Staff, Families and Positive Behavioural Support: A Systems View

Dr Nick Gore: Bergen 2023



Introductions

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- **OPractitioner**
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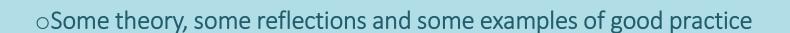


- oPeople with learning disabilities
- oAutistic people
- oThose that care and support them
- OServices and systems
- oPeople!



Today

- oPBS/PAS and working with key people (staff and families)
- OA systems view of behaviours that challenge
- OPartnership working with staff
- OPartnership working with families





Partnership working with staff and families has been a considered a key component of PBS for sometime...

Positive Behavioural Support in the UK: A State of the Nation Report

Positive Behavioural Support in the UK: A State of the Nation Report

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What this "state of the nation" report seeks to address

The 2013 International Journal of Positive Behavioural Support (LIPBS) special issue 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 2013-2022

In 2013, the LIPBS special issue sought to "put a marker in the sand that makes sure that people are describing and implementing the same approach when nating their colcurs to the PBS mast" (Alen 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" at nex or displaying behaviours that challenge." Two years earlier a BBC investigation had uncovered the systematic abuse of residents of Whiterbourne View, a cerehome 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, 2012s), was a lack of guidance on best practice around PBS. Furthermore, there was title understanding that PBS is a service delivery model rather than a single "intervention", or of the implications of this for people with a hearing dealthilly, and bloose who are important to them including their families, along with implications for service providers, support workers, and health, education and social care professionals.

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- Contributors to the section, "PBS for people with learning disabilities A refined and updated definition for the UK", this issue, p9 ff.
- Consistent with a UK context, throughout this report we use the term "learning disability" rather than "intellectual disability".
- We use the term "behaviours that challenge" rather than "challenging behaviour" to reflect the most common language use in the UK at this time.

@ Bild, International Journal of Positive Behavioural Support, 12, Supplement 1, 2022

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

Abstrac

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 drive aim to outline a framework for the deliver or 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 mutil-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 deliverv, training and research.

Keywords: Positive behavioural support, definition, core concepts

Introduction

nternational evidence regarding challenging behaviour lisplayed by children, young people and adults with ntellectual or developmental disabilities is strongly in avour of positive behavioural support (PBS) as a model of intervention. This now includes systematic and metaanalytic reviews of single-case and small group designs that demonstrate significant reductions (typically greater than 50 per cent) in challenging behaviour following PBS ntervention (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 two-treatment study focusing on support for families in community settings (Durand et al, 2012) and a UK andomised controlled trial in which challenging behaviour splayed 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 UK, in the last ten years a variety of policy documents and professional guidelines have drawn on PBs as model of best practice for supporting people who daps challenging behaviour (British Psychological Society, 2004; Department of Health 2007; Royal Colege of Psychietrists, British Psychological Society & Royal Colege 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 veriety of audiences and serve a variety of aims.

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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*

	1. Prevention and reduction of challenging behaviour occurs within the context of					
Values	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					
	4. An understanding that challenging behaviour develops to serve important					
Theory and Evidence	functions for people					
Base	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					
	7. A data-driven approach to decision making at every stage					
Process	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					

Key Components (Gore et al., 2022)



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

Key points of emphasis in 2022

- o'Key people' rather than 'stakeholders'
- oExpertise of family members in particular
- oBoth working alongside and providing support
- oPartnership working and co-production
- oChallenging and traumatic experiences for families (that relate to supporting a relative with behaviours that challenge <u>AND adverse experiences with the system</u>)

oThe need to synthesis and balance priorities and perspectives between key people

How We Did It

A team of **24** UK contributors with special interests and experience in PBS, from a range of (sometimes-overlapping) groups, **co-developed this definition**.

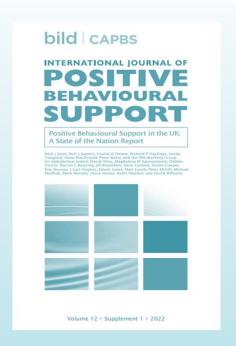
People with lived experience as a person:

owith a learning disability;

owho is autistic;

owho has a history of displaying behaviours that challenge;

owho is a family carer.



Researchers and people from a variety of professional backgrounds who have experience of:

oService delivery, commissioning, training and practice across child, adult, health, education and social care contexts.

eWorking as front-line support staff; Speech and Language Therapists; Nurses; Psychiatrists; Occupational Therapists, Clinical Psychologists, Physiotherapists, and Behaviour Analysts.

Over a **five+ month** period, with **meetings tailored** to meet the particular **requirements of each contributor** and lots of drafts back and forth

Why Working in Partnership is an Essential Component of PBS: A Systems View

A long standing emphasis on systems change as a core feature of PBS

Carr (2002)

In providing support we should focus our efforts on fixing problem contexts, not problem behaviour

Carr (2007)

The Central Independent variable in PBS is systems change

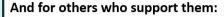
Behaviors that challenge a systems view:

- oNOT something that is considered to occur WITHIN the individual
- oDEFINED by the IMPACT it has for the person and OTHERS at a personal and SOCIETAL level
- ols influenced by a range of CONTEXTUAL / ENVIRONMENTAL variables including social environments/THE BEHAVIOUR & WELLBEING OF OTHERS

What kind of impacts are we talking about?

A range of negative impacts for the individual:

- Physical harm
- Abusive treatment
- Restrictive treatment and exclusion



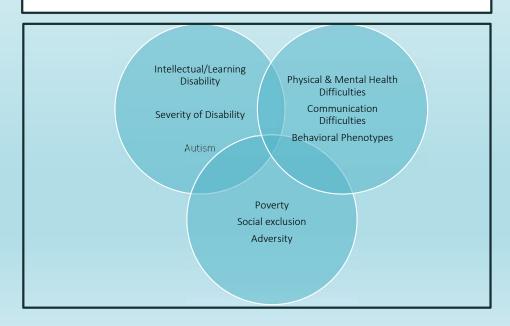
- oPhysical harm
- OStress and emotional difficulties
- o Reduced opportunities, isolation



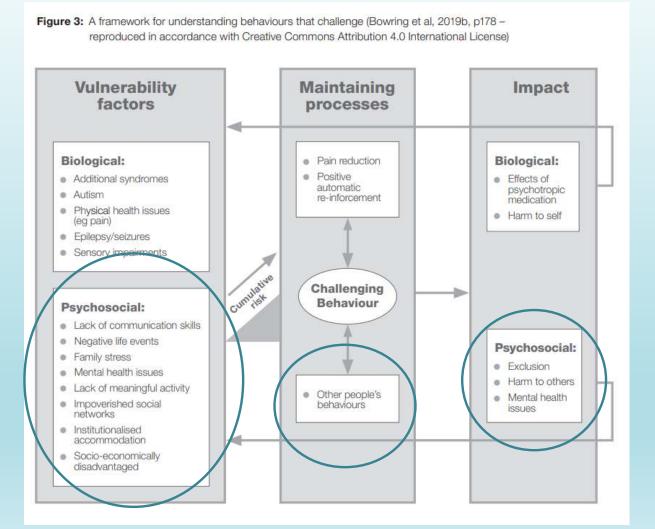
Winterbourne View Hospital (2011)



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



2022 Definition: A Biopsychosocial model of behaviours that challenge



An updated/revised version

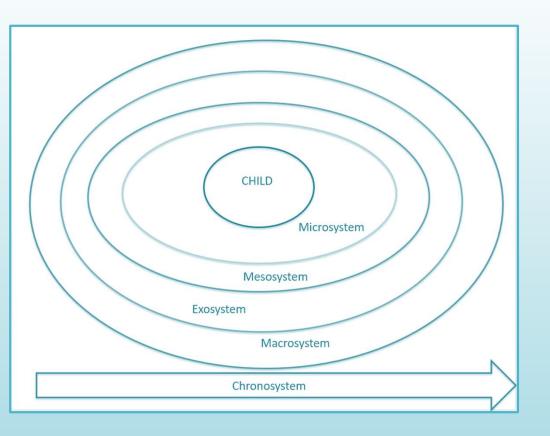
Lists additional vulnerability factors in bio and psycho-social groupings

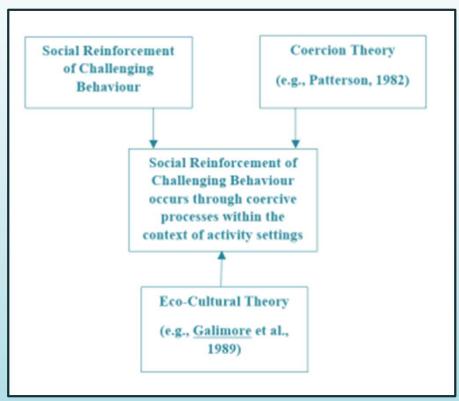
Emphasis on combination of multiple factors that incrementally add to overall risk

Positive automatic reinforcement is referenced

Includes psychotropic medication as a negative impact that also feeds back to increase vulnerability

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





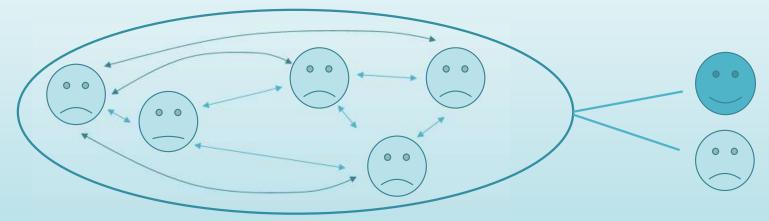
Ecological Systems Theory

(Bronfenbrenner, 1979/2006)

Ecological family-focused delivery of PBS:
Lucyshyn et al 2104

What are human systems?

Systems are made of different elements. How, elements in a system are structured and interact, determines how individual elements operate (the 'behaviour of the individual') but also how the system operates (the 'behaviour of the system')

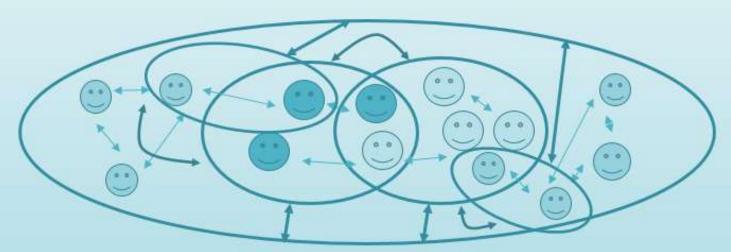


All people live as part of multiple systems.

For instance, a person is often part of a family. The way members of the familiy are organised and interact, determines both how each person functions <u>and how the</u> <u>family functions as a whole</u>. At the same time, a person, and each family member, may be part of a school or work system, health and social care system, community or peergroup system...

Systems can be examined at big scales (e.g., the political system of a country) or very fine-grained levels (e.g., the way in which two people interact or even ways in which different elements of a person's physiology interact).

Different systems may interact with one another at meta-levels and/or be 'nested' within one another.



- 1 Elements interacting within systems
- 2 The same elements crossing over into other systems
- 3 The systems interacting with each other

Systems can and do change over time, but can also be maintained for long periods.

Some systems may be unhelpful to individual members or groups but pervade where there is benefit to other people and parts of the system... where there is reinforcement at a systems level

(And factors that determine how an overall system operates and how individuals within a system operate are related but not necessarily the same).



What this means for Behaviours that Challenge:

oPeople who display behaviour that is challenging will have come to do so through experiences and interactions encountered in multiple systems throughout their life course.



oSuch systems will have come to 'select' behaviours that challenge as the optimal, or only viable, way for a person with learning disabilities to function in these contexts.



But it also means, the behaviour of other people, groups and organisations in these systems concerns responses that are a functional product of system structures and interactions, even where non-desirable.

e.g., controlling, reprimanding, punishing, ignoring, restricting or apathetic responses

Blaming other people in the system (and even organisations) for the way they behave makes no more sense than blaming a person with learning disabilities for displaying challenging behaviour

- We need to understand, eliminate and replace problematic system structures and contingencies
- We need to build systems that support positive values and good lives for all

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

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, is 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

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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A lot needs to happen to make PBS happen!

Denne, Jones, Hughes, Gore, Jackson-Brown, Toogood (2020)

Implementing evidence-based practice in the learning disability care sector: The challenge of delivering what works

Tizard Learning Disability Reviews (2020) 25 (3)

A model from implementation science

Implementation science is concerned with the translation of findings from research into practice. Fixsen et al. (2005) proposed a model of implementation arguing that it is successful when four components are addressed:

- 1. Practitioners have competencies to deliver core intervention components
- 2. Organisations provide the necessary infrastructure for training, supervision and outcome evaluation
- 3. Communities and customers are fully involved in the selection and evaluation of interventions and practices
- 4. Regional and national policies and legislation create a favourable environment for implementation.

These four components are interrelated, and necessarily involve multiple systems.

Wider policy context

Informed and enabling communities

Organisational factors

Core implementation components

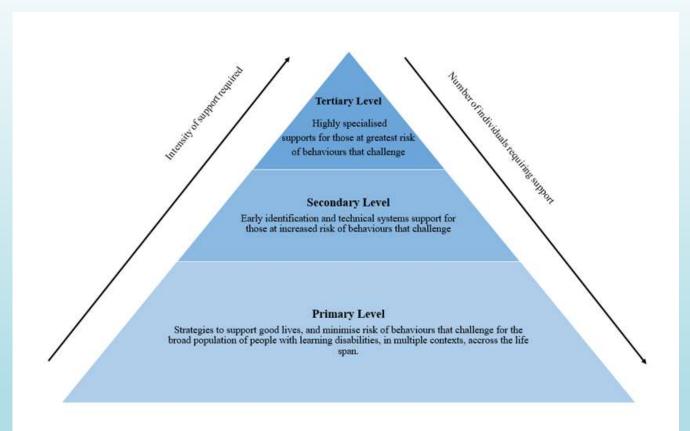


Figure 4: A Tiered Positive Behavioural Support Approach (*Note*. The size of the tiers in the figure are illustrative only).

A big part of <u>systems</u> <u>change</u> involves and can be driven by partnership working and support for family caregivers and staff:

- Decision Making
- Training and Information
- o Wellbeing

Partnership Working with Staff

Supporting & Empowering Staff

Who are front line support staff?

In the UK:

- OVarying in level of education/training
- Receive relatively low pay
- oTraditionally not highly valued by community
- May experience stress, burnout and trauma in context of work (though these relationships are not straight forward)
- Critical to the daily life of people they support
- oPart of organisational systems and influenced by these systems. Often with minimal agency
- OPeople! Who are part of multiple other systems. People with families, passions, life histories, worries and ambitions...

We need staff to be:

oCompassionate,

oCreative.

o Flexible

oAmbitious

o Dedicated

oTo value and focus on the special qualities, needs and dreams of the people they support

And yet the personal circumstances of staff and the organisation and functioning of services often do not support these qualities. Staff are:

oTold what to do

Olnvisible when things go well

oBlamed when it goes wrong

Expected to leave life at the door

We except staff to be person centred and to support good lives when organisations are often not person centred to them or in support of their life quality or self-determination...

How staff behave is a systems issue

e.g., controlling, reprimanding, punishing, ignoring, restricting or apathetic responses (responses that set the occasion for and reinforce behaviours that challenge)

Organisation
Wide Positive
Staff Support
Baker & Gore
(2019)

Intensive supports Tertiary Prevention

- Group defusing
- Group debrief
- Psychological Therapy e.g. EMDR, CBT

Targeted supports Secondary Prevention

- End of shift stand down/diffusion
 - Informal peer support

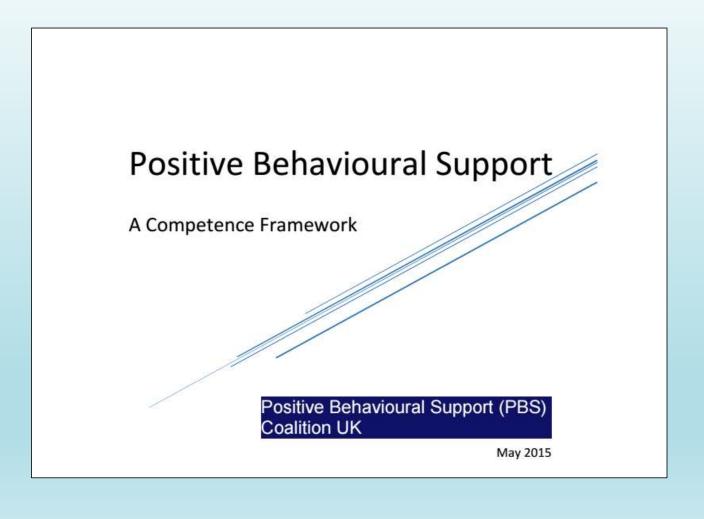
Universal supports Primary Prevention

- Clear job role prescribed
- Trauma informed training/induction
 - Supervision
- Acceptance & Mindfulness-Based Stress Management
- Management of challenging behaviour within PBS framework
- Frequent consultation with staff about support (e.g., incident forms)

A systems solution/strategy

- Knowledge/training
- Supportive CultureWellbeing

Be clear about roles, and support training and development



Overall structure

Г	1	Creating high quality care and support	2.	Functional contentual and still-	1	Developing and implementing a Debauter Comment
	1.		2.	Functional, contextual and skills	3.	Developing and implementing a Behaviour Support
		environments		based assessment		Plan (BSP)
						Evaluating intervention effects and on-going
						monitoring
	1.1	Ensuring that services are values led	2.1	Working in partnership with	3.1	Understanding the rationale of a BSP and its uses
				stakeholders		
	1.2	Knowing the person	2.2	Assessing match between the	3.2	Synthesizing data to create an overview of a person's
				person and their environment and		skills and needs
		\		mediator analysis		
	1.3	Matching support with each person's capabilities	2.3	Knowing the health of the person	3.3	Constructing a model that explains the functions of a
	-	and with goals and outcomes that are personally		3 • • • • • • • • • • • • • • • • • • •		person's challenging behaviour and how those are
		important to them	\			maintained
	1.4	Establishing clear roles and effective team work	2.4	Understanding the principles of	3.4	Devising and implementing multi-element evidence
			F	behaviour (4 term contingency);		based support strategies based on the overview and
				understanding the function of		model Antecedent strategies
				behaviour		Antecedent strategies
	1.5	Supporting communication	2.5	Supporting data driven decision		Developing functionally equivalent alternative
	1.5	Supporting communication	1.5	making		behaviour (to CB)
	1.6	Supporting choice		Assessing the function of a person's		Increasing skills and communication
	1.6	Supporting choice	1.6	behaviour		Systems change and contextual interventions
		• The state of the	L_			, ,
	1.7	Supporting physical and mental health	2.7	Assessing a person's skills and	3.5	Devising and implementing a least restrictive crisis
	MARKET AND A			understanding their abilities		management strategy
	1.8	Supporting relationships with family, friends and	2.8	Assessing a person's preferences		Arousal curve
		wider community		and understanding what motivates		Reactive strategies
		/		them		
	1.9	Supporting safe, consistent and predictable			3.6	Developing the plan; outlining responsibilities and
		environments				timeframes
	1.10	Supporting high levels of participation in			3.7	Monitoring the delivery of the BSP
	1 2000 0000	meaningful activity				(procedural/treatment fidelity/integrity)
	1.11	Knowing and understanding relevant legislation			3.8	Evaluating the effectiveness of the BSP
		3				,
	1.12	A commitment to Behaviour Skills Training			3.9	The BSP as a live document

People with learning Disabilities (x2)

Family Caregivers (x5)

Service Providers (x1)

Commissioners and Care Managers (x3) Observation
Checklist for
Inspections (x1)

Related <u>co-produced PBS Academy</u> resources to support implementation

Standards for:

- Services
- Training
- Individual practitioners

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

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 Part of a primary/preventative tier within a broader conceptualisation of PBS

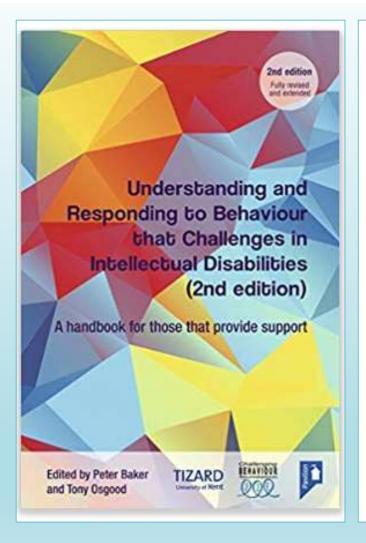


Practice leadership

Effective Practice leaders develop and maintain high quality support by:

- oFocusing, in all aspects of their work, on the quality of life of the people being supported and the effectiveness of the support being provided.
- oClarifying roles, expectations and guidance to ensure those providing support have clear goals for, and a specific understanding of, how to support individuals
- OAllocating and organising resources to deliver high quality support, when and how the people being supported need and want it.
- OCoaching supporters to deliver high quality support by spending time modelling good practice, observing support being delivered and providing focused, constructive feedback.
- Reviewing the quality and effectiveness of support and utilising supervisions and team meetings to continue to improve practice and ensure consistency.

Empower, reinforce and harness the expertise of front line staff – lead and value by making more valued leaders!



Chapter 16: We are all in this together: supported staff

By Peter Baker & Nick Gore

Does behaviour that challenges cause staff stress?

At first glance it would appear to be an obvious statement that working with people with intellectual disabilities who present behaviour that challenges is stressful, and has a negative impact on the psychological well-being of staff. Indeed, there is some research that suggests staff who provide direct care to people with behaviour that challenges are particularly prone to experiencing stress and burnout. However, and perhaps surprisingly, the link between behaviour that challenges and negative emotional states for staff is not always straightforward, and in some studies not evidenced at all. What appears to be the case is that whilst experiencing and managing behaviour that challenges can be difficult for staff, there are other factors that influence how the member of staff actually feels and responds to these feelings.

Research has identified the complexity of what determines well-being of staff in these situations and has concluded that it is often the characteristics of the organisation that provides the support to the person that are more important determinants than the behaviour itself (Hatton et al, 1999). These include how the care is organised, the clarity of the roles that staff have, and the extent to which staff are supported by the organisation. Individual factors specific to each member of staff have also been shown to be influential. The beliefs and attributions a staff member has in relation to a person with a learning disability, and why they engage in the behaviour that challenges, are all important in determining how they feel if and when exposed to an incident. For example, a staff member would be more likely to experience a negative emotional reaction if they think the person has control over how they are behaving, that 'they are doing it on purpose', or 'doing it to wind me up' etc. Similarly, the extent to which a staff member feels able and equipped to cope (both with the behaviour they are exposed to and their own emotional states) will have an influence, as will any pre-existing mental health problems the staff member has that may not be directly related to their work.

Understanding and Responding to Behaviour that Challenges in Intellectual Disabilities © Pavilion Publishing and Media Ltd 2019.

Support resilience and wellbeing

- For staffs own sake
- 2. For the sake of the people they support

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Outcomes of a 'Train the Trainers' approach to an acceptance based stress intervention in a specialist challenging behaviour service

Outcomes of a 'Train the Trainers' approach to an acceptance based stress intervention in a specialist challenging behaviour service

Mark P Smith and Nick J Gore²

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- ² Clinical Psychologist and Lecturer in Learning Disability, Tizard Centre, University of Kent at Canterbury, UK

Abstract

Background: The application of acceptance and commitment therapy (ACT) principles to occupational stress is a relatively recent development, and a pilot study by Noone and Hastings (2009) suggests it may be a helpful approach with staff in ID services. The aims of the present study were to replicate the workshop format developed by Noone and Hastings and to expand on this by training a group of 'ACT novices', recruited from the workforce, to deliver the training.

Method and materials: A total of 72 staff working in specialist challenging behaviour services participated in one of six workshops (consisting of a whole day and a half-day follow-up six weeks later) which were staggered over a six-month period. A range of measures were used at five time points (two baseline measures, one post-intervention measure and two follow-up measures) to evaluate the outcome of the intervention.

Results: There were significant improvements at different time points on the General Health Questionnaire, the Maslach Burnout Inventory (Depersonalisation sub scale); a number of sub scales on the Staff Stress Questionnaire and the Dysfunctional Attitude Scale. However, there were no significant changes in measures on Acceptance (Acceptance and Action Questionnaire); not, and Values (Support Staff Values Questionnaire), which are key ACT concepts.

Conclusions: The findings compare well to prior studies in the area, particularly when considered within the context of a train the trainers model. However, complete support for an ACT model was not demonstrated which provides opportunities for further research in the field.

Keywords: Intellectual disability, challenging behaviour, staff stress, acceptance and commitment therapy (ACT), train the trainers.

Introduction

The delivery of effective support to service users with intellectual disability (ID), especially those requiring consistent and complex interventions due to challenging behaviour, is highly dependent on family and front line care staff. In the field of positive behavioural support (PBS), individuals in these roles are often described as the 'mediators' (Alien, 1999), as they are key agents in the delivery of interventions prescribed by professionals. There is now an increasing recognition that mediator analysis and interventions, which takes into account the

psychological needs of staff, is a key component in the development and implementation of successful interventions for service users (Allen, 1999).

Studies that have focused on the needs and characteristics of mediators point to evidence that staff in ID services are at risk of experiencing stress and burnout (Devereux et al, 2009; Robertson et al, 2005). This risk may be increased for those workers exposed to severe challenging behaviour (Flastings, 2002) and where appropriate support from colleagues and the

A brief Acceptance Commitment Therapy intervention for frontline staff

Delivered by team leaders, trained by psychologists

Positive outcomes from 3 months post-intervention with regards:

- o Burnout
- Staff Stress
- General Health

Other examples of ACT interventions since: e.g., McConachie, D.A.J., McKenzie, K., Morris, P.G. & Walley, R.M. (2014). Acceptance and mindfulness-based stress management for support staff caring for individuals with intellectual disabilities. Research in Developmental Disabilities, 35, 1216-1227. (RCT)

Critical Incident Stress Management (CISM)

 A model designed to enable organisations to support their staff in dealing with potentially impactful incidents. It is designed to ensure resilience and to provide support after the incidents have occurred.

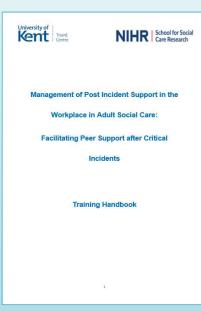
• CISM has been widely used in emergency services and the military

Critical Incident Stress Management (CISM)

Four Elements

- 1.Immediate support meeting ('defusing')
- 2.Debriefing
- 3. Follow up care
- 4.Preventative measures the 'culture of support' within the organisation

We aimed to adapt CISM as a service wide intervention specifically for adult social care staff working with people with Learning Disabilities who present with behaviours that challenge and explore the feasibility of using this (Baker, Gore et al., ongoing)



- Package of staff care following traumatic incidents e.g., serious assault, restraint, anything that has significant emotional impact on team
- Reduces potential for post-traumatic stress reactions, helps wellbeing & team cohesion, improves retention

Who are family carers?

Parents and adult family members like any other but in exceptional circumstances...who experience many joys associated with supporting a relative but many additional challenges

Emotional difficulties amongst family carers of children with learning/developmental disabilities are high relative to other parents/siblings (e.g. Baker, Blacher, Crnic, & Elebrock, 2002; Baker, McIntyre, Blacher et al. 2003; Davis & Carter, 2008; Hastings, 2002; Naylor & Prescott, 2004).

These difficulties appear to develop early - parents of children with learning disabilities and/or Autism found to be more likely than other parents to experience elevated levels of stress by the time their child is 5 years old (Totsika et al. 2011a; Totsika et al. 2011b).

Beyond other characteristics of the child (i.e., severity of disability or adaptive skills), **Challenging behaviour** tends to be the most reliable predictor of such difficulties for families (Baker et al., 2003; Hastings, 2002a).

So 'stress' and behaviors that challenge go hand in hand for families

Stress also makes it difficult to support many other parenting tasks (responding to behaviors that challenge, supporting sleep, teaching skills and communication) which then influences child behaviour and wellbeing and development

But critically - stress is more likely for family caregivers of children with learning and developmental disabilities:

Not because they are personally more vulnerable:

But because of the situations **and systems** they find themselves in coupled with the lack of support from others.

Anyone in the same situation would feel/react the same....

Wellbeing workshops for family carers

Workshops aiming to support family carers of children who display challenging behaviour to maintain their own wellbeing

Based on Acceptance and Commitment Therapy



- 2 day long workshops
- Piloted and qualitatively evaluated in Ealing service
- 9 family caregivers (of children 9-14) at risk of residential placement due to behaviour)
- We could actually talk about the fact that some of our kids hit and punch ... we usually can't talk about [these things] anywhere else'. (P1)

But so much of the stress, emotional difficulty and trauma families experience is <u>because</u> of 'the system'

- oLack of support
- oHaving to fight
- oBeing let down
- oBeing blamed and judged
- oHaving their hands tied and mouths gaged by services and professionals

It's not enough to offer support – to put on a sticking plaster. We need to change the entire way the system operates

Working in Partnership - Why do this?

This is **not the way interventionists** have **always** (or do always) **work**. Often there is an explicit or implicit suggestion (even at subtle levels) that *'the professional knows best'*:

- They have been trained the most......They are most objective.....They are most experienced.....
- oThe most 'expert'.....

However, working in true partnership with families to facilitate behavioural support can mean *Professionals are given access to a rich resource and opportunity to learn and develop from and with caregivers:*

They are relieved of the deluded pressure of having to know everything and make everything better as the lone expert.

The Necessity of Partnerships with families: Working in partnership (done properly) <u>really works!</u> It makes for better outcomes for everyone:

- The most appropriate and helpful goals can be identified
- Olnformation and insights can be obtained in detail to enrich assessments
- oCaregivers identify solutions that are particular to their circumstances, fit with their situation and are perhaps unknown to others
- oCaregivers are motivated, empowered and knowledgeable in ways that mean they can drive changes now and in the future

Some Examples of Partnership Working with Families

Journal of Child and Family Studies https://doi.org/10.1007/s10826-019-01398-5

ORIGINAL PAPER



Making it Meaningful: Caregiver Goal Selection in Positive Behavioral Support

Nick James Gore 61 - Peter McGill - Richard Patrick Hastings23

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Abstrac

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 good 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 challenging, 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) (Toskia 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 evidencebased and ethical approach to supporting people with IDD

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- Department of Psychiatry, School of Clinical Sciences at Monath Health, Centre for Developmental Psychiatry and Psychology, Monath University, Melboume, Australia

in relation to BTC through a synthesis of Beha vior 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; Horner et al. 1990; Kincaid et al. 2016). Strategies and interventions selected within the framework should herefore 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 (Hassings

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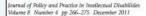
Partnership working in PBS process

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)

Journal of Policy and Practice in Intellectual Disabilities



Challenging Behavior Training for Teaching Staff and Family Carers of Children With Intellectual Disabilities: A Preliminary Evaluation

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Abstract Training programs on the topic of challenging behaviors have often been offered to teaching staff and family carers of children with intellectual disabilities (ID). These efforts have been found to be effective in bringing about positive changes for both children with ID and those who support them. Generally, such training has been offered to ether staff onling carers but not at the same time. The authors conducted a study to evaluate the efficacy of a brief training program delivered at the same time to teaching staff and family carers (who were involved with the same child). The study also examined differences in outcomes between the two groups, which were drawn from local schools where some children exhibited challenging behaviors. But leaching staff and family carers completed the Checklist of Challenging Behaviour, the Challenging Behaviour Scale, and the Emotional Reactions to Challenging Behaviour Scale prior to, and following, the training workshops. The workshops were divided into two segments. The ontent was the same, but in the first segment, one was held for teaching staff and one for parent carers he second segment, both groups met together. After the first segment, all participants completed a related homework task before joining each other for the second segment. Training used a functional model of challenging behavior and facilitated the production of Individualized support plans for the target children. Significant positive changes were found regarding ratings of challenging behavior, participants' causal attributions, and emotional reactions following the training. Some differences were found regarding combined training to support challenging behavior in children with ID.

Keywords: challenging behavior, comparative methods, intellectual disability, training

INTRODUCTION



to an individual, vidual's access to nay include selfge. It is reported ties (ID) display ior, and a further werity (Kiernan &

rs tend to persist d (Murphy et al., seing, such behaval life (McIntyre, i, Taylor, & Reid, onded to by use llen, Hawkins, &

of Kent, Canterbury

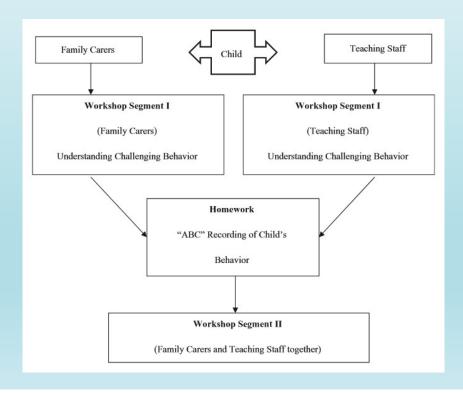
Cooper, 2006; Emerson, 1995; Kiernan & Kiernan, 1994). These approaches may have little positive effect (Brylewski & Duggan, 2004) and put people at further risk of harm (Hawkins, Allen, & Lepkins, 2004).

Consequences of challenging behaviors for those persons who support a child can be debilitating. For teachers, challenging behaviors are a major source of stress and cause disruption in the classroom (Hastings, 2002a; Male, 2003). The negative emotional impact of challenging behavior for parents is now well established (Baker, Blacher, Crnic, & Eddebrook, 2002; Beck, Daley, Hastings, & Stevenson, 2004; Hastings, 2002b; Hodapp, Dykens, & Masino, 1997; Lecavalier, Leone, & Wiltz, 2006; Orsmond, Seltzer, Krauss, & Hong, 2003; Woolfson, Taylor, & Mooney, 2011).

Challenging behaviors can, however, be reduced through the use of positive behavioral supports (Ball, Bush, & Emerson, 2004; Carr et al., 19995; Koegel et al., 1996; LaVigna & Donnellan, 1986). These approaches recognize the function that challenging behaviors serve and develop alternative, socially accepted ways to meet an individual's needs. Thus, an emphasis is placed on working in partnership with people who are involved in the individual's care, including close engagement with families (Gavidia-Payne & Hudson, 2002).

2011 International Association for the Scientific Study of Intellectual Disabilities and Wiley Periodicals, Inc

- 1. Ensuring families have the information and training they need
- 2. Connecting families with professionals and modelling partnership working
- 3. Families as Trainers/Facilitators harnessing, promoting and driving change through the power of lived experience



Family Carers as Co-Researchers

Positive Behavioural Support in the UK: A State of the Nation Report

Positive Behavioural Support in the UK: A State of the Nation Report

Nick J Gore, Suzi J Sapiets, Louise D Denne, Richard P Hastings, Sandy Toogood, Anne MacDonald, Peter Baker and the PBS Working Group (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 and David Williams

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What this "state of the nation" report seeks to address

The 2013 International Journal of Positive Behavioural Support (LIPRS) special issue advinced and 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 2013-2022

the sand that makes sure that people are describing and implementing the same approach when nalling their colours to the PBS mast" (Allen and Baker, 2013, p4). There was disability² at risk of displaying behaviours that challenge.² 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

In 2013, the UPBS special issue sought to "out a marker in 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 an urgent need for this at the time; a need that was specific Winterbourne (Department of Health, 2012a), was a lack to the UK context of supporting people with a learning 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 with implications for service providers, support workers, and health, education and social care professionals.

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- Contributors to the section, "PBS for people with learning disabilities A refined and updated definition for the UK", this issue, p9 ff.
- Consistent with a UK context, throughout this report we use the term "learning disability" rather than "intellectual disability"
- We use the term "behaviours that challenge" rather than "challenging behaviour" to reflect the most common language use in the UK at this time,

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ORIGINAL ARTICLE

WILEY

'Different things at different times': Wellbeing strategies and processes identified by parents of children who have an intellectual disability or who are autistic, or both

Joanna Griffin 1 | Nick Gore 2 0

¹Faculty of Post-Qualification and Professiona Doctorates Metanoia Institute London UK ²Tizard Centre, University of Kent, Canterbury, Kent CT2 7LR. UK

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Present address

Joanna Griffin, CEDAR, University of Warwick Coventry CV4 7AL, UK.

Background: Most parents of children with an intellectual disability or who are autistic identify positives in their family life and their own wellbeing, in addition to reported mental health challenges. Several models and interventions have been developed in relation to parent carer wellbeing. Few studies have asked parent carers how they support their own wellbeing.

Method: Adopting an interpretive phenomenological approach this study utilised semi-structured interviews. Seventeen parent carers were asked what supported their emotional wellbeing. Template Analysis was applied to develop themes

Results: All participants identified factors that supported their wellbeing. Themes included strategies that countered stress (time for themselves, relaxation, 'parking' difficulties) and broader wellbeing strategies (finding meaning life direction, greater understanding of child). An ongoing process of supporting wellbeing by 'Reorienting and Finding Balance' appeared central.

Conclusions: Self-identified, multi-dimensional strategies benefit parents' emotional wellbeing and should be considered in the context of support provided to families.

autism, emotional wellbeing, intellectual disability, mental health, parent carers

1 | INTRODUCTION

Research commonly suggests that relative to other parents, parent carers of children with an intellectual disability, who are autistic, or carer wellbeing. Second, parent carer coping strategies in relation to both, are at increased risk of mental health difficulties (Hayes & Watson, 2013; Rydzewska et al., 2021). Despite these risks, and the broad array of coping strategies and their relationship with mental challenges and stressors experienced by parent carers, many also health have been explored using different methods. For example, a identify positive aspects (e.g., personal growth, putting things into perspective) of parenting a child with additional developmental needs wellbeing (Benson, 2014). Another study, using parent-completed (Hastings, 2016: Jess et al., 2017). Factors that influence parent carer questionnaires, suggested an association between active-avoidance wellbeing have been drawn out across several lines of research. First, coping and poorer maternal mental health (Adams et al., 2018).

social support for parent carers, such as family support and friends/ peers (Shilling et al., 2014), as well as availability of resources and services (Stanford et al., 2020) have been found as beneficial to parent psychological wellbeing have been the focus of some studies. Here, a longitudinal study found that psychological reframing was positive for

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Early Positive Approaches to Support (E-PAtS)

Dr Nick Gore - Tizard Centre University of Kent

1. What is E-PAtS?

An 8 session group for families of young children (0-5) who have a learning or developmental disability

Supports resilience and wellbeing for family caregivers, positive development for children and proactive access to services.

2. Why E-PAtS?

Raising children brings both joys and challenges to families.

Families of children with disabilities sometimes need some extra support to navigate through challenges that relate to their child's particular needs.

E-PAtS provides high quality information and sensitive support in the early years to help build bright futures for children with disabilities and their families.

3. How?

E-PAtS is facilitated by a trained professional and trained family carer who work in partnership

Materials and sessions have been co-produced by family carers and professional experts and provide strategies for using now and in the future

Group sessions are designed to be emotionally supportive and meet the needs of a diverse range of families, supporting children with a variety of needs

4. What is covered?

- Accessing services and supports
- Emotional wellbeing and resilience for caregivers
- Supporting sleep for children
- Supporting communication
- Supporting skills development
- Positive approaches to behaviours that challenge

5. What families say:

Just wanted to let you know that today for me was a massive success. I really enjoyed the training and came home with so much!!!

I haven't stopped talking about the training to (my partner) and what I gained from the course as well as how open and honest everyone was and all the vital information I received from such an early onset.

I really can't wait until Wednesday



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WILEY

Early positive approaches to support (E-PAtS): Qualitative experiences of a new support programme for family caregivers of young children with intellectual and developmental disabilities

Nick Com | Jill Bradshaw | Richard Hastings |

Joanne Sweeney³

Debbie Austin

University or navel, Canterbury, Kent, UK

PCTEIAR, University of Warwick, Coventry, UK Moncap NI, Moncap Centre, Beltact, UK *Landy Carer

38 Stratifizate, Titard Centre, Comwellis North Cast, University of Kent, Carderbury, Kent. CT2 7NF, UK.

Abstract

Background: Early Positive Approaches to Support (E-PAtS) is a co-produced and co-facilitated group programme that aims to provide early years support to family caregivers of children with Intellectual and Developmental Disabilities

Method: Thirty-five caregivers who had attended E-PAtS groups took part in individual interviews or focus groups. Caregiver experiences concerning attendance of E-PAIS were explored, in relation to process variables and perceived outcomes. Interviews were thematically analysed.

Results: Three major themes were identified: our group, evolving emotions, and posilive approaches. Being with and being supported by other families was very important to caregivers. Families reported increased confidence and greater realisation of the need for self-care. Children were reported to show fewer behaviours that challenge and increases in adaptive skills. Findings corresponded to mechanisms and outcomes in the E-PAtS logic model.

Conclusion: E-PAtS shows promise as one way families and children with Intellectual and Developmental Disabilities can access early years support.

early intervention, family carers, intellectual and developmental disabilities, positive approaches, wellbring

1 | INTRODUCTION

Family caregivers provide rich accounts of positive gains appropriated with raising a child with Intellectual and Developmental Disabilities but are also known to be at bigh risk of storm and constioned difficult. month (Care & O'Reille 2016: Charboick et al. 2019) and namenting ties (Hantings, 2016), even when their child is under 5-year-old (Totaka et al., 2011). Many caregivers find 81 equipped to support the child and caregiver: Priday et al., 2017; Kirkpatrick et al., 2019).

developmental needs of children with intellectual disability through typical parenting approaches alone and without additional support (Decadas et al. 2017: Plant & Sanders, 2007: Williamburn Storr, 2014). Early concurrs for campivers commonly relate to communication their child to sleep (affecting the wellbeing and functioning of both

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Early Positive Approaches to Support (E-PAtS): Qualitative Experiences of a New Support Programme for Family Caregivers of Young Children with Intellectual and Developmental Disabilities Journal of Applied Research in Intellectual Disabilities

'Legitimacy and authenticity, if you haven't lived it, you don't have a clue. Having someone that is in the trenches, you pay more attention to someone who has been through it' (FG4 L1)

'What the session taught me is two things, one is I have to look after myself, coz who is going to look after [name of child], it isn't about just me soldiering on I actually have to look after myself coz I have got somebody else to look after as well and for your own mental wellbeing you've got to' (PC2 L2)

Conclusions

Prevention and reduced risk of behaviours that challenge is determined by well-functioning, resilient **SYSTEMS** of support focussed on creating good lives

A lot needs to happen to make PBS happen!

But partnership working with staff and families is a driver for systems change

Staff and Families need to be:

- oListened to
- OSupported and resilient
- oTrained and knowledgeable
- OValued and empowered as key agents for meaningful and positive change





Any Questions?



