully in its social organisation (Oliver, 2013). The work of PBS seeks to transform systems that do not adequately address rights, support and learning needs and that disempower or exclude people with learning disabilities. As in 2013 (Gore et al., 2013), strategies and technologies selected within the 2021 PBS definition support people to do more of the things that are important to and for them. This means people with learning disabilities being supported to learn, build upon, and use important skills and communications (a constructional philosophy, Goldiamond, 1974) and to express themselves and make choices that are positively acted upon (a right to self-determination, Wehmeyer et al., 2007; Agran and Brown, 2016). People with learning disabilities want and have the right to be listened to and supported effectively (Department of Health, 2008). PBS is committed to supporting people with learning disabilities to have control and autonomy throughout their lifetime.

3. Partnership working and support for key people

People with learning disabilities for whom PBS is the focus are the ultimate authorities in determining goals and support for their own lives. Given communication challenges, PBS generally also requires close engagement with other people who know, advocate, support, and care for an individual with learning disabilities to help identify and clarify goals, strategies, and outcomes for support (see Who is PBS For?). Family members, friends, support staff, and other key people often have expertise related to the support needs, history, circumstances, and preferences of an individual they care for. Those working within

a PBS framework hold these key people in high regard (e.g., Carr et al., 2002; Dunlap and Fox, 2007; Lucyshyn, Dunlap and Albin, 2002; Gore et al., 2013). Partnership working is an essential context for co-production models with key people supported to be active informants and agents of change in PBS (e.g., Denne et al., 2015; Lucyshyn and Zumbo, 2018; McLaughlin et al., 2012).

Family members, in particular, often see issues and solutions professionals do not see, and know and love their realtive in a way that services cannot (O'Brien and O'Brien, 2002). Families have often supported and advocated for their relative through challenging times and may have experienced stress and trauma in the context of absent, variable, ineffective, or aversive supports from professional services (Baker et al., 2021; Griffith and Hastings, 2014). Those working within a PBS framework afford special significance to the expertise and experience of families, recognising that parents and other family members (including siblings and grandparents) usually have long-standing and enduring knowledge of their relative (see Gore, McGill & Hastings, 2019). In PBS, there is recognition that families can offer unique insights and solutions within the PBS process, gained through lived experience, and are often best placed to inform and implement strategies (in both family and service contexts) that facilitate positive outcomes for all people and partnership working in PBS is recognised as key to supporting such outcomes (Brotherson et al., 2010; Summer et al., 2007)

Sometimes, there may be competing priorities or differences of opinion between a person with a learning disability and key people (e.g., family members and various professionals) and also between key people. Those working within a PBS framework take care to appreciate and synthesise the knowledge and opinions of key people and to identify directions for support that are most central to the rights, needs, preferences, and desires of the person with a learning disability. At the same time, there is recognition in PBS that key people may be experiencing the impact of behaviours that challenge or other adversities

themselves, which may also be part of the context in which this behaviour is maintained (Bowring et al., 2019b; Gore, Hastings and Brady, 2014). Those working within a PBS framework therefore also attend closely to understanding the support, training needs, and emotional wellbeing of family carers and paid staff. Co-producing interventions that support positive outcomes for key people further strengthens sustainable systems of care for people with learning disabilities in PBS (Gore et al., 2014; Singh et al, 2021).

4. **Elimination of aversive, restrictive and abusive practices**

Across the life span, people with learning disabilities, and their families, are at heightened risk of social inequities (e.g., exposure to poverty, barriers to accessing education and healthcare) and adversities (e.g., family breakdown, bullying and harassment, abuse, some of which may be associated with trauma) (e.g., Emerson 2012a: Emerson and Hatton 2014; Jones et al., 2012; McDonnell et al., 2019). These contexts and experiences have a detrimental influence on the development and maintenance of emotional difficulties and behaviours that challenge (Emerson, 2012b; Emerson, 2013; Bowring, et al., 2019b). Services and systems often fail to provide effective and timely support or accommodate the needs of people with learning disabilities and their families, which further contributes to, and may exacerbate, adversities encountered (Baker et al., 2021; Griffith and Hastings, 2014).

People with learning disabilities who display behaviours that challenge are at particularly heightened risk of harsh, disrespectful, restrictive, and abusive responses from others responsible for their care. In the context of behaviours that challenge, people with learning disabilities may experience over medication, cancellation of family contacts or activities in the name of "risk management." They may also experience physical and mechanical restraint, seclusion and isolation, emotional and physical abuse (e.g., Department for Education and Department of Health and Social Care, 2019; Department of Health, 2012a; McQuire et al., 2015; Emerson and Einfeld, 2011). These experiences may be

traumatic for people with learning disabilities (e.g., Keesler and Isham, 2017) and their families (e.g., Baker et al., 2021) and are also associated with emotional difficulties and behaviours that challenge (e.g., Bowring et al., 2019b).

Those using a PBS framework work to eliminate use of aversive, restrictive, and abusive practices to ensure the rights of people with learning disabilities and key people in their lives. Use of such practices is inconsistent with PBS due to their detrimental effect on quality of life, emotional wellbeing, and relationships. Elimination of these practices means, firstly, that pain, shame, or fear-inducing responses (i.e., those that cause physical, sensory or emotional pain, are dehumanizing, or violate people's basic rights) are never used as part of PBS, a founding and sustained commitment of the approach (Carr et al., 2002; Gore et al., 2013; Horner et al., 1990; LaVigna and Donnellan, 1986). Harsh reprimands, time out, physical or mechanical restraint that inflicts pain or discomfort, deliberate exposure to stimuli or environments that generate distress, overcorrection, or loss of 'privileges' that are central to a person's wellbeing, for instance, are never selected as interventions in PBS (e.g., LaVigna and Willis, 2012).

It also means those working within a PBS framework are mindful of the subjective aspects of adversity, how these might change for people across contexts, and the ways different interactions and stimuli may be experienced as aversive by different people (for instance how physical touch may be experienced by people with particular sensory sensitivities in ways that are distressing). Assessments in PBS should carefully consider the aversive and traumatic experiences people with learning disabilities and key people in their lives may have encountered. Interventions within a PBS framework should include guidance and strategies that ensure emotional and physical support for people with learning disabilities and key people in their lives where adversity and trauma have been (or continue to be) experienced (Byrne, 2020; Keesler and Isham, 2017; Paterson, Young and Bradley, 2017).

Those operating within a PBS framework also work to eliminate the use of aversive, restrictive, or abusive responses for individuals that may already be in place or deemed necessary, by creating alternative systems of support. A range of evidence-based, non-aversive reactive strategies can be incorporated as part of a multi-component plan (e.g., strategic capitulation, stimulus change, diversion to preferred activities) and mitigate the need for "last resort" strategies (e.g., Crates and Spicer, 2016; LaVigna and Willis, 2002; MacDonald, Hume and McGill, 2010). Whilst it is also recognised that physical interventions may be required in extreme situations to ensure people's safety, the use of and reliance on physical interventions is minimised in the context of PBS. Those working within a PBS framework are committed to using and developing non-aversive reactive strategies that reduce the escalation, distress, and impact of behaviours that challenge within the context of a broader preventative approach.

Finally, a commitment to eliminating aversive, restrictive, and abusive practices, means that those working within a PBS framework advocate for and support wider systems change to reduce broader exposure to adversity for people with learning disabilities and key people in their lives at a societal and whole population level (Challenging Behaviour National Strategy Group, 2019; NHS Improving Quality, 2015; Restraint Reduction Network, 2021).

Theory and Evidence Base

Theoretical and empirical research evidence is needed for both ethical and practical reasons, to design and deliver supports that are the least restrictive and the most efficient and effective as possible. People have the right to expect the best quality support available. Within PBS, this means developing theories and evidence that are consistent with rights and values, and using these to guide the selection of particular strategies.

Theoretical assumptions in PBS are informed by an holistic and contextualised, biopsychosocial model that concerns how and why people with learning disabilities may

come to display behaviours that challenge and the functions these may serve (Bowring et al., 2019b; Hastings et al., 2013). This model and many of the practises used in PBS are grounded in the behavioural sciences in ways that are consistent with rights and values, and provide reliable, objective, and compassionate ways to understand and support people.

Theories and evidence that underpin both this conceptual model and methods of support are continually evolving and those that fit the values and aspirations of PBS are easily assimilated into the 2021 definition. Those using PBS embrace and facilitate innovation and the development of high quality evidence and theory from across behavioural sciences and other evidence-based disciplines, lived experience, and multiple professions. Using PBS means being committed to identifying the best ways to achieve good lives for people with learning disabilities and for those who care, support, or are important to them in other ways, and to understand and reduce development and maintenance of behaviours that challenge (Carr et al., 2002; Gore et al., 2013).

5. A biopsychosocial model of behaviours that challenge

PBS is underpinned by a biopsychosocial conceptual model that draws together learning from multiple fields of research to help understand how and why people with learning disabilities display behaviours that challenge (Bowring et al., 2019b; Hastings et al., 2013) (see Figure 3). The conceptual model for PBS is consistent with, and helps substantiate, rights and values based components and supports a dynamic relationship between behaviours that challenge and life quality. Those working within a PBS framework do not adopt a deficit or medical model of disability but are concerned instead with understanding people's holistic needs and experiences. Based on the biopsychosocial model, those using PBS view all behaviours as purposeful and meaningful (i.e., functional) and existing within complex and cumulative interactions between multiple biological, psychological, and social contexts and systems. [INSERT FIGURE 3 ABOUT HERE]

Building from the underpinning biopsychosocial model, areas for assessment and multi-component intervention include support for needs common to people with learning disabilities (e.g., communication challenges, mental health difficulties, physical health difficulties, sensory needs) and those relating to people with specific genetic conditions (e.g., particular health conditions). It also includes people's current circumstances and historical experiences (e.g., trauma and exposure to adversity and deprivation), together with the responses of their support system (e.g., the actions of other people) and the direct and indirect impacts of behaviours that challenge (e.g., physical harm, reduced quality of life).

The biopsychosocial model highlights key behavioural processes that help explain and predict in finer detail how behaviours that challenge are maintained in these contexts and inform the delivery of support at an individual level (e.g., processes of holistic, functional assessment and multi-component behaviour support planning). The model also prompts supports and changes required at a broader, systems, population level (e.g., reducing exposure to adversity and increasing access to high quality support for people with learning disabilities in general). To "be PBS", practices and supports must be conceptually consistent with this model.

6. Behavioural approaches to learning, experience, and interaction

PBS has a fundamentally behavioural orientation (Carr et al., 2002; Gore et al., 2013; Horner et al., 1990; Kincaid et al., 2016) that provides a pragmatic solution to supporting people with learning disabilities and key people in their lives. Behavioural approaches concern scientific study and application of ways people learn and respond in relation to areas of need, life experiences, interactions with others, and aspects of their environment (Cooper, Heron and Heward, 2020). Behavioural approaches focus on the identification of variables that can be reliably evidenced in testable ways and used to both predict and influence change. Behavioural approaches are "doing-focused". Other elements of the PBS definition (i.e., the

promotion of rights and values) define which behaviours are the focus for change and the most ethical behavioural technologies that can be used to support this.

Behavioural approaches (as used in PBS) are compassionate, and constructional (Association for Behaviour Analysis International, 2021; Friman, 2021). They provide a practical way of supporting engagement for people with learning disabilities for whom communication may be a challenge, helping to understand the wishes, behaviour, and wellbeing of people with learning disabilities and other key people across systems (e.g., Gore and Baker, 2017). Behavioural approaches in PBS span active participation and engagement, enhancing communication, teaching new skills, and designing supportive environments in ways that are helpful for reliably supporting an individual's life quality and reducing behaviours that challenge.

The biopsychosocial model underpinning the PBS framework incorporates key behavioural concepts from behavioural science (e.g., those relating to a four-term contingency) (e.g., Carr, 1994; McGill, 1999; Toogood, 2011). Methods and practices from Applied Behaviour Analysis are also utilised in many PBS processes (Baer, Wolf and Risley, 1968; Dunlap et al., 2008). These methods and practices support identification, analysis, and purposeful change of the contexts in which people live with regard to antecedent events, consequences, and other learning processes to support behaviour and wellbeing.

Behavioural approaches, or practices labelled as such, have at times been used in ways that have been highly aversive, dehumanising, and traumatic for people with learning disabilities, people with mental health difficulties, autistic people, those with other neurological conditions, and those who support and care for them (e.g., Guess et al., 1987). Punishment-based interventions have also been part of, or the focus of some behavioural research outside of PBS (e.g., Lydon et al., 2015). Highly aversive, punishment-focused, poor, and abusive practice is not unique to behavioural approaches. However, the misuse of

behavioural approaches in these harmful ways continues to be of great concern. Indeed, PBS was developed in direct recognition, and strong opposition, to the mis-use of behavioural approaches (see Who is PBS For?).

As described above, those working within a PBS framework do not use procedures that any partner (especially the person or family) or society more broadly, would consider as being ethically unacceptable. The 2021 PBS definition underscores the continued commitment of PBS to select from within behavioural (and all other approaches) only those practices that ensure dignity and agency, and support a personally meaningful good life, rejecting the use of aversive, restrictive, or other non-compassionate, abusive, and dehumanising practices.

Acts that induce pain, shame, fear, or distress (e.g., physical actions, harsh reprimands, timeout, or contingent removal of preferred items associated with pain or discomfort) should never be utilised as interventions within PBS. Practices of this nature are, however, known to be employed, inadvertently or purposefully, by others in care and education systems, who are not operating within a PBS framework (e.g., Positive and Active Behaviour Support Scotland and Challenging Behaviour Foundation, 2020). Sometimes these practices are described using euphemistic terms as if they are non-aversive (e.g., "chill out time" rather than time out or seclusion) or as if they are in the person's best interests (e.g., "natural consequences"). A close technical appreciation and understanding of behavioural approaches in PBS is necessary to identify, challenge, and replace such practices as part of PBS implementation.

7. **Multi-profession and cross-discipline approaches**

Working within a PBS framework demands flexibility and openness to emerging ideas whilst maintaining a rigorous approach to developing and scrutinising evidence to ensure support is effective and of the highest possible quality. In addition to the primary use

of behavioural approaches, PBS incorporates a range of other evidence-based strategies that are consistent with the rights and values and underpinning biopsychosocial conceptual model of PBS. As a multi-collaborator approach, those using PBS value expertise of people from a variety of professional backgrounds, and those with lived experience, and embrace evidence-based approaches from several disciplines. Use of PBS is not the preserve of any one profession or discipline (see PBS in the UK). Rather it is the training and competencies of individuals that govern use of PBS. Knowledge and understanding needs to be integrated and disseminated between key people at every level of a support system (Denne et al., 2015, 2020).

Application of additional theories and evidence-based approaches is necessary to build upon core behavioural methods and practices and to ensure PBS reaches its broad aims, particularly with regard to positive and sustained systems change (Carr, 2007; Gore et al., 2013). Here, for example, Eco Cultural Theory (Gallimore et al., 1989; Lucyshyn et al., 2004), Family Systems Theory (Dunst and Trivette, 1988; Guralnick, 2005) and theories from implementation science (Denne et al., 2020; Fixsen et al., 2005) and Organisational Behaviour Management (e.g., Williams and Grossett) have relevance and value in facilitating prosocial and nurturing environments.

Behavioural, Cognitive Behavioural, and Mindfulness and Acceptance-Based approaches, are evidence-based ways to support coping and self-management for people with learning disabilities, family carers, and staff (e.g., Hoffman et al.,; Jackson-Brown and Hooper, 2009; Jahoda et al, 2015; Smith and Gore, 2011; Singh et al., 2021; Unwin et al., 2016). These approaches may have clear utility as part of a multi-component PBS support plan or other systems level strategy. Integration of approaches from neuroscience and psychiatry have also been used to help reduce diagnostic-overshadowing, irrational psychotropic prescribing for behaviours that challenge, and iatrogenic harm, in the context of

multi-component PBS support plans (Cornwall Partnership NHS Foundation Trust, 2021; NHS England, 2019; Royal College of Psychiatrists, 2021; Gerrard et al. 2019).

In UK children's services, strengths-based coaching to promote self-management and problem solving (e.g., Occupational Performance Coaching, Graham, Kennedy- Behr and Ziviani, 2020 and the Primary Service Provider Approach to Teaming, Sheldon and Rush, 2020) have also been utilised to support family-centred outcomes focused on daily activities (occupations) and quality of life. Approaches to supporting good communication, including Augmentative and Alternative Communication, are particularly key to both achieving high quality of support, and enabling people with learning disabilities to use the communication skills they have to increase their choice and control (Bradshaw, 2001).

Many of these approaches are utilised as standalone interventions in other contexts and, in and of themselves, do not constitute PBS (see Figure 1). PBS is a delivery framework that is dynamic and evolving but clearly anchored in the behavioural sciences. To "be part of the PBS framework", these approaches need to be consistent with the rights, values and biopsychosocial model underpinning the framework, and employed as part of a range of strategies that complement the primary use of behavioural approaches (Gore et al., 2013)

Process and Strategy

Process and strategy in PBS concern the way high quality support is delivered. Process and strategy integrate rights and values, evidence and theory-based components in the everyday experiences of people with learning disabilities and their support networks. This includes the fundamental way in which data-based decisions are made throughout PBS implementation to ensure both personalised and effective support. It also includes the strategic organisation and selection of supports in ways that recognise and respond proactively to the full range of contexts and variables known to influence life quality and

behaviours that challenge across systems of care. PBS strategies are informed by the underpinning functional and contextual biopsychosocial model.

PBS is a whole-systems approach (Carr, 2007). The 2021 definition builds on systems thinking that has conceived multi-tiered PBS strategies, nested into systems that operate at primary, secondary, and tertiary prevention levels (Allen, et al., 2013b; Leitch, Jones and MacDonald, 2020). A public health, tiered approach that maximises life quality and minimises the risk of behaviours that challenge in this way (as depicted in Figure 4) is central to the 2021 PBS definition and distinct from conceptions of PBS that have concerned tertiary level supports only. Whilst a tiered approach is also a characteristic of School Wide Positive Behaviour Support (Sugai and Horner, 2006; Beqiraj et al., 2021), the 2021 PBS definition is specific to support that is focused on people with learning disabilities, across settings and age groups. Strategies and focus reflected in tiers (particularly with regards to the primary tier) therefore differ between the 2021 PBS definition and most models of School Wide Positive Behaviour Support. [INSERT FIGURE 4 ABOUT HERE]

At a primary tier, strategies in the 2021 PBS definition aim to support good lives and minimise the risk of behaviours that challenge for the broad population of people with learning disabilities and their families across the lifespan and multiple contexts. This includes orientating service systems to be in line with the aspirations and principles of PBS, together with broader goals for influencing policy and resources, reducing exposure to adversity, and changing social attitudes in ways that are supportive of people with learning disabilities and their families. Creating high quality support and care environments are a notable primary tier strategy, in the 2021 definition. Programmes that facilitate self-determination for people with learning disabilities and key people in their lives with regard to skills, opportunities, and wellbeing can also operate at a primary tier.

More focused strategies are utilised at a secondary tier for the early identification, prompt and technical systems support of people with learning disabilities, and their support networks, in the context of increased levels of need, complexities of circumstance, and risk of behaviours that challenge. Finally, the most intensive and highly specialised systems of support are organised at a tertiary level. These supports focus on people with learning disabilities, and those key people in their lives, at greatest risk of behaviours that challenge, in the context of the most complex needs and circumstances. Early identification of people and systems at greatest risk is critical to ensure timely and effective support. Whilst the intensity of supports increases with each tier, the number of people requiring that level of support likely reduces. Furthermore, organising supports in this way is predicted to increase life quality and reduce the number of people presenting with behaviours that challenge (and the severity, risk, and impact of such behaviours), at a population level, over time.

Process and strategy also attend closely to issues of implementation, systems for monitoring and evaluating practice and support structures, approaches, knowledge, and relationships at a systems level. Taken together, these processes and strategies maximise effectiveness and integrity of delivery to support positive outcomes with regard to good lives and reduced risk and impact of behaviours that challenge

8. Evidence informed decisions

Careful and considered decision making in PBS ensures consistency across all components of the 2021 PBS definition. In particular, those implementing PBS need to be able to evidence objectively why particular goals are selected for support, how conclusions are reached during assessment, how interventions are designed and implemented, and whether meaningful outcomes are achieved (Carr et al., 2002; Gore et al., 2013). Evidence-informed decision-making and selection of support components that are coherent and work together is a high-level skill that requires training, supervision, and good understanding of the

evidence/knowledge base from those leading a PBS process. In PBS, there is recognition that applied contexts are complex and multiple methods of data collection are required to build a picture of situations to inform decisions.

Data-based decision making is integral to behavioural approaches and includes sophisticated methods of assessment and observation (e.g., experimental analysis, momentary time sampling, see Cooper et al., 2020) but within PBS can also include simpler ways of gathering reliable and useful information (e.g., Antecedent Behaviour Consequence charts, diaries). PBS also embraces use of evidence-based data collection methods that have been developed in non-behavioural disciplines (e.g., the use of Talking Mats® by Bradshaw et al., 2018 and Gore et al., 2021). Methods of gathering evidence within PBS need to be appropriate to the requirements of any given process (sufficient to objectively inform a decision) and ensure a balance between data quality and non-intrusiveness (Carr et al., 2002).

Decision making in PBS often requires multiple perspectives and integration of multiple types of data (i.e., information), gathered from many key people. This means selecting strategies and making decisions based on evidence that is collected throughout PBS implementation by, for example, front line workers, expert consultants, family caregivers and people with learning disabilities. Data sources need to be shared and explored in meaningful ways between partners and utilised to directly inform the support people with learning disabilities and those who care for them receive.

Data are not gathered “for data’s sake”, and data that are gathered must be used to inform practice. Typically, it is necessary to use a variety of methods to capture evidence that both fit with the resources and understanding of partners and support an ethical and effective means of operating. It is critical to integrate data sources with first-hand accounts of lived experience to ensure the needs and wishes of people with learning disabilities and other key

people, and the most effective approaches available for supporting these, are identified and implemented.

9. High quality care and support environments

The biopsychosocial model that underpins PBS highlights a range of situational variables including quality of life and support that increase vulnerability to behaviours that challenge for people with learning disabilities. Contexts in which people receive little stimulation or interaction, or experience high levels of aversive control and other adversity for instance (e.g., Langthorne, McGill and O'Reilly, 2007), are known to set the occasion for behaviours that challenge which serve key functions (namely sensory, attention, escape, and avoidance).

Consistent with the biopsychosocial model, those working within a PBS framework design and ensure physical and social environments that support good lives for people with learning disabilities and reduce the risk of behaviours that challenge, by mitigating key maintaining processes and vulnerability factors commonly associated with the functions these often serve. Supporting good lives in PBS creates alternate developmental trajectories for people with learning disabilities at risk of developing behaviours that challenge. For those already engaging in behaviours that challenge, it can neutralise factors that evoke responses that are challenging and/or that function as maintaining consequences.

In the UK, strategy and process in this area has included an approach typically referred to as Capable Environments (McGill et al., 2020), which may encompass several other evidence-based best practice models for supporting life quality outcomes for people with learning disabilities. Capable environments in which, for example, people are supported to access preferred activities, maintain good physical health, engage in positive interactions, and exercise choice and control, are associated with enhanced life quality and reduced risk of challenging behaviour. In particular, Active Support (e.g., Beadle-Brown, Murphy and

Bradshaw, 2017) and Augmentative and Alternative Communication (e.g., Enderby et al., 2013; Royal College of Speech and Language Therapists, 2021) have a strong evidence base (e.g., O'Neill, Light and Pope, 2018). These approaches have demonstrated utility in improving quality of life, engagement, and skill development, with associated reductions in risk of behaviours that challenge in some contexts (e.g., Bradshaw, 2013; Jones et al., 2013; Bigby et al., 2020). Active Support and Augmentative and Alternative Communication approaches can readily be incorporated as part of a capable environments approach within PBS.

At a primary tier, a capable environments approach can be used within PBS to support good lives for the broad population of people with learning disabilities throughout the life course (Jones and Lowe, 2008). This includes ensuring high quality support for people who currently display behaviours that challenge and promoting high quality supports more widely, to reduce (proactively) the risk of such behaviours being presented by people with learning disabilities in the future. Support of this nature can also be utilised as part of a secondary or tertiary tier of intervention, via additional person-centred goal selection processes and assessments to help personalise strategies further, and/or assessment at a whole group or whole service level (e.g., McGill et al., 2018).

10. Bespoke assessment

At tertiary and sometimes secondary tiers, PBS includes personalised assessments that identify the circumstances under which an individual with a learning disability displays behaviours that challenge. Bespoke, functional assessments of this nature are consistent with the functional, biopsychosocial model of behaviours that challenge that underpins PBS and the behavioural science integral to the framework (e.g., Beavers, Iwata and Lerman, 2013; O’Neil et al, 1997; Sprague and Horner, 1995).

Functional assessments support an empathetic and non-judgemental account of the life and experiences of people who display behaviours that challenge and those who support them and provide the basis for individualised, PBS support planning (e.g., Sugai, Lewis-Palmer and Hagan-Burke, 2000; Toogood, 2011; Willis, LaVigna and Donellan, 1993). They are a data-driven, holistic, and systematic approach to identifying (objectively) which areas of need, environmental variables and interactions explain when, where, and how an individual displays behaviour that challenge (e.g., Sugai et al., 2000). Person-centred goal formation is a critical element within PBS processes and needs to guide assessment (e.g., Carr, 2007; Gore et al., 2021; Fox and Emerson, 2010). The focus for any functional assessment should be on behaviour(s) that have been agreed, through consultation with partners (including, where possible, the focal person themselves), to be negatively impacting the life and wellbeing of the person with a learning disability and/or other key people.

Functional assessments involve the integration of multiple data sources and require special skills and training. They incorporate a variety of behavioural approaches that include experimental analysis, direct behavioural observation, and data collection utilising less direct means (e.g., rating scales and structured interviews) (e.g., Cooper et al., 2020; O'Neil et al., 1997). Assessment approaches should also be individualised and utilised through a partnership approach, with flexibility and sensitivity, whilst gathering the highest quality data possible (e.g., Carr et al., 2002). This often means supporting other key people to develop skills in assessment methods and designing or selecting methods that suit their needs and circumstances (e.g., Dunlap et al., 2001; Dunlap and Fox, 2007; Willis et al., 1993).

Opportunities to engage directly with people with learning disabilities as part of their own assessment should be sought (e.g., Bradshaw et al, 2018; Wehmeyer et al., 2004). Methodologies drawn from other disciplines may be helpful in this regard and specialist assessments led by key professionals (e.g., assessment of any underlying medical conditions,

such as a specialist epilepsy assessment) can provide further contextual information as part of a functional assessment process (e.g., Cornwall Partnership NHS Foundation Trust, 2021).

Functional assessments are not static. The needs and circumstances of people with learning disabilities and those who care for them will change over time and so assessment should be an open-ended and open-minded process of discovery. The depth and scope of an assessment will vary in relation to an individual's needs, circumstances, and the nature of behaviours that challenge. Increased levels of technical expertise and depth of assessment are required as complexity of need and situation, and severity and impact of behaviours that challenge, increase and are typical of tertiary tier support (NICE, 2015).

11. Multi-component personalised support plans

Combining the findings of functional assessment with person-centred goal selection provides the core process for developing multi-component plans that both support good lives for individuals with learning disabilities and other key people, and reduce the risk and impact of behaviours that challenge (e.g., Weiss and Knoster, 2008). All support plans in PBS should be focused on ways to achieve personalised goals and outcomes for a person with a learning disability with regards to their life quality and behaviours that challenge (Carr et al, 2002; LaVigna and Willis, 2005). Support plans in PBS often also incorporate strategies that support the needs and wellbeing of other key people as part of this context (as described below). PBS plans may call for a variety of adaptions to environments, ways other people provide support, and provision of additional resources within current support contexts and/or advocate for the development of, or access to, alternative services and support systems.

Creating coherent support plans requires technical competence, training, and supervision. An important skill set in PBS is the synthesis and interpretation of assessment data and the subsequent formulation and elaboration of its meaning in relation to personalised goals. It is crucial that intervention strategies are consistent with the overarching goals for an

individual's support, and the findings of functional assessment, and that all intervention components are consistent with one another. To ensure supports are bespoke to the needs and circumstances of the person and their support system, individualised support plans should be developed through partnership working and consultation with key people (Carr et al., 2002; Dunlap and Fox, 2007; Lucyshyn et al., 2002). This should include seeking ways to incorporate the views and experiences of the focal person with learning disabilities (e.g., McKenzie et al., 2018b; Gore et al., 2021; Breeze, 2021).

Behaviour support plans will typically be multi-component, as a variety of strategies are required to guide how other people can best respond to the range of contextual factors associated with the development and maintenance of behaviours that challenge and life quality (e.g., Chaplin, Hastings and Noone, 2014; Cook et al., 2007). PBS support plans need to include ethical and non-aversive reactive strategies, tailored to an individual's needs and circumstances (e.g., Allen, 2002; LaVigna and Willis, 2002). These components are designed to minimise harm and support people with learning disabilities and others in instances where behaviours that challenge occur and/or where there are indicators that an episode of such behaviour will likely soon occur. As referenced earlier, a variety of evidence based, non-aversive reactive strategies and literature concerning de-escalation can readily inform personalised ways to reduce the severity or impact of behaviours that challenge, eroding the dependence of support systems to utilise strategies that may be aversive or restrictive (e.g., Crates and Spicer, 2016; MacDonald et al, 2010).

PBS strategy and intervention are, however, predominantly proactive in nature (Carr et al., 2002; Carr, 2007; Gore et al., 2013), with the overriding aim of reducing the likelihood, severity, or impact of behaviours that challenge over time by supporting good lives for people and mitigating specific risk factors across systems of support. This includes the provision of support that is early, both in terms of the life course and in terms of the cycle of occurrence

of behaviours that challenge (Allen et al., 2013b; Gore et al., 2014). Whilst all behaviour support plans in PBS will be personalised, they will routinely include strategies that guide how others can best support environmental enrichment and mitigate contexts that evoke behaviours that challenge (i.e., antecedent interventions, Luiselli and Cameron, 1998; Horner et al., 2000 Luiselli, 2006). This may include, for instance, instruction on ways to minimise aspects of an environment that cause sensory distress to an individual with a learning disability or to ensure they have frequent opportunities to access preferred items, people, and activities.

Behaviour support plans in PBS also routinely include strategies that those supporting an individual can use, to help teach skills that are helpful for the individual's life across a broad range of contexts (i.e., skills that provide functionally equivalent alternatives to behaviours that challenge and/or coping and other self-support strategies to help manage and promote independence in everyday life). For instance, this may include teaching an individual how to communicate when they need a break, to use public transport, to make a snack, to manage anxiety, to cope with unexpected changes to their routine, or to advocate for themselves (e.g., Carr and Durand, 1985; LaVigna and Willis, 2005; Lindgren et al., 2020; McGill et al., 2005).

Finally, behaviour support plans in PBS will often include strategies to inform how teams can support positive change in systems that surround the individual and improve quality of life and wellbeing for other key people. These supports will connect closely to contextual factors and interactions that influence behaviours that challenge. This may include, for example, both competence-based training and emotional support for carers and staff (e.g., Baker and Gore, 2019; Gore and Umizawa, 2011; MacDonald, McGill and Murphy, 2018; Singh et al., 2021; Reid, Sholl and Gore, 2013). A balance of support strategies in all of these areas, informed by individualised goals and assessment findings, are

integral to supporting rights and good lives and reducing behaviours that challenge within PBS.

12. Implementation, monitoring and evaluation

Those working within a PBS framework pay close attention to processes of implementation to embed strategies and processes of positive change at a systems level and build good lives for people with learning disabilities and other key people in their lives (Allen et al., 2013a). First, PBS plans are designed to reflect the particular characteristics of the person and the environments in which they will be used, and of key people who will use them. To be effective, interventions used within a PBS framework need to be both evidence-based and realistic, tailored to fit within cultural contexts and resources across real-world settings (e.g., Albin et al., 1996; Carr et al., 2002; Dunlap et al., 2001; Lucyshyn and Zumbo, 2018). Partnership working and co-production facilitate the development of PBS strategies that reflect the lives and circumstances of people with learning disabilities, families, support staff, and organisations and lead to meaningful and enduring positive change.

Second, organisational and systems support for the implementation of PBS plans, with close attention to issues of procedural fidelity (Brady, Padden and McGill, 2019), is critical and a required competence for PBS practitioners (PBS Academy, 2015). It is not sufficient (and typically will be ineffective) for a PBS plan to be handed to key people with the expectation that this will be readily and fully utilised without further training, support, or resources. Those working within a PBS framework recognise that implementation of support strategies relies upon behaviour change of family or paid staff (who may be experiencing stress and other adversities), often in ways that require ongoing efforts to modify interactions with, and environments for, the individual for whom they care. Family caregivers have described learning to use PBS as adopting a new “way of life” and sensitive and ongoing

support is typically called for when implementing PBS in family settings in particular (Brotherson et al., 2010; Dunst et al., 1994; Summers et al., 2007).

All PBS planning should include clear guidance on exactly when and how strategies will be implemented and by whom (Horner et al., 2000; Horner and Sugai, 2018;). Additional guidance together with training, mentoring, and modelling is also required to support PBS implementation and data-based monitoring systems to record the use of strategies need to be established early and reviewed regularly (LaVigna, Christian and Willis, 2005; McGill et al., 2018). Further guidance, systems support, and training may be necessary where PBS plans have not been adequately implemented, with modification of plans and development of additional strategies and workforce development often required over time (Denne et al., 2015).

A range of variables are known to affect implementation of support strategies in learning disability services (e.g., Bigby et al., 2020), with effective practice leadership (Deveau, 2019; Deveau and McGill, 2014) a key strategy to support understanding and behaviour of paid staff within PBS in the UK (see Deveau, Ockenden and Bjorne, 2021). Other systems-wide interventions, such as learning from critical incidents and constructive approaches to risk management are also important in supporting the implementation of PBS and play a key role in reducing the use of restrictive practices (Allen, 2011; Deveau, 2012; Ridley and Leitch, 2019).

Finally, those using PBS should consider and identify ways to evaluate outcomes that reflect the full breadth of the framework across those levels of a support system, relevant to the specific implementation context (Fox and Emerson, 2010; Gore et al., 2020; Hagiliassis, Marco and MacDonald, 2019). Outcome evaluation needs to utilise reliable and accurate data-based procedures, implemented and appraised in partnership with all involved to ensure

individualised goals are achieved and to promote the long-term development and maintenance of behavioural supports (Bowring et al., 2019b; Kincaid et al., 2002).

Evaluation needs to include dimensions of behaviours that challenge (e.g., the occurrence and/or severity of behaviours that are the focus of support planning). Outcome evaluation for people with learning disabilities must, however, also include dimensions of life quality that correspond to the rights and particular needs, preferences, goals, and aspirations of individuals. This includes both consideration of the elimination of restrictive practices and adversities, and enhancements with regards to opportunities, health and wellbeing, agency, and relationships. Finally, PBS practitioners should consider outcomes for key people relevant to the implementation context and include these within evaluations to capture secondary outcomes pertaining to wellbeing, knowledge, life quality, and other key variables of concern for paid staff, families, and organisations.

The Evidence Base for PBS

Since 2013, there have been a number of published research studies and reviews of studies that provide evidence about the effectiveness of a PBS framework, especially in the UK. In this short section, we provide a narrative to link together recent evidence (mainly, but not exclusively, since 2013) and to give a clear summary of what is known about the effectiveness of PBS. This exercise also clearly demonstrates where the gaps are in the current evidence base. We are using "effectiveness" in this section to refer to outcomes for people at risk of behaviours that challenge in terms of both positive change in their quality of life and reduction in these behaviours. Other outcomes have been reported in PBS studies, including staff knowledge, confidence, or competence, but these are (potentially important) intermediate outcomes and without evidence of change for people who display behaviours that challenge such evidence is incomplete. Other outcomes for people who display

behaviours that challenge are also important (not least, their personalised goals for their lives), but have not typically been measured and reported in existing larger scale effectiveness research studies.

First, the behavioural intervention technologies integral to PBS have been examined in terms of effectiveness multiple times for several decades. In a high quality meta-analysis of 285 single case experimental and small N design studies, Heyvaert et al. (2011; also recently used in UK guidance from NICE; NICE, 2015) showed that reductions in behaviours that challenge were associated with large effect sizes across these studies. However, these behavioural technologies are only one part of the PBS framework and so this evidence does not fully speak to the effectiveness of PBS, although the outcomes tested are measured at the level of individuals who display behaviours challenges.

Another core part of a PBS framework is to make positive changes to a person's physical and social environment and the care that the person receives – essentially addressing some of the multiple antecedent risk factors and processes associated with behaviours that challenge. McGill et al. (2018) implemented such a setting wide model in a cluster randomised controlled trial (RCT) of 24 accommodation settings in a large social care provider organisation in the UK and showed significant improvements in the quality of care delivered and associated reductions in challenging behaviour in the intervention group. Again, targeting care improvements and reducing risk factors by supportive interventions is a core part of PBS, but not the whole of the framework. Thus, this high quality RCT provides partial support for PBS as a whole and confirms the value of practice that constitutes a part of the PBS framework.

Perhaps the only way to fully test a PBS framework in the context of the UK is to evaluate outcomes from services that deliver a PBS model. Establishing a specialist challenging behaviour or PBS team to receive referrals and to work with people display

behaviours that challenge is a common service model in the UK (Davison et al., 2015; Hassiotis et al., 2021). In an early RCT, Hassiotis et al. (2009) tested outcomes for 63 individuals with learning disability and behaviours that challenge assigned randomly to be referred to a specialist "behaviour therapy" team (although not described explicitly as delivering a PBS model) in the UK NHS (plus usual care) or to usual care alone. Behaviours that challenge reduced significantly in those referred to the specialist team; an effect that was maintained over two years (Hassiotis et al., 2011). An economic analysis of the costs of the intervention approaches showed that there was no difference in the total cost of the specialist team treatment model (with usual care) in comparison to usual care alone after two years. Thus, for the same cost, delivering support for people with behaviours that challenge through a specialist behavioural team model was shown to produce better outcomes.

A number of less robust evaluations of the outcomes for individuals with learning disabilities referred to specialist PBS services have also been published (e.g., Allen et al., 2011; Dilks-Hopper et al., 2019; Mclean, Grey and McCracken, 2007) and add to the evidence that the findings from the Hassiotis et al. (2009) RCT can be replicated in wider practice. Notably, Bowring et al. (2020) reported outcomes for both adults and children with a learning disability who received specialist supports from a single PBS team in Jersey. Outcome measures were gathered at referral and then at a follow-up point as the case was being closed to the PBS team. Bowring et al. (2020) reported medium to large effect size improvements in quality of life, large effect size reductions in behaviours that challenge, and positive feedback from family caregivers and various professionals about the service and the changes observed in the lives of the children and adults who received supports.

Although delivering PBS through a specialist team or service may be effective, recent data on PBS also very clearly show what is not effective. Specifically, it is common to train health and care staff in the principles of PBS and some of the associated technologies often in

relatively short training courses. The logic of such training is presumably that this may increase staff skills and that this will change elements of their practice and lead to positive change for people with learning disabilities. Hassiotis et al. (2018) carried out a cluster RCT of PBS training with data from 23 community learning disability services (246 adults with a learning disability) in England. In the intervention arm of the trial, two staff from each service received six days of training following a model that was typical for PBS training, and results in the production of behaviour support plans to summarise assessment and intervention recommendations. The comparison was care as usual, but no specific data were gathered about whether care as usual may also have included PBS.

Results from the Hassiotis et al. (2018) RCT showed no evidence of improvements in behaviours that challenge for participants of services in the intervention arm of the trial compared to care as usual. Similarly, there were no group differences on secondary outcomes at follow-up. Data were also reported from independent ratings of the quality of the behaviour support plans produced by staff in the PBS training arm of the trial; and the behaviour support plans were all rated as Weak. One interpretation of these findings is that typical PBS training in the form of short courses did not lead to adequate quality delivery of supports, and thus did not lead to positive changes for adults with learning disabilities. These data suggest that typical PBS training in UK settings may be of questionable effectiveness.

However, considerable variability in outcomes from PBS training have been reported. MacDonald et al. (2018) evaluated the impact of a year-long training programme in PBS delivered to 50 managers of community-based services for people with behaviours that challenge who then led implementation of PBS in their services. A non-randomised control group design was used, and data were collected pre and post training, and at six-month follow-up. Outcomes included changes in both challenging behaviour and quality of life. Significant reductions in behaviours that challenge were noted but no change in quality of

life. It is possible that as teams in services become more experienced in delivering PBS, they are also able to affect positive quality of life changes as well as reductions in behaviours that challenge (cf. Bowring et al., 2020).

As can be seen, there has not really been a robust evaluation of a PBS framework in a UK setting to date. There are RCTs that show what might work (specialist teams or services) and what might not (short PBS training courses). Additional practice and training studies have also shown how individual components may be effective, and overall attention to the quality of care has predictable effects on reducing challenging behaviour. In order to establish a definitive evidence base, additional RCTs are required of the different contexts in which PBS services might be delivered (e.g., social care, special schools, family homes), and with particular foci (e.g., as early intervention for young children, and even in assessment and treatment settings to test short term assessment and treatment models of care).

Also lacking has been research that seeks to understand how and why PBS services or interventions work and when they do not work. This is crucial research, since questions about how services utilising PBS should be designed and delivered, and what contextual and other factors may be associated with the effectiveness of PBS, are those that will have the most direct implications for practitioners and services. There are also few examples of more robust research in which key parts or the whole of PBS are co-produced with people with learning disabilities and their family carers. Given the commitment of engagement and co-production within PBS, this is a serious omission.

A Logic Model for PBS

In their evaluation of the impact of the PBS Academy, Scott, Denne and Hastings (2018b) used a logic model to frame an analysis of the PBS Academy activities and the relationship between those activities and outputs. They identified the need for “a generalised

framework for evaluating impact in the learning disabilities field" and suggested that logic models provide this (Scott et al., 2018b p125). At the time logic models were a relatively new concept in academic research, although they have been used to evaluate planned programmes of change in other fields, including public policy programmes and interventions, for many years (Rogers, 2008). Increasingly, however, logic models are being used in academic studies and being asked for by grant providers as part of the evaluation of interventions that they are proposing to fund. They are a requirement, for example, of the National Institute of Health Research, Research for Patient Benefit programme, as well as interventions funded by the Education Endowment Foundation.

Logic models are a "visual representation of a theory of action or programme logic guiding the design and implementation of a programme or policy and can be used as a tool for building a relevant evaluation design" (Shakman and Rodriguez, 2015 p3). They can also be used to communicate a shared understanding and anticipated outcomes of a programme of change (McLaughlin and Jordan, 1998). And whilst logic models share common features such as outlining the problem being addressed, providing the context within which the programme of change is being delivered, identifying inputs or activities, and describing desired outcomes, formats and content vary. The logic model used in the PBS Academy evaluation was a relatively straightforward description of the relationship between the PBS Academy's resources, activities, and outputs (particularly in relation to key partners) and identified short, medium, and longer-term outcomes. For the evaluation of interventions, it is important to understand the change processes involved and the underlying mechanisms of those changes; the aim being to identify and explain those factors responsible for the programme's (i.e., intervention's) success or failure (Weiss, 1997). These include theoretical, delivery, and implementation process mechanisms. In the Shakman and Rodriguez (2015) definition cited above, the word "tool" is critical. A logic model is not an "end product" or

static document. Rather, it is a resource to be used as part of an evaluation, as it provides a means of testing the assumptions and components of an intervention or programme that plans for change.

The absence of a "robust evaluation of a PBS framework in a UK setting to date" is a serious gap in our understanding of PBS, as is a lack of research that "seeks to understand how and why PBS services or interventions work and when they do not work". A logic model for PBS could guide such an evaluation. As a starting point, and drawing upon the themes explored throughout this report and at this stage of development, the following logic model (Figure 5) is proposed at this point in time. The content under each of the headings is more fully developed across the four sections of this report and will not be explored further here. It is important to stress, however, that this is only a starting point. McLaughlin and Jordan (1998) outline a five-stage process of constructing a logic model. The final and critical step, stage five, is an iterative process of key partner consultation and verification. Only once this has happened can the model become a tool to guide any evaluation of PBS implementation. The importance of co-production has been highlighted and the aim of this report to prompt debate about "further thinking on PBS" has been stated. A logic model partner consultation is arguably a useful next step. [INSERT FIGURE 5 ABOUT HERE]

Conclusion

The current report represents the state of the nation for PBS in 2021 in the UK. Significant evolution has taken place in how we describe and implement PBS over time, including in the short time since the 2013 IJPBS special issue. There have also been developments in relation to the practice and research evidence base. However, the PBS "project" in the UK is not complete. As we have discussed, there is still a need for additional evidence about the PBS approach and in particular the key aspects of successful

implementation. Research and practice in PBS also have much to do to continue to incorporate co-production with and leadership by people with learning disabilities and others, including family carers. The initial drafting of a Logic Model for PBS (see Figure 5) is also a significant step forward, but is the first time (that we are aware of) that such a Logic Model has been drafted. Thus, this needs testing in practice and further development.

Importantly, the field of PBS does not and should not stand still. Change has been such since 2013 that we were compelled to provide an updated perspective on PBS in the UK and, in particular, to refine the definition of PBS. We must expect further developments and changes over the next decade, and perhaps even more rapidly. We also encourage practitioners of PBS and others to directly engage in developing the practice base and evidence for PBS by sharing the results of innovative, person-centred, and co-produced practice. This is a crucial part of the life of PBS in the UK and internationally.

References

Agran, M and Brown, F (2016) ‘Self-determined behaviour change: The need for capacity, opportunity and support’, *Developmental Neurorehabilitation,* 19(6), 405-409.

Albin, RW, Lucyshyn, JM, Horner, RH and Flannery, KB (1996) ‘Contextual fit for behaviour support plans: a model for “goodness of fit”’ in LK Koegel, RH Koegel and G Dunlap (Eds.) *Positive Behavior Support: Including People with Difficult Behavior in the Community*, Baltimore: Brookes.

All Wales Challenging Behaviour Community of Practice [CBCoP] (2019) ‘The All Wales Challenging Behaviour Community of Practice: Update’, *International Journal of Positive Behavioural Support,* 9(2) 57-60.

Allen, D (2011) *Reducing the use of restrictive practices with people who have intellectual disabilities: A practical approach*. Kidderminster: BILD Publications.

Allen, D (2002) ‘Behaviour change and behaviour management’ in Allen D (ed.) *Ethical approaches to physical interventions: Responding to challenging behaviour in people with intellectual disabilities*. Kidderminster: BILD Publications/Plymstock. pp. 3-14.

Allen, D and Baker, P (2013) ‘Special issue: Defining positive behaviour support’, *International Journal of Positive Behavioural Support,* 3(2), 3-4.

Allen, D, McGill, P, Hastings, RP, Toogood, S, Baker, P, Gore, NJ and Hughes, CJ (2013a) ‘Implementing positive behavioural support: Changing social and organisational contexts’, *International Journal of Positive Behavioural Support,* 3(2), 32-41.

Allen, D, Langthorne, P, Tonge, B, Emerson, E, McGill, P, Fletcher, R, Dosen, A and Kennedy, C (2013b) ‘Towards the prevention of behavioural and psychiatric disorders in people with intellectual disabilities’, *Journal of Applied Research in Intellectual Disabilities*, 26(6), 501-514.

Allen, D, Lowe, K, Baker, P, Dench, C, Hawkins, S, Jones, E and James, W (2011) 'Assessing the effectiveness of positive behavioural support: The P-COP Project', *International Journal of Positive Behavioural Support*, 1(1), 14-23.

Allen, D, Kaye, N, Horwood, S, Gray, D and Mines, S (2012) 'The impact of a whole-organisation approach to positive behavioural support on the use of physical interventions', *International Journal of Positive Behavioural Support*, 2(1), 26-30.

Allen, D, James, W, Evans, J, Hawkins, S and Jenkins, R (2005) 'Positive behavioural support: Definition, current status and future directions', *Tizard Learning Disability Review,* 10(2), 4-11.

Association of Chief Executives of Voluntary Organisations (2016) *Time for change: The challenge ahead.* Available at: https://www.acevo.org.uk/reports/time-for-change-the-challenge-ahead/ (Accessed 08 April 2021).

Association for Behaviour Analysis International (2020) *Association for Behaviour Analysis International.* Available at: https://www.abainternational.org/welcome.aspx (Accessed: 19 January 2021).

British Institute of Learning Disabilities (2018) *PBS Standards for Wales.* Available at: https://www.bild.org.uk/resource/pbs-standards-for-wales/ (Accessed 02 November 2021).

Baer, DM, Wolf, MM and Risley, T (1968) 'Current dimensions of applied behaviour analysis', *Journal of Applied Behaviour Analysis*, 1(1), 91-97.

Baker, P and Gore, N (2019) 'We're in this together: Supported staff", in Baker P and Osgood T (eds.) *Understanding and responding to behaviour that challenges in intellectual disabilities: A handbook for those who provide support*. Brighton, UK: Pavilion, pp 159-166.

Baker, P., Cooper, V., Tsang, W., Garnett, I., & Blackman, N. (2021). A survey of complex trauma in families who have children and adults who have a learning disability and/or autism. *Advances in Mental Health and Intellectual Disabilities*.

Barnoux, MF (2021) 'Special Issue on positive behavioural support in secure/forensic settings', *International Journal of Positive Behavioural Support,* 11(1), 4-6.

Beadle-Brown, J, Murphy, B and Bradshaw, J (2017) *Person-centred active support*. Canterbury, UK: Pavilion

Beadle-Brown, J, Leigh, J, Whelton, B, Richardson, L, Beecham, J, Baumker, T and Bradshaw, J (2016) 'Quality of life and quality of support for people with severe intellectual disability and complex needs', *Journal of Applied Research in Intellectual Disabilities*, 29(5), 409-421.

Beavers, GA, Iwata, BA and Lerman, DC (2013) 'Thirty years of research on the functional analysis of problem behaviour', *Journal of Applied Behavior Analysis*, 46(1), 1-21.

Beqiraj, L, Denne, LD and Hastings, RP (2021) 'Positive behavioural support for children and young people with developmental disabilities in special education settings: A systematic review' (manuscript under review)

Bigby, C, Bould, E, Iacono, T and Beadle-Brown, J (2020) 'Predicting good active support for people with intellectual disabilities in supported accommodation services: Key messages for providers, consumers and regulators', *Journal of Intellectual & Developmental Disability*, 45(3), 279-289.

Botha, M, Hanlon, J and Williams, GL (2021) 'Does language matter? Identity-first versus person-first language use in autism research: A response to Vivanti', *Journal of Autism and Developmental Disorders*, 1-9.

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood,* 3(1), 18-29.

Bowring, DL, Totsika, V, Hastings, RP and Toogood, S (2020) 'Outcomes from a community-based positive behavioural support team for children and adults with developmental disabilities', *Journal of Applied Research in Intellectual Disabilities*, 33(2), 193–203

Bowring, DL, Totsika, V and Hastings, RP (2019a) 'Designing specialist community-based behavioural support teams', *International Journal of Positive Behavioural Support,* 9(2), 4-15.

Bowring, DL, Painter, J and Hastings, RP (2019b) 'Prevalence of challenging behaviour in adults with intellectual disabilities, correlates, and association with mental health', *Current Developmental Disorders Reports,* 6(4), 173-181.

Bradshaw, J (2013) 'The use of augmentative and alternative communication apps for the iPad, iPod and iPhone: an overview of recent developments', *Tizard Learning Disability Review,* 18(1), 31-37.

Bradshaw, J (2001) 'Complexity of staff communication and reported level of understanding skills in adults with intellectual disability', *Journal of Intellectual Disability Research*, 45(3), 233-243.

Bradshaw, J, Gore, NJ and Darvell, C (2018) 'Supporting the direct involvement of students with disabilities in functional assessment through use of Talking Mats®', *Tizard Learning Disability Review,* 23(2), 111-116.

Brady, L, Padden, C and McGill, P (2019) 'Improving procedural fidelity of behavioural interventions for people with intellectual and developmental disabilities: A systematic review', *Journal of Applied Research in Intellectual Disabilities*, 32(4), 762-778.

Breeze, J (2021) 'Including people with intellectual disabilities in their own behaviour support plans', *Tizard Learning Disability Review*, early online view.

Bromley, J and Emerson, E (1995) 'Beliefs and emotional reactions of care staff working with people with challenging behaviour', *Journal of intellectual Disability Research*, 39(4) 341-352.

Brotherson, MJ, Summers, JA, Naig, LA, Kyzar, K, Friend, A, Epley, P, Gotto, GS and Turnbull, AP (2010) 'Partnership patterns: addressing emotional needs in early Intervention', *Topics in Early Childhood Special Education,* 30(1), 32-45.

British Psychological Society (2018) *Committee and working group position statement on PBS*. Available at: https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Divisions/DCP/Positive%20Behaviour%20Support.pdf (Accessed: 08 April 2021).

Byrne, G (2020) 'A systematic review of treatment interventions for individuals with intellectual disability and trauma symptoms: A review of the recent literature', *Trauma, Violence, & Abuse*, 1-14.

Care Quality Commission [CQC] (2020) *The state of care on mental health services 2014-2017: Findings from CQC's programme of comprehensive inspections of specialist mental health services.* Available at https://www.cqc.org.uk/publications/themed-work/interim-report-review-restraint-prolonged-seclusion-segregation-people (Accessed: 08 April 2021).

Carr, EG (2007) 'The expanding vision of positive behaviour support: Research perspectives on happiness, helpfulness, hopefulness', *Journal of Positive Behavior Interventions,* 9(1), 3-14.

Carr, EG (1977) 'The motivation of self-injurious behavior: A review of some hypotheses', *Psychological Bulletin*, 84(4), 800-816.

Carr, EG (1994) ‘Emerging themes in the functional analysis of problem behaviour’, *Journal of Applied Behaviour Analysis,* 27(2), 393-399

Carr EG and Durand VM (1985) ‘Reducing behavior problems through functional communication training’, *Journal of Applied Behavior Analysis,* 18(2), 111-126.

Carr, EG, Dunlap, G, Horner, RH, Koegel, RL, Turnbull, AP, Sailor, W, Anderson, JL., Albin, RW., Koegel, LK and Fox, L (2002) ‘Positive behavior support: Evolution of an applied science’, *Journal of Positive Behavior Interventions*, 4(1), 4-16.

Chaplin, J, Hastings, RP and Noone, S (2014) ‘Improving the quality of behavioural support plans through service development initiatives’, *International Journal of Positive Behavioural Support*, 4(2), 14-23.

Chapman, R and Bovell, V (In press) ‘Neurodiversity, advocacy, anti-therapy’ in Sturmey, P and Matson, J (eds.) *Handbook of autism and pervasive developmental disorder*. Springer.

Cluley, V (2018) ‘From “Learning disability to intellectual disability” - Perceptions of the increasing use of the term “intellectual disability” in learning disability policy, research and practice’, *British Journal of Learning Disabilities*, 46(1), 24-32.

Cook, CR, Crews, DS, Browning-Wright, D, Mayer, RG, Gale, B, Kraemer, B and Gresham, FM (2007) ‘Establishing and evaluating the substantive adequacy of positive behavioural support plans’, *Journal of Behavioural Education*, 16(3), 191-206.

Cooper, JO, Heron, TE and Heward, WL (2020) *Applied Behavior Analysis.* 3rd edition. NJ: Pearson/Merrill-Prentice Hall.

Cornwall Partnership NHS Foundation Trust (2021). *Connect behaviours.* Available at: https://www.cornwallft.nhs.uk/connect-behaviours-1/ (Accessed 04 November 2021).

Crates, N and Spicer, M (2016) 'Reactive strategies within a positive behavioural support framework for reducing the episodic severity of aggression', *International Journal of Positive Behavioural Support,* 6(1), 24-34.

Davison, S, McGill, P, Baker, P and Allen, D (2015) 'A national UK survey of peripatetic support teams for children and adults with intellectual and developmental disability who display challenging behaviour', *International Journal of Positive Behaviour Support*, 3(1), 25-33.

Denne, Louise D, Gore, Nick J, Hughes, JC, Toogood, S, Jones, E, Brown, FJ (2020) 'Implementing evidence-based practice: the challenge of delivering what works for people with learning disabilities at risk of behaviours that challenge', Tizard Learning Disability Review, 25(3), 133-143.

Denne, L, Jones, E, Lowe, K, Brown, FJ and Hughes, JC (2015) 'Putting positive behavioural support into practice: The challenges of workforce training and development', *International Journal of Positive Behavioural Support*, 5(2), 43-54.

Denne, LD, Noone, SJ, Gore, NJ, Toogood, S, Hughes, CJ, Hastings, RP, Allen, D, Baker, P and McGill, P (2013) 'Developing a core competencies framework for positive behaviour support: Issues and recommendations', *International Journal of Positive Behavioural Support,* 3(2), 24-31.

Department for Education and Department of Health and Social Care (2019) *Reducing the need for restraint and restrictive intervention: Children and young people with learning disabilities, autistic spectrum conditions and mental health difficulties in health and social care services and special education settings*. London: Department for Education and Department of Health and Social Care.

Department of Health (2015) *Mental Health Act 1983: Code of Practice*. Norwich: TSO.

Department of Health, Skills for Health and Skills for Care (2014) *A positive and proactive workforce. A guide to workforce development for commissioners and employers seeking to minimise the use of restrictive practices in social care and health*. Leeds: Skills for Care.

Department of Health (2012a), *Transforming care: A national response to winterbourne view hospital. Department of Health review: Final report*. London: Department of Health. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf (Accessed 08 April 2021).

Department of Health (2012b). *DH winterbourne view review: Concordat: Programme of action.* London: Department for Health.

Department of Health (2008) *Real involvement: Working with people to improve health service*. London: Department of Health.

Deveau, R (2019) 'Practice leadership and behaviour that challenges' in Baker P and Osgood A (eds.) *Understanding and responding to behaviour that challenges in intellectual disabilities* (2nd edition). Shoreham by Sea UK: Pavilion.

Deveau, R (2012) 'Reducing the use of restrictive practices with people who have intellectual disabilities: A practical approach', *Tizard Learning Disability Review*, 17(1), 49-51.

Deveau, R and McGill, P (2014) 'Leadership at the front line: Impact of practice leadership management style on staff experience in services for people with intellectual disability and challenging behaviour', *Journal of Intellectual and Developmental Disability*, 39(1), 65-72.

Deveau, R, Ockenden, J and Björne, P (2021) 'Exploring new ways of thinking about and developing staff practice: The role of modes of thinking', *Tizard Learning Disability Review*, 26(2), 90-99.

Dilks-Hopper, H, Jacobs, C, Sholl, C, Gore, NJ and Falconer, C (2019) ‘The Ealing Intensive Therapeutic and Short Breaks Service: An update five years on’, *Tizard Learning Disability Review*, 24(2), 56-63.

Dunlap, G and Fox, L (2007) ‘Parent-professional partnerships: A valuable context for addressing challenging behaviours’, *International Journal of Disability, Development and Education,* 54(3), 273-285.

Dunlap, G, Carr, EG, Horner, RH, Zarcone, JR and Schwartz, I (2008) ‘Positive behaviour support and applied behaviour analysis: a familial alliance’, *Behavior Modification*, 32(5), 682–698.

Dunlap, GJS, Newton, L, Fox, N, Benito, B and Vaughn, B (2001) ‘Family involvement in functional assessment and positive behaviour support’, *Focus on Autism and Other Developmental Disabilities,* 16(4), 215-221.

Dunst, CJ and Trivette, CM (1988) ‘A family systems model of early intervention with handicapped and developmentally at-risk children’ in Powell DR (ed.) *Parent education as early childhood intervention: Emerging directions in theory, research, and practice.* Norwood, NJ: Ablex, pp. 131-179.

Dyck E., Russell G. (2020) Challenging Psychiatric Classification: Healthy Autistic Diversity and the Neurodiversity Movement. In: Taylor S., Brumby A. (eds) Healthy Minds in the Twentieth Century. Mental Health in Historical Perspective. Palgrave Macmillan, Cham.

Emerson, E (2012a) ‘Deprivation, ethnicity and the prevalence of intellectual and developmental disabilities’, *Journal of Epidemiology and Community Health,* 66(3), 218-24.

Emerson, E (2012b) ‘Commentary: Childhood exposure to environmental adversity and the well-being of people with intellectual disabilities’, *Journal of Intellectual Disability*

Research, 57(1), 589-600.

Emerson, E and Einfeld, S (2011) *Challenging Behaviour.* New York: Cambridge University Press.

Emerson, E and Hatton, C (2014) *Health inequalities and people with intellectual disabilities*. Cambridge: Cambridge University Press.

Emerson, E and McGill, P (1989) 'Normalization and applied behaviour analysis: Values and technology in services for people with learning difficulties', *Behavioural Psychotherapy,* 17(2), 101-117.

Enderby, P, Judge, S, Creer, S and John, A (2013) *Communication Matters – Research Matters: an AAC Evidence Base. Communication Matters*. Available at: https://www.communicationmatters.org.uk/wp-content/uploads/2019/01/2013_AAC_Evidence_Base_Beyond_the_Anecdote.pdf (Accessed 01 November 2021).

Evans, IM and Meyer, LH (1985) *An educative approach to behavior problems: A practical decision model for interventions with severely handicapped learners.* Baltimore: Brookes.

Fixsen, DL, Naoom, SF, Blase, KA, Friedman, RM and Wallace, F (2005) *Implementation research: A synthesis of the literature*. Tampa, FL University of South FL, Louis de la Parte FL Mental Health Institute: The National Implementation Research Network.

Friman, PC (2021) 'There is no such thing as a bad boy: The circumstances view of problem behavior', *Journal of Applied Behavior Analysis,* 54(2) 636-653.

Gallimore, R., Weisner, TS, Kaufman, SZ and Bernheimer, LP (1989) 'The social construction of ecocultural niches: Family accommodation of developmentally delayed children', *American Journal of Mental Retardation*, 94(3), 216-230

Gerrard, D, Leadbitter, A, Lee, R, Rhodes, J and Ling, J (2019) 'Does positive behavioural support (PBS) help or hinder a STOMP medication challenge?' *Advances in Mental Health and Intellectual Disabilities, 13*(3/4), 102-112.

Goldiamond, I (1974)' Toward a constructional approach to social problems: Ethical and constitutional issues raised by applied behavior analysis', *Behaviorism,* 2(1), 1-84.

Gore, NJ and Baker, P (2017) 'Mental health as motivational operation: Service-user and caregiver emotional states in the context of challenging behaviour', *International Journal of Positive Behavioural Support*, 7(1), 15-23.

Gore, NJ, Jones, E and Stafford, V (2020) 'Building core domains for the evaluation of PBS: A consensus-based approach', *International Journal of Positive Behavioural Support,* 10(1), 4-15.

Gore, NJ, McGill, P and Hastings, RP (2021) 'Personalized goals for positive behavioral support: Engaging directly with children who have intellectual and developmental disabilities', *Journal of Child and Family Studies,* 30(2), 375-387.

Gore, NJ, McGill, P and Hastings RP (2019) 'Making it meaningful: Caregiver goal selection in positive behavioural support. *Journal of Child and Family Studies,* 28(6), 1703-1712.

Gore, NJ, Hastings, RP and Brady, S (2014) 'Early intervention for children with learning disabilities: Making use of what we know', *Tizard Learning Disability Review*, 19(4), 181-189.

Gore, NJ and Umizawa, H (2011) 'Challenging behaviour training for teaching staff and family carers of children with intellectual disabilities: a preliminary evaluation', *Journal of Policy and Practice in Intellectual Disabilities*, 8(4), 266-275.

Gore, NJ, McGill, P, Toogood, S, Allen, D, Hughes, C, Baker, P, Hastings, RP, Noone S and Denne, L (2013) 'Definition and scope for positive behaviour support', *International Journal of Positive Behavioural Support* 3(2), 14-23.

Graham, F, Kennedy- Behr, A and Ziviani, J (2020) *Occupational Performance Coaching A Manual for Practitioners and Researchers.* Routledge.

Griffith, GM and Hastings, RP (2014) 'He's hard work but he's worth it: The experience of caregivers of individuals with intellectual disabilities and challenging behaviour: a meta-synthesis of qualitative research', *Journal of Applied Research in Intellectual Disabilities*, 27(5), 401-419.

Grove, N, Bunning, K, Porter, J and Olsson, C (1999) 'See what I mean: Interpreting the meaning of communication by people with severe and profound intellectual disabilities', *Journal of Applied Research in Intellectual Disabilities*, 12(3), 190-203.

Guess, D, Helmstetter, E, Turnbull, HR and Knowlton, S (1987) *Use of aversive procedures with persons who are disabled: An historical review and critical analysis*. Seattle: Association for Persons With Severe Handicaps

Guralnick, MJ (2005) 'Early intervention for children with intellectual disabilities: Current knowledge and future prospects', *Journal of Applied Research in Intellectual Disabilities,* 18(4), 313-324.

Hagiliassis, N, Marco, MD and MacDonald, A (2019) 'PBS outcomes measurement: A new taxonomy to support organisational implementation', *International Journal of Positive Behavioural Support*, 9(2), 16-24.

Hassiotis, A, Canagasabey, A, Robotham, D, Marston, L, Romeo, R and King, M (2011) 'Applied behaviour analysis and standard treatment in intellectual disability: 2-year outcomes', *The British Journal of Psychiatry*, 198(6), 490-491.

Hassiotis, A, Kouroupa, A, Jones, R, Morant, N, Courtenay, K, Hall, I, Crossey, V, Romeo, R, Taggart, L, Langdon, P and Ratti, V (2021) 'Clinical and cost evaluation of intensive support team (IST) models for adults with intellectual disabilities who display

challenging behaviour: A comparative cohort study protocol', *BMJ Open*, 11(3), p.e043358.

Hassiotis, A, Poppe, M, Strydom, A, Vickerstaff, V, Hall, IS, Crabtree, J, Omar, RZ, King, M, Hunter, R, Biswas, A and Cooper, V (2018) 'Clinical outcomes of staff training in positive behaviour support to reduce challenging behaviour in adults with intellectual disability: Cluster randomised controlled trial', *The British Journal of Psychiatry*, 212(3), 161-168.

Hassiotis, A, Robotham, D, Canagasabey, A, Romeo, R, Langridge, D, Blizard, R, Murad, S and King, M (2009) 'Randomized, single-blind, controlled trial of a specialist behavior therapy team for challenging behavior in adults with intellectual disabilities', *American Journal of Psychiatry*, 166(11), 1278-1285.

Hastings, RP, Allen, D, Baker, P, Gore, NJ, Hughes, JC, McGill, P, Noone, SJ and Toogood, S (2013) 'A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities', *International Journal of Positive Behavioural Support,* 3(2), 5-13.

Higgens, L (2021) 'Secure unit: Positive behavioural support and restraint reduction in a unit for offenders with an intellectual disability and/or autism: Practice paper', *International Journal of Positive Behavioural Support,* 11(1), 42-54.

Ho, H, Perry, A and Koudys, J (2021) 'A systematic review of behaviour analytic interventions for young children with intellectual disabilities', *Journal of Intellectual Disabilities Research,* 65(1), 11-31.

Hoffmann, AN, Contreras, BP, Clay, CJ and Twohig, MP (2016) 'Acceptance and commitment therapy for individuals with disabilities: A behavior analytic strategy for addressing private events in challenging behavior', *Behavior Analysis in Practice*, 9(1), 14-24.

Horner, R.H., Dunlap, G., Koegel, R,L., Carr, E.G., Sailor, W., Anderson, J., Albin, R.W., and O'Neill, R.E. (1990) Toward a Technology of "Nonaversive" Behavioral Support, *The Journal of The Association for the Severely Handicapped,* 15(3) 125-132

Horner, RH, Sugai, G, Todd, AW, and Lewis-Palmer, T (2000) 'Elements of behaviour support plans: A technical brief', *Exceptionality: A Special Education Journal*, 8(3), 205-215.

Horner, RH and Sugai, G (2018) 'Future directions for positive behavior support: A commentary', *Journal of Positive Behavior Interventions*, 20(1), 19-22.

Hughes, EC and Huerta, E (2016) 'Reducing episodic severity of challenging behaviours in public school settings using the multi-element behavioural support plan', *International Journal of Positive Behavioural Support,* 6(2) 12–27.

Iwata, BA, Pace, GM, Dorsey, MF, Zarcone, JR, Vollmer, TR, Smith, RG, Rodgers, TA, Lerman, DC, Shore, BA, Mazaleski, JL and Goh, HL (1994) 'The functions of self-injurious behavior: An experimental-epidemiological analysis', *Journal of Applied Behavior Analysis*, 27(2), 215-240.

Jackson-Brown, F and Hooper, S (2009) 'Acceptance and commitment therapy (ACT) with a learning disabled young person experiencing anxious and obsessive thoughts', *Journal of Intellectual Disabilities*, 13(3), 195–201

Jahoda, A, Melville, C, Pert, C, Cooper, S, Lynn, H, Williams, C and Davidson, C (2015) 'A feasibility study of behavioural activation for depressive symptoms in adults with intellectual disabilities', *Journal of Intellectual Disability Research*, 59(11), 1010-1021.

Jones, E and Lowe, K (2008) 'Active support is person-centred by definition', *Journal of Intellectual and Developmental Disability,* 33(3), 274-277.

Jones. E, Lowe, K, Brown, S, Albert, L, Saunders, C, Haake, N and Leigh, H (2013) 'Active support as a primary prevention strategy for challenging behaviour', *International Journal of Positive Behavioural Support*, 3(1), 16-30.

Jones, L, Bellis, MA, Wood, S, Hughes, K, McCoy, E., Eckley, L., Bates, G, Mikton, C, Shakespeare, T and Officer, A (2012) ‘Prevalence and risk of violence against children with disabilities: A systematic review and meta-analysis of observational studies’, *The Lancet*, 380(9845), 899-907.

Keesler, JM and Isham, C (2017) ‘Trauma-informed day services: An initial conceptualization and preliminary assessment’, *Journal of Policy and Practice in Intellectual Disabilities,* 14(2), 164-175.

Kincaid, D, Knoster, T, Harrower, JK, Shannon, P and Bustamante, S (2002) ‘Measuring the impact of positive behaviour support’, *Journal of Positive Behavior Interventions*, 4(2), 109-117

Kincaid, D and Fox, L (2002) ‘Person-centred planning and positive behavior support’ in Holburn S and Mount B (eds.), *Person centred planning: Research, practice and future directions*. Baltimore, MD: Paul H. Brookes Publishing.

Kincaid, D, Dunlap, G, Kern, L, Lane, KL, Bambara, LM, Brown, F, Fox, L and Knoster TP (2016) ‘Positive behavior support: A proposal for updating and refining the definition’, *Journal of Positive Behavior Interventions*, 18(2), 69-73.

Kruger, B and Northway, R (2019) ‘An exploratory study of behaviour specialist experiences of involving service users in the development of their positive behavioural support plans’, *Journal of Intellectual Disabilities,* 32(2), 160-174.

Langdon, PE, Dalton, D, Brolly, K, Temple, D, Thomas, C and Webster, T (2017) ‘Using positive behavioural support as a treatment for trauma symptoms with a man with intellectual disabilities’, *International Journal of Positive Behavioural Support*, 7(1), 31-37.

Langthorne, P, McGill, P and O'Reilly, M (2007) ‘Incorporating 'motivation' into the functional analysis of challenging behavior: On the interactive and integrative

potential of the motivating operation', *Behavior Modification*, 31(4), 466-487.

LaVigna, G.W., & Donnellan, A.M. (1986) *Alternatives to punishment: Solving behavior problems with non aversive strategies*. New York: Irvington Publishers, Inc.

LaVigna, GW and Willis, TJ (2012) 'The efficacy of positive behavioural support with the most challenging behaviour: The evidence and its implications', *Journal of Intellectual and Developmental Disability*, 37(3), 185-195.

LaVigna, GW and Willis, TJ (2005) 'Episodic Severity: An overlooked dependent variable in the application of behaviour analysis to challenging behaviour', *Journal of Positive Behaviour Interventions*, 7(1) 47–54.

LaVigna, G W and Willis, T J (2002) 'Counter-intuitive strategies for crisis management within a non-aversive framework', in Allen D (ed.), *Behaviour management guidelines in intellectual disabilities: Ethical responses to challenging behaviour*. Kidderminster: BILD, pp. 89-103.

LaVigna, GW, Christian, L, Willis, TJ (2005) 'Developing behavioural services to meet defined standards within a national system of specialist education services', *Paediatric Rehabilitation,* 8(2), 144-155.

Leitch, S, Jones, E and MacDonald, A (2020). *UK PBS Alliance organisational and workforce development framework.* Availible at: https://www.bild.org.uk/wp-content/uploads/2020/10/PBS_Workforce_Development_Framework_Final.pdf (Accessed 04 November 2021).

Lindgren, S, Wacker, D, Schieltz, K, Suess, A, Pelzel, K, Kopelman, T, Lee. J, Romani, P and O'Brien, M (2020) 'A randomized controlled trial of functional communication training via telehealth for young children with autism spectrum disorder', *Journal of Autism and Developmental Disorders,* 50(12), 4449-446.

Loomes, R, Hull, L and Mandy, WPL (2017) 'What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis', *Journal of the American Academy of Child & Adolescent Psychiatry,* 56(6), 466-474.

Lucyshyn, J and Zumbo, BD (2018) 'Transforming coercive processes in family routines: Family functioning outcomes for families of children with developmental disabilities', *Journal of Child and Family Studies,* 27(9), 2844-2861.

Lucyshyn, JM, Irvin, LK, Blumberg, ER, Laverty, R, Horner, RH and Sprague, JR (2004) 'Validating the construct of coercion in family routines: Expanding the unit of analysis in behavioural assessment with families of children with developmental disabilities', *Research and Practice for Persons with Severe Disabilities, 29*(2), 104-121.

Lucyshyn, JM, Dunlap, GE and Albin, RW (2002) *Families and positive behavior support: Addressing problem behavior in family contexts*. Baltimore, MA: Paul H Brookes Publishing.

Luiselli, JK (2006) *Antecedent assessment and intervention: Supporting children and adults with developmental disabilities in community settings*. Baltimore: Paul H. Brookes Publishing Co.

Luiselli, JK and Cameron, MJ (eds.) (1998) *Antecedent control: Innovative approaches to behaviour*. Baltimore, MD: Brookes Publishing Company.

Lydon, SA, Healy, O, Morna, L and Foody, C (2015) 'A quantitative examination of punishment research', *Research in Developmental Disabilities,* 36, 470-484.

MacDonald, A, Hume, L and McGill, P (2010) 'The use of multi-element behaviour support planning with a man with severe learning disabilities and challenging behaviour', *British Journal of Learning Disabilities*, 38(4), 280-285.

MacDonald, A, McGill, P and Murphy, G (2018) ‘An evaluation of staff training in positive behavioural support’, *Journal of Applied Research in Intellectual Disabilities*, 31(6), 1046-1061.

Mclean, B, Grey, IM and McCracken, M (2007) ‘An evaluation of positive behavioural support for people with very severe challenging behaviours in community-based settings’, *Journal of Intellectual Disabilities*, 11(3), 281-301.

McDonnell, CG, Boan, AD, Bradley, CC, Seay, KD, Charles, JM and Carpenter, LA (2019) ‘Child maltreatment in autism spectrum disorder and intellectual disability: Results from a population-based sample’, *Journal of Child Psychology and Psychiatry*, 60(5), 576-584.

McGill, P (1999) ‘Establishing operations: implications for the assessment, treatment and prevention of problem behaviour’, *Journal of Applied Behaviour Analysis*, 32(3), 393-418.

McGill, P, Bradshaw, J, Smyth, G, Hurman, M and Roy, A (2020) ‘Capable environments’, *Tizard Learning Disability Review*, 25(3), 109-116.

McGill, P, Vanono, L, Clover, W, Smyth, E, Cooper, V, Hopkins, L, Barratt, N, Joyce, C, Henderson, K, Sekasi, S, Davis, S and Deveau, R (2018) ‘Reducing challenging behaviour of adults with intellectual disabilities in supported accommodation: A cluster randomized controlled trial of setting-wide positive behaviour support’, *Research in Developmental Disabilities*, 81, 143-154.

McGill, P, Teer, K, Rye, L and Hughes, D (2005) ‘Staff reports of setting events associated with challenging behaviour’, *Behaviour Modification*, 29(4), 599-615.

McKenzie, K, Hardy, C, Whelan, K, McNall, A, Noone, S. and Chaplin, J (2018a) ‘The views of carers about support for their family member with an intellectual disability:

With a focus on Positive Behavioural Approaches', *Health & Social Care in the Community*, 26(1), 56-63.

McKenzie Whelan, KJ, Mayer, C, McNall, A, Noone, S and Chaplin, J (2018b) '"I feel like just a normal person now": An exploration of the perceptions of people with intellectual disabilities about what is important in the provision of positive behavioural support', *British Journal of Learning Disabilities*, 4(6), 241-249.

McLaughlin, JA and Jordan, GB (1998) 'Logic models: a tool for telling your program's performance story', *Evaluation and Program Planning*, 22(1), 65-72.

McLaughlin, TW, Denney, MK, Snyder, PA and Welsh, JL (2012) 'Behaviour support interventions implemented by families of young children: Examination of contextual fit', *Journal of Positive Behaviour Interventions,* 14(2), 87-97.

McLennan, K, O'Regan, D, Coleman, S, Bretherton, S, Cooper, P, Hove, M, McWade, P and Toogood, S (2017) 'Providing positive behavioural support services: Quality of life and challenging behaviour outcomes for a sixteen year old with intellectual disability', *International Journal of Positive Behavioural Support*, 7(2), 24-36.

McQuire, C, Hassiotis, A, Harrison, B and Pilling, S (2015) 'Pharmacological interventions for challenging behaviour in children with intellectual disabilities: A systematic review and meta-analysis', *BMC Psychiatry*, 15(303), 1-13.

Murphy, J and Cameron, L (2008) 'The effectiveness of Talking Mats with people with intellectual disability*', British Journal of Learning Disability,* 36(4), 232-241.

National Institute for Health and Care Excellence [NICE] (2015) *Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges.* Available at: https://www.nice.org.uk/guidance/ng11 (Accessed 04 November 2021).

National Institute for Health and Care Excellence [NICE] (2018) *Learning disabilities and behaviour that challenges: Service design and delivery.* Available at: https://www.nice.org.uk/guidance/ng93 (Accessed 04 November 2021).

NHS England. (2019). *Stopping the over-medication of children and young people with a learning disability, autism or both (STOMP) and supporting treatment and appropriate medication in paediatrics (STAMP).* Available at: https://www.england.nhs.uk/wp-content/uploads/2019/02/STOMP-STAMP-a5-leaflet.pdf (Accessed 04 November 2021).

NHS Improving Quality (2015). *Winterbourne medics programme: Improving the use of medicines in people with learning disabilities.* London: NHS Improving Quality

O'Brien, C and O'Brien, J (2002) 'A history of person-centered planning' in Holburn, S and Vietze, P (eds.) *Person-centered planning: Research planning and future directions*. Baltimore, MD: Paul Brookes, pp. 3-28.

Oliver, M (2013) 'The social model of disability: Thirty years on', *Journal of Disability and Society, 28*(7), 1024-1026.

O'Neill T, Light J and Pope L (2018) 'Effects of interventions that include aided augmentative and alternative communication input on the communication of individuals with complex communication needs: A meta-analysis', *Speech, Language, and Hearing Research*, 61(7), 1743-1765.

O'Neil, RE, Horner, RH, Albin, RW Sprague, JR, Storey, K and Newton, JS (1997) *Functional assessment and program development for problem behavior: A practical handbook*. Baltimore: Brookes/Cole Publishing.

Paley, S, Swayn, N, Leitch, P and Kallis, K (2020) 'Developing a framework for reducing restrictive practices in Queensland state schools', *International Journal of Positive Behavioural Support,* 10(2) 5-12.

Paris, A, Toogood, S, Grindle, C, Jackson Brown, F, Denne, LD, Nicholls, G, and Hastings, RP (2019) ‘Function-based behavioural assessment and support in a UK special education school: A series of Tier 3 multi-component case studies’, *International Journal of Positive Behavioural Support,* 9(1), 16-29.

Paterson, B, Young, J and Bradley, P (2017) ‘Recognising and responding to trauma in the implementation of PBS’, *International Journal of Positive Behavioural Support,* 7(1), 4-14.

Positive and Active Behaviour Support Scotland and Challenging Behaviour Foundation, (2020). *Reducing restrictive intervention for children and young people*. Available at: https://www.challengingbehaviour.org.uk/wp-content/uploads/2019/01/rireportfinal.pdf (Accessed 04 November 2021).

PBS Academy (2015) *Positive Behavioural Support Competence Framework.* Available at: http://pbsacademy.org.uk/pbs-competence-framework/ (Accessed 04 November 2021).

Reid, C, Sholl, C and Gore, NJ (2013) ‘Seeking to prevent residential care for young people with intellectual disabilities and challenging behaviour: Examples and early outcomes from the Ealing intensive therapeutic and short break service’, *Tizard Learning Disability Review*, 18(4), 171-178.

Restraint Reduction Network (2021) *Restraint Reduction Network.* Available at: https://restraintreductionnetwork.org/ (Accessed 19 October 2021).

Ridley, J and Leitch, S (2019) *Restraint Reduction Network (RRN) Training Standards.* Available at: https://bildact.org.uk/wp-content/uploads/2019/10/BILD_RRN_standards_final.pdf (Accessed 04 November 2021).

Robertson, J, Emerson, E, Hatton, C, Elliott, J, McIntosh, B, Swift, P, Krinjen-Kemp, E, Towers, C, Romeo, R, Knapp, M and Sanderson, H (2002) 'Longitudinal analysis of the impact and cost of person-centred planning for people with intellectual disabilities in England', *American Journal on Mental Retardation,* 111(6), 400-416.

Rogers, PJ (2008) 'Using programme theory to evaluate complicated and complex aspects of interventions', *Evaluation,* 14(1), 29-48.

Romski, M, Sevcik, RA, Barton-Hulsey, A and Whitmore, AS (2015) 'Early intervention and AAC: What a difference 30 years makes', *Augmentative and Alternative Communication*, 31(3), 181-202.

Royal College of Psychiatrists (2021). *Stopping the overmedication of people with intellectual disability, autism or both (STOMP) and supporting treatment and appropriate medication in paediatrics (STAMP).* Available at: https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/position-statements/position-statement-ps0521-stomp-stamp.pdf?sfvrsn=684d09b3_6 (Accessed 04 November 2021).

Royal College of Psychiatrists (2018) *Restrictive interventions in in-patient intellectual disability services: How to record, monitor and regulate*. College Report CR220. Available at: https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr220.pdf?sfvrsn=c74ad0e4_2 (Accessed 08 April 2021).

Royal College of Speech and Language Therapists (2021) *Augmentative and alternative communication (AAC) overview*. Available at: https://www.rcslt.org/speech-and-language-therapy/clinical-information/augmentative-and-alternative-communication/ (Accessed 19 October 2021).

Schalock, RL, Brown, I, Brown, R, Cummins, RA, Felce, D, Matikka, L, Keith, KD and

Parmenter, T (2002) 'Conceptualization, measurement and application of Quality of Life for persons with intellectual disabilities', *Report of an International Panel of Experts,* 40(6), 457-470.

Scott, SJ & Denne, LD (2017) UK Positive Behavioural Support (PBS) Academy Evaluation and Impact Study. *Report to funders* (available from authors)

Scott, SJ, Denne, LD and Hastings, RP (2018a) 'Assessing the impact of the UK Positive Behavioural Support (PBS) Academy: An internet survey', *International Journal of Positive Behavioural Support,* 8(1), 29-38.

Scott, SJ, Denne, LD and Hastings, RP (2018b) 'Developing a logic model to guide evaluation of impact for learning disability projects: the case of the Positive Behavioural Support (PBS) Academy', *Tizard Learning Disability Review*, 23(3) 125-132.

Scottish Government (2018). *The coming home report: Complex care needs and out of area placements*. Available at: https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/ (Accessed 22 July 2021).

Scottish Government (2019) *The keys to life: Implementation framework and priorities 2019-2021*. Available at: https://keystolife.info/wp-content/uploads/2019/03/Keys-To-Life-Implementation-Framework.pdf (Accessed 22.7.21).

Shakman, K and Rodriguez, SM (2015) *Logic model for program design, implementation and evaluation: Workshop toolkit*. U.S. Department of Education: National Center for Education Evaluation and Regional Assistance. Available at: http://files.eric.ed.gov/fulltext/ED556231.pdf (accessed 27 September 2021).

Singh, NN, Lancioni, GE, Medvedev, ON, Hwang, YS. and Myers, RE (2021) 'A component analysis of the mindfulness-based positive behavior support (MBPBS) program for

mindful parenting by mothers of children with autism spectrum disorder', *Mindfulness,* 12(2), 463-475.

Skills for Care (2021) *PBS training peer review pilot*. Available at: https://www.skillsforcare.org.uk/Learning-development/ongoing-learning-and-development/behaviours-which-challenge/PBS-training-peer-review-pilot.aspx (Accessed 22 July 2021).

Skills for Health, Health Education England and Skills for Care (2019) *Learning Disabilities Core Skills Education and Training Framework.* Available at: https://www.skillsforhealth.org.uk/images/services/cstf/Learning%20Disability%20Framework%20Oct%202019.pdf (Accessed 08 April 2021).

Smith, MP and Gore, NJ (2011) 'Outcomes of a "train the trainers" approach to an acceptance based stress intervention in a specialist challenging behaviour service', *International Journal of Positive Behaviour Support,* 2(1), 39-48.

Sprague, JR and Horner, RH (1995) 'Functional assessment and intervention in community settings', *Mental Retardation and Developmental Disabilities Research Reviews*, 1(2), 89-93.

Sugai, G and Horner, RH (2009) 'Defining and describing schoolwide positive behavior support' in Sailor W, Dunlap G, Sugai G and Horner R (eds.) *Handbook of positive behavior support.* Boston, MA: Springer, pp. 307-326.

Sugai, G and Horner, RH (2006) 'A promising approach for expanding and sustaining school-wide positive behavior support', *School Psychology Review,* 35(2), 245-259.

Sugai, G and Horner, RH (2002) 'The evolution of discipline practices: School-wide positive behavior supports', *Child and Family Behavior Therapy,* 24(1-2), 23-50.

Sugai, G, Lewis-Palmer, T and Hagan-Burke, S (2000) 'Overview of the functional assessment process', *Exceptionality: A Special Education Journal*, 8(3), 149-160.

Summers, JA, Marquis, J, Mannan, H, Turnbull, AP, Fleming, K, Poston, DJ, Wang, M and Kupzyk, K (2007) 'Relationship of perceived adequacy of services, family-professional partnerships and family quality of life in early childhood service programmes', *International Journal of Disability, Development and Education,* 54(3), 319-338.

Tassé, MJ Schalock, RL, Balboni, G, Bersani Jr, H, Borthwick-Duffy, SA, Spreat, S, Thissen, D, Widaman, KF and Zhang, D (2012) 'The construct of adaptive behaviour: Its conceptualization, measurement, and use in the field of intellectual disability. *American Journal on Intellectual Disabilities*, 117(4), 291-303.

The Challenging Behaviour Foundation National Strategy Group (2019). *The Challenging Behaviour Foundation Charter.* The Challenging Behaviour Foundation. Available at: https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/cbfcharterweb1.pdf (Accessed 9 November 2021)

Toogood, S (2011), 'Using contingency diagrams in the functional assessment of challenging behaviour'*, International Journal of Positive Behavioural Support*, 2(1), 3-10.

Toogood, S, Saville, M, McLennan, K, McWade, P, Morgan, G, Welch, C and Nicholson, M (2015) 'Providing positive behavioural support services: Specialist challenging behaviour support teams', *International Journal of Positive Behavioural Support*, 5(1), 6-15.

Totsika, V, Hastings, RP, Emerson, E, Berridge, DM, & Lancaster, GA. (2011a) 'Behaviour problems at five years of age and maternal mental health in autism and intellectual disability', *Journal of Abnormal Child Psychology,* 39(8), 1137-1147.

Totsika, V, Hastings, RP., Emerson, E, Lancaster, GA and Berridge, DM (2011b) 'A population-based investigation of behavioural and emotional problems and maternal mental health: associations with autism and intellectual disability', *Journal of Child*

Psychology and Psychiatry, 52(1), 91-9.

Towel, D (1987) 'Foreword', in Blunden R and D. Allen D (eds.) *Facing the challenge: An ordinary life for people with learning difficulties and challenging behaviour*. London: Kings Fund Publishing Office.

Townsend-White, C, Pham, ANT and Vassos, MV (2012) 'A systematic review of quality of life measures for people with intellectual disabilities and challenging behaviours', *Journal of Intellectual Disability Research*, 56(3), 270-284

UNICEF (2021) *The United Nations Convention on the Rights of the Child*. Available at: https://www.unicef.org.uk/what-we-do/un-convention-child-rights/ (Accessed: 21 October 2021).

United Nations (2021) Universal Declaration of Human Rights Available at: https://www.un.org/en/about-us/universal-declaration-of-human-rights (Accessed: 19 October 2021)

Unwin, G, Tsimopoulou, I, Kroese, BS and Azmi, S (2016) 'Effectiveness of cognitive behavioural therapy (CBT) programmes for anxiety or depression in adults with intellectual disabilities: A review of the literature', *Research in Developmental Disabilities*, 51-52, 60-75.

Wehmeyer, ML, Baker, DJ, Blumberg, R and Harrison, R (2004) 'Self-determination and student involvement in functional assessment', *Journal of Positive Behavior Interventions,* 6(1), 29-35.

Wehmeyer, ML, Agran, M, Hughe, C, Martin, JE, Mithaug, DE and Palmer, SB (2007) *Promoting self-determination in students with developmental disabilities*. New York, NY: Guilford Press.

Weiss, CH (1997) 'How can theory-based evaluation make greater headway?', *Evaluation Review*, 21(4), 501-524.

Weiss, NR and Knoster, T (2008) 'It may be non-aversive but is it a positive approach? Questions to ask throughout the process of behavioural assessment and intervention', *Journal of Positive Behaviour Interventions,* 10(1), 72-78.

Welsh Government (2018, June) *Learning disability: Improving lives programme*. Available at: https://gov.wales/sites/default/files/publications/2019-03/learning-disability-improving-lives-programme-june-2018.pdf (Accessed 04 November 2021).

Welsh Government. (2021). *Reducing restrictive practice framework.* Available at: https://www.bild.org.uk/wp-content/uploads/2020/01/reducing-restrictive-practices-framework.pdf (Accessed 04 November 2021).

Williams, DE and Grossett, DL (2011) 'Reduction of restraint of people with intellectual disabilities: An organizational behavior management (OBM) approach', *Research in Developmental Disabilities: A Multidisciplinary Journal*, 32(6), 2336-2339.

Willis, TJ, LaVigna, GW and Donnellan, AM (1993) *Behavior Assessment Guide*, California: Institute for Applied Behavior Analysis.

Wolfensberger, W. (1972) *The principle of normalization in human services*. Toronto. National Institute on Mental Retardation.

Wolfensberger, W (1983) 'Social role valorization: A proposed new term for the principle of normalization', *Mental Retardation*, 21, 234-239.

Wolfensberger, W and Glenn, L (1975) *Program analysis of service systems (PASS): A method for the quantitative evaluation of human services* (3rd ed.). Vol. 1: Handbook. Vol. 2: Field manual. Toronto, ON: National Institute on Mental Retardation.

	Goal to reduce behaviours that challenge	**No focal goal to reduce behaviours that challenge**
Goal to increase skills, opportunities and/or environments that support life quality	**Positive Behavioural Support** Reduced risk of behaviours that challenge in the context of increased life quality	**Other Person Centred Supports** (e.g., Person Centred Planning) **Other Constructive Behavioural Approaches** (e.g., Precision Teaching) **Other Biopsychosocial Approaches** (e.g., Approaches to supporting communication) **Other Rights and Values Movements** (e.g., Self-Advocacy, Deinstitutionalisation)
No focal goal to increase skills, opportunities and/or environments that support life quality	**Aversive Behavioural Practices** (e.g., timeout, over-correction, other aversive punishments alone) **Other Biopsychosocial Approaches** (e.g., psychotropic medication alone) **Other Restrictive Practices** (e.g., seclusion, restraint)	**Services and supports that seek to contain behaviours that challenge in circumstances associated with deprivation, restrictiveness and poor quality of life** (e.g., non-habilitative secure provision, many everyday provisions that, often hampered by lack of skill and resource, tolerate and accept both continued behaviours that challenge and poor life quality)

Figure 1: The Combined Goals of Positive Behavioural Support as From Other Approaches

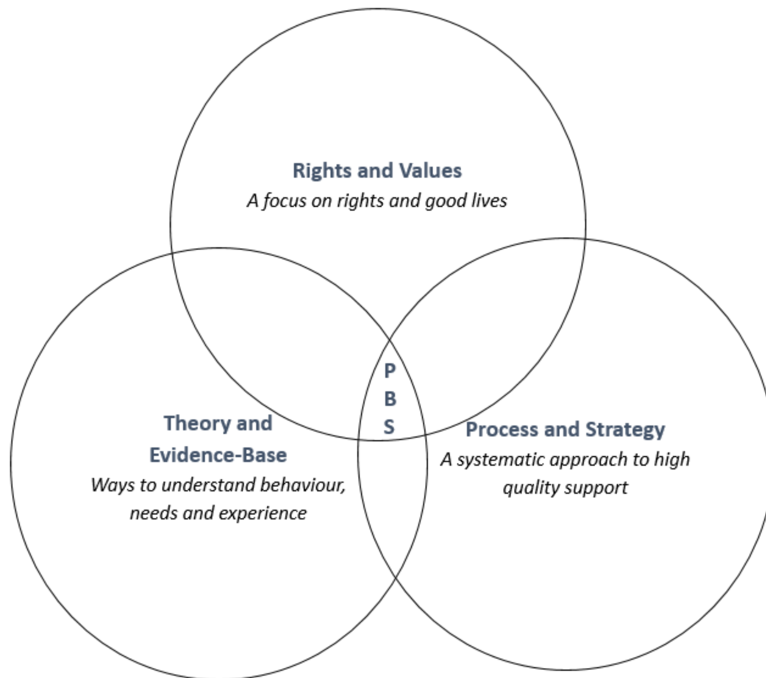

Figure 2: Major Categories in the 2021 Definition of Positive Behavioural Support

Table 1: Key Components of Positive Behavioural Support Included in the 2021 Definition

Domain	Component
Rights and Values: A focus on rights and good lives	1. Person-centred foundation
	2. Constructional approaches and self-determination
	3. Partnership working and support for key people
	4. Elimination of aversive, restrictive, and abusive practices
Theory and Evidence Base: Ways to understand behaviour, needs, and experience	5. A biopsychosocial model of behaviours that challenge
	6. Behavioural approaches to learning, experience, and interaction
	7. Multi-profession and cross-discipline approaches
Process and Strategy: A systematic approach to high quality support	8. Evidence informed decisions
	9. High quality care and support environments
	10. Bespoke assessment
	11. Multi-component, personalised support plans
	12. Implementation, monitoring, and evaluation

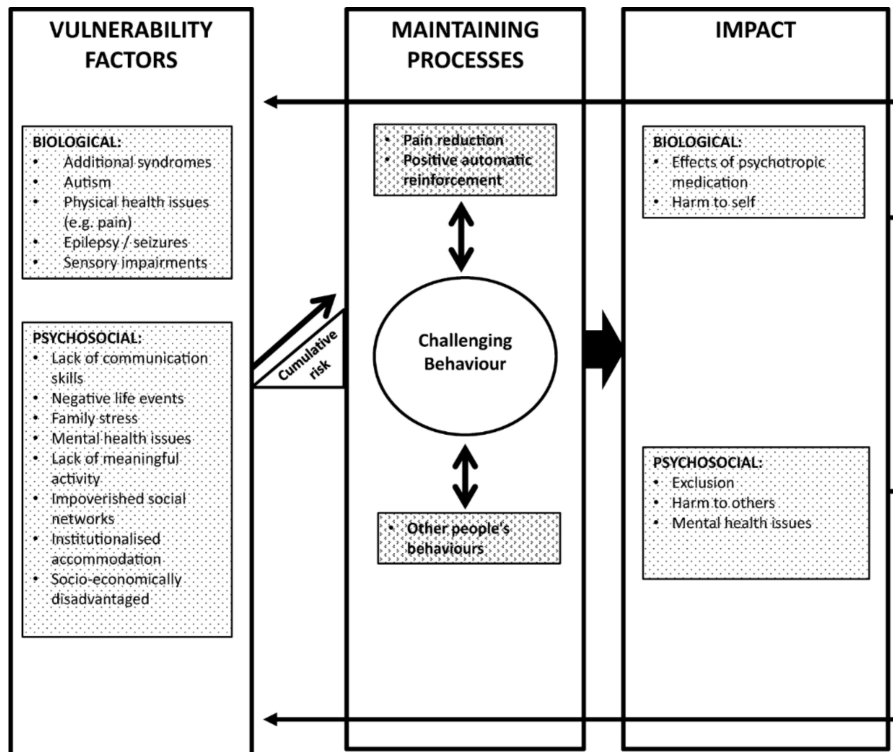

Figure 3: A Framework for Understanding Behaviours that Challenge (Bowring et al., 2019b, p178 – reproduced in accordance with Creative Commons Attribution 4.0 International License)

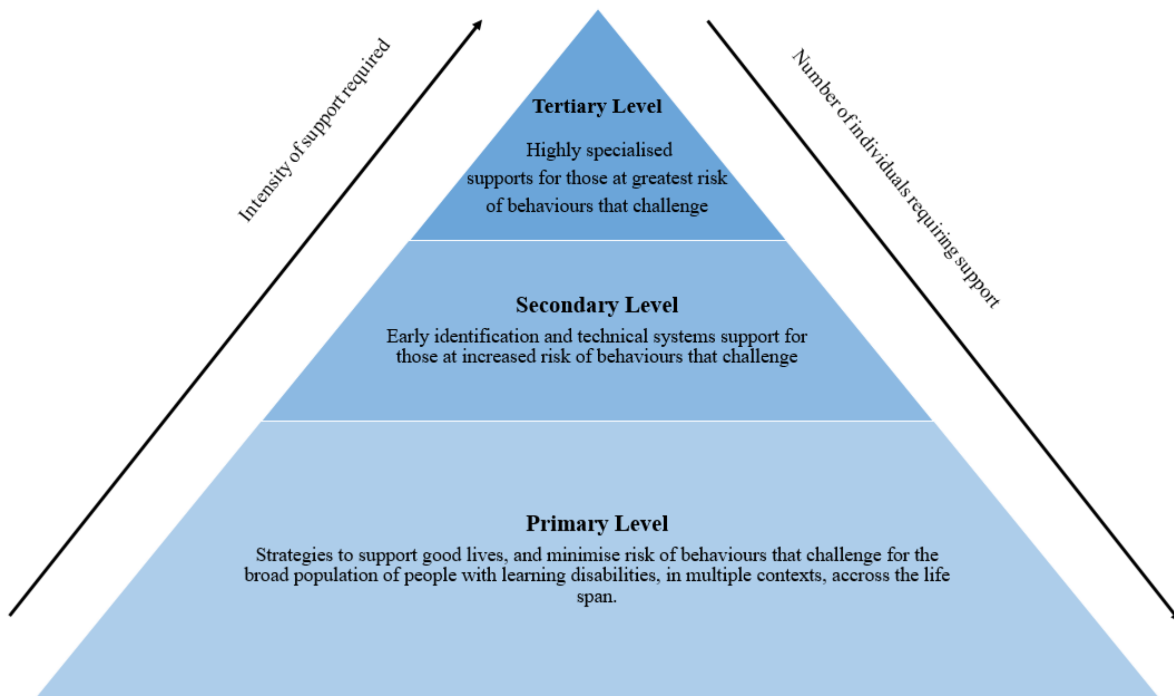

Figure 4: A Tiered Positive Behavioural Support Approach (*Note.* The size of the tiers in the figure are illustrative only).

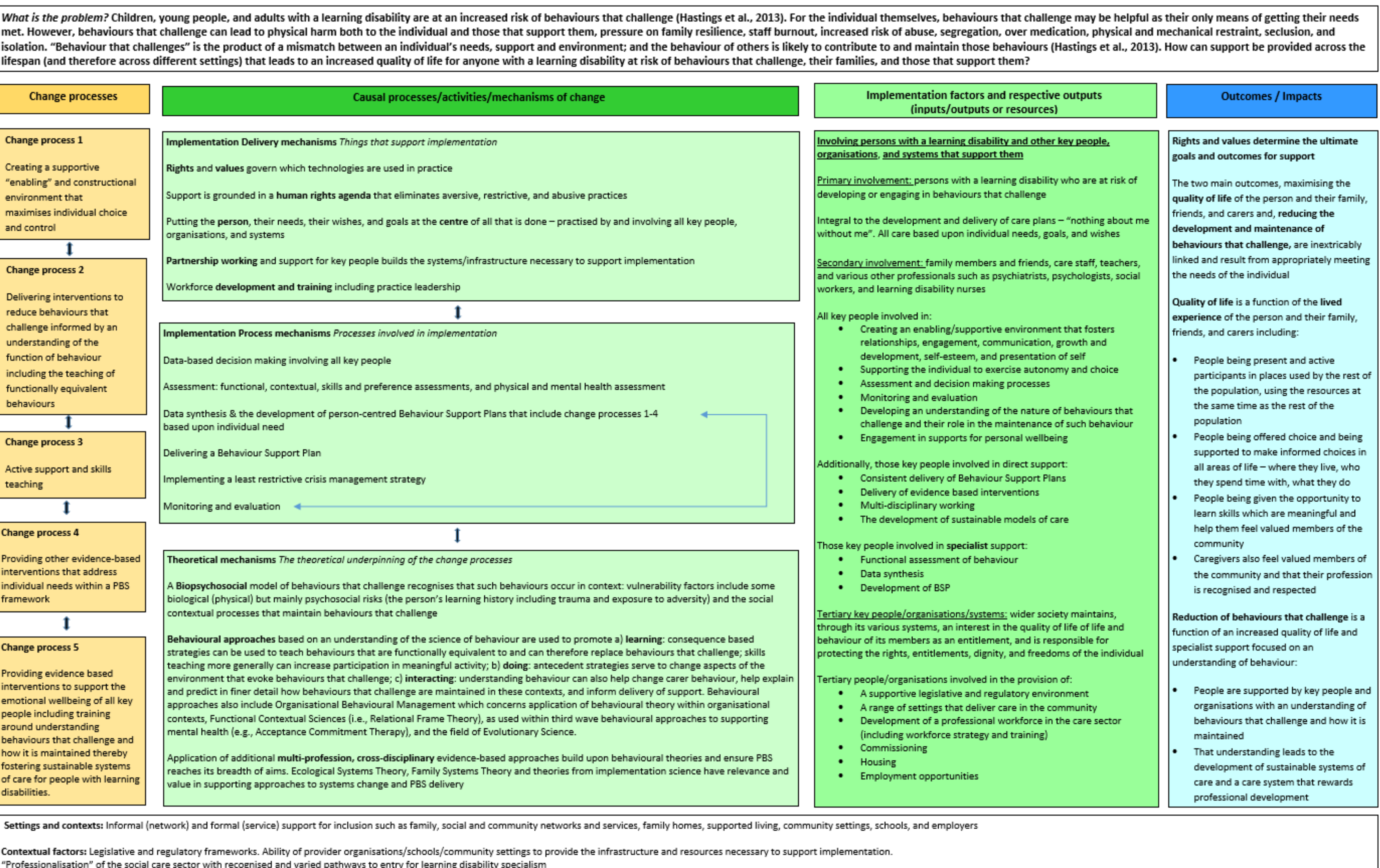

Figure 5: Proposed Logic Model Diagram for Positive Behavioural Support (Working Document)