

Delivering what works for people with learning disabilities and those that support them

2021 Good Practice PBS Conference

Dr Nick Gore

Tizard Centre, University of Kent, UK



thank you



PBS Cooperative



NHS England and NHS Improvement – South West
Health Education England



Welcome and Introductions

Dr Nick Gore (DClinPsy, PGCHE, BSc-Hons)

Clinical Psychologist, Senior Lecturer and Researcher

Teaching

Short courses as well as undergraduate and postgraduate programmes

PhD students

Consultancy

Training for services, commissioners

Clinical support for individuals, families, services

Research

Applied research focused predominantly on improving support and quality of life for people with disabilities.

Policy

Support for development of policy and best practice guidance





Me!

ABA and PBS post-graduates - Summer 2019

- Challenging Behaviour
- Positive Behavioural Support
- Early Intervention

○*Psychologist, Lecturer, researcher...*

dad...husband, brother, son.....
scout leader, runner, trustee.....



People's **whole life**, what they *experience and share* and how all of this can fit together!

PBS is...

An evidence based approach for supporting people with Intellectual Disability who display or are at risk of displaying behaviors that challenge...

Yes...

But it needs to be so much more..

1) Nobody gets through life without experiencing emotional or behavioural difficulties— at least sometimes

We are all living in the same world, with bodies and brains that work in roughly similar ways

2) None of us are an island unto ourselves – we all influence one another and are influenced by one and other



We are all in the same boat

We have to live, support and *decide* together – at an individual and systems level

All of this rings true in the context of behavior that challenges:

Behavior that challenges:

- has a variety of negative impacts on multiple people across multiple settings
- is influenced by multiple factors that interact in complex ways

Behavior that Challenges is Everybody's Business...

What 'we' need is a common framework or model that concerns.....

What **people** do and experience, how they interact and how all of this can fit together



Could PBS provide at least part of this or aspire to do so?

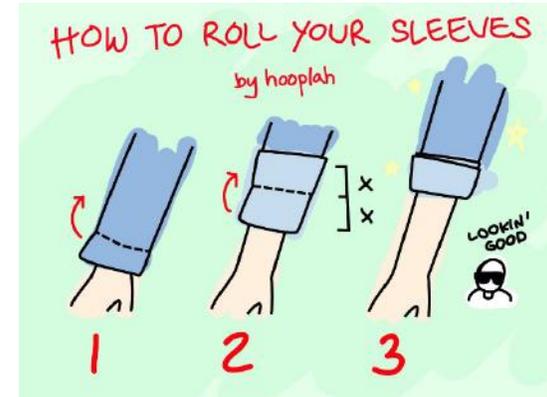
A Plan for Today

- **A brief presentation!**



Some key developments in the evolution of PBS in the UK over recent years:

- Conceptualisation
- Implementation



That reflect the influence and adaptations made to a **UK context**

- ***Explore some of the possible next steps for the PBS community***

Do **NOT** want to:

- Teach any one to suck eggs
- Imply this is the way it must be done



*But to **share** some reflections on some of the developments in UK*

With recognition that the evolution of PBS can best be mediated by communities (such as this one) working together

To begin at a beginning

Thinking concerning PBS in the UK has been going on for sometime...

Bringing together the two major theoretical influences of SRV/Normalisation & ABA

'Applied behaviour analysis can be characterised as a technology bereft of any guiding principles regarding either goal selection or procedural acceptability.

Normalisation, on the other hand, represents a value-laden conceptual framework bereft of any systematic technology for affecting behavioural change'

Emerson & McGill (1989)

Underpinning ideas of PBS have also been promoted in the UK in one form or another for sometime...



Challenging behaviour: a unified approach

Clinical and service guidelines for supporting people with learning disabilities who are at risk of receiving abusive or restrictive practices

College Report CR144
June 2007

Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists

Approved by Central Executive Committee: March 2007

Due for review: 2012

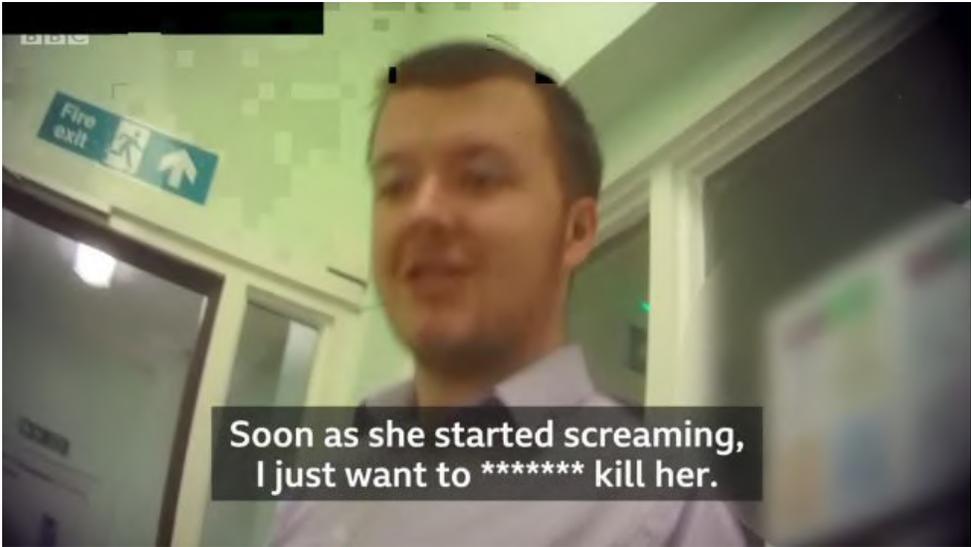
And yet...



The Silent Minority (1981):
Borocourt, Reading, Berks
and St Lawrence's Hospital



**Winterbourne View
Hospital (2011)**



Whorlton Hall (2019)



Hmmm, well not really...but perhaps a bit closer?

Denne, L., Gore, N., Hughes, J., Toogood, S., Jones, E. and Brown, F. (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*.

Implementing evidence-based practice: the challenge of delivering what works for people with learning disabilities at risk of behaviours that challenge

Louise D. Denne, Nick J. Gore, J. Carl Hughes, Sandy Toogood, Edwin Jones and Freddy Jackson Brown

Abstract

Purpose – There is an apparent disconnect between the understanding of best practice and service delivery in the support of people with learning disabilities at risk of behaviours that challenge. We suggest, as a problem of implementation. The purpose of this paper is to explore reasons why this might be the case: a failure to recognise the collective works of successive generations of research and practice; and a failure to address the macro-systems involved and systems changes needed to support implementation.

Design/methodology/approach – This paper reviews the consensus that exists in respect of best practice. Drawing upon ideas from implementation science the paper highlights the complexities involved in the implementation of all evidence-based practices and uses this as a framework to propose ways in which an infrastructure that facilitates the delivery of services in the learning disabilities field might be built.

Findings – This paper highlights core recommended practices that have been consistent over time and across sources and identifies the systems involved in the implementation process. This paper demonstrates that many of the necessary building blocks of implementation already exist and suggests areas that are yet to be addressed. Critically, the paper highlights the importance of, and the part that all systems need to play in the process.

Originality/value – In the absence of any generalised implementation frameworks of evidence-based practice in the learning disabilities field, the paper suggests that the findings may provide the basis for understanding how the gap that exists between best practice and service delivery in the support of people with a learning disability at risk of behaviours that challenge might be closed.

Keywords Adult social care, Learning disabilities, Challenging behaviour, Positive behaviour support, Implementation, Evidence-based practice

Paper type Conceptual paper

Background

An estimated 2.16% of adults and 2.5% of children in the UK have a learning disability (LD), approximately 1.5 million people (Mencap, 2020). This may be a small number in terms of the overall population requiring care, but people with LD are at a higher risk than others of developing behaviour that challenges. These behaviours, by definition, have a significant impact on well-being and life quality (Hastings *et al.*, 2013) for the person and their family. In turn, they represent a particular challenge to services and organisations, whose goal is to ensure people with LD have the same quality of life and opportunities as anyone else (NHS England, Local Government Association and Association of Directors of Adult Social Services, 2015).

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Lessons from the collective works of each generation are not fully recognised; or, if recognised, are not given sufficient time to be implemented.

Selected key guidance and resources

1. Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs (The Mansell reports) Department of Health (1983, 2007)
 2. Challenging Behaviour: A Unified Approach (Royal College of Psychiatrists, 2007, 2016)
 3. Statement of Ethics for Professionals who Work in Learning Disability Services Post Winterbourne View (Learning Disability Professional Senate, 2014)
 4. Guidance for Commissioners of Mental Health Services for People with Learning Disabilities. (Joint Commissioning Panel for Mental Health, 2013)
 5. The Challenging Behaviour Charter (Challenging Behaviour National Strategy Group, 2009)
 6. Delivering Effective Specialist Community Learning Disabilities Health Team Support to People with Learning Disabilities and their Families or Carers (Learning Disability Professional Senate, 2015)
 7. Positive and Proactive Care, Reducing the need for restrictive interventions (Social Care, Local Government and Care Partnership Directorate, 2014)
 8. Winterbourne View – Time for Change: Transforming the Commissioning of Services for People with Learning Disabilities and/or Autism (Transforming Care and Commissioning Steering Group, 2014)
 9. Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities whose Behaviour Challenges (NICE, 2015)
 10. Learning disabilities and behaviour that challenges: service design and delivery (NICE, 2018)
 11. Building the Right Support (NHS England, et al, 2015)
 12. The PBS Competence Framework and associated resources (PBS Academy 2015)
 13. Ensuring quality services Core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges (LGA, NHS England, 2014)
-

Semantics: Terms used by different stakeholder groups (and within groups) may not have the same meaning as when used by others

Policy and guidance often use **midlevel terms** to try and increase accessibility (and, perhaps, acceptability) but can create the conditions for **ambiguity**.

Descriptions of processes and definitions have evolved over time and sometimes terminology used to describe concepts has changed.

Developing new and innovative approaches is important but...

...can be a response to 'crises' and creating what look like new solutions rather than building upon an existing evidence base.

- Despite these possibilities, **some of the messages, and the theories** on which these have been based, **have been constant** and do appear to underline key strategy areas.
- Core recommended practices that have been consistent over time and across sources can be identified.

Many of these practices are found in current definitions of Positive Behavioural Support (PBS) in the UK...

...though not always referred to explicitly...

Table 1 Summary of recommended practices and selected quotations from the documents/guidance they feature in

<i>Key recommended practices</i>	<i>Selected quotations</i>
Approaches are led by values of social equality, inclusion, cultural and environmental improvement and a person-centred promotion of human rights	"People who present behavioural challenges can and should be supported in living close to home, integrated within the community, engaged in activities that promote optimum quality of life and with the support that ensures protection of their human rights" (Royal College of Psychiatrists, 2007/2016) pp. 4 "People will be supported to exercise their universal human rights to be healthy, full and valued members of their community with respect for their culture, ethnic origin, religion, age, gender, sexuality and disability" (Learning Disability Professional Senate, 2014) pp. 5
A focus on the individual and person-centred interventions	"Successful services provide individualised pathways of care, based on a thorough understanding of the individual and their experience. It should be person-centred" (Joint Commissioning Panel for Mental Health, 2013) pg. 3 "Instead of commissioning services for groups, support is designed for one person at a time, based on a whole-life care plan that focusses on what matters to the person and their family" (Transforming Care and Commissioning Steering Group, 2014) pp. 33
Supports are designed to address the person, their needs (physical and mental well-being) desires and ambitions, their environment and the interaction between the two	"Challenging behaviour is socially constructed; it is the product of individual and environmental factors interacting together" and "where individuals with problems are cared for in environments which do not respond well to their needs, challenging behaviour is likely to develop" (Department of Health, 1983/2007) pp. 7 "Address the key areas of a person's life, health and well-being which are most concern . . . recognizing individual needs, hopes, desires and capacities" and "see 'behaviour that challenges and complex support needs in context', thereby responding to individuals by first removing stressors and building on capacity assets, rather than pathologising problems with individuals that require restrictive or 'removal' treatment responses" (Learning Disability Professional Senate, 2015) (pp. 7 and 11)

First things first....define what it is
you are trying to implement and
how it is supposed to work

What can we agree on?! Working in Partnership

A conceptual framework for understanding why challenging behaviours occur in people with developmental disabilities

Richard P Hastings, David Allen, Peter Baker, Nick J Gore, J Carl Hughes, Peter McGill, Stephen J Noone and Sandy Toogood

Abstract

Background: To be able to define positive behavioural support (PBS), describe PBS interventions and clarify the individual and organisational competencies needed to support PBS, a clear underlying conceptual framework is needed to identify why challenging behaviours occur.

Method and materials: Non-systematic review and discussion of the state of research and theoretical evidence focusing on vulnerability factors for challenging behaviours, maintaining processes, and the social impact of challenging behaviour.

Results: Understanding challenging behaviour is related most strongly to context. First, challenging behaviours are defined in terms of their social effects. Second, vulnerability factors for challenging behaviour include some biological factors, but mainly psycho-social risks relating to the life situation and inequalities experienced by people with developmental disabilities. Third, social contextual processes are primarily responsible for maintaining challenging behaviours.

Conclusions: PBS is a broad approach to understanding and intervention referring to multiple contributing factors and processes. To describe PBS without reference to an underlying theoretically grounded conceptual framework would lead to an impoverished version of the approach.

Keywords: Challenging behaviour, positive behavioural support, causation, conceptual framework

Introduction

Interventions designed to ameliorate problems faced by individuals with developmental disabilities¹ need to be informed by a model or framework that describes an understanding of the problem (Hastings, 2013). Positive behavioural support (PBS) is no exception. To learn about PBS without understanding what the intervention approach is designed to do, or why PBS exists in the form that it does, would represent an incomplete and impoverished picture.

The need to elucidate the assumptions about the origins of a clinical problem to inform an intervention approach should not be a surprise to anyone reading this paper. In individual clinical practice, especially when applying

psychological interventions, a professional will develop a formulation of the problem and use that formulation to inform the focus of therapeutic intervention (see chapters in Taylor et al., 2013). Within PBS, formulation may be given a different name (generation of causal hypotheses, hypotheses about the function of a challenging behaviour) but it is a similar process. For example, any PBS intervention should be informed by functional assessment data (O'Neill et al., 1990). Indeed, there is evidence that including a functional analysis as a part of intervention for challenging behaviour significantly improves outcomes (e.g. Scotti et al., 1991).

¹ Developmental disability will be used as a term including children and adults with intellectual disability (ID) and those with autism, following international terminological conventions. Where evidence cited refers specifically to individuals with ID or with autism, this will be made explicit.

Definition and scope for positive behavioural support

Nick J Gore, Peter McGill, Sandy Toogood, David Allen, J Carl Hughes, Peter Baker, Richard P Hastings, Stephen J Noone and Louise D Denne

Abstract

Background: In light of forthcoming policy and guidance in the UK regarding services for people who display behaviour that challenges, we provide a refreshed definition and scope for positive behavioural support (PBS). Through doing this we aim to outline a framework for the delivery of PBS that is of practical and strategic value to a number of stakeholders.

Method and materials: We draw extensively on previous definitions of PBS, relevant research and our professional experience to create a multi-component framework of PBS, together with an overall definition and a breakdown of the key ways in which PBS may be utilised.

Results: The framework consists of ten core components, categorised in terms of values, theory and evidence-base and process. Each component is described in detail with reference to research literature and discussion regarding the interconnections and distinctions between these.

Conclusions: We suggest the framework captures what is known and understood about best practice for supporting people with behaviour that displays as challenging and may usefully inform the development of competences in PBS practice, service delivery, training and research.

Keywords: Positive behavioural support, definition, core concepts

Introduction

International evidence regarding challenging behaviour displayed by children, young people and adults with intellectual or developmental disabilities is strongly in favour of positive behavioural support (PBS) as a model of intervention. This now includes systematic and meta-analytic reviews of single-case and small group designs that demonstrate significant reductions (typically greater than 50 per cent) in challenging behaviour following PBS intervention (Carr et al., 1999; Dunlap and Carr, 2007; Goh and Bambara, 2013; LaVigna and Willis, 2012). It also includes a smaller number of randomised trials, including a two-treatment study focusing on support for families in community settings (Durand et al., 2012) and a UK randomised controlled trial in which challenging behaviour displayed by adults with intellectual disabilities reduced by 43 per cent after PBS intervention compared with standard treatment (Hassiotis et al., 2009).

Whilst developments and implementations in the UK have generally advanced more slowly than those in the US, in the last ten years a variety of policy documents and professional guidelines have drawn on PBS as a model of best practice for supporting people who display challenging behaviour (British Psychological Society, 2004; Department of Health 2007; Royal College of Psychiatrists, British Psychological Society & Royal College of Speech & Language Therapists, 2007). At times these documents have also incorporated guidance from authors who either advocate alternative approaches to the management of challenging behaviour or embed the principles and procedures of PBS within broader recommendations in an attempt to reach a variety of audiences and serve a variety of aims.

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Implementing positive behavioural support: changing social and organisational contexts

David Allen, Peter McGill, Richard P Hastings, Sandy Toogood, Peter Baker, Nick J Gore and J Carl Hughes

Abstract

Background: Social and organisational contexts have a major influence on both challenging behaviour and interventions designed to ameliorate such behaviour and improve quality of life.

Method and materials: A non-systematic review was conducted in order to identify social and organisational factors that impact upon positive behavioural support (PBS) intervention.

Results: A series of micro and macro influences on intervention effectiveness were identified. Possibilities for improving intervention effectiveness that extend the scope of traditional behavioural interventions were discussed.

Conclusions: Implications and opportunities for building capacity at an individual service user, organisational and cultural level are highlighted.

Keywords: Positive behavioural support, PBS, mediators, organisation, capacity building.

Introduction

Though once seen as an almost inevitable concomitant of intellectual disability, challenging behaviour is now recognised to be the product of a complex interaction between biological, developmental and environmental factors (Hastings et al., this issue; Langthorne et al., 2007). This understanding is central to the concept of challenging behaviour itself, the term being intended to emphasise that:

'... such challenges represent challenges to services rather than problems which individuals ... in some way carry around with them.'
(Blunden and Allen, 1987, p. 14)

Support for this concept has come from research which has repeatedly demonstrated that certain immediate ('micro') characteristics of the social environment (such as social distance and aversive stimulation) underpin the motivation for much challenging behaviour (McGill, 1999). On a broader ('macro') level, the absence of sufficient capability and capacity in systems to support people with challenging behaviour has been shown to be a key organisational determinant of family/service breakdown and subsequent out of area placement (Goodman et al., 2006; Phillips and Rose, 2010). The desire to build such capability and capacity has therefore been at the heart of UK policy for several decades. This is evident in the Mansell Report (Department of Health, 2007) and in

the more recent response to the Winterbourne scandal (Department of Health, 2012). A person's immediate and broader environments therefore play a significant role in determining both whether challenging behaviour is presented in the first place and the service pathway followed thereafter (Allen, 1999; Hastings et al., this issue).

While achieving behavioural change has been repeatedly demonstrated at an individual service user level within the research literature, being able to implement and sustain behavioural support at the volume required to meet the needs of all those who present with challenging behaviours is a critical objective that the field has historically failed to meet. In reviewing the commonalities and differences between applied behaviour analysis (ABA) and positive behavioural support (PBS), Dunlap et al (2008) noted that one distinguishing feature of the latter is its desire to make behaviour change strategies more effective in 'complex settings and at multiple levels and larger scales of implementation' (pp. 688-89) such as 'local, regional, and state-wide programs' (p. 690). Carr (2007, p. 4) also suggested that 'the central independent variable in PBS is systems change' and there is some limited evidence to suggest PBS interventions that include a focus on achieving such change are more effective (Carr et al., 1999). This has led to the use of concepts from the organisational psychology

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Developing a core competencies framework for positive behavioural support: issues and recommendations

Louise D Denne, Stephen J Noone, Nick J Gore, Sandy Toogood, J Carl Hughes, Richard P Hastings, David Allen, Peter Baker and Peter McGill

Abstract

Background: Widespread adoption of positive behavioural support (PBS) will stand and fall on the extent to which we can develop a competent workforce. The case for the development of a competence framework for PBS is presented.

Method and materials: We review the role that competence frameworks play in evidence-based practice and outline some of the ways in which they have been defined and structured. We describe the process used to develop the UK Autism Education Competence Framework (ABACF) and discuss the particular issues that need to be considered when developing a competence framework specifically for PBS.

Results: We propose a conceptual model illustrating what a PBS competence framework might look like and suggest a process for its development.

Conclusions: Competence frameworks are one means of translating evidence into practice. To be effective they must be an integral part of all aspects of service provision and must be grounded in the defining components of the discipline they describe.

Key words: Competence framework, competencies, positive behavioural support, challenging behaviour

Introduction

People with an intellectual disability have a vulnerability to develop behaviours that challenge others (Hastings et al., this issue). It is therefore imperative to develop services that are built around the best available evidence-based interventions. A service that is structured around a positive behavioural support (PBS) approach is currently considered best practice in the care of those who may present with challenging behaviour (Royal College of Psychiatrists, British Psychological Society & Royal College of Speech & Language Therapists, 2007). It follows that if this population is to be supported effectively, there is a need for a significant investment across all services in the UK to build a systemic competence in PBS delivery. This competence not only needs to be represented in front line staff routinely engaged directly with service users, but in the whole system that supports the direct service deliverer (see Allen et al., this issue).

Prevalence of challenging behaviour is considerable in populations of people with intellectual disability (Allen, 2008; Allen, Lowe, Matthews and Arnes, 2012) and service provision increasingly relies more on independent service providers to offer the complete range of care. Arguably, it is also the case that commissioners of services have little clear criteria to judge the quality of service providers in their ability to meet the complex needs of the service users who are ultimately under their care. How should commissioners decide who and what services are adequately equipped to provide best available care for this user group? McGill (2013) addressed some of these issues with the development of a service specification for PBS. This outlines the essential criteria of quality service provision and will be incorporated into a new core specification for specialist services. The specification calls for staff to have the necessary training in PBS. What is

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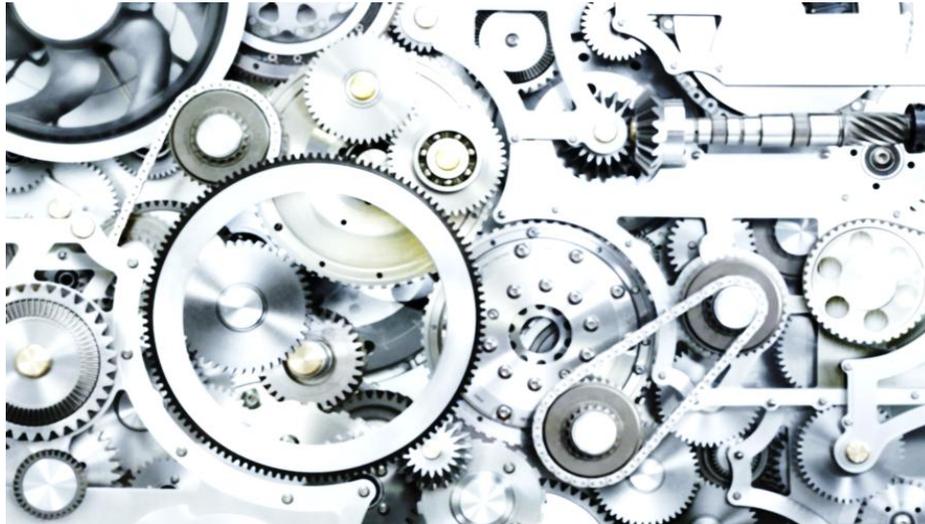
MARVEL

AVENGERS

ASSEMBLE



How does it work?



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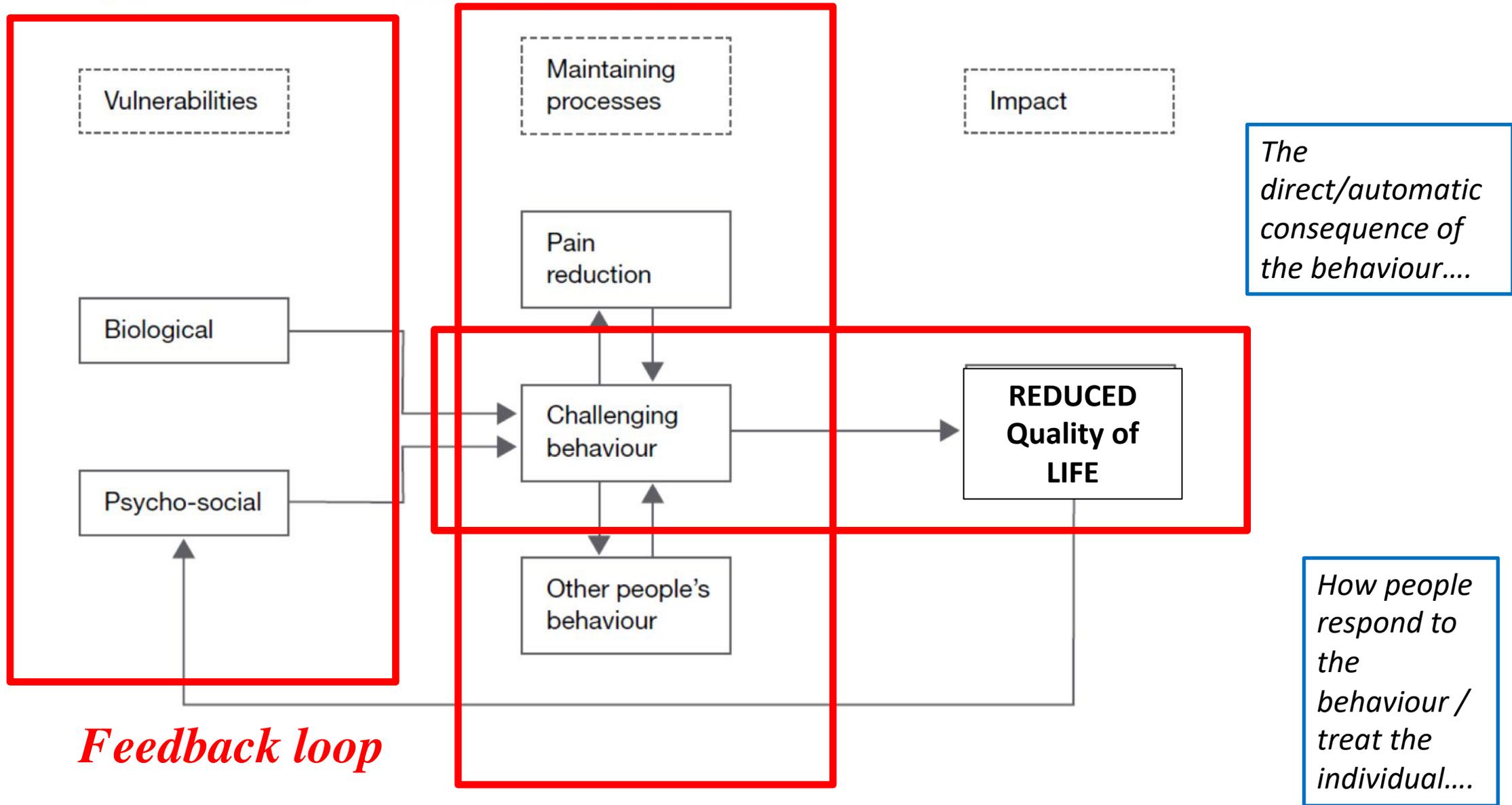
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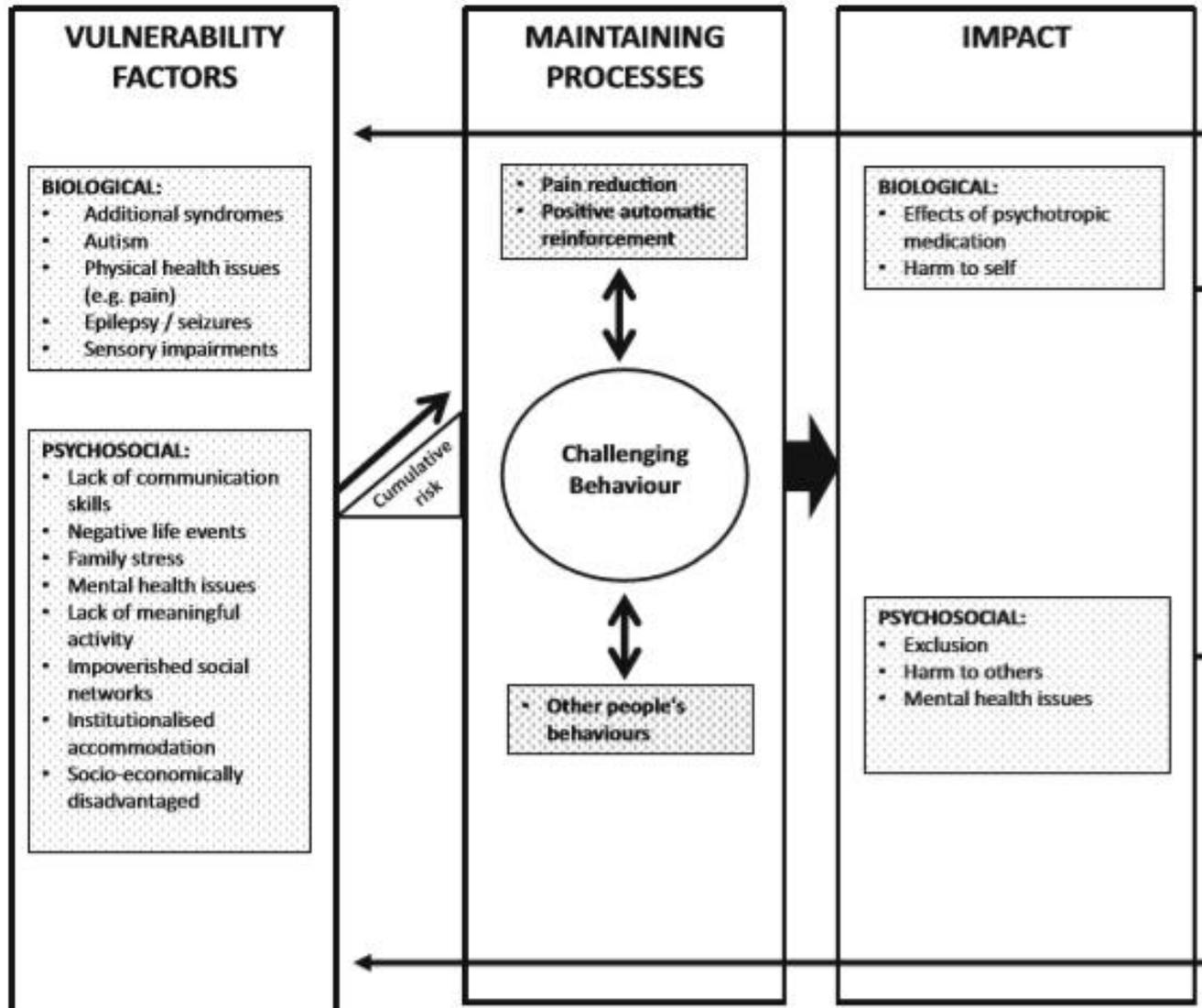
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- A Bio-psycho-social model that underpins Positive Behavioral Support
- Draws together what is known about CB from a range of disciplines
- Informs how a range of approaches and disciplines can provide support and create change
- ***Clearly illustrates some of the key behavior analytic principles that relate to what we know about the development of challenging behavior and how to support in this context***

Figure 2 A framework for understanding why challenging behaviours occur



Bowring, D.,L., Painter, J., & Hastings R.P. (2019). Prevalence of challenging behaviour in adults with intellectual disabilities, correlates and association with mental health. *Current Developmental Disorder Reports*, 6, 173-181



- **An updated/revised version**
- Listing additional vulnerability factors in bio and psycho-social groupings
- Emphasis on combination of multiple factors that incrementally add to overall risk of CB
- Ensured positive automatic reinforcement is referenced
- Included psychotropic medication as a negative impact that also feeds back to increase vulnerability

Fig. 2 A revised (building on Hastings et al. 2013) framework for understanding challenging behaviour. Adapted with permission from the *International Journal of Positive Behavioural Support*

Introduction

Mental health as motivational operation: Service-user and caregiver emotional states in the context of challenging behaviour

Mental health as motivational operation: Service-user and caregiver emotional states in the context of challenging behaviour

Nick Gore and Peter Baker
Tizard Centre, University of Kent

Abstract

This brief conceptual paper seeks to address the role of mental health and the experience of negative life events in the positive behavioural support framework in relation to the behaviour of both service users and caregivers and some of the implications this may suggest for intervention. It is argued that the conceptualisation of mental health related variables as motivating operations is parsimonious at a theoretical and practical level and may create one way of generating further synergies within the field of IDD.

Keywords: Intellectual disability, mental health, trauma, motivational operations

Introduction

Proponents of trauma informed care have often been critical of traditional behavioural interventions offered to individuals with intellectual disabilities who present challenging behaviour. In particular, Harvey (2012), who provided a seminal text in this area, highlighted concerns such as a disregard of physical health issues, reliance on brief periods of observation, over-reliance on medication, the use of restrictive practices that may perpetuate behavioural crisis and over-reliance on contingency management. Of note is that the same criticisms of traditional behavioural interventions were raised by early proponents and developers of PBS (Carr et al, 2002; Baker and Shepard 2006; Dunlap, Sailor, Horner and Sugai, 2009). Similarly, there is commonality between PBS and many of the approaches promoted by Harvey; for example, an emphasis on prevention and manipulation of antecedents, a focus on relationships and rapport and avoiding behavioural crisis through secondary prevention strategies. Yet Harvey (2012) does not appear to effectively distinguish PBS from traditional behavioural approaches, leading to claims that are at times inaccurate and may ultimately perpetuate poor practice in the support of people with intellectual disabilities.

Most noticeably, Harvey, in her trauma informed behavioural interventions book, rejects the use of functional behavioural assessment (FBA) on the grounds that it is about controlling people and instils a narrative of the person being manipulative. These criticisms are difficult to sustain when considering FBA within a PBS framework, where practices are primarily concerned with generating hypotheses that relate to a broad range of contextual factors which will ultimately be used to inform the support of greater individual choice, predictability and personal control (Gore et al, 2013). The overriding message surrounding PBS's use of FBA is that behaviours are not random, but serve key communication functions and are displayed by the individual to support fundamental needs.

As an alternative to FBA, Harvey argues for a thorough social history, a focus on behaviours as recognisable symptoms of trauma and listing of all possible triggers and anniversaries. Whilst this assessment methodology has some commonalities with FBA, it could present major problems to the practitioner in terms of arriving at a useful and valid formulation, as much of the data could be correlational and unverifiable. Although the fluctuating nature of trauma related responses both

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- *A brief presentation of a relatively brief article!*
- **Gore, N.J., & Baker, P. *International Journal of Positive Behavioural Support* (2017), 7 (1), 15-23**
- ***Builds on Special Edition of IJPBS* Autumn 2013 – outline, describe and clarify PBS Framework**
- ***Draw closer connections between approaches to understanding challenging behaviour and emotional health for people with intellectual disabilities and those who support them***

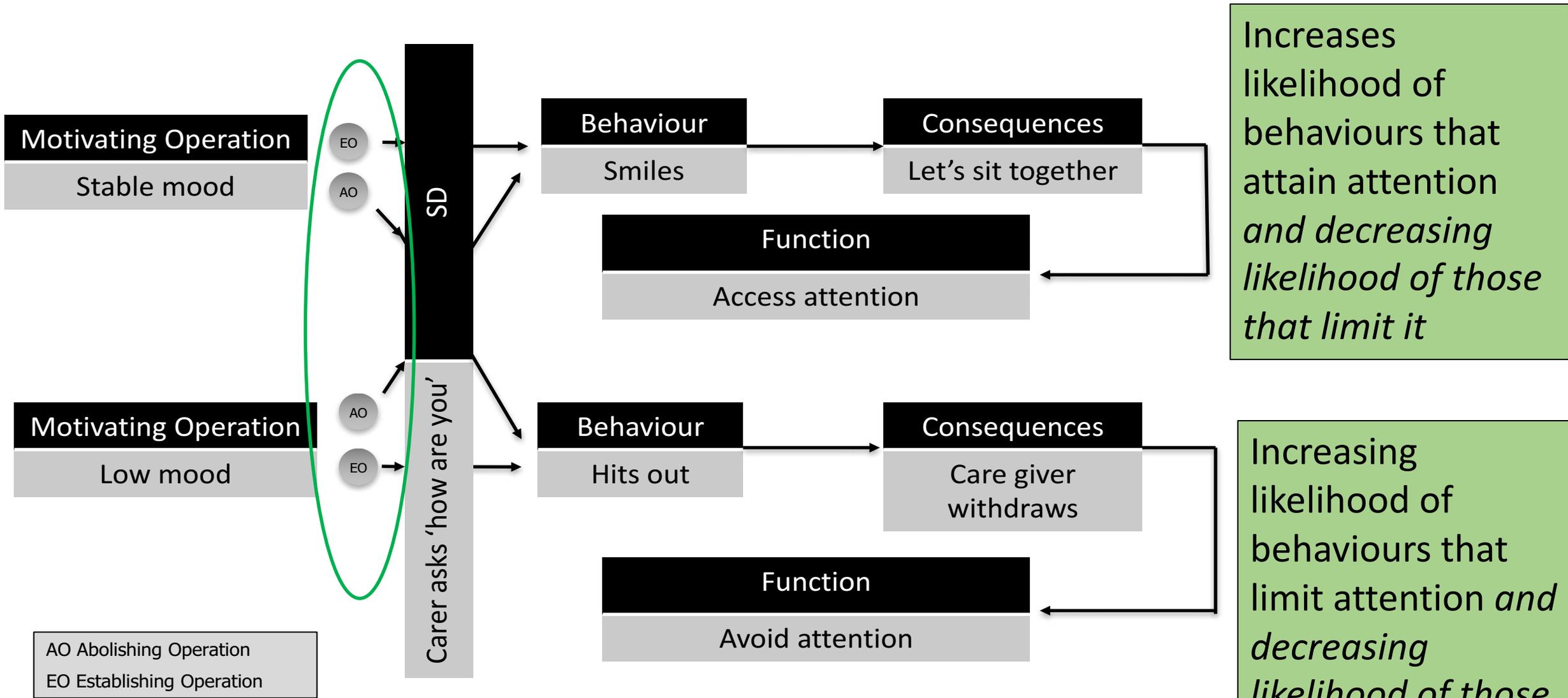


Fig 1c Mood as an MO for adaptive behaviour

Just an example.....

Definition and scope for positive behavioural support

Nick J Gore, Peter McGill, Sandy Toogood, David Allen, J Carl Hughes, Peter Baker, Richard P Hastings, Stephen J Noone and Louise D Denne

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Introduction

International evidence regarding challenging behaviour displayed by children, young people and adults with intellectual or developmental disabilities is strongly in favour of positive behavioural support (PBS) as a model of intervention. This now includes systematic and meta-analytic reviews of single-case and small group designs that demonstrate significant reductions (typically greater than 50 per cent) in challenging behaviour following PBS intervention (Carr et al, 1999; Dunlap and Carr, 2007; Goh and Bambara, 2013; LaVigna and Willis, 2012;). It also includes a smaller number of randomised trials, including a two-treatment study focusing on support for families in community settings (Durand et al, 2012) and a UK randomised controlled trial in which challenging behaviour displayed by adults with intellectual disabilities reduced by 43 per cent after PBS intervention compared with standard treatment (Hassiotis et al, 2009).

Whilst developments and implementations in the UK have generally advanced more slowly than those in the US, in the last ten years a variety of policy documents and professional guidelines have drawn on PBS as a model of best practice for supporting people who display challenging behaviour (British Psychological Society, 2004; Department of Health 2007; Royal College of Psychiatrists, British Psychological Society & Royal College of Speech & Language Therapists, 2007). At times these documents have also incorporated guidance from authors who either advocate alternative approaches to the management of challenging behaviour or embed the principles and procedures of PBS within broader recommendations in an attempt to reach a variety of audiences and serve a variety of aims.

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- Again – not new information as such
- Consensus
- Clarity
- Practice focussed / pragmatic
- *Grounding in a basic science of human behaviour*
- *Reflective of UK context and other models of practice*

Gore, N.J., McGill, P., Toogood, S., Allen, D., Hughes, C., Baker, P., Hastings, R.P., Noone S., & Denne, L. (2013). **Definition and Scope for Positive Behaviour Support.**
International Journal of Positive behavioural Support

Values	1. Prevention and reduction of challenging behaviour occurs within the context of increased quality of life, inclusion, participation, and the defence and support of valued social roles
	2. Constructional approaches to intervention design build stakeholder skills and opportunities and eschew aversive and restrictive practices
	3. Stakeholder participation informs, implements and validates assessment and intervention practices
Theory and Evidence Base	4. An understanding that challenging behaviour develops to serve important functions for people
	5. The primary use of Applied Behaviour Analysis to assess and support behaviour change
	6. The secondary use of other complementary, evidence-based approaches to support behaviour change at multiple levels of a system
Process	7. A data-driven approach to decision making at every stage
	8. Functional assessment to inform function-based intervention
	9. Multicomponent interventions to change behaviour (proactively) and manage behaviour (reactively)
	10. Implementation support, monitoring and evaluation of interventions over the long term

✧ A framework not a single treatment.....

The *primary* use of **Applied Behaviour Analysis** to assess and support behaviour change.....

But

In the context of **person centred approaches and social role valorisation...**

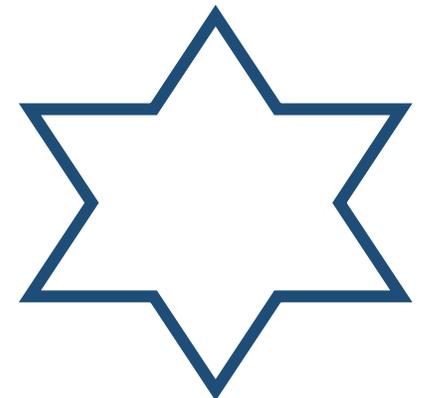
VALUES

1. Prevention and **reduction of challenging behaviour occurs within the context of increased quality of life**, inclusion, participation, and the defence and support of valued social roles

- *CB is defined by impact on wellbeing and quality of life and influenced by a range of bio-psycho-social variables.*
- *When an individual's needs, preferences and circumstances (and those of the wider support system) are fully and appropriately supported their quality of life is likely to be high and challenging behaviour is likely to be low.*

In PBS increasing QOL is therefore both an intervention and primary outcome.

Reducing the occurrence of CB is secondary



VALUES

2. Constructional approaches to intervention design build stakeholder skills and opportunities and eschew aversive and restrictive practices

- PBS is about **increasing skills and opportunities** and **making people's lives bigger**, fuller and increasingly satisfying.

PBS = Doing and learning more to support better lives

- **Aversive and restrictive practices fly in the face of this.** They often arise in attempts to directly reduce CB without taking account of the full range of causal factors; **limit what an individual does or has the chance to do and by definition are experienced as unpleasant or painful.**

No aversive or restrictive practices for PBS!

VALUES

3. Stakeholder participation informs, implements and validates assessment and intervention practices

- CB develops and has impact across a broad range of contexts.

In PBS **EVERYONE** in the system has a part to play and needs to be supported.

Theory and Evidence

- CB develops and is maintained by the interplay of a range of biological and psychosocial factors and interactions. It reflects a person's best attempt to meet their basic and specific needs. (*FUNCTIONAL MODEL*)
- **ABA** is the bedrock for understanding how CB develops and in accordance with the values base described above, informing the PBS processes of assessment, intervention and evaluation.
- PBS encourages and **embraces use of other evidence-based approaches** that fit with the conceptual model underpinning the framework.
- PBS also includes interventions aimed at **creating and maintaining change to the broader system** that influences CB displayed by an individual.

Process

- It's all about the **data!** A scientific approach to decision making is used throughout the PBS process
- **Holistic and individualised assessment** that reliably identifies the function of an individual's behaviour provides a foundation for the PBS process. It **directly informs which interventions are selected** and how these are implemented to increase the likelihood of effectiveness (*FUNCTIONAL ASSESSMENT*)
- Multiple factors influence development and maintenance of CB and so **multiple interventions are typically called for**. These need to both provide constructive and functionally-related **ways of increasing quality of life and reducing CB overtime together with non-aversive ways of supporting people when CB does occur**.
- PBS is not a quick fix and there is a need to continue to **monitor effectiveness and develop support accordingly over time** – to build and sustain rich, satisfying lives.

UK Support for PBS

Local Government Association **NHS England**

Ensuring quality services

Core principles for the commissioning of services for children, young people, adults and older people with learning disabilities and/or autism who display or are at risk of displaying behaviour that challenges

Publications Gateway reference 01197



Department of Health

Positive and Proactive Care: reducing the need for restrictive interventions

Prepared by the Department of Health

Department of Health **Skills for Health** **skillsforcare**

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



Assessing the impact of the UK Positive Behavioural Support (PBS) Academy: An internet survey

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Abstract

Background: The Positive Behavioural Support (PBS) Academy is a collective of organisations and individuals in the UK working together to promote PBS as a framework for working with children and adults with intellectual disabilities who are at risk of behaviour that challenges. This paper presents a stakeholder perspective of the activities of the PBS Academy as part of an overall evaluation and impact study of its work to date.

Methods and materials: The study used an internet-based survey designed by the authors and members of the PBS Academy.

Results: Over one third of participants rated the activities of the PBS Academy as being done 'well' or 'very well' and the resources developed by the Academy were rated as 'useful' or 'very useful' by over 70% of participants for all but one resource. The most frequently used resources were the *PBS Competence Framework* and the *International Journal of Positive Behavioural Support (IJPBS)* 2018 special edition articles by Gore et al and Hastings et al. The PBS Academy was rated as having done less well in bringing stakeholders together to share practice.

Conclusions: The results suggest that there is a role for a national body for PBS in the UK, with a focus on facilitation and enablement, especially in relation to workforce and individual professional and service development.

Keywords: Positive behavioural support, intellectual disability

Introduction

Positive Behavioural Support (PBS) is recognised in the UK as an effective and ethical way of supporting people with intellectual disabilities who are at risk of behaviour that challenges, and has been recommended in several key policy documents and professional guidelines (National Institute for Health and Care Excellence, 2015; Local Government Association and NHS England, 2014; Department of Health, 2014; Skills

for Care and Skills for Health, 2014; Skills for Care and National Development Team for Inclusion, 2013). Despite this, many in the field remain concerned that there is a 'significant lack of shared understanding as to what this approach actually entails and evidence that services are simply re-labelling existing approaches as PBS without any discernible change in practice' (Challenging Behaviour Foundation, 2014, p1). These

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- **Conceptual model paper and definitions paper both voted very useful or useful by over 95% of sample (349)**



Some Tools and Resources to Support Implementation



Resources for people with learning disabilities,
family carers, staff and commissioners:

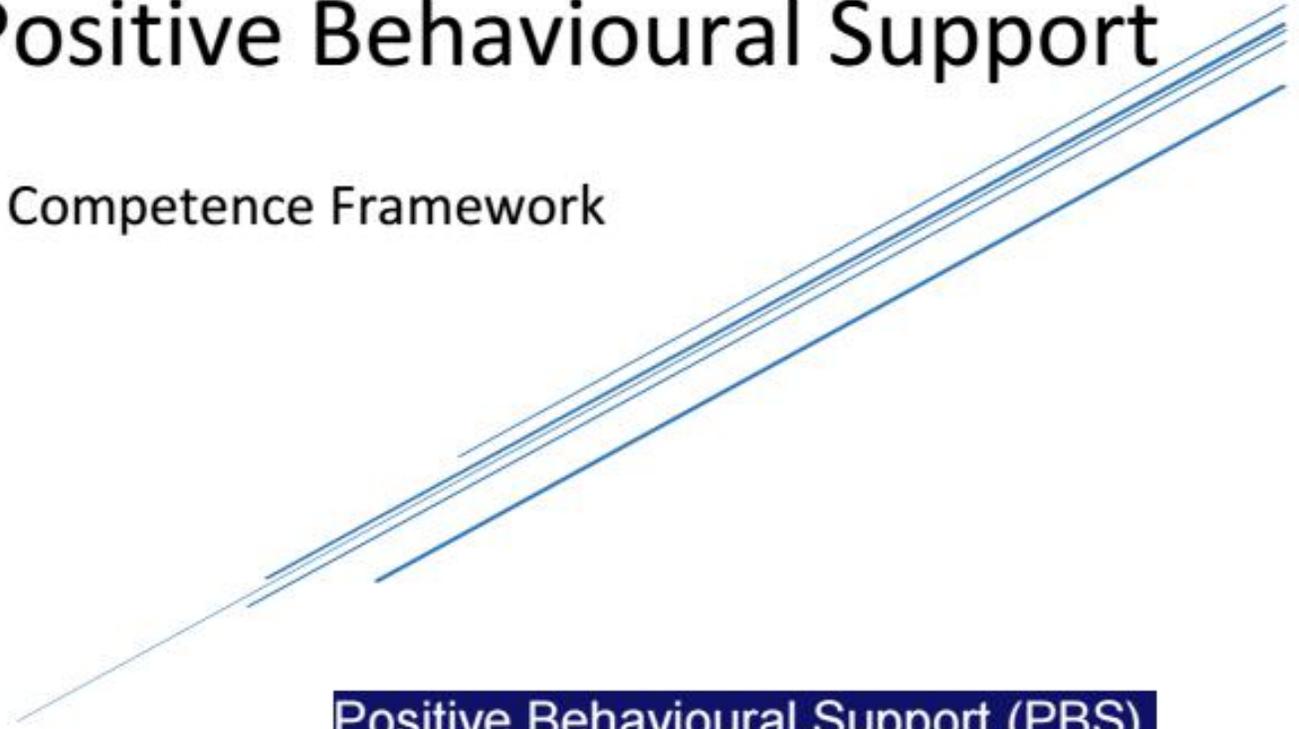
PBS is everybody's business

Stakeholder involvement



Positive Behavioural Support

A Competence Framework



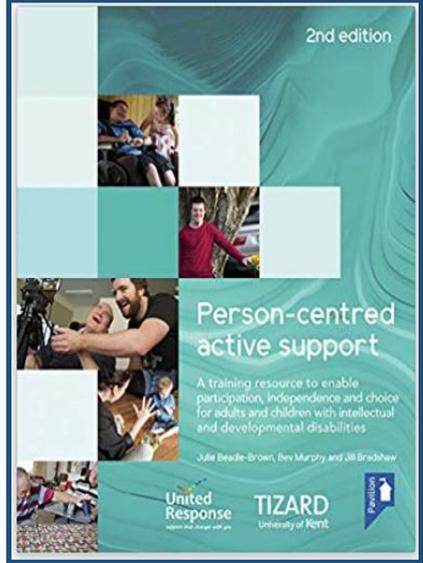
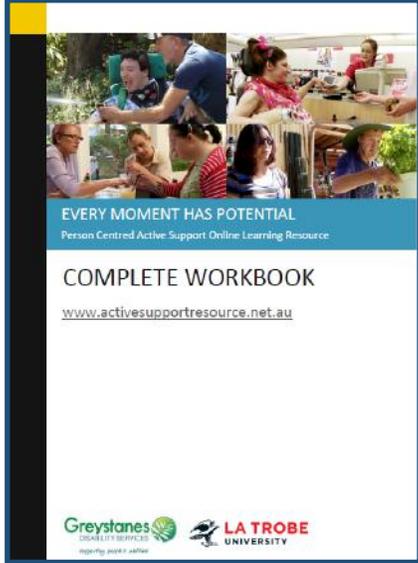
Positive Behavioural Support (PBS)
Coalition UK

May 2015

Overall structure

1. <i>Creating high quality care and support environments</i>	2. <i>Functional, contextual and skills based assessment</i>	3. <i>Developing and implementing a Behaviour Support Plan (BSP) Evaluating intervention effects and on-going monitoring</i>
1.1 Ensuring that services are values led	2.1 Working in partnership with stakeholders	3.1 Understanding the rationale of a BSP and its uses
1.2 Knowing the person	2.2 Assessing match between the person and their environment and mediator analysis	3.2 Synthesizing data to create an overview of a person's skills and needs
1.3 Matching support with each person's capabilities and with goals and outcomes that are personally important to them	2.3 Knowing the health of the person	3.3 Constructing a model that explains the functions of a person's challenging behaviour and how those are maintained
1.4 Establishing clear roles and effective team work	2.4 Understanding the principles of behaviour (4 term contingency); understanding the function of behaviour	3.4 Devising and implementing multi-element evidence based support strategies based on the overview and model Antecedent strategies
1.5 Supporting communication	2.5 Supporting data driven decision making	<ul style="list-style-type: none"> • Antecedent strategies • Developing functionally equivalent alternative behaviour (to CB)
1.6 Supporting choice	2.6 Assessing the function of a person's behaviour	<ul style="list-style-type: none"> • Increasing skills and communication • Systems change and contextual interventions
1.7 Supporting physical and mental health	2.7 Assessing a person's skills and understanding their abilities	3.5 Devising and implementing a least restrictive crisis management strategy
1.8 Supporting relationships with family, friends and wider community	2.8 Assessing a person's preferences and understanding what motivates them	<ul style="list-style-type: none"> • Arousal curve • Reactive strategies
1.9 Supporting safe, consistent and predictable environments		3.6 Developing the plan; outlining responsibilities and timeframes
1.10 Supporting high levels of participation in meaningful activity		3.7 Monitoring the delivery of the BSP (procedural/treatment fidelity/integrity)
1.11 Knowing and understanding relevant legislation		3.8 Evaluating the effectiveness of the BSP
1.12 A commitment to Behaviour Skills Training		3.9 The BSP as a live document

Person Centred Active Support



A proven, evidence-based approach to care and support that **enables and empowers people with intellectual disabilities to participate in all aspects of life** (Mansell, J. & Beadle-Brown, J., 2012)

- **Every moment has potential**
- **Maximising choice and control**
- **Little and often**
- **Graded assistance**



Providing the 'conditions/foundation for PBS' or... ***a primary/preventative tier within a broader conceptualisation of PBS?***

Reducing challenging behaviour of adults with intellectual disabilities in supported accommodation: A cluster randomized controlled trial of setting-wide positive behaviour support

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ARTICLE INFO

Number of reviews completed in 2
This paper belongs to SE: Clustered/
Longitudinal

Keywords:

Intellectual disability
Adults
Challenging behaviour
Positive behaviour support
Randomized controlled trial
Supported accommodation

ABSTRACT

Background: Improving the quality of social care through the implementation of setting-wide positive behaviour support (SWPBS) may reduce and prevent challenging behaviour.

Method: Twenty-four supported accommodation settings were randomized to experimental or control conditions. Settings in both groups had access to individualized PBS either via the organisation's Behaviour Support Team or from external professionals. Additionally, within the experimental group, social care practice was reviewed and improvement programmes set going. Progress was supported through coaching managers and staff to enhance their performance and draw more effectively on existing resources, and through monthly monitoring over 8–11 months. Quality of support, quality of life and challenging behaviour were measured at baseline and after intervention with challenging behaviour being additionally measured at long-term follow-up 12–18 months later.

Results: Following intervention there were significant changes to social care practice and quality of support in the experimental group. Ratings of challenging behaviour declined significantly more in the experimental group and the difference between groups was maintained at follow-up. There was no significant difference between the groups in measurement of quality of life. Staff, family members and professionals evaluated the intervention and its outcomes positively.

Conclusions: Some challenging behaviour in social care settings may be prevented by SWPBS that improves the quality of support provided to individuals.

1. Introduction

Challenging behaviour remains a significant problem in supported accommodation settings for people with intellectual disabilities (cf. Department of Health, 2007). Almost half of residential services use restrictive responses such as physical intervention (Deveau & McGill, 2009). Challenging behaviour is associated with placement breakdown (Phillips & Ross, 2010) and the costly

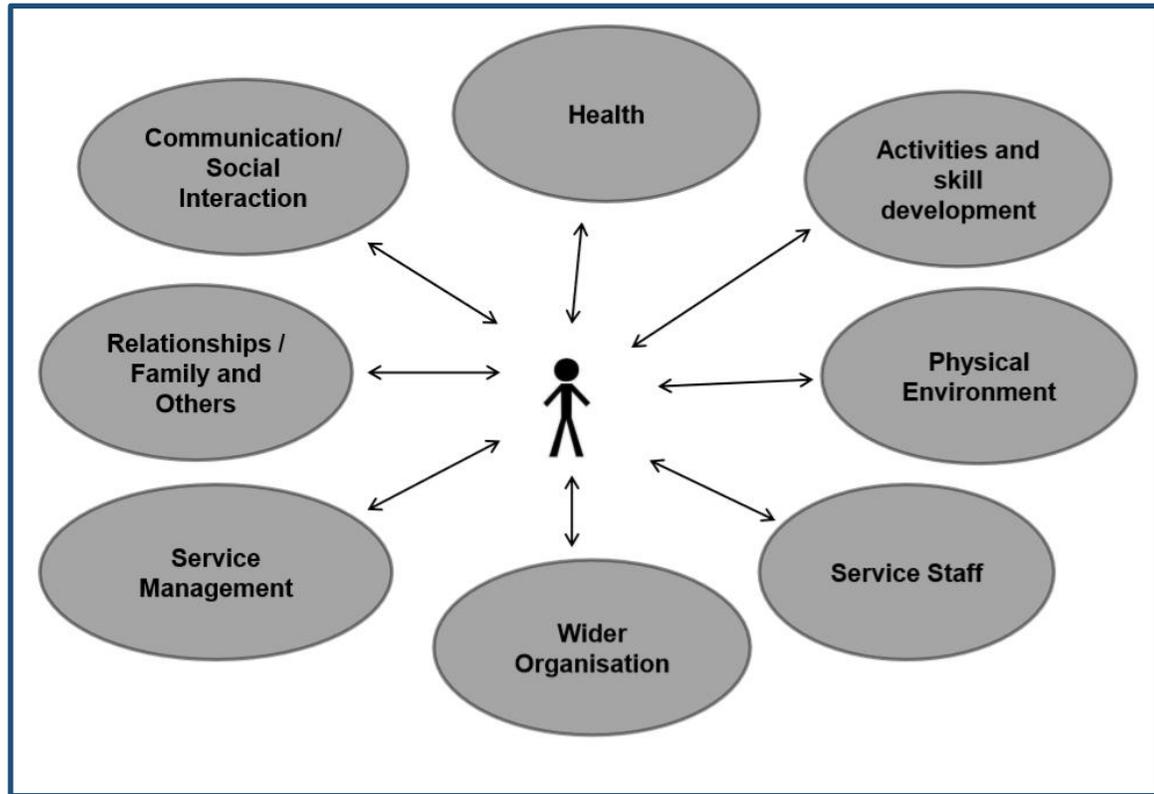
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<https://doi.org/10.1016/j.ridd.2018.04.020>

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Setting Wide PBS Approach:

- Significant improvements on social care and quality of support
- Significant (maintained) reductions in CB for experimental group



Sample section

2.6	Assessing the function of a person's behaviour		
	Things you need to know	Things you need to do	Why is important?
DC	<p>What is meant by the term functional assessment and what a functional assessment aims to do</p> <p>What is meant by the term functional analysis and what a functional analysis aims to do</p>	<p>Contribute to the assessment process as required</p> <p>Support the person through the assessment process as appropriate</p> <p>Support other key stakeholders through the assessment process as appropriate</p>	<p>A PBS plan is based on the principles of behaviour analysis, in identifying the functions of the behaviour to develop a multi-element plan</p> <p>Evidence suggests that including a functional analysis as a part of intervention for challenging behaviour also improves outcomes (e.g. Scotti et al., 1991; Carr et al., 1999; Didden et al., 1997; Campbell, 2003; Harvey et al., 2009)</p>
SUP/ MGR	<p>A range of functional assessment tools and their strengths and limitations</p> <p>The triangulation of data from a number of sources</p>	<p>Use multiple-data gathering tools to compensate for weaknesses in individual measures</p> <p><i>Use a range of functional assessment tools and support stakeholders participation where appropriate: Semi structured interviews; Rating Scales; Reviewing recordings; Direct observation strategies; Triangulation of data</i></p> <p><i>Take an active role in supporting ORG/CST specialists in the conduct of hypothesis testing through experimental functional analysis</i></p>	
ORG / CST	<p>The importance of having specialist behaviour analytic services to assess the function of behaviour</p>	<p><i>Complete functional assessment incorporating all variables of the person, environment, staff team and organization</i></p>	

People with
learning
Disabilities (x2)

Family
Caregivers (x5)

Service
Providers (x1)

Commissioners
and Care
Managers (x3)

Observation
Checklist for
Inspections (x1)

**Related co-produced PBS Academy resources to support
implementation**

Standards for:

- Services
- Training
- Individual practitioners

<http://pbsacademy.org.uk/other-pbs-resources/>

Strengths, Skills and
Training Needs of PBS
Practitioners who work
with Children and Young
People in the UK

The Survey: *First time* the competency guide has been used in research

Now we have some agreement on what should be happening – lets take a look to see what *is* happening!

(To what extent is PBS being implemented?)

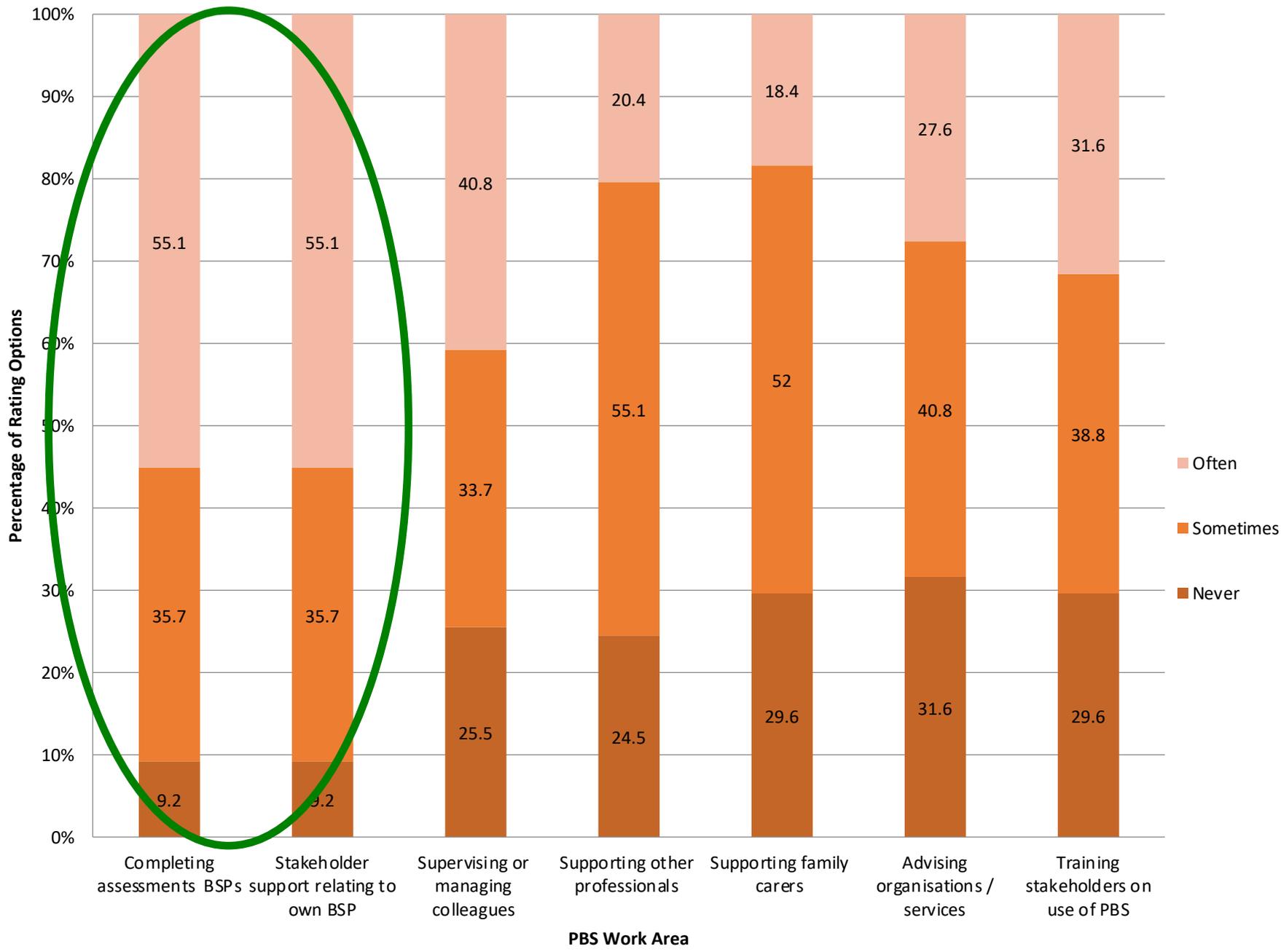
- Focus on **practitioners who are operating at behavior specialist, supervisor level and higher level specialist / consultant level** to support **children and young people** with disabilities in relation to behavior that challenges :

“I use PBS to support other people who provide direct care (family caregivers and/or staff) to children or young people with learning disabilities or Autism Spectrum Condition or to other members of my team who have this kind of role.”

- **What skills and experiences are they bringing to this and how does this relate to best practice?**
- **What are their training needs?**
- **100** practitioners across England, Wales, Scotland and Northern Ireland

3 Key findings:

- Training needs and perceived competence **varied in accordance with both years of experience and levels of training/qualification**
- Overall perceived ***training needs for intervention competences were higher*** than for assessment based areas
- **What people could perhaps do and what they were doing did not always marry up...**



Significantly more likely to do these relative to all other areas
Small degree of stakeholder involvement / systems working

What people can do and what they are actually doing might be quite different – particularly in this aspect of PBS

A systems issue?
Organisational barriers?

**A Framework for the
Evaluation of
Positive Behavioural
Support in the UK:
A Delphi Study**

Building core domains for the evaluation of PBS: A consensus-based approach

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²Learning Disability and Mental Health Service Delivery Unit, Bridgend

Abstract

Background: The PBS framework brings together values, theory and procedures that principally facilitate high quality lifestyles and constructive changes for people with disabilities, other stakeholders and organisations. Most commonly, however, PBS research has focused on a small range of potential outcomes, with a primary emphasis on reducing behaviour that challenges (CB). Agreeing a more comprehensive set of outcome domains that fit with the UK context is important for ensuring the implementation and development of PBS.

Method and materials: This study used a three phase, consensus-building approach to identify a set of core outcome domains for PBS. Phase One comprised a four-round Delphi exercise to identify an initial pool of domains and overall structure. Subsequent phases involved stakeholder voting exercises to identify core domains and a stakeholder representative group to shape final wording.

Results: A total of 23 core domains were identified that covered a broad scope of outcomes for people with disabilities, family and paid caregivers, and systems change at an organisational level.

Conclusions: The identified domains provide a useful structure to support the evaluation and implementation of PBS in the UK with potential benefits for people with disabilities, families, professionals and commissioners. The core domains will also allow for development of focused research programmes to build a more detailed evidence base for best practice.

Keywords: PBS; outcomes; consensus; Delphi; evaluation

Introduction

Positive behavioural support (PBS) has evolved as a framework to support people with intellectual and developmental disabilities (IDD) who present (or are at risk of presenting) behaviour that challenges (CB). PBS might therefore be considered an intervention for primarily reducing CB, and has indeed at times been described as such (eg Hassiotis et al., 2018, p161). The underlying philosophy, values-base, theoretical stance and practice of PBS are, however, far more nuanced.

Principally, whilst PBS is intended to ensure reduced risk of CB over the long term, the fundamental focus of the framework concerns support for enhanced

life-style and life quality (Gore et al, 2013). This overriding premise is grounded in the values base of PBS, a person centred focus in support of social inclusion and participation, and theoretical and research-informed evidence (Carr et al, 2002).

Poor quality of life (QoL) and adversity, across a range of domains (eg health, wellbeing, relationships) is more common amongst people with IDD of all ages relative to the general population (eg Emerson and Hatton, 2014; Lunsy and Benson, 1999; Santoro, Shear and Haber, 2018). At the same time, factors pertinent to poor QoL are known risk factors for the development

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Process	7. A data-driven approach to decision making at every stage
	8. Functional assessment to inform function-based intervention
	9. Multicomponent interventions to change behaviour (proactively) and manage behaviour (reactively)
	10. Implementation support, monitoring and evaluation of interventions over the long term

Gore, N.J., Jones, E., 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

Outcomes in the evaluation of PBS need to reflect defining principles and features:

- To provide evidence for their effectiveness and relevance
- To drive and focus goals and interventions throughout a PBS pathway – supporting implementation with integrity

The **PBS framework** places a theoretical and practical emphasis on: enhancing **quality of life; systems change** and **stakeholder engagement**

It could however, be argued that **PBS related research** has typically concentrated on demonstrating **outcomes that relate to behaviors that challenge** (typically in the context of an increase in an alternative/adaptive behavior of some form)

The **objective** of the current study was therefore to create a consensus **framework** regarding outcome **domains** that are required to more **comprehensively** evaluate use of PBS

Delphi-panel

- ✧ 10 PBS Research/practitioners in the UK
- ✧ 4 Stages
- ✧ Develop a broad range of outcome domains that could be applicable to PBS evaluation in different contexts

Voting Exercises

- ✧ 73 Practitioners, with some family caregivers and other professionals
- ✧ 3 events
- ✧ Identifying a subset of key areas that might be more routinely included in evaluations

Domain Area	Number of Items
Individual Level - Person with IDD	
QOL	33 (across 8 sub-categories)
Costs and quality of support received	11
Challenging behaviour	4
Mediator Level – Family Caregivers	
Physical, psychological and emotional wellbeing	7
Family Quality of Life	7
Relationship with focal person	3
Quality of support received	5
Skills knowledge and attitudes	7
Mediator Level – Care Staff	
PBS values (knowledge, attitudes and attributions)	10
PBS Theory (knowledge, attitudes and attributions)	8
PBS Process (knowledge, attitudes and attributions)	14
Wellbeing and work performance	16
Systems Level – Services, Organisations and Localities	
Service/organisation/locality Quality	10
Service/organisation/locality Functioning	12
PBS Systems	15
TOTAL	162

Focal Individual Level

- Choice making and control
- Relationships with family and friends
- Community presence and participation
- Engagement and activity
- Support for communication
- Health and fitness
- Emotional wellbeing
- Personal living environment
- Experience and support concerning aversive, restrictive and abusive practices
- Caregiver and staff understanding of person's support needs
- *Frequency, severity, intensity, duration, management difficulty and range of behaviours that challenge*

Increasing Direct Engagement with Stakeholders in PBS

PBS demands stakeholder engagement and the ultimate stakeholder is...

The focal person themselves!

Often however, it is **other people who decide** on goals for behavior support, and serve as informants throughout the PBS process, with the **individual not consulted** directly or significantly

Communication and interaction difficulties make this a challenge...

...but this is a challenge the PBS community must embrace.

Commentary

Supporting the direct involvement of students with disabilities in functional assessment through use of Talking Mats®

Jill Bradshaw, Nick Gore and Cathy Darvell

Abstract

Purpose – Bowling *et al.* describe ways of using the Behavior Problems Inventory – Short Form, illustrating how to use clinical norms to evaluate change. This commentary focuses on the importance of considering information gained directly from people with intellectual and developmental disabilities (IDD) during assessment. The paper aims to discuss these issues.

Design/methodology/approach – A pilot project involved interviews with four children with IDD. A Talking Mats® (TM) framework was used to gather children's views regarding challenging behaviours (CBs) and variables relevant to a functional behavioural assessment, such as things they found to be reinforcing, things that set the occasion for CB and things that helped prevent this.

Findings – The children were able to provide information and insight into several areas that are influential in the maintenance of behaviour that challenges. Some of this information may not have been obtainable from other sources or informants using traditional assessment methods alone.

Originality/value – Gathering the views of people with IDD is important. The Convention on the Rights of Persons with Disabilities (United Nations, 2009) states that people have the right to be heard. Many people with IDD have difficulties communicating. A TM framework is one method by which people may be able to express their views. Taking the views of the individual into account during the process of gathering information about behaviours that challenge should lead to greater understanding of the functions of any behaviours and therefore to more targeted, acceptable and effective forms of support.

Keywords Challenging behaviour, Communication challenges, Alternative and augmentative communication, Functional behavioural assessment, Talking Mats, User views

Paper type Research paper

Introduction

Children with intellectual and developmental disabilities (IDD) are at increased risk of displaying behaviours that challenge, relative to peers who do not have disabilities (Totsika *et al.*, 2011). Without appropriate support such behaviours tend to persist (Murphy *et al.*, 2005) and significantly impact on the health and wellbeing of the child and those that care for them (Emerson and Einfeld, 2011). A large body of research has demonstrated that challenging behaviour (CB) often serves important functions for the individual who displays it (Hastings *et al.*, 2013). In this light, interventions that respond proactively to functions of CB identified for an individual and support communication, quality of life, health and wellbeing more broadly are recognised as the most effective way of both improving positive outcomes and reducing CB over the long term (Gore *et al.*, 2013).

Jill Bradshaw and Nick Gore are Senior Lecturers in Intellectual and Developmental Disability and Cathy Darvell is a Postgraduate student, all at the Tizard Centre, University of Kent, Canterbury, UK.

Direct Involvement of Students with IDD in Functional Assessment Work

- Things I like (reinforcers)
- Things I do (challenging behaviour)
- Things that help on a bad day (de-escalation strategies)
- Things that make for a bad day (setting events, MOs, discriminative stimuli)



Personalized Goals for Positive Behavioral Support: Engaging Directly with Children who have Intellectual and Developmental Disabilities

Nick James Gore¹ · Peter McGill¹ · Richard Patrick Hastings^{2,3}

Accepted: 23 November 2020
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Abstract

Stakeholder involvement is fundamental to Positive Behavioral Support yet research in this area rarely obtains views of children with Intellectual and Developmental Disabilities. This study aimed to develop and demonstrate a means of engaging directly with children to identify personalized goals and priorities for their future support. An augmented communication approach was used to facilitate interviews with children who had a range of disabilities and displayed behavior that challenges. The interviewer asked children about activities, their own behavior, a caregiver's behavior, and quality of life to focus future potential assessment and intervention. We completed interviews in at least some areas with 9 out of 14 children. Children prioritized goals for future support and evidenced insight into behavior, needs, and preferences. These findings have promising implications for further direct engagement of children with disabilities throughout a support pathway to achieve outcomes rich in social validity.

Keywords Positive Behavioral Support · Children · Goals · Engagement · Communication

Highlights

- This study interviewed children with Intellectual and Developmental Disability about their goals and priorities for support.
- An augmentative communication approach (Talking Mats) was used.
- Children who completed interviews identified goals and priorities for their behavior, caregivers and other life areas.
- It is possible to engage directly with some children who have intellectual and developmental disabilities in behavior support research and practice.

Children with Intellectual and Developmental Disabilities (IDD) typically present with a range of difficulties concerning communication and adaptive skills; often experience physical health problems and encounter psychosocial

adversity, all of which places them at increased risk of behaviors that challenge (CB) relative to their peers (Gore et al. 2014; McClintock et al. 2003; Totsika et al. 2011a, b). Positive Behavioral Support (PBS) incorporates and builds upon the concepts and applications of behavioral science (Baer, Wolf and Risley 1968), human rights and values-based approaches to provide a framework of evidence-based practice for those at risk of CB (Carr et al. 2002; Gore et al. 2013; Horner et al. 1990; Kincaid et al. 2016). PBS recognizes that CB develop within the context of biological and psychosocial aspects of disability and via interactions between an individual, people around them and their environment to serve important functions (Hastings et al. 2013).

Based on this understanding, PBS seeks to enhance skills, opportunities, environments and interactions in ways related to an individual's specific needs and aspirations and

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Direct Involvement of Students with IDD in Goal Selection for PBS

- Things I like to do (reinforcers and preferred activities)
- Things I'd like to do more (adaptive behaviours)
- Things I'd like to do less (challenging behaviours)
- Things others do (caregiver behaviours)
- Things that are important (Quality of Life)



What are some of the things you like?

a) Put it here if you like it – here if you like it a bit - or here if you do not like it

b) Tell me about doing.....is it something you like a lot, like a little bit/not sure about or do not like?

Would you like to do more of these things in the future? Which ones?

Fig. 1 TM example: "Things you like" (Laura). The Symbols are designed and © to Adam Murphy 2015 and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission



We all do things which aren't so positive sometimes. What are some of the other things you do?

Would you like support to do any of these things less in the future? Which ones?

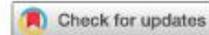
***Have a freak out'
'[pulling hair] - when
I'm stressed I always do
that' (Ben)***

***'[Helping other people] - I
do that a lot, like help with
my mum's shopping' and
'well Chris has crutches at
my school. Got him pencils
or a chair' (Natasha)***

***'Less shouting and
smacking. I want those to go
whoosh out the door'***

(David)

***'Always be a bit hard
when see new people
and say hello to new
people' (Emily)***



Making it Meaningful: Caregiver Goal Selection in Positive Behavioral Support

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Abstract

Objectives Positive Behavioral Support (PBS) is considered the treatment framework of choice for children with intellectual and developmental disabilities (IDD) at risk of behavior that challenges. PBS demands stakeholder engagement, yet little research has explored goal formation in this context for caregivers of children with IDD.

Methods We used Talking Mats and semi-structured interviews to support 12 caregivers of children with IDD who displayed behaviours that challenge, to develop goals for PBS. Interviews covered quality of life for caregivers and their child, adaptive and challenging aspects of child behavior, and aspects of caregiver's own behavior.

Results Caregivers were able to form individualised and meaningful goals in relation to all domains, demonstrating rich insight into personal needs and needs of their child. The process of forming goals was psychologically and emotionally complex given prior experiences and needs of participants but effectively supported by the interview method.

Conclusions We conclude that goal formation in PBS requires careful consideration and structuring but has the potential to support effective working relationships and ensure assessment and intervention is aligned with the needs and aspirations of families.

Keywords PBS · Caregivers · Goals · Challenging Behavior

Children and young people with intellectual and developmental disabilities (IDD) are at high risk of developing behaviors that challenge (BTC) (Totsika et al. 2011a, 2011b). By definition these behaviors have a negative impact upon an individual's wellbeing and life quality (Emerson 1995; Emerson and Einfeld 2011) and impact negatively upon the wellbeing and life quality of those who care for them (Baker et al. 2003; Hastings 2002; Woodman et al. 2015).

Positive Behavioral Support (PBS) provides an evidence-based and ethical approach to supporting people with IDD

in relation to BTC through a synthesis of Behavior Analytic (Baer et al. 1968) and Person Centred (Kincaid and Fox 2002) approaches. The PBS framework aims to increase skills, arrange opportunities and alter environments in accordance with individual needs and aspirations, to bring about positive changes in Quality of Life (QoL) and reduce risk of BTC over the long term (Carr et al. 2002; Gore et al. 2013; Homer et al. 1990; Kincaid et al. 2016). Strategies and interventions selected within the framework should therefore be highly individualised, rich in social and ecological validity and linked to socially and personally meaningful outcomes (Carr et al. 2002; Carr 2007; Gore et al. 2013).

The person centred foundations of PBS call for close collaboration between practitioners and stakeholders (Dunlap et al. 2008; Gore et al. 2013; Lucyshyn et al. 1997; McLaughlin et al. 2012). In the case of children, this typically includes working in partnership with family caregivers who are likely to know the child best, be experiencing the impact of behavior that challenges (BTC) and be highly motivated to invest in positive change (Dunlap and Fox 2007, 2009; Gore et al. 2014). Caregivers' own behavior is also often interconnected with that of their child (Hastings

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Supporting goal selection for caregivers:

- ✧ Same kind of questions, same kind of framework:
- ✧ Supports meaningful goal formation and insight and motivation
- ✧ Sensitive to caregiver's emotional state, experiences and expectations

We could sit at a table and have a meal, if we do that that's bringing a family component into her life so she's going to feel safe because knows a family that loves her and that would build the relationships in turn (3)



Hmmm, well not really...but perhaps a bit closer?

Denne, L., Gore, N., Hughes, J., Toogood, S., Jones, E. and Brown, F. (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*.

Implementing evidence-based practice: the challenge of delivering what works for people with learning disabilities at risk of behaviours that challenge

Louise D. Denne, Nick J. Gore, J. Carl Hughes, Sandy Toogood, Edwin Jones and Freddy Jackson Brown

Abstract

Purpose – There is an apparent disconnect between the understanding of best practice and service delivery in the support of people with learning disabilities at risk of behaviours that challenge. We suggest, as a problem of implementation. The purpose of this paper is to explore reasons why this might be the case: a failure to recognise the collective works of successive generations of research and practice; and a failure to address the macro-systems involved and systems changes needed to support implementation.

Design/methodology/approach – This paper reviews the consensus that exists in respect of best practice. Drawing upon ideas from implementation science the paper highlights the complexities involved in the implementation of all evidence-based practices and uses this as a framework to propose ways in which an infrastructure that facilitates the delivery of services in the learning disabilities field might be built.

Findings – This paper highlights core recommended practices that have been consistent over time and across sources and identifies the systems involved in the implementation process. This paper demonstrates that many of the necessary building blocks of implementation already exist and suggests areas that are yet to be addressed. Critically, the paper highlights the importance of, and the part that all systems need to play in the process.

Originality/value – In the absence of any generalised implementation frameworks of evidence-based practice in the learning disabilities field, the paper suggests that the findings may provide the basis for understanding how the gap that exists between best practice and service delivery in the support of people with a learning disability at risk of behaviours that challenge might be closed.

Keywords Adult social care, Learning disabilities, Challenging behaviour, Positive behaviour support, Implementation, Evidence-based practice

Paper type Conceptual paper

Background

An estimated 2.16% of adults and 2.5% of children in the UK have a learning disability (LD), approximately 1.5 million people (Mencap, 2020). This may be a small number in terms of the overall population requiring care, but people with LD are at a higher risk than others of developing behaviour that challenges. These behaviours, by definition, have a significant impact on well-being and life quality (Hastings *et al.*, 2013) for the person and their family. In turn, they represent a particular challenge to services and organisations, whose goal is to ensure people with LD have the same quality of life and opportunities as anyone else (NHS England, Local Government Association and Association of Directors of Adult Social Services, 2015).

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Implementation of evidence-based practices in any field involves complex systems; requiring macro and systems-level changes across all sectors to ensure delivery

- **Implementation science** is concerned with the translation of findings from basic research in clinical settings into practice that is effective, sustainable, offers consumer choice and leads to meaningful outcomes (Novins et al., 2013).
- Following a systematic review of the implementation of evidence-based practice, **Fixsen et al. (2005)** proposed a model of implementation

Implementation



Figure 1: Multilevel Influences on Successful Implementation based on Fixsen et al., (2005)

Successful implementation depends upon...

- Practitioners can competently deliver **core implementation components**
- **Organisations** provide the necessary infrastructure for training, supervision and outcome evaluation;
- **Communities** and customers are fully involved in the selection and evaluation of interventions and practices; and
- Regional and national **policies** and legislation create a favourable environment for implementation.

These **four** components are interrelated and necessarily involve multiple systems

An analysis of the current provision of services for people with learning disabilities at risk of behaviours that challenge in accordance with this framework is encouraging (with some of those examples discussed today)

*Key elements across all four elements of the model have already been achieved... **but this model also helpfully highlights areas for further development to support better implementation...***

PBS training modules that map onto the PBS Academy training standards **built into teacher training, LD nursing training and clinical psychology courses?**

A system of accreditation/certification to give commissioners confidence in the quality of services they may be procuring?

Alignment of CQC and OFSTED inspection processes and best practice?

Alignment of HR strategies across organisations **to promote the development of a high quality workforce?**

Additionally...there is an important gap in the literature around understanding exactly how competing contingencies within systems may support and/or pose barriers to implementation...

Conclusions and Questions

A whistle-stop tour!

Some of the things we do have as a community:

- A clearer **conception** of PBS – that fits with the UK context
- A range of related **materials and tools** to support implementation
- Some established ways of working in **partnership**
- **Some policy that is supportive**

Some new directions of travel:

- **A framework for thinking about implementation?**
- ***Some* strategy areas for the future**
- **Amazing opportunities like today for committed folk to come together....**

Some things to think and talk about:

- ✧ **What** examples do we have of successful systems implementation to ensure **all** components of PBS come together in services and people's lives...
- ✧ What **other key strategies** and pieces of work are needed **to support better PBS implementation** in the future?
- ✧ What can **we** (as a PBS community) do more of **to support and learn from one and other further?**
- ✧ ***How has PBS evolved in recent years and how might it best evolve in the future?***

Thank you and Questions



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