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

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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 over-riding 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; Lunsky 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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of CB, but when these are effectively supported within function-informed strategy, the risks and impacts of such behaviour can be reduced (Hastings et al, 2013).

PBS also demands support and collaboration with stakeholders and the development of resilient support systems to ameliorate risk factors across social contexts at a macro-level (McLaughlin et al, 2012; Carr, 2007, p4). This includes both use of PBS where the primary focus is support for an individual, and also the delivery of PBS through the support of natural mediators at a whole service, locality or population level (Allen et al, 2013; McGill et al, 2018).

Whilst PBS is relatively well-defined in the literature, there has been something of a disconnect between this and the way PBS outcomes are operationalised in research. Carr et al (1999) highlighted this concern at an early stage in a seminal review of PBS research. This review provided an encouraging collation of available research, but highlighted that the primary focus of articles concerned reductions in CB. In some instances, reported outcomes also included skill developments and social validity but there was a striking absence of studies that measured changes in life quality (included by only 2.6% of studies).

Aligning outcome measurement with the values, theory and change processes central to PBS is fundamental to building an evidence base and ensuring effective practice and service delivery. Though the scope of outcomes addressed in PBS research has increased over time, many limitations remain. Conroy et al (2005) noted that the majority of 73 studies concerning positive behavioural interventions for children (1998–2003) did not provide additional outcome measurement beyond those concerned with challenging and adaptive behaviours. Several more recent reviews of PBS have reported promising trends in the scope and focus of interventions, training and outcome measurements such as social validity (Clarke and Dunlap, 2008; O'Dell et al, 2011; Clarke, Zakszeski and Kern, 2018; LaVigna and Willis, 2012; MacDonald and McGill, 2013). Evaluation of life style, life quality, stakeholder and broader system-change has, however, in the majority of cases either not been explicitly discussed (Clarke and Dunlap, 2008; LaVigna and Willis, 2012), or is highlighted as a deficit and a recommended priority area for future research (O'Dell et al, 2011; MacDonald and McGill, 2013).

Whilst reviews have typically demonstrated a lack of evidence (or attempts to gather evidence) in relation to the full breadth of possible PBS outcomes, gathering data related to these is feasible. Multiple evaluation tools that do this to varying degrees exist, though often these have not been developed for the specific purposes of PBS outcome evaluation. These include measurement tools focused on challenging behaviour, adaptive behaviour and QoL for people with IDD and QoL, knowledge and behaviour change relevant to other stakeholders (Turton, 2015; Townsend-White, Pham and Vassos, 2012; Perry et al, 2015; Summers et al, 2005). More challenging perhaps has been the identification of measurement tools suitable to the evaluation of system-wide interventions concerning people with IDD and CB, though resources have been developed and utilised in the broader application of school-wide PBS (eg Bradshaw et al, 2008).

Further to this, Fox and Emerson (2010) developed 'Positive Goals for Positive Behavioural Support', a goal-based outcome tool of 38-items related to QoL, adaptive skills and other outcomes theoretically achievable via delivery of PBS on a case by case basis. However, there appears to be no published use of this tool in services, or research following development, and whilst outcomes for stakeholders and services are referenced, this is always within the context of support provided to an individual. As previously discussed, PBS implementation may occur at multiple levels, including whole groups, classes, services, organisations and localities/populations, and outcome evaluation in this respect is also required.

Some systematic approaches to gather and collate a broader range of PBS-relevant outcome data across services and clinical practice exist. For instance, Kincaid et al (2002) evaluated outcomes within 78 child-centred services in the USA via a questionnaire reporting on behaviour change (reductions in CB and acquisition of adaptive behaviours), perceived intervention effectiveness and individual QoL. More recently, Bowring et al (2019) reported on outcomes that included behaviour change and life quality across adult services in Jersey, and Hagiliassis, Marco and MacDonald (2019) described an outcomes approach developed by a service-provider in Australia.

Achieving more widespread and systematic evaluation of PBS that drives and informs sustainable and universal improvements for service delivery and the lives of individuals, however, may call for a more research-informed approach. Given the developments and increased collaborations concerning PBS in the UK in recent years, a refreshed effort to establish a consensus-based approach to outcome measurement also appears both promising and achievable.

This article reports on a three-phase Delphi research programme established to support development of a comprehensive set of core outcome domains for the evaluation of PBS in the UK context through a consensus-building approach. The study aimed to agree a set of domains that could guide routine selection of evaluation measures across multiple contexts and modes of implementation, encompassing a broad range of relevant outcomes for individuals, stakeholders and organisations.

Consistent with the aspiration of building consensus through a collaborative approach, Phase One of the study used a Delphi panel method (Linstone and Turoff, 1975; Adler and Ziglio, 1996) to create an overall framework structure and pool of outcome domains. The Delphi method creates consensus amongst experts in a specific subject area who comment on questions and statements over a series of rounds, rather than a single one-off survey (Linstone and Turoff, 1975; Adler and Ziglio, 1996). The procedure involves participation of well-defined, small panels (typically 10–15) where members have high levels of expertise and similar backgrounds; panel members' responses are kept anonymous; feedback (quantitatively and qualitatively) is provided to all panel members over consecutive rounds, and via this iterative process, a final consensus-based resource is generated.

In Phase Two of the study, the views of practitioners, caregivers and other professionals were incorporated. A series of voting exercises with stakeholder groups were conducted to identify key outcome domains for routine use, with final wording and edits made by a stakeholder representation group in Phase Three. In this article we describe the methods utilised in each phase, presenting these together with a summary of results that led to selection of the final set of core outcome domains. We discuss the possible use of these domains within service delivery and research, and consider next steps and directions for development and evaluation of the PBS framework.

Method

Ethics

Ethical approval for all phases of this study was sought from and approved by the Tizard Centre Ethics Committee at the University of Kent, England.

Phase 1: Delphi-panel exercise

Participants

Participants were researchers and clinicians in the field of IDD, with expertise and experience in PBS. An invitation to participate was sent to all members of the Sharland Foundation Developmental Disabilities Research and Impact Network (SF-DDARIN) (a network of behaviourally-orientated IDD researchers from across the UK). Additionally, invitations were sent to individuals from the primary author's professional networks, who had an established track record of research relevant to PBS but were not members of SF-DDARIN. Electronic information letters were distributed, and participants who were interested in taking part returned a consent form.

The Delphi panel for Round One comprised ten people (five males and five females) from England, Wales and Scotland. A panel of ten also participated in Rounds Two and Three. Of these, nine had participated in the initial round and one had not. The demographics remained the same, with a similar split of males and females and representation from the three countries. In Round Four, the panel comprised nine participants, all of whom had taken part in earlier rounds.

Delphi process

In each of the four rounds, a link to a Google Forms online questionnaire was e-mailed to each panel member along with instructions and additional feedback data as relevant. Participants were requested to complete a questionnaire within a two- to four-week period. Questionnaires were automatically uploaded onto a database that could only be accessed by the research team. Participants' names were not used, and they were asked to generate a personal code to enter onto questionnaires but to not disclose this to the research team or other panel members. This method ensured that panel members could respond anonymously but that responses could be linked between rounds.

Round One

Round One required participants to provide open-text responses in relation to starter questions that prompted consideration of different perspectives, levels of implementation and key components of a PBS framework. Participants were firstly asked to detail outcome areas of significance for 12 stakeholder groups (ie people with IDD, caregivers, staff). Whilst this process was not equivalent to direct consultation with these stakeholder groups, panel members had considerable experience of stakeholder collaboration and were well placed to consider these perspectives, albeit from a researcher/clinician perspective. Participants were also asked to reflect on PBS outcomes relevant at different levels of a support system including an individual level (where support concerned a single person with IDD or support for individual mediators), a small group level (such as classes of children with IDD; families or staff teams), organisational level (ie whole service or school), and at a community, geographical area or whole population level. Finally, participants were asked to consider outcomes that reflected values, theory and processes central to PBS, with an additional open response section to suggest any other outcome areas not otherwise covered.

Round One responses were analysed thematically using a framework approach (Ritchie and Spencer, 1994) and presented to panel members in Round Two as outcome domains structured around these levels and categories. In this round, participants were asked to rate the relevance of each domain as an outcome for PBS (0 = not applicable as an outcome area, 1 = applicable and 2 = highly applicable), or to indicate if further clarification was required. Panel members were also asked to provide comment on the overall structure and analysis.

Delphi studies typically use a decision-making rule based on consensus of 80–90% of panel responses. In this study, we considered consensus agreement to be 80% of the panel rating a domain as relevant or highly relevant. Clarification for a domain was indicated when requested by 10% of the panel for domains that had not reached consensus, and 20% for those that had.

In Round Three, panel members were asked to provide further input and response to those domains that had not reached consensus or required further clarification. Participants were asked to provide further clarification or refined wording for domains that had previously appeared ambiguous, and to provide free-text responses that argued for or against inclusion of these. Responses from Round Three were collated and the lead author refined the wording of any ambiguous domains based on participants' suggestions. Justifications and challenges provided by panel members were arranged in summary tables for each area item.

In Round Four, all domains that had not reached consensus, and those which had been considered ambiguous, were re-presented to panel members along with summary tables produced at the end of Round Three and a summary of group responses from Round Two. Participants were asked to rate domains for a second time using the same scale used previously. The same consensus decision-making rules used in Round Two were adopted for agreement and clarity.

Phase Two: Voting exercises

Participants

Participants for Phase Two were 75 adults, recruited at three events concerning PBS/people with IDD. Participants reflected a range of stakeholder groups (typically support workers, other practitioners, family caregivers and commissioners) with varying degrees of PBS knowledge/experience. There were some limitations with demographic information collected, with only 65 participants providing this, and variability in terms of fields completed. The overall sample (where demographic information was provided), comprised 43 females and 20 males, aged 21–65, who largely identified as practitioners (41), and had experience/knowledge of PBS from between 1 and 39 years. Family caregivers also participated, so their views are included, but this was not indicated by available demographic forms.

Process

Each voting exercise took 60–90 minutes and, following information and consent procedures, began with a brief presentation outlining the methodology and findings from Phase One. Participants were then handed four tables of the major outcome level categories previously generated. Each table was further divided into sub-categories that contained a number of outcome domains. Participants were invited to prioritise domains by selecting up to two from within each sub-category that they considered most important as an outcome for PBS. Additionally, participants were permitted to select two further domains within each category level. At the end, participants discussed their experience of the exercise and indicated any additional areas they considered important that were not covered.

Phase 3: Final wording

Final wording of domains was shaped through a process of structured consultation between the primary author and a panel of four stakeholder representatives. This was an iterative process that occurred over several rounds of feedback and discussion. Stakeholders included two members of the Delphi panel (including the second author), one family caregiver representative from Phase Two and a PBS researcher/practitioner who had not otherwise taken part. The group therefore included those who had been involved at the previous stages of the project, and could reference ideas and decisions made throughout, and those who had not previously participated, and viewed items for the first time.

Panel representatives were provided with a copy of the core domains identified in Phase Two and asked to suggest wording that could increase accessibility and consistency whilst retaining the scope and meaning of the outcome area and overall domain. In a small number of instances, where participant ratings only discriminated between domains to a very slight degree, and/or where these had some overlap in their focus, stakeholders were asked to attempt wording that could combine these. Final edits were made by the first author following this consultation.

Figure 1: Outcome framework structure following Delphi Phase One

Level categories

(individual; family caregiver mediator; paid staff mediator; systems)

Sub-categories

(ie support received; family quality of life; wellbeing and work performance of staff; PBS systems)

Outcome domains

(ie staff manage the demands of their role and maintain positive wellbeing over the long term even when recognising challenges to this)

Results

Phase One: Delphi-panel exercise

Round One

A total of 164 outcome domains were identified. These were nested within 15 thematic sub-categories, that had coherence within four higher order categories or levels (individual; family caregiver mediators; staff mediators and service, organisation and locality systems) as described below. This structure is also presented in *Figure 1*.

Individual level category

The first category, individual level, concerned outcomes relating to the experience and behaviour of a focal person with IDD, that could be grouped with three sub-categories: quality of life, support received and behaviour that challenges. The sub-category quality of life included 48 domains organised into 8 groupings, relating to the broader QoL literature (self-determination; family and interpersonal relationships; social inclusion; personal development; physical wellbeing; emotional wellbeing; material wellbeing and rights) (Schalock, 2004).

> *Have a good quality of life, supported to make informed choices and have control…have relationships with family and friends…participate in the community….*

The sub-category support received contained 11 domains concerning access to supports consistent with PBS values and practices, and experience of approaches counter to PBS (ie aversive and restrictive practices):

> *Levels of happiness or satisfaction with their support and those providing their support…*

The final sub-category in this level, behaviour that challenges, included four domains that concerned directly observable dimensions of CB and other indicators of such behaviour (ie school exclusions).

> *Reduction in frequency, intensity and duration of challenging behaviour. Increase in the reported ease of management of behaviour.*

Family caregiver mediator level category

The second category, family caregiver mediator level, related to the behaviour, experiences and opportunities of whole families and individual family caregivers in the context of supporting a person with IDD. A total of five sub-categories could be identified. The first two sub-categories concerned the physical and emotional wellbeing of caregivers (seven domains) and family quality of life (eight domains covering family relationships and wellbeing, together with social and community access for families).

> *Improvement in quality of life for caregivers… good health and wellbeing, reductions in stress.*

> *For family carers to access social activity…*

The third sub-category (three items) focused on caregivers' 'relationship with the focal person' with IDD (including perceptions of this person and opportunities to spend time together).

> *Being able to support their relative in their own community/within relatively easy access, being able to have family and community relationships… that their family member feels valued…*

A further five items related to stakeholder satisfaction and perceptions of support received by family carers and their relative (quality of support received).

> *Satisfaction with the support their family member is receiving… satisfaction with the training and support they have received…*

Finally, the sub-category skills, knowledge and attributions (eight items) reflected caregiver understanding and reactions to CB and supporting the needs of their relative with IDD.

> *Better understanding of their family member; more confidence in dealing with challenging behaviour…*

Paid caregiver/staff mediator level category

The third level category also concerned mediators who provide support to a focal person or people with IDD but focused on paid care staff behaviour, experiences and opportunities. Outcome areas were thematically organised into four sub-categories. The first of these (10 items) concerned staff members' knowledge, attributions and understanding of PBS values:

> *A belief that reduced levels of behavioural challenge are not the goal unless this is also accompanied by increases in quality of life… commitment to person-centred approaches...*

The second sub-category, PBS theory, reflected staff understanding, knowledge and behaviour in relation to conceptual and evidence-based elements of PBS, with the third sub-category referencing staff variables in relation to PBS process and practice:

> *Their beliefs about challenging behaviour and why it happens; in their understanding of functions of behaviour and how this applies to the individual they support; more empathy and understanding of why a person's life experiences may lead them to challenge…*

The last sub-category in this level (16 items) concerned wellbeing and work performance of staff, including aspects of emotional wellbeing and coping, job satisfaction and perception and support within an organisation.

> *Staff satisfaction with the support they are receiving and the training they have received; staff injuries, staff satisfaction in their role… quality and frequency of practice leadership/supervision.*

Systems level category

The final level concerned outcome areas focused on change or maintenance of whole service, organisation and locality systems, with 38 domains derived from panel member responses, organised within three sub-categories. Outcomes that spanned staff culture, organisational resilience, service size, inspection and stakeholder satisfaction were grouped within the sub-category, systems quality.

> *Better functioning teams who work more as a team...*

A further subcategory of domains, systems functioning, was included that referenced staffing variables (such as turnover, ratios and recruitment), together with items that referenced placement breakdowns, waiting list lengths and community integration.

> *Improved local infrastructure and expertise; greater cost efficiency; fewer placement breakdowns.*

Finally, the sub-category PBS systems brought together domains that related to the presence of strategies and structures to support implementation of a PBS framework across services, organisations and localities.

> *A clear evidence-based care pathway delivered by staff skilled and trained to deliver it…*

Round Two

Overall, 19 domains did not meet the consensus criteria and/or required clarification. Of these, six were from the individual level (including an item related to sensory functioning); three were from the family caregiver mediator level category (including 'marital satisfaction'); three were from the paid caregiver/staff mediator level category (including 'resilience') and seven were from the systems level category (including an item relating to staff recruitment). All 19 were re-presented to panel members in Round Three.

Round Three

Qualitative data were reviewed by the first author to support initial revised wording of all items that required clarification, and then re-presented to panel members. Panel members provided a range of justifications, queries and challenges in response to each domain within Round Three. Supporting statements that provided context or rationale for the domain were provided in several cases:

> *Ongoing challenging behaviour leads to poor morale and difficulty in recruitment of staff – when this situation is positively impacted by PBS, then it becomes much easier to recruit and retain staff.*

Similarly, panel members clarified challenges to inclusion of domains in several instances:

> *It's a bit indirect as a PBS outcome.*
>
> *This is very ambitious as an outcome PBS can achieve as influenced by many other variables.*

Round Four

The vast majority of re-presented domains (17) achieved consensus criteria during this round with 10 rated applicable/highly applicable by 100% of members. Two domains did not meet consensus. This included one domain from the family caregiver mediator level (relating to relationship with spouse), rated as applicable/highly applicable by 66.6% of members and one domain from the systems level (waiting lists for PBS services), rated applicable/highly applicable by only 77.7% of members.

Phase Two: Voting exercises

Data completion and analysis

Of the 75 participants who took part, 73 completed the exercise at all four levels and two completed the first three levels only. A vote percentage was calculated for each domain by dividing the number of votes made within each sub-category by the sample size x 100 at each workshop and overall (noting that participants could make at least two votes within any sub-category, plus any additional votes that were permitted across the level category, or make no votes at all).

A decision process was established, to identify the most frequently voted-for domain within each sub-category. First, we identified the domain that received the highest percentage of votes overall within a sub-category. Second, we checked whether this domain also reflected selections at each individual workshop. If a domain received the highest percentage of votes overall, and was one of the top two domains voted for during at least two of the workshops, it was taken as the key domain. This method ensured that key domains were determined by a combination of the overall number of votes, but also representativeness across the workshops (each of which reflected a slightly different demographic and stakeholder representation).

Findings

Table 1 presents the domains that met the decision rule together with the percentage of total votes these received within each sub-category. In the majority of cases, these domains were clearly voted for more commonly than others within the sub-category, with a small number of exceptions where domains were only slightly differentiated by participant ratings as follows:

Within the sub-category, quality of life: rights (individual level), the presented domain was only voted for 3% more than the next most frequently selected domain ('person is free from aversive, restrictive practices – the focal person is not exposed to any form of abusive behaviour and a focal person who has previously been exposed to aversive practice is supported appropriately', 59%). Participant feedback also suggested some difficulty in discriminating between what was covered in the 'abuse' and 'aversive and restrictive practice' domains.

Similarly, within the sub-category, PBS process, the selected domain was only 3% higher than the next most frequently voted for domain 'understanding and use of behaviour support plans' (37%). Finally, within the sub-category, PBS systems, the selected domain received 39% of votes but this was only 1% higher than the 'practice leadership' domain.

Table 1: Outcome domains most voted for

Individual level	**Votes**
Choice making and control (quality of life: self-determination)	89%
Quality of relationships with family and friends (quality of life: interpersonal relationships)	85%
Community participation, inclusion, integration, presence (quality of life: social inclusion)	72%
Engagement in meaningful activities (quality of life: personal development)	62%
Positive health and lifestyle behaviours (quality of life: physical health)	68%
Positive psychological/emotional/mental health and wellbeing (quality of life: emotional wellbeing)	77%
Match between physical environment and individual's specific needs (quality of life: material wellbeing)	93%
Person is free from abuse and abusive practices; the focal person is not exposed to any form of abusive behaviour and a focal person who has previously been exposed to aversive practice is supported appropriately (quality of life: rights)	62%
Staff/caregiver understanding of individual's needs and behaviours (supports received)	66%
Frequency, severity, intensity, duration, management difficulty and range of challenging behaviours (behaviour that challenges)	89%
Family caregiver mediator level	
Positive psychological/ emotional/mental health and wellbeing (psychological and emotional wellbeing)	48%
Quality of family relationships (family quality of life)	68%
Quality of relationship with focal person (relationship with focal person)	92%
Involvement in planning/advocacy/service support (quality of support received)	55%
Confidence/self-efficacy/sense of competence in responding to challenging behaviour (skills, knowledge and attributions)	69%
Paid staff mediator level	
Understanding relationships between quality of support, quality of life and challenging behaviour (PBS Values)	64%
Knowledge and understanding of PBS framework (PBS theory)	67%
Adherence to/use of and implementation of behaviour support plans	40%
Staff manage the demands of their role and maintain positive wellbeing over the long term even when recognising challenges to this (wellbeing and work performance)	27%
Systems level	
Staff communication and culture reflects values of a PBS framework (systems quality)	47%
Collaboration, team working, team communications and team relationships are improved (systems functioning)	45%
Shared (PBS/functional) model to guide practice across service/organisation/locality (PBS systems)	39%

Final wording

Stakeholder representatives suggested a variety of ways to refine wording of core domains and ways to combine items that were only slightly differentiated by participant voting as indicated above. In addition, two further domains were incorporated from the sub-category, quality of life: personal development, which had included a particularly high number of domains (8) central to PBS. First, the core domain concerning engagement in meaningful activity was expanded to also encompass skills development, and second, an additional domain was selected from this grouping that concerned support for communication, which again had been embedded within other domains in Phase One. The final core items following this editorial process are presented in *Table 2*.

Table 2: Outcome domains with final wording

Individual level
Choice making and control
Relationships with family and friends
Community presence and participation
Skill development and meaningful activities
Health and fitness
Emotional wellbeing
Personal living environment
Experience and support concerning aversive, restrictive and abusive practices.
Caregiver and staff understanding of person-specific support needs
Support for communication
Dimensions and management difficulty of behaviours that challenge

Family caregiver mediator level
Caregiver emotional wellbeing
Family relationships
Relationship between caregiver and relative
Caregiver engagement in support for their relative
Caregiver beliefs about the support they provide to their relative

Paid staff mediator level
Staff understanding of relationships between quality of support, quality of life and behaviour
Staff understanding of the PBS framework
Staff understanding and use of behaviour support plans
Staff emotional wellbeing in relation to their support role

Systems level
Reflection of PBS values within culture of organisation
Team working, communication and collaboration
Organisation-wide guidance and practice leadership concerning the PBS framework

Discussion

In recognition of the limited scope of outcomes routinely evaluated in PBS practice and research, this study aimed to build a more comprehensive set of core domains through a consensus building approach. The Delphi method provided a robust approach to gathering and considering expert views, with the voting exercises and final wording process providing good potential for extended stakeholder involvement in shaping a set of core outcomes with contextual fit to PBS in the UK. These study phases were not without limitations. Arguably, a greater number and diversity of initial Delphi-panel members and stakeholders would have been desirable. It is notable that the study did not include attempts to engage directly with people with IDD (though related work is under way by the lead author). The overall structure, core set and method of production does, however, provide a helpful step forward for the field. The full range of domains is expansive, conceptually coherent and consistent with models of PBS, and references systems level implementation.

Implications and recommendations for PBS practice and research

Multiple reviews have included recommendations that future PBS research addresses a broader range of outcome measurements. In particular, the need to consider routine measurement of QoL at an individual and family level, and to consider outcomes for systems-level intervention, has been a re-occurring theme as described previously. The outcome domains produced within this study provide a useful reference to researchers to select a variety of evaluation measurements in this regard.

Several authors (eg Kincaid, 2018) have stipulated that by investigating additional outcomes of this nature, PBS research can begin to advance the field by answering more specific questions about utility and effectiveness. As PBS evolves, it becomes increasingly important to explore at both a whole framework and component level, providing greater detail of factors that concern effectiveness. Systematic exploration of a variety of outcomes as relevant to different contexts of PBS implementation will be required if researchers are to address what works for whom, when, where and how.

Second, high numbers of children and adults with IDD live within family/home environments, and family caregivers are recognised as being highly committed and critical to implementing PBS when given appropriate support and information (eg Dunlap and Fox, 2007). In addition to supporting research that focuses on the needs and expertise of family caregivers, the outcome domains may help families be more aware of the full scope of the ways PBS can benefit them. This could empower caregivers to request and expect support, and work towards achieving positive outcomes for themselves and their relative with IDD. Consumer-led approaches have often helped drive developments in health and social care and have been reflected in family focused PBS discourses (Summers et al, 2007). Use of the outcome domains to support work with families, presented in an appropriate format, has parallels to other resources created for and with family caregivers (ie Scott, Denne and Hastings, 2018).

Many of the possible benefits for family caregivers will also be true for paid staff. PBS, as it has evolved in the UK in particular, greatly values the role of caregivers (both unpaid and paid) as mediators for quality support and, consequently, prioritises the wellbeing and skills development of the workforce. Increasing research in this area will be helpful for identifying optimal approaches to supporting staff and promoting staff development. It is also probable that providing staff with knowledge of desired PBS outcomes may help to achieve this by confirming and supporting positive aspirations and clarifying expected roles, conditions that are closely associated with staff wellbeing (Hatton et al, 1999).

Finally, scaling up PBS practice at a service or locality level to ensure effective, consistent and sustained delivery is an ongoing challenge. The domains identified in this study should provide a helpful reference and guide to commissioners and others, since these include good coverage of outcomes focused on implementation at a macro level. Outcome areas at the individual and mediator levels should also be of interest and value to professionals within these roles. For instance, in addition to gathering outcomes concerning system structures, it should be possible to systematically collate outcomes that correspond to repeated delivery of PBS to individuals and families. Both policy makers and researchers are tasked with a challenge of identifying more nuanced strategies concerning effective PBS implementation that can accommodate the idiosyncrasies of different localities and avoid generic or over-simplified guidance. Close adherence to a conceptually coherent outcomes framework is critical to inform such work.

Future research and development

In their current form, the core outcome domains would seem to have a number of potential uses. These are likely to be considerably enhanced, however, by further developing an outcomes framework in accordance with the principles of PBS, to respond to both research limitations and practical considerations. Two key questions can be prioritised in this regard:

First, which measurement tools and/or other data collection processes might best be utilised to capture outcomes in these domains? Some prior reviews of literature will be helpful in this regard, but it will also be important to conduct a mapping of this with reference to the current domains, and identify gaps in current resources and utility of these in different contexts.

Second, although the core set of domains should relate to many situations, it is very probable that a process of selecting an evaluation focus within this structure will be required. This will be particularly important when working at an individual level to identify and select personally meaningful outcome areas for people with disabilities and family caregivers. Very little research concerning outcome selection by stakeholders appears to have been conducted, though demonstrations are now beginning to emerge (eg Gore, McGill and Hastings, 2019) which, combined with the findings of the current study may provide a further key mechanism to drive PBS evaluation and evolution.

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