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Positive Behavioural Support for Children with Intellectual and Developmental Disabilities in the UK: Enhancing Service Delivery, Stakeholder Engagement and Early Years, Proactive Supports for Families

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Abstract

Background and Research Questions

Relative to their typically developing peers, children with Intellectual and Developmental Disabilities (IDD) are at increased risk of developing behaviours that challenge (CB), which is associated with a range of negative impacts for both the child and their family. Positive Behavioural Support (PBS) has come to be recognised as the evidence-based intervention (framework) of choice for people with IDD of all ages who present or are at risk of presenting with CB. Several developments have occurred in recent years to define and support PBS implementation in ways that fit with a UK context. Building upon this body of work, this thesis explored three key questions within the overall context of seeking to enhance support for children with IDD at risk of CB: Firstly, how can delivery of high quality PBS be supported within services? Secondly, how can stakeholder engagement be maximised to enhance support for children with IDD and their families? Thirdly, how can proactive support for children with IDD and families be enhanced in the early years?

Methods and Results

Five empirical studies were completed grounded within an initial and ongoing discussion of literature. The first study (Chapter Two) comprised a survey of 100 child-focused practitioners in the UK to explore perceived competencies and training needs in PBS services. In addition to highlighting strengths in some competencies, the survey identified a particular need to better support practitioners with regards intervention and evaluation. The second study (Chapter Three) responded to this need and the limited range of outcomes that are typically included in PBS research. This study used a four-round Delphi process to create a PBS-evaluation framework that detailed 162 outcome domains structured across four systems levels. Two further studies were completed (Chapters Three and Four) that connected to PBS outcomes and stakeholder engagement. These studies explored use of a novel-interview procedure based on Talking Mats to support family caregivers, and children and young people with IDD themselves, to identify priorities and goals for their own behavioural support. Findings from both studies supported the utility of this approach, and processes that related to engagement with children and partnership working with families were highlighted through a qualitative analysis. The final study (Chapter Seven) evaluated delivery of the Early Positive Approaches to Support (E-PAtS) programme (a logic model for which was presented in Chapter Six) through interviews with 35 caregivers raising a young child with IDD. Qualitative analysis of findings from this study highlighted positive outcomes for children and their families following attendance of the programme that connected to conceptual mechanisms that had been hypothesised.

Conclusions

Conclusions made throughout the thesis, and during the final discussion chapter, connect to the continued evolution of the definition and scope for PBS within the UK and effective implementation by services. Recognising and responding to the expertise and needs of a workforce, maintaining a systems-wide focus on outcomes that are consistent with the full aspirations of PBS, and ensuring a context of proactive partnership working with families and children appears critical.

Chapter One: Children with Intellectual and Developmental Disability, Behaviours that Challenge and Quality of Support: An Introduction

Overview

This chapter provides an introduction to the thesis, beginning with a brief review of relevant literature, and culminating in research questions and an outline for how these are approached within the five empirical studies that follow. Literature includes key information concerning diagnosis, prevalence and needs of children with Intellectual and Developmental Disabilities (IDD) and a discussion of Behaviours that Challenge (CB) with regards definition, risk and impact. Conceptual accounts that highlight and summarise causal and maintaining variables central to the development of CB amongst children with IDD follow, with particular consideration of the model provided by Hastings et al. (2013). From this theoretical basis, the chapter then provides a synopsis of the evolution of Positive Behavioural Support (PBS), with a focus on definition and practice within the United Kingdom (UK) and the development of a Competencies Guide. The literature section concludes with a discussion of current challenges and opportunities for children with IDD, their families and service development in a UK context at this time, creating a foundation for research questions central to the thesis.

Children with Intellectual Disabilities

Definition, Aetiology and Prevalence

Global definitions and diagnostic criteria for Intellectual Disability (ID) vary in wording (e.g., American Association on Intellectual and Developmental Disabilities' (AAIDD) Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, 2013; World Health Organisation's International Classification of Diseases, 1992, 2018), but typically identify three core features: An impairment in intellectual or cognitive functioning (commonly assessed via performance on standardised tests of intelligence, with an Intelligence Quotient score of 70, two standard deviations below the mean, taken as a clinical cut-off for diagnosis of mild ID); reduced ability to function independently or acquire everyday (adaptive) skills (which is also measurable, on multi-domain standardised tests of adaptive functioning such as the Vineland Adaptive Behaviours Scales (Sparrow, Cicchetti, & Balla, 2005); and recognition that difficulties in both of these areas arise during childhood (prior to the age of 18 years).

Regarding aetiology, ID may be caused by factors that include: hereditary and other genetic anomalies, where ID may present as a feature of a behavioural phenotype (e.g., Down Syndrome, Fragile X-Syndrome); metabolic disorders (e.g., Hypothyroidism and Phenylketonuria, PKU); maternal health difficulties and exposure to toxins during the perinatal period, and health complications, injury and toxin exposure to children directly. There is also substantial evidence that social, economic and environmental variables during early infancy and childhood play an influential and interacting role with genetic and organic factors in causation and development of (mild) ID (Carr & O'Reilly, 2016a; Iarocci & Petrill, 2011).

Reported prevalence of ID also varies internationally, with higher overall estimates found for low and middle-income countries and a pooled (administrative) prevalence rate of 9.2 per 1000 globally (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Latest figures for England specifically, based on national data obtained in 2015 (Public Health England, 2016), that combined information collected by government departments among people using services, and the results of epidemiological research, gave overall population predictions of 1,087,100 people with ID. Concerning children and young people, based on data obtainable from the Department of Education regarding those with a statement/Education Health and Care plan or identification through Action Plus categories corresponding to ID, prevalence of

ID in England was estimated as 2.5% (a total of 170,975 children and young people) (Public Health England, 2016).

Terminology

Historically, a range of additional terms have been used to refer to people with ID, many of which have, or came to have, stigmatising connotations (e.g., mental retardation). In the United Kingdom (UK) the term Learning Disability is more frequently adopted in policy documentation, service and professional guidance. Unlike the internationally recognised term of ID, in the United States (US) and in some other countries, the term Learning Disability is however, more typically used to refer to people with specific educational needs (e.g., Dyslexia) but who do not otherwise meet the diagnostic criteria for ID described above.

In clinical practice, younger children in the UK, US and elsewhere who present with needs corresponding to ID may be more likely to receive a diagnosis of Global Developmental Delay (GDD) (defined as significant delayed development in two or more of the following areas: gross or fine motor, speech/language, cognitive, social/personal, and activities of daily living; DSM, 5th edition). GDD is reserved as a diagnoses for children under the age of 5 years but is considered to be a predictor of future diagnosis of ID (Moeschler, 2008).

Finally, in research, the term Intellectual and Developmental Disability (IDD) is frequently used (internationally) to refer to individuals who may have an ID, or diagnosis closely connected to this (e.g., GDD) and/or another developmental neurological condition (most commonly those who are Autistic). Whilst ID and other developmental neurological conditions such as Autism are separable, this term reflects an increased chance of comorbidity (e.g., estimates of up to 40 % of the ID population meeting diagnostic criteria for Autism: Matson, & Shoemaker, 2009; Arvio, & Sillanpa, 2003) and several shared areas of support need. As such, IDD will typically be used as a term throughout this thesis with this broader population the overall focus of work.

Characteristics and Needs

For several decades, the fundamental goal of much national policy has been to ensure people with IDD experience the same opportunities and have the same quality of life outcomes, as anyone else (Department of Health 1993, 2007, 2010; NHS England, Local Government Association and Association of Directors of Adult Social Services, 2015). At a population level, people with IDD do however, present with a number of needs that require well planned and skilled support and are at increased risk of exposure to a variety of adversities that need to be mitigated, if these goals are to be achieved routinely.

By definition, children and young people with IDD are more likely than their peers to experience difficulties in learning everyday skills that support independence and agency over their environment and, which by extension, includes difficulties in other key areas of development including communication (Carr, & O'Reilly, 2016b; Chadwick, Buell & Goldbart, 2019), self-care (Anil, Shabnam & Narayanan, 2019; Tassé et al., 2012) and sleep (Krakowiak, Goodlin-Jones, Hertz-Picciotto, Croen, & Hansen, 2008; Priday, Byrne, & Totsika, 2017).

Children and young people with IDD are also far more likely than those without IDD to experience physical health, sensory and mobility difficulties, often as part of a genetic syndrome (Hall, Arron, Sloneem & Oliver, 2008; Oeseburg, Dijkstra, Groothoff, Reijneveld, & Jansen, 2011; Young-Southward, Rydzewska, Philo & Cooper, 2017) and at least as likely (and in some cases more so) to develop mental health and emotional difficulties (Einfeld, Ellis, & Emerson, 2011; Emerson & Hatton, 2007) in addition to behaviours that challenge (as will be discussed below).

Beyond this, incidence of poverty amongst families of children with IDD is heightened (Emerson, 2004; 2012a; 2012b) and children with ID are known to experience more adverse life events than their peers. This includes problems within the family, including parental separation and bereavements (Hatton & Emerson, 2004) and mistreatment from others. For instance, Sullivan and Knutson (2000) found children with IDD are three to four times more likely to experience neglect, physical abuse and sexual abuse than their peers (with this being most pronounced at the preschool age). Children with ID are also more likely to be bullied (Department for Children, Schools and Families, 2008) and excluded from school (Department for Education, 2010) with others at increased risk of needing to attend a residential school at a distance from the family home if support needs cannot be met locally (see below).

Behaviours that Challenge

Definition

Behaviours that Challenge (CB) may take many forms but often include acts of self-injury, aggression towards others and property destruction, that in terms of magnitude (frequency, intensity and duration) and severity of impact (on the individual and others) exceed the kind of more transient behavioural difficulties that are common amongst children as part of typical development (i.e., tantrum-type behaviour at around age two-years). Whilst some research has defined particular topographical categories of CB as a focus of study (e.g., aggression; Arron, Oliver, Moss, Berg, & Burbidge, 2011 or self-injury Cooper et al., 2009a) a broader, socially constructed, definition of CB is used by many researchers. Such a definition has several advantages in clinical practice and is adopted most often in policy, professional guidance and by service organisations in the UK (e.g., Royal College of Psychiatrists, British Psychological Society and Royal College of Speech and Language Therapists, 2007).

Emerson (1995) described how CB might best be conceptualised as a social construction, given variability in behaviours which are and are not considered challenging across cultural and situational contexts, in accordance with social rules, expectations and the perceptions and attributions of a social community. Given this, Emerson defined CB (in 1995 with revised wording in 2001 and by Emerson & Einfeld in 2011) as any behavior(s) perceived as atypical to the cultural context that occurs with sufficient magnitude so as to impact on the health and safety of the individual or others or limit access and use of resources in the community:

> *"Culturally abnormal behaviour(s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities" (Emerson & Einfeld, 2011, p. 4)*

This definition allows for flexibility in practice but, more significantly, connects to underpinning research concerning the development and maintenance of CB and creates a foundation for a functional and humanistic approach to intervention (see below). The definition recognises that the knowledge, understanding and resources of a support system are part of what determines whether a behaviour is experienced as challenging, with the implication that environmental systems therefore need careful consideration in research and practice.

The definition also counters a medical-model view that CBs are inevitable, or assumptions that such behaviours are a manifestation of deviancy or deliberate acts, with intention to manipulate or cause harm. Rather, the definition allows for a person-centred standpoint in which the 'behaviour' is something that is displayed 'by' a person that leads to clear effects or outcomes, as opposed to something that a person 'has' or 'is' which defines their identity or value and is seemingly fixed. Finally, by underscoring the significant impact for both the individual who displays such behaviour and others around them, the definition creates a premise for focussing support for CB on the alleviation of physical and emotional suffering and the promotion of life quality.

Prevalence and Persistence

Whilst CB may be displayed by anyone, it is widely recognised that people with IDD are at increased risk of developing such behaviour. Across age groups, an estimated 10-15% of people with IDD are likely to display CB, though methodological differences (Emerson & Einfeld, 2011; Simó-Pinatella, Mumbardó-Adam, Alomar-Kurz, Sugai, & Simonsen, 2019), topography of focus (e.g., Cooper, et al., 2009a; Cooper, et al., 2009b; Crocker et al., 2006; Lowe et al., 2007) and contextual and demographic characteristics of the population under study (many of which concern specific risk factors as discussed below) give rise to variability in reported prevalence.

Notably, prevalence rates vary in accordance with age, often emerging in childhood, and without intervention, persisting and peaking during later adolescence and young adulthood (Emerson & Einfeld, 2011: Murphy et al., 2005). This is attested to in the small number of studies that have examined child populations specifically (e.g., Kiernan & Kiernan, 1994; Male & Rayner, 2009; Simó-Pinatella et al., 2019). For instance, 93% of head teachers in specialist schools estimated that up to a quarter of their students displayed CB when surveyed in the study by Male and Rayner (2009), with 7% estimating that this was between 25% and 50% of students. Again, methodological and contextual differences have resulted in some quite different prevalence estimates and this includes reports of rates as high as 94% or 100% (Simó-Pinatella et al., 2019). More conservatively, based on an amalgamation of larger data sets (and items corresponding to a restricted range of CB topographies on a broader questionnaire of child development) it has been estimated that around 40,000 children in the UK are likely to have an ID and display CB (Cooper et al., 2014).

Consistent with these findings, children with IDD have been found at increased risk of developing CB, when compared to other (typically developing) children. These differences are notable from a young age. Secondary analysis of large, population, data sets in the UK has demonstrated that even by five years, children with IDD are at heightened risk of developing CB (Totsika et al., 2011a; 2011b) with 30% of young children with ID (aged zero to three) displaying behaviour problems (Emerson & Einfeld, 2010). Across a wider range of ages in childhood, 21% of children with IDD (compared to 4% of children without disabilities) meet diagnostic criteria for conduct disorder (Emerson & Hatton, 2007) and children with IDD (as has been discussed) are more likely to present with other developmentally-realted behavioural difficulties in areas such as sleep and feeding (Gal et al., 2011; Krakowiak et al., 2008; Quine, 2001).

Impact

Challenging behaviours have widespread negative impact on individuals and their families. For the individual, CB increases risk of injury, abuse, and harsh restrictive management approaches during childhood (Adams & Allen, 2001; Allen et al., 2006), with heightened use of physical restraints and chemical/medical interventions by carers, staff and organisations supporting children with IDD when CB is displayed (Adams & Allen, 2001; Allen, Hawkins, & Cooper, 2006; Emerson & Einfeld, 2011; McGill, Papachristoforou, & Cooper, 2006; McGillivray & McCabe, 2006; McQuire, Hassiotis, Harrison, & Pilling, 2015; Menon, Baburaj, & Bernard, 2012; Unwin & Deb, 2011; Wodehouse & McGill, 2009). Furthermore, children who display CB often encounter difficulties in accessing recreational, community and educational services (McGill et al., 2006; Wodehouse & McGill, 2009). Those who display severe forms of CB may be required to enter residential school placements, with CB often cited as a key reason that families seek out-of-home placements for their children (McGill, Tennyson, & Cooper, 2005). These are costly, may be some distance from the family home (Pilling et al., 2007) and may be linked to out-of-area placements during adulthood which are also associated with poor outcomes for people with IDD and their families (Allen, Lowe, Moore, & Brophy, 2007; Beadle-Brown, Mansell, Whelton, Hutchinson, & Skidmore, 2006; Gore et al., 2015;; Hassiotis, Parkes, Jones, Fitzgerald, & Romeo, 2008;).

Regarding impact on others, stress and burnout is often reported amongst staff who support children with IDD who display CB (Hastings & Brown, 2002; Kelly, Carey, McCarthy, & Coyle, 2007; Male, 2003). Of particular significance to this thesis, emotional/mental health difficulties amongst parents and siblings of children who display CB are also high relative to members of other families (Baker et al., 2003; Bromley, Hare, Davison, & Emerson, 2004; Hastings, 2002; Naylor and Prescott, 2004; Lecavalier, Leone, & Wiltz, 2006) and CB, beyond other characteristics of the child (i.e., severity of disability or adaptive skills), tends to be the most reliable predictor of such difficulties for families (Baker et al., 2003; Hastings, 2002a). As with CB, such difficulties appear to develop early, with parents of children with IDD likely to experience elevated stress by the time their child is five years old (Totsika et al., 2011a; 2011b).

Family carers of children with IDD also report many positive experiences when raising their child (Hubert, 2010; Kenny & McGilloway, 2007), and heightened stress, even in the context of CB, is not inevitable. Some of the variation in emotional wellbeing for families appears to relate to other psychological characteristics of caregivers (Glidden & Natcher, 2009; Resch et al., 2012; Totsika & Hastings, 2009) but is also attributable to availability and quality of social and professional support (Brown, Geider, Primrose & Jokinen, 2011; Griffith & Hastings, 2014; McConkey, Gent & Scowcroft 2013). Here, however, it is notable that many families report dissatisfaction with services or that support is not available (Griffith & Hastings, 2013; Wodehouse, & McGill, 2009).

Risk Factors

Several risk factors that can be classified as characteristics (or needs) of the child are associated with increased risk of CB (in contexts where such needs have not been adequately supported) amongst people with IDD. In addition to age (see earlier), this includes gender, severity of disability and communication and/or social skills impairment (Emerson & Einfeld, 2011; Lowe et al., 2007; McClintock, Hall & Oliver, 2003) whereby males are more likely to display CB; certain topographies of CB are more common amongst people with more severe ID (e.g., self-injury), and overall risk of CB is correlated with severity of communication impairment.

Further to these factors, physical health complexities (especially those associated with pain), sensory and mobility impairments (Cooper et al., 2009a; De Winter, Jansen, & Evenhuis, 2011; Emerson et al., 2001; Kiernan & Kiernan, 1994) and mental health difficulties (Holden & Gitlesen, 2003; Moss et al., 2000) are known risk factors for CB. General risk of CB and development of particular (sometimes idiosyncratic) topographies of behaviour are also associated (and included in the behavioural phenotype) of some genetic syndromes (e.g. Arron et al., 2011; Holden & Gitlesen, 2006) and other patterns of behaviour (impulsivity, hyperactivity, and repetitiveness) are known to predict later development of behavioural difficulties amongst both children with and without IDD (Burbidge et al., 2010).

It is not always possible to separate out the unique influence of particular risk factors given the fact these frequently co-occur. Links are also often apparent between different risk factors and occurrence of CB and this has been explored particularly within the context of behavioural phenotype research. For instance, children with Cornelia de Lange Syndrome have a predisposition to experience gastro-intestinal reflux (Hall et al., 2008). It has been suggested that pain caused by this condition may account for the high number of people with this syndrome who engage in self-injurious behaviour (with recognition that treatment of reflux often leads to subsequent reductions in self-injury within this population; Peebles & Price, 2012).

The extent to which people with IDD who present with combinations of these individually-focused risk factors develop CB is also likely to reflect interplay with other socio-environmental factors. This includes environments where physical and social support arrangements are unsuited to an individual’s needs and, consistent with what is known about behavioural contingencies (see below), create conditions in which development of CB becomes a near inevitable consequence (i.e., environments high in levels of demand, low in levels of choice and control and where there are limited opportunities for stimulation and interaction; Langthorne, McGill & O'Reilly, 2007).

Other literature has identified broader contextual factors that are also known risk factors for the development of emotional and behavioural difficulties in the general population. As has been discussed, children with IDD are at increased risk of being raised in poverty and experience more adverse life events than their peers, including abuse, family problems and exclusion (all of which predict development of behavioural difficulties in general, see below). Given cognitive impairment is associated with reduced resilience in the face of adversity, children with IDD are also likely to be particularly vulnerable to the negative influence of such challenging social-economic circumstances, life experiences and interactions with others (Emerson, 2013).

Parental mental health/emotional difficulties and coercive parenting styles (see below) are also known risk factors for development of CB *and* are both more likely amongst families of lower social-economic status (Emerson, 2004). The Family Stress Model (Conger & Donnellan, 2007) may be one way of understanding how these multiple relationships contribute to the development of emotional and behavioural difficulties amongst children with disabilities and their families (Emerson, 2013; Totsika, Hastings, Vagenas, & Emerson, 2014) with evidence showing that parental experience of economic difficulties increases likelihood of emotional difficulties which, via further influence on caregiver interactions, has implications for the behaviour and wellbeing of children (Totsika, Hastings, Emerson & Hastings, 2020).

Conceptual Models of CB and Developmental Processes

The array and dynamic complexity of factors and contexts associated with risk of CB is considerable. There have, however, been some attempts to create conceptual accounts that provide an integration of these variables and highlight key processes concerning maintenance and development of behaviour. These have utility in both research and clinical contexts for guiding development of assessment and intervention. Three such accounts will be discussed, in which several synergies are apparent, with each fundamentally conceiving CB as contextually controlled, learnt behaviour, and founding assumptions on a common operant behavioural model.

Like all operant behaviour, each of these accounts highlights that CB is maintained by its consequences, with both instances of negative reinforcement (e.g., a reduction in demands placed on the individual immediately following an instance of CB) and positive reinforcement (e.g., access to preferred tangible, similarly contingent upon CB) serving to increase future likelihood of such behaviour in similar contexts in the future. In these accounts there is explicit recognition that reinforcing stimuli may be socially mediated (i.e., in the context of an interaction with another person) and/or automatic (i.e., a change in levels of sensory stimulation) (the later with regards two of the accounts, Langthorne et al., 2007; Hastings et al., 2013) These models also suppose that topography of CB is not a predictor of the contingencies that determine its maintenance; that multiple forms of behaviour may be maintained by common contingencies and that the same behaviour may be maintained by different contingencies dependent upon context.

An extensive body of experimental behaviour analytic work has attested to the conception of CB as operant behaviour in this way with the development of procedures that reliably identify reinforcing contingencies and demonstrate behaviour change dependent on environmental manipulations (Carr et al., 1999; Iwata et al., 1982; Lloyd & Kennedy, 2014). Within this literature, four common behavioural contingencies have typically been identified and commonly described as ‘functions of CB’. These concern access to preferred tangible items/activities, access to attention, escape from demands or other aversive stimuli, and modification of sensory stimulation (Emerson & Bromley, 1995; Iwata et al., 1982; Lloyd & Kennedy, 2014).

The first model, developed by Langthorne et al. (2007) (see Figure 1), categorises known risk factors for CB into those that concern characteristics of the focal individual (‘challenging needs’) and those that concern characteristics of the social and physical environment (‘challenging environments’). Langthorne et al. suggest that combinations of these factors create those very (‘aberrant’) contingencies that experimental analysis has identified as central to maintenance of CB and commonly occur in naturalistic, community settings. Central to this model is particular emphasis on the principle of motivational operations within a four-term contingency, with both challenging needs (e.g., aversion to eye-contact amongst people with Fragile-X Syndrome) and aspects of a challenging environment (e.g., deprivation of social interaction) indicated in determining the value of reinforcing consequences.

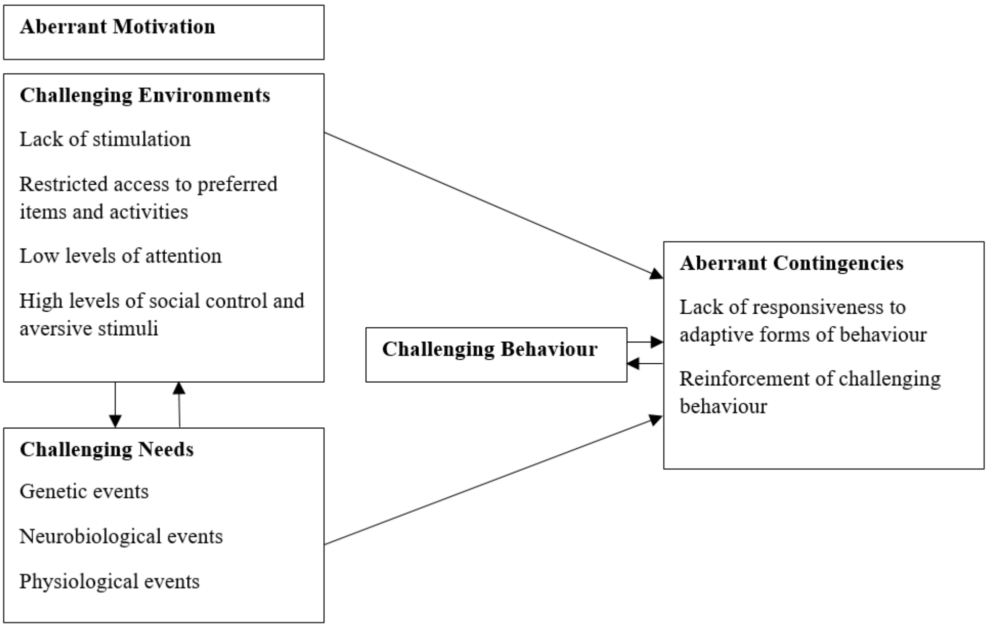

Figure 1: Conceptual Model of Challenging Behaviour by Langthorne, McGill & O'Reilly, 2007

The second area to conceptually account for development of CB connects with broader parenting literature that has demonstrated how overly permissive, inconsistent or inflexible and harsh caregiver-child interactions are predictive of behaviour difficulties amongst typically developing children (Eddy et al., 2001; Patterson, 1982). These associations have been applied to help understand and reduce behaviour difficulties amongst those with IDD by a variety of researchers through development of parenting interventions (i.e., Sanders et al., 2004). The work of Lucyshyn et al. (2004) is however, particularly pertinent, in that it connects with much of the IDD specific literature discussed thus far in this chapter.

Lucyshyn et al. (2004) highlighted and described three key developments within the fields of child development and IDD and proposed a means of combining these to further an understanding of the behaviour of children with IDD in family contexts, through an expanded unit of analysis (see Figure 2). Firstly, Lucyshyn et al. underscored the strength of evidence concerning social reinforcement of CB but noted that historically, most literature in this area has emphasised contingences that maintain the child's behaviour, with less regard for those that concern the behaviour of a caregiver. Coercion Theory (Patterson, 1982) by contrast concerns microsocial interactions and expands the unit of analysis to reinforcement at the level of child-caregiver dyad. It is of note that some literature within the field of IDD has in fact concerned processes of mutual reinforcement (e.g., Oliver, 1995; Oliver et al., 2005), though arguably these have perhaps received less attention or application within CB intervention.

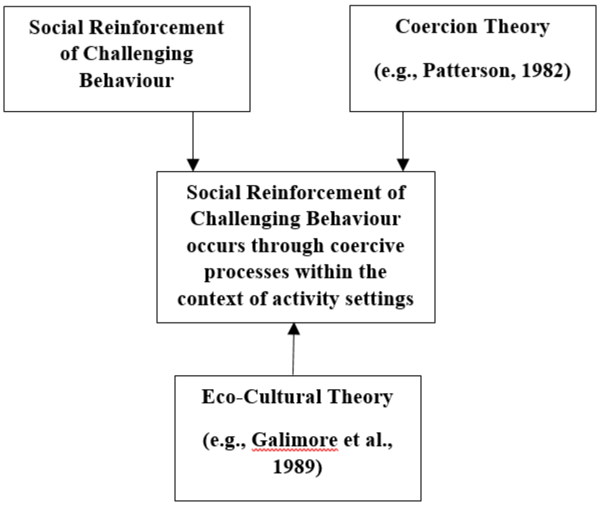

Figure 2: Conceptual Considerations of Challenging Behaviour by Lucyshyn et al., 2004

Within the Coercion Theory literature, two patterns of interaction appear to be commonly indicated in the maintenance of CB and relate to demand avoidance and attention maintained functions. In each case, CB functions as an aversive stimulus to caregivers, with subsequent acts that result in (short term) termination of the behaviour (e.g., the removal of demands for a child or the provision of attention whether in the form of praise of reprimand) therefore negatively reinforced for caregivers. Coercion Theory has generally been applied to typically developing populations but is consistent with the underpinning operant processes discussed thus far and has some helpful utility to understanding the situation for children with IDD.

Complexities of need for children with IDD, as discussed previously, are considerable and mean caregivers are faced with a high number of challenges that are, at times, extreme and extend beyond those encountered by other families. Children with Smith-Magenis syndrome for instance, often develop self-injurious behaviour from a young age that includes illomania (pulling out finger and toe nails) and polyembolokomnia (insertion of objects into body orifices) (Finucane & Haas-Givler, 2009). Experiencing behaviour such as this will be inherently aversive to caregivers and it is probable that without support little of what they have experienced previously will have fully or directly prepared them to respond in ways that do not inadvertently reinforce the behaviour.

The third area of literature discussed by Lucyshyn et al. draws on the concept of activity settings (routines in which children interact with family members and others at home and in the community). Eco-cultural Theory (Gallimore, Weisner, Kaufman & Bernheimer, 1989) suggests that ecological and cultural variables that are known to influence development for children are mediated through such activities. Furthermore, the theory posits that over time, families engage in or seek to construct, activity settings that are consistent with shared goals and values and that accommodate and respond to characteristics of the child. Given this Lucyshyn et al. proposed that behavioural assessment of CB should consider coercive processes, with activity settings as a unit of analysis. This principle assumption, that coercive patterns (associated with maintenance of CB) occur in the context of everyday family routines, has been further explored and evidenced throughout a series of studies by Lucyshyn et al. (2009) including as a basis of intervention (Lucyshyn et al., 2007).

Extending the scope of social contexts considered within conceptual accounts in this way has a range of positive implications, highlighting the profound influence that caregivers have on the development of children, but also seeking to understand rather than judge or blame caregivers for their behaviour or situation. A bidirectional influence between caregiver and child wellbeing and behaviour has been demonstrated in several longitudinal studies (Baker et al., 2003; Lecavalier et al., 2006; Neece et al., 2012). At the level of the caregiver system, it is recognised that behaviour and wellbeing of caregivers affects the development of children, yet at the same time the behaviour of their child impacts on caregiver emotional functioning and behaviour (Hastings, 2002), particularly with contexts of impoverished support (Chen and Kaplan, 2001; Kochanska et al., 2012; Waylen & Stewart-Brown, 2009).

The final model to be discussed was created by Hastings et al. (2013) as part of a special edition journal publication focussed on development of Positive Behavioural Support (PBS) in the UK (see below). The aim of the article was not to create a new model or account. Rather, Hastings et al. sought to synthesise existing literature to provide a common and guiding model for understanding the theoretical basis and practical implementation of Positive Behavioural Support in a UK context. The model has been highly influential within the UK with some further additions made by Bowring, Painter and Hastings (2019) in later years.

The model (see Figure 3 that includes and highlights edits made by Bowring et al., 2019) is presented as a flow diagram structured around three main columns, that together account for development and maintenance of CB (depicted in the central box) within the IDD population. Firstly, the model highlights that by its very (socially constructed) definition, CB results in a range of impacts for the individual and others as has been summarised throughout this chapter. Whilst the original 2013 model surmised these impacts in a single box, the 2019 model separated these into psychosocial and biological impacts and highlighted additional impacts (namely psychotropic medication and development of mental health difficulties). This element of the model therefore makes the Emerson definition of CB central but presented in this way also underscores how impacts can be conceived as separable from behaviour and therefore potentially amenable to change (even in contexts where the actual behaviour persists).

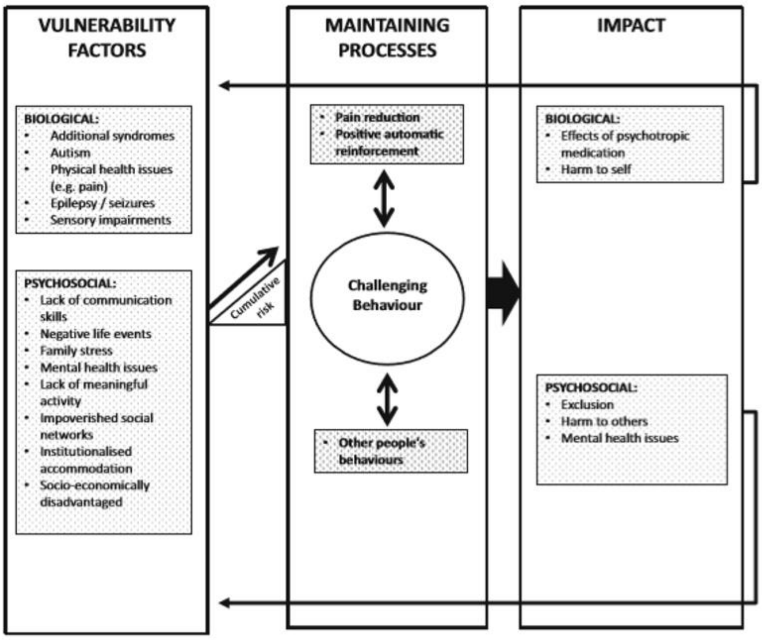

Figure 3: A Conceptual Model of Challenging Behaviour by Hastings et al., 2013; Bowring et al., 2019

The left-hand column of the model is termed ‘vulnerability factors’ and summarises much of what has been discussed in terms of known, population level risk factors for CB amongst people with IDD. The 2013 version of the model categorised these (for clarity and pragmatic purposes) into those factors that might be deemed biological (e.g., physical health complications) and those that are more psycho-social in nature (e.g., exposure to adversity). The 2019 updates to the model listed an increased number of exemplars and also stressed further the cumulative influence and dynamic interplay that is likely between these risk factors. In both cases, by highlighting the connection between these variables and risk of CB development the model created a premise for a range of proactive and systems level strategies that might prevent the overall risk of CB by support that attends to the broader social and environmental context (rather than, or in addition to, the CB itself). The model also includes a feedback loop whereby it is recognised that vulnerability is perpetuated or increased further still by the impacts associated with CB (which in and of themselves are risk factors for CB).

Finally, the middle column of the model, termed ‘maintaining factors’ summarises the core operant processes that concern both social and automatic contingencies of reinforcement for CB (with the positive automatic functions captured in the 2019 updated model). Furthermore, in discussion and with reference to a further diagram, Hastings et al. unpacked a range of variables and processes that help to understand the behaviours of caregivers (where these function in ways that reinforce the CB of people with IDD). This includes reference to literature concerning the emotional vulnerabilities of those supporting an individual who displays CB, and the array of likely interactions between caregiver wellbeing and behaviour. It also includes reference to attribution literature concerning interplay between caregiver beliefs, behaviour and emotion (e.g., Totsika et al., 2014; Baker et al., 2003) and lastly, highlights how broader socio-cultural (and political) contexts (including those embedded in service structures and approaches) are likely to influence what caregivers, think, feel and do.

As with the Langthorne et al. (2007) model, this account therefore captures the range of risk factors and core operant processes known to influence development and maintenance of CB but also (as with the work of Lucyshyn et al.) carefully examines the processes and contexts that concern caregiver behaviour and wellbeing by drawing on broader sources of literature within the field of IDD. More so the model is presented in a manner that is highly accessible (increasing utility to a range of stakeholders) and closely aligned with the conceptualisation and practice of PBS in the UK. The Hastings et al. account is therefore taken as the core model (along with other literature pertaining to PBS in the UK as discussed below) for formulating research questions within the current thesis.

Frameworks for Support in the UK

Treatment of people with IDD who present with CB in the UK has undergone radical change within the past five decades, gaining momentum in the context of both developments in the field of behaviour analysis (Baer, Wolf, & Risley, 1968) and a global trend towards deinstitutionalisation and the growth of the human rights movement (Tyne & Williams, 1979; Wolfensberger &Glenn, 1975). During this period, the overarching values and principles of good support have emphasised the right of people with IDD to experience opportunities and life quality, that is the same as for anyone else, regardless of whether they display CB. UK national policy and guidance has also, routinely, highlighted the central role of behavioural approaches to bring about positive change for people with IDD in ways that are consistent with a human rights agenda (Mansell, 2010; NHS England, Local Government Association & Association of Directors of Adult Social Services, 2015) and distinct from, the frequently aversive, non-functional, practices that typified earlier behavioural modification service responses (LaVigna & Donnellan, 1986).

A variety of seminal projects demonstrating the potential for actualising these ambitions for people with IDD and the services that support them were conducted in the UK during the late 1960s, 1970s and 1980s (NIMROD, 1978; Mansell, Felce, Jenkins, de Kock & Toogood, 1987; Tizard, 1969). These were consistent with the values and conceptions expressed in normalisation theory and social role-valorisation (Wolfensberger, 1971; O'Brien & Tyne, 1981) and drew upon non-aversive and personalised behaviour change procedures grounded in a holistic and functional assessment of the needs and behaviour of individuals. The premise for synthesising values-based and pragmatic (evidence-based) approaches in this manner was captured succinctly in a landmark discussion by Emerson and McGill (1989). Here, it was noted that (at the time), normalisation theory presented as a strong, values-based, vision for services, but one which lacked the practical means of achieving its aims, whilst behavioural analysis (again at the time) presented the technological means, but not the guiding ethics that might be used to determine change.

The combination of non-aversive behavioural approaches, the ideals of normalisation and principles of other values-based movements (e.g., person centred approaches) continued to typify many approaches to service developments in the UK during the decades that followed. In addition to individual, function-based programmes of support, this included identifying and supporting features of what later came to be described as a ‘capable environment’ (McGill, Bradshaw, Smyth, Hurman, & Roy, 2020) in which optimal outcomes for people with IDD might best be supported at scale and (through the reduced occurrence of what Langthorne et al. term ‘aberrant contingencies’) in which CB became less likely. This included pragmatic approaches to supporting meaningful engagement in activity, maximising choice and control, increasing communication opportunities and other skills development for people with IDD through development of training programmes for care staff and organisations (e.g., Jones et al., 1999)

In 1993, the Department of Health published definitive guidance on best practice for services for people with ID who display CB (The Mansell Report), building on research across these areas, with a reiteration of the same key messages produced in 2007. A wealth of further policy documents, professional and commissioning guidelines have been produced in the UK since (e.g., A Unified Approach, 2007; 2016; Learning Disability Professional Senate, 2014: Challenging Behaviour National Strategy Group, 2009; NICE, 2015; NHS England, Local Government Association and Association of Directors of Adult Social Services, 2014; Transforming Care and Commissioning Steering Group, 2014). Whilst the language and scope of each has varied, taken as a body of literature, these documents have shared a number of key principles. The specific commonalities and features of each publication are beyond the scope of this chapter but have previously been summarised by the current author in collaboration with others in the field (Denne, Gore, Hughes, Toogood, Jones & Jackson-Brown, 2020). Most notably however, this body of work collectively reflects a consensus on use of non-aversive behavioural approaches within the context of normalisation, social-role valorisation and person-centred values as best practice. Whilst not always explicitly referend to as such, these principle recommendations reflect central dimensions of a Positive Behavioural Support Framework.

Positive Behavioural Support in the UK

In parallel to growing dissatisfaction and concern regarding support for people with IDD within the UK, challenges to the use of aversive behavioural practices (and recognition of the technological limitations of values-based approaches alone) arose within the US and elsewhere during the 1970/80's giving rise to the development of Positive Behavioral Support (PBS). Built on a fundamental premise of combining evidence-based and ethically sound practices to support people with IDD at risk of CB, PBS has continued to develop since this period to become an intervention framework of choice, for supporting both adults and children within educational and family contexts in the UK (e.g., Department for Education & Department of Health & Social Care, 2019; Department of Health, Skills for Health & Skills for Care, 2014).

Multiple definitions and descriptions of PBS have been created (Carr et al., 2002; Hoerner et al., 1990; Kincaid et al., 2016). Whilst each definition has shared a common foundation, each has also reflected the terminology and cultural context in which it was created, and ideas and technologies within the field that have been refined overtime. With recognition of PBS as an evolving science; Carr et al, 2002) a refreshed definition of PBS was therefore proposed in 2013 to reflect research, contemporary practice and service structures in the UK specifically (Gore et al., 2013). This 'definition and scope' for PBS was created by a group of UK behavioural researchers and practitioners through a synthesis of existing literature and professional opinion, and since this date has achieved good impact in the field, influencing a range of practical, research and policy initiatives (Scott, Denne & Hastings, 2018). Given this, and its overall UK focus, the current thesis therefore draws closely on this definition of PBS, both in the development of research questions and the chapters that follow.

A Ten Component Framework

Like several prior accounts (Dunlap & Carr, 2007; LaVigna & Willis, 1992), the 2013 UK definition conceptualised PBS as a multi-component framework (rather than a specific treatment or unitary intervention) for understanding CB displayed by an individual (typically those with an IDD) and providing support at a systems level. The definition recognised that PBS may be implemented across a range of settings (e.g., residential services, Grey and McClean, 2007; schools, Goh & Bambara, 2013 and family homes, Durand et al., 2013) and be coordinated by individual practitioners (e.g. Emerson et al., 1987; Toogood et al, 1994), professional teams (e.g. Allen et al, 2005; Hassiotis et al, 2009) or whole organisations and communities (Allen, Kaye, Horwood, Gray, & Mines, 2012; Sugai & Horner, 2009).

Regardless of the mode or context of implementation, the definition proposed 10 core components that were considered characteristic and essential for delivery of PBS. Components concerned a range of evidence-based practices, values and conceptual principles and drew from prior (international) PBS literature and the field of CB more broadly. It was recognised that components overlapped, and likely interacted in multiple and dynamic ways. The critical importance of attending to all components was therefore stressed, rather than considering these as a menu of choices. The 10 components (see Table 1) were divided into those pertaining to values (three components), theory and evidence-base (three components) and process (four components) and unpacked throughout the remainder of the definitions and scope article. An overview of each component is summarised below (with several of these explored in greater detail during subsequent chapters of the thesis).

Table 1: The 10 Components of PBS as defined by Gore et al., 2013.

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

Values

The first values component concerned the central focus of PBS to support enhanced quality of life and inclusion for people with IDD, with interventions that have this primary aim, and which are derived through a holistic behavioural assessment, being the central means through which reductions in, or prevention of, CB may subsequently be met (Allen, 2005; Carr, 2007). Behavioural support within the framework was therefore proposed as needing to centre on an individual's needs, preferences and aspirations with ambitions to facilitate long-term, positive lifestyle changes, including enhanced wellbeing and greater meaningful participation in the community.

Consistent with a human rights agenda, the second values component underscored the non-use of aversive and restrictive practices (i.e., those that have been used historically by some behavioural modification approaches) within PBS (Allen, 2002; Carr et al., 2002; LaVigna & Donnellan, 1986). Here, it was stated that such practices should be minimised in assessment and behaviour support planning procedures and challenged and reduced whenever encountered in naturalistic settings.

Secondly, and with direct correspondence to quality of life outcomes, and early philosophical underpinnings of PBS (Goldiamond, 1974), this component highlighted the fundamental constructional nature of PBS practices. Rather than seeking to reduce (challenging) behaviours directly (which would commonly be associated with the functional use of punishment), PBS interventions were recognised as focussing on increasing repertoires of adaptive behaviour (e.g., through behavioural skills teaching) and maximising positive opportunities (including those that support choice and control, engagement in favoured activities and meaningful relationships) (Dunlap & Carr 2007; Emerson & Einfeld, 2011).

The final values component highlighted the centrality of partnership working with stakeholders throughout a PBS pathway. Stakeholders were taken to include peers and paid staff, but also (and consistent with family-focused models of PBS; Lucyshyn, Dunlap, & Albin, 2002) parents, siblings and other family members This component recognised that a range of stakeholders, are both part of the context in which CB may develop and be maintained for a focal individual and themselves at risk of harm, emotional difficulties and reduced life quality as a consequence of exposure to such behaviour. This component therefore emphasised that stakeholders should be engaged as informants and agents of change in assessment, evaluation, planning and implementation stages of PBS, drawing on personal insights and experiences to ensure contextually sensitive goals and forms of support (Dunlap, Carr, Horner, Zarcone, & Schwartz, 2008). Additionally, the component referenced how stakeholders may themselves require training and support as part of a system-based package of interventions (Dunlap et al., 2010).

Theory and Evidence-Base

Much of the discussion concerning components within this section has already been explored in detail earlier in this chapter and so will only be touched upon briefly at this point. The first theory and evidence-base component connects directly to the socially constructed definition of CB (Emerson, 1995) and the Hastings et al. (2013) conceptual account of the development and maintenance of CB, with recognition of both broad contextual, and microsocial operant, processes and the functional nature of such behaviour in the lives of people with IDD. Conceptual underpinnings that correspond to a four-term contingency are also reflected in the second component that highlights Applied Behavioural Analysis (Baer et al., 1968) as a foundation for the majority of assessment and intervention practices within PBS. Here it was emphasised that such practices are selected within the context of the guiding ethical components (i.e., are non-aversive) of the PBS framework. Furthermore, this component detailed how PBS utilises a flexible approach to assessment methods with attention to the broader context (at micro and macro levels of a system) and commitment to social and ecological validity beyond demonstrations of experimental control (practices which are less commonly reflected in the wider practice of ABA).

Finally, the scope and ambition of PBS (as an evolving science) to also draw on practices and approaches beyond those rooted in ABA, was captured in the sixth principle (Carr et al., 2002). Here it was highlighted that a variety of approaches (that correspond to the overall functional model of CB described in component four) are likely within scope for PBS and necessary to achieve the kind of system-wide and organisational change demanded of the framework (Carr, 2007; Carr et al., 2002). This was suggested to include training, self-management or therapeutic interventions with focal individuals, their staff and family carers (MacDonald & McGill 2013; Gore & Umizawa, 2011; Smith & Gore, 2011) and would likely include other evidence-based approaches from disciplines such as Speech and Language Therapy.

Process

Taken together, the process components describe the pragmatic steps and strategies typically involved in delivery of PBS to actualise the theoretical and values based components of the framework. Here, it is first noted (component eight) that decision making throughout each stage of a PBS pathway (and within each procedure) should be both driven by values and rooted in data (Carr et al., 2002). This overall approach connects closely to the applied behaviour analytic aspects of PBS but also ensures an accountable and ethical approach. Actions are not taken on the basis of judgement or opinion alone in which the perspectives or competing agendas of others may otherwise bias an appreciation of an individual’s true needs and aspirations or limit support for these.

The ninth component outlined the purpose and operation of individualised, holistic assessment within PBS in which both micro-operant contingencies and aspects of the broader context are explored through variety of methods to identify the function of CB displayed by a focal individual. Here it was again referenced that multiple procedures typical within a functional assessment are grounded in ABA (Iwata et al., 1982; O'Neill et al., 1997; Sprague & Horner, 1995;), but should be selected with sensitivity to the ecological context and completed through partnership working with stakeholders (Sugai, Lewis-Palmer & Hagan-Burke, 2000). A key aspect of this process was also identified as the means by which different data sources are synthesised to create working hypotheses to guide subsequent intervention.

The final, tenth component concerned intervention development, implementation and evaluation. Given the broad range of factors associated with maintenance and risk of CB and the values captured in components one to three, PBS interventions should be multi-component and correspond to both findings of functional assessment and needs and preferences of the focal person and other stakeholders (Sugai et al., 2000; Toogood, 2011; Willis, LaVigna & Donellan, 1993). Critically, the majority of interventions within a PBS behaviour support plan were described as proactive, in that they should function at a systems level to increase quality of life by enhancing skills and valued opportunities and mitigating antecedent contexts that evoke CB (Carr et al., 2002; Durand, 1990). Such interventions were recognised as having long-term focus (Carr et al., 2002; LaVigna & Willis, 2005), to necessitate further support and guidance for implementation by stakeholders (Horner et al., 2000) and to require ongoing monitoring, evaluation and refinement as part of a data informed iterative process (LaVigna, Christian & Willis, 2005).

A PBS Competency Guide

Competency guides seek to define the skills and knowledge required to implement a procedure or intervention with fidelity, and have been developed for a variety of professional groups in the UK (e.g., National Occupational Standards for Psychology, 2013; The Speech, Language and Communication Competence Framework, 2011), including front line delivery of Applied Behaviour Analysis (The UK ABA Autism Education Competence Framework Level 1 – UKAAECF: Denne, Hastings, Hughes, Bovell & Redford, 2011; Denne, Thomas, Hastings & Hughes, 2015), to support, train and assess performance of professionals. Regardless of differences in presentation and conception, these frameworks outline what are considered fundamental requirements for safe and effective professional practice.

PBS, as has been outlined, is a service-delivery model that may include input from a range of professional and stakeholder groups, but whilst other professional competency guides may correspond with some features of the PBS framework, it is unlikely that these will be sufficient to ensure optimal delivery of PBS across settings. The need and value of developing a competency guide specifically for the delivery of PBS in the UK was therefore described in a further paper published as part of the 2013 International Journal of Positive Behavioural Support Special Edition (Denne et al., 2013).

Based on the Gore et al. (2013) definition of PBS, Denne et al. (2013) detailed examples of expertise and corresponding credentials that might best be associated with optimal delivery of both the evidence-based and values-based components of PBS, across different levels of a support system. A first, and fundamental level, was conceived to reflect front-line practitioners, those with regular face-to face contact with service-users and so in highly influential positions. Here it was suggested, for example, that the ability to conduct all aspects of a functional behavioural assessment might not be a realistic (or necessary) routine expectation for those working at this level of the system. It would however, be necessary for practitioners operating in these roles to have an understanding of this process, and be aware of environmental conditions and other variables that influence maintenance of behaviour.

Denne et al. (2013) also identified a second tier of support that concerned supervisors and managers. The primary function of practitioners operating in these roles was considered to relate most centrally to supporting those at level one. Having some increased understanding of assessment and intervention procedures was therefore considered necessary for managers and supervisors to guide practice and ensure integrity of implementation. Beyond this, Denne et al. (2013) identified ‘specialist and consultant’ system levels where a high degree of competence would be necessary to support and lead across systems in general and to provide focussed support to individuals with the most complex needs.

Formal creation of a UK PBS Competencies Guide[1] was later advanced within the context of ‘phase two’ activities co-ordinated by the PBS Academy (formerly PBS Coalition), a UK collective of researchers, practitioners and other stakeholders in the field of PBS (Scott et al., 2018). Work on the guide began in 2014 (documented by Branch & Denne, 2015) through a series of workshops and collaborative writing and editing exercises between members of the PBS Academy. This included authors who had contributed towards the International Journal of Positive Behavioural Support Autumn 2013 special edition articles and other practitioners and academics. Writing and discussion drew heavily on the Gore et al. (2013) definitions article and the Denne et al. (2013) article. The final guide was endorsed by 27 organisations, released in May 2015, and had received 4,500 viewings by autumn of that year.

As with all resources produced by the PBS Academy, the Competency Guide was made freely available for download under a Creative Commons Attribution-Share Alike 4.0 International Licence (which also permitted individuals and organisations to utilise the guide in ways best suited to their particular needs, with citation to the Academy). Notably, a publication by Scott et al. (2018) that concerned an evaluation of the impact of the PBS Academy resources and activities amongst 278 (typically professional) stakeholders, reported

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[1] Formally called the UK PBS *Framework* but referred to as a *Guide* throughout this thesis to reduce confusion with other PBS Frameworks that are referenced.

that the Competency Guide was deemed as ‘very useful’ or ‘useful’ by 89% of those who took part. Following initial development of the Competency Guide, the PBS Academy also undertook a range of projects to develop further tools and resources for different stakeholder groups and functions. Further details concerning content of the guide are provided in Chapter Two of this thesis.

Dissatisfaction and Concerns Regarding Behavioural Approaches

This chapter has thus far presented a case for the use of PBS, a behaviourally-based approach, to support children and young people with IDD and their families. It is important to note however, that whilst there is, in the main, strong support for use of PBS in the UK in policy and from key stakeholders, concerns and dissatisfactions have also been voiced. It is very important that these views and experiences are recognised and considered carefully in future research and practice.

Particular criticism for behavioural approaches has been raised by the neuro-divergent community, typically by adults who are autistic and able to self-advocate. Some concerns have also been expressed by families of people with disabilities, again typically where their relative has a diagnosis of autism, and some professionals. Views are often expressed within the context of discussions on social media platforms, rather than within the context of research, but there have been a small number of key publications that have captured some of these views and responses from behavioural practitioners and academics.

Applied Behavioural Analysis

Leaf et al. (2021) appraised, in detail, a range of concerns that have been posited in relation to ABA with the intention of both learning how to improve future support and addressing any misconceptions. It is the current author’s view that considerable care needs to be taken in this regard. People’s views and experiences must be respected and recognised as being born out of a lived reality. People’s views and experiences always tell us something, and it is for the field to address any misconceptions, not those people for whom support is the focus. A humble approach that is open to feedback and ready to change is also important for scientific discovery and to honour the ethics of any support system. At the same time, it is important to adopt an academically rigorous approach to ensure that developments and practice are based on accurate and evidence based assumptions.

Leaf et al. (2021) note that many of the concerns raised about ABA are referenced to the seminal work of Lovaas and colleagues during the first Young Autism Project (YAP) spanning the 1960s to 1980s. This includes use of punishment-based procedures, rigidity and intensity of approach and outcomes that focused on ‘cure’ of autism. The authors (who include researchers who served on this project for 20 years) note that within the context of this project, several procedures changed over time (e.g., physical punishments were not used after the 1970s and a ratio of at 100 reinforcing responses to 1 punitive one was established) and others were not a representative feature of the work (i.e., there was considerable flexibility with regards personalisation of interventions throughout; intensity of programmes was an average of 40 hours a week rather than a fixed criteria, not much more than a typical school week, is supported by multiple reviews indicating associations between intensity and effectiveness, and none demonstrating associations with adverse outcomes).

The authors note that the social context of the time meant that many children with autism were deemed in-educable and housed within large institutions, with some engaging in life-threatening self-injury. The term ‘cure’ is recognised as unhelpful, but one that changed later and was based on objectively definable diagnostic criteria within this context. The authors also note that further complications have arisen due to the way behavioural terminology is sometimes used in different contexts. For instance, in behavioural terms ‘punishment’ refers to any consequence that leads to a future reduction of a behaviour, with naturally occurring examples occurring throughout life that are not necessarily aversive (e.g., being told not to do something). In more common language use punishment is strongly associated with dehumanising, upsetting or pain inducing acts only. Leaf et al. (2021) go on to explore these and other criticisms (e.g., use of extinction, interventions for stereotypic behaviour change) in more recent ABA practice. Here it is recognised that there is variability in how ABA is used and a variety of suggestions are made to enhance effective and ethical practice in the future.

Positive Behavioural Support

Within social media, many of the concerns raised in relation to PBS mirror those made of ABA. These approaches are often discussed interchangeably, viewed as one and the same, or with a suggestion that PBS is really ABA in 'disguise'. Two notable grey-literature publications in the UK have presented views that reflect these perspectives, one from the standpoint and authorship of a neuro-divergent academic (Milton, 2018) and the other from a clinical psychologist in private practice (McDonnell, 2019).

Whilst respecting the views and opinions of both authors, the key points discussed by Leaf et al. (2021) and reflected in other contemporary descriptions of ABA as regards behaviours that challenge (e.g., Friman, 2021) have relevance to critiquing the accuracy of several points made within these articles. More so, the definition of PBS and history of how the framework has evolved laid out in the early part of this thesis contests the view that ABA and PBS are indistinguishable. Here the values, evidence base and practice of PBS in the UK contrast quite considerably with descriptions made by both Milton (e.g., that it is unsympathetic to a social model of disability) and McDonnell (e.g., that functional assessment is overly simplistic).

As stated at the start of this section, it is the author's view that the experiences and views of stakeholders, particularly those with lived experience, must be listened to and used to inform future developments for the field. It is not sufficient, and largely ineffective, to engage in a purely academic debate with regards scientific accuracy, though the consequences of not doing so at all are also very concerning and may include cuts to services, changes in policy and insufficient or ineffective support for children, young people and their families (Leaf et al., 2021). Within these accounts of PBS some key themes are notable and important for both the field and this thesis to consider. Firstly, there is considerable variation in what people (including those who might use services and professionals) understand PBS to be and how this is likely used in practice. Secondly, both Milton and McDonnell express a broader view that behavioural approaches have not attended sufficiently to seeking the views of people for whom support is the focus to identify goals for intervention. With regards this point, Leaf et al. (2021), also recognise that whilst social validity is a hall mark of ABA, measurement of this is often lacking in behavioural research. Finally, There is recognition (from MacDonald in particular) that those people who may be required to implement a behaviour support plan (be that families or staff) may be experiencing emotional and resource difficulties, and that these need to be carefully considered within the context of intervention.

Development of Research Questions

People with IDD represent a relatively small group but one characterised by diverse complexities of need (in addition to strengths and positive qualities), for whom support is often inadequate, adversity common, and risk of CB greatly heightened. Such behaviour, by definition, is associated with a range of negative outcomes for people with IDD, their families and society more broadly. A fundamental focus on enhancing the quality of support for people with IDD in relation to CB is therefore warranted.

Several well-publicised scandals in the UK have highlighted the vulnerabilities of adults with IDD who present with CB (see Mitler, 2010). At the time of developing research questions for this thesis, this included an exposé of abuse inflicted upon people with IDD by staff at Winterbourne View Hospital. Media coverage of these events gave rise to public outcry and triggered the development of a governmental programme of work (Transforming Care, Department of Health 2012a; 2012b) to reduce the number of adults with IDD residing (long-term) within Assessment and Treatment Units of this nature. This was established initially as an adult-focussed work stream. As has been discussed however, CB typically develops much earlier. Adults within Winterbourne View were of course once children, many of whom had been known to present with CB at early life stages, and experience a stream of family and placement breakdowns and failures of care.

Lobbying by key third-sector organisations (e.g., The Challenging Behaviour Foundation) clarified the need to also consider earlier and preventive support (especially for children) as part of the Transforming Care initiatives, and this was latter recognised and incorporated into key strategies (e.g., Ensuring Quality Services, 2014). This situation did however, underscore the particular need to develop better service provision for children and young people with IDD, and early intervention initiatives with regards CB. Significantly, whilst PBS approaches had often typified at least some adult IDD services in the UK, these were largely unused in child services and early intervention approaches for CB have been relatively scarce in the research literature (Gore, Hastings & Brady, 2013). A particular focus on research to better inform support for children with IDD and their families was therefore justified.

PBS has been recognised as the evidence-based intervention (framework) of choice for people with IDD of all ages who present or are at risk of presenting with CB. Research evidence for PBS includes a variety of research syntheses, reviews and meta-analyses demonstrating effectiveness across age groups for multi-element interventions (Carr, et al., 1999; Lavigna & Willis, 2012) those corresponding to particular functional interventions (e.g., Kurtz, Boelter, Jarmolowicz, Chin, & Hagopian, 2011) and specific topographies of CB (e.g., Prangnell, 2010). A smaller number of reviews that reflect some elements of PBS have focussed on children (Conroy, Dunlap, Clarke, & Alter, 2005; Goh & Bambara, 2012) and some key studies have been conducted demonstrating effectiveness and utility of PBS within family-focussed contexts (e.g., Durand et al., 2012). A PBS framework was therefore considered the most ethical and effective basis for organising and delivering services for those at risk of CB and approaching research questions for this thesis.

Key Research Questions

Within the overall context of seeking to enhance service provision for children with IDD at risk of CB, this thesis explores three key questions. Each question is grounded in the UK definition of PBS and prompts further exploration and development of components from the framework. Whilst multiple questions are possible, the selected areas are considered to have particular strategic value and concern the generation of new knowledge, in less well-researched areas, intended to make an important contribution to the field more broadly.

1. **How can delivery of high quality PBS be supported within services?**

Given the assumptions that PBS offers an ethical and evidence-based approach of choice for supporting people at risk of CB, and recognising how this has historically been underutilised in children's services, it is critical to explore how delivery of this framework can be implemented with integrity in UK child services.

2. **How can stakeholder engagement be maximised to enhance support for children with IDD and their families?**

The third values component of the UK PBS definition highlights the central importance of partnership working with stakeholders. Stakeholders include professionals but in the context of children (in particular) the role of families and partnership working has been highlighted as fundamental to the success of PBS. Notably, and conceptually, stakeholders also include the focal person themselves, yet little research has explored how children with IDD might be consulted directly within PBS. Identifying opportunities and developing procedures to ensure and bolster stakeholder involvement in PBS is therefore of upmost importance.

3. **How can proactive support for children with IDD and families be enhanced in the early years?**

Demonstrations of PBS within the literature suggest effectiveness of this framework for children in general, but less research has focussed on younger children. It is known however, that even by age 5 years, children with IDD are at increased risk of CB. Much is also known about risk factors and the early development of such behaviour yet few interventions have been developed that attempt to mitigate these proactively and support for families is typically minimal at this time. There is a pressing need therefore to explore mechanisms and approaches by which effective support might best be provided to young children with IDD, building on ideas central to PBS, family-focused literature and the CB field more generally.

Overview of Chapters and Studies

Research questions are approached across five empirical studies and two further chapters. At the end of each chapter, implications for practice and further research are discussed within the context of key research questions as detailed below. A narrative connecting findings and discussions back to the three research questions is included between each main chapter.

Chapter Two: Skills, Experience and Training Needs of Service Professionals

In relation to the first research question, Chapter Two explores the competencies of professionals within the UK regarding delivery of PBS. This study comprises a survey administered to 100 participants to help identify the extent to which current practice reflects key dimensions of PBS and to identify priorities for future training to build an increasingly effective workforce for high quality PBS delivery. The survey was developed with close correspondence to the UK PBS Competencies Guide.

Chapter Three: Developing an Outcomes Framework for the Evaluation of PBS

The third chapter explores a further response to the first research question. Outcome measurement within UK child services are discussed, building a premise for supporting better service provision through the development of a PBS outcomes framework and mechanisms of evaluation. A case for the potential of outcome measurement to support fidelity of PBS implementation is made with an additional connection to findings from Chapter Two regarding low practitioner confidence in PBS evaluation. This chapter then reports on a second empirical study that focuses on the development of a framework to capture the breadth of outcomes possible within PBS. The study utilises a four-stage Delphi-Panel method, building consensus from the views of professional stakeholders and so connecting to some degree to the second research question also.

Chapter Four: Making it Meaningful: Caregivers Goals and Priorities for PBS

Chapter Four focusses most directly on the second research question with a focus on engagement with family caregivers. The study develops an interview process for supporting meaningful goal selection (a largely under-researched area) for PBS with caregivers that considers a range of support areas and is sensitive to caregiver’s emotional needs and circumstances. A qualitative analysis of interviews is provided to identify core processes that support stakeholder engagement and broader themes concerning strengths and needs of caregivers.

Chapter Five: I do it quite a lot: Children's Goals and Priorities for PBS[2]

The rational and methodology developed in Chapter Four is extended to support direct engagement with children with IDD in Chapter Five. This study addresses a significant gap in prior literature to support direct consultation with children with IDD and complexities of communication need within a PBS pathway. The chapter presents quantitative and qualitative data on children's engagement with regards different question areas and individual goals selected for future behavioural support.

Chapter Six: Early Positive Approaches to Support (E-PAtS): A Logic Model

In the context of question area three, Chapter Six outlines the Early Positive Approaches to Support (E-PAtS) programme. E-PAtS has been developed through the leadership of Gore in partnership with family caregivers and a range of other stakeholders, building on core aspects of PBS and other family focused approaches to operate at a universal (primary tier) intervention level. E-PAtS is routinely co-facilitated by family caregivers and has several intended mechanisms focused on caregiver engagement (thus connecting to research question area two). E-PAtS also focuses on support for children 5 years and under and seeks to proactively address many of the known risk factors and contexts associated with development of CB. This chapter outlines a logic model for E-PATS developed throughout the timeframe of the thesis and therefore presents this programme as one possible means of addressing the third research question.

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[2] Chapters Four and Five are written in a briefer publication-style

Chapter Seven: Early Positive Approaches to Support: Family Views and Experiences

Chapter Seven continues to explore the third research question, reporting on a qualitative evaluation of E-PAtS groups piloted across Northern Ireland and in the North of England. Data based on interviews with 35 family caregivers following attendance of an eight-session E-PAtS are analysed to explore experiences, outcomes and process of engagement within the context of the E-PAtS logic model.

Chapter Eight: Final Conclusions and Future Directions

The final chapter of the thesis revisits each research question and summarises and synthesises findings from each study. Additional pieces of work completed outside of the context of this thesis, but triggered by the studies contained within, are referenced with recommendations for practice and future research in the field outlined.

Chapter Two: Skills, Experience and Training Needs of Service Professionals

Overview

Chapter One provided an overview of literature, and a functional conceptual account, of the development and maintenance of behaviours that challenge (CB) for people with Intellectual and Developmental Disabilities (IDD). Based on this conception, Chapter One also described Positive Behavioural Support (PBS), as an evidence-based, service delivery solution to supporting those at risk of CB, to experience high quality life styles and outlined the development of a PBS Competencies Guide. Whilst the logic and scientific rationale for PBS has therefore been reviewed in detail, ensuring implementation of PBS in practical terms requires further consideration. Fundamentally, delivery of PBS is dependent on the behaviour of a well-trained and skilled workforce, empowered stakeholders and well-organised systems and services. In response to Research Question One ('How can delivery of high quality PBS be supported within services?') this chapter therefore explores what practitioners, operating as part of a support system, do, know and need, regarding delivery of PBS.

The chapter begins with a consideration of the critical importance of a skilled workforce and prior literature concerning workforce development in the field of PBS (Part One). A rationale is made for use of competency frameworks to guide further training and development, followed by a more detailed description of the structure of the UK PBS Competency Guide as introduced in Chapter One. Based on this background and justifications, the chapter then reports (Part Two) on a survey designed to identify the perceived skills and training needs of practitioners who use a PBS framework to support children with IDD in the UK. The survey was created with close correspondence to the UK PBS Competency Guide and administered to 100 professionals working across different settings. Skills that typify the current UK workforce operating in managerial and consultant level roles and identification of future training needs in specific competencies are reported, followed by an exploration of next steps for delivery of high quality PBS within services.

Part One

A Workforce Focus

The rationale for analysing and supporting workforce development in the context of PBS has been carefully considered and articulated by Denne, Jones, Lowe, Jackson-Brown and Hughes (2015). Denne et al. (2015) begin their appraisal with recognition that much of the support provided for people with IDD who display (or are at risk of displaying) CB is provided on the 'front-line' by relatively unqualified, and low-paid staff (e.g., support staff and teaching assistants). Turnover of such staff is often high, and on-the-job training typically minimal. Where training is received this often focuses on mandatory requirements and if relating to behavioural approaches will most commonly consider reactive rather that proactive approaches (without comprehensive consideration of functional concepts). The authors note that this latter point may also reflect broader national confusion at a services level that reactive approaches and training equate to 'PBS.'

Denne et al. (2015) further recognised that delivery of PBS typically requires input from a range of other professionals that may have particular expertise in their given field (for instance behaviour specialists, psychologists, speech and language therapists, nurses). These profession-specific skills are likely to have relevance and application to PBS but will not necessarily reflect the broader spectrum of skills required to deliver PBS in its entirety. It is of further note that others have also raised concern that particular training in PBS for allied health professionals (such as clinical psychologists) is often lacking or inconsistent, and therefore at odds with the PBS activities that might be expected of those operating in such roles in the field of IDD (Noone & Chaplin, 2017; Scior, Jackson Brown, Gore, Morris, & Armstrong, 2017).

A fourth area of concern raised by Denne et al. (2015) relates to the multitude of settings in which PBS may be required and the small number of available accredited training programmes in PBS. Given the overall size of the potential workforce that may be involved in PBS delivery, this represents a major challenge. More so, at the time of writing it was the case that no nationally-agreed standards existed concerning the content for such programmes (for PBS specifically) and that there was no professional regulation of those working in the PBS field. Denne et al. (2015), commented that many individuals and services may have therefore been claiming to deliver PBS, (and this being particularly likely given the recent increase in expectations by commissioners and promotion of PBS in policy and guidelines), but in effect be operating in ways that did not align with the framework as defined by expert concerns.

Supporting Staff Development

PBS training for service-professionals has received prior research attention and reported some promising, if limited, outcomes. Macdonald and McGill (2013) appraised 14 articles, identified in a systematic review of staff training in PBS. Of these, and of particular interest to the current study, 10 included (or concentrated solely on) outcomes for staff members themselves. These outcomes included those that were considered indirect, indicators of what staff might actually do when supporting individuals within a PBS framework, with studies cited by Lowe et al. (2007), McGill et al. (2007) and Gore and Umizawa (2011) that had measured changes in staff knowledge, attributions, or emotional responses post-training. Theoretically, it may be argued that changes captured in these areas corresponded to changes in actual staff practices. McGill and MacDonald argued however, that little evidence exists to actually support this premise. Certainly, from a behavioural standpoint what is being measured in these studies is how staff respond to verbal relations presented in a questionnaire, the contextual dimensions of which are likely quite different to those concerning staff behaviour in other circumstances.

Macdonald and McGill also identified outcomes from staff following PBS training that were more practice-orientated. Of the 10 studies focusing on staff outcomes, seven reported on staff skills such as the creation of behaviour support plans. Several other studies, since this review, have also appraised post-training changes in staff performance in this kind of way (e.g., Chaplin, Hastings, & Noone, 2014; Wardale, Davis, Caroll, & Vassos, 2014). For instance, O'Dwyer, McVilly and Webber (2017), reported improvements in the quality of behavioural support plans (as assessed by the Behaviour Support Plan Quality Evaluation guide II; Browning-Wright, Saren & Mayer, 2003) produced by staff who had undertaken four-days of training in PBS. In a later study, Macdonald, McGill and Murphy (2018) also went on to evaluate elements of staff knowledge and interactions between staff and people with IDD post-PBS training, and some dimensions of leadership through a more robust research design.

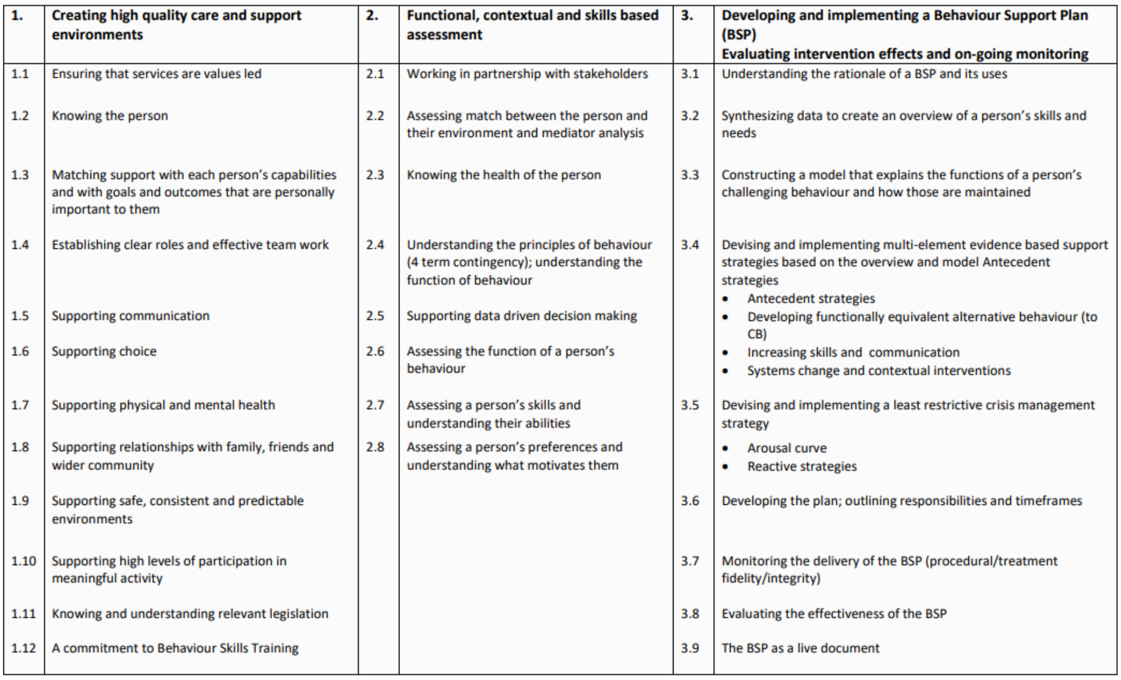
Taken together, these studies suggest that it is generally possible to increase the knowledge and skills of staff working in services through training in a manner that results in changes in skills and knowledge relevant to PBS. As a body of literature, for informing workforce development at scale however, two key limitations are notable. Firstly, as has been indicated, the relationship between outcome measures employed and the actual performance of staff is not always clear. Additionally, as will be discussed, even when measurement has focused more directly on staff performance, this has focussed on only a subset of the range of skills that fall within the broad scope of PBS delivery. A third and related point concerns the actual training provided in these studies. MacDonald and McGill (2013) noted considerable variation in training format and content. Seemingly, a systematic and sustainable approach to workforce development at scale must ensure a consistent and comprehensive approach to what is included in PBS staff training. Bringing all of these limitations together means developing a robust and consistent approach to training with a clear outcomes focus, a recommendation also made by others in the international PBS field (e.g., Crates & Spicer, 2012) but as yet largely unachieved in the UK. A competency-based approach to training and evaluation of staff performance presents as a particularly helpful approach for advancing PBS practice and implementation in this way.

A Competency-Based Approach

The background and process of developing a PBS Competencies Guide with contextual fit to the UK has already been outlined in Chapter One. Developing competency-based research and practice requires a more detailed appreciation of the content and scope that the Guide covers, which will now be provided. Firstly, the fundamental structure of the framework is divided into three main areas that concern distinct but related processes and forms of support within PBS (Table 1). Throughout the Guide competencies are detailed both in terms of things an individual ‘needs to know’ and those they need to be able ‘to do’, with further rationale for inclusion of the competency provided in each case. Two of the overall areas concern the core assessment and behaviour support strands that are traditionally conceived within PBS to meet the needs of people with IDD who have developed behaviours that challenge.

Functional, Contextual and Skills Based Assessment (Area Two), focuses on practices to ensure support is based on a detailed understanding of a person’s needs, preferences, abilities and communication style, together with the function(s) that CB serves for them. A total of 8, sub-competency areas that relate to functional, contextual and broader skills assessment are listed. Developing and Implementing a Behaviour Support Plan (BSP) (Area Three) concerns competencies that ensure a detailed and comprehensive behaviour support plan is developed, based on prior assessment, that is personalised to support an individual. This area also includes competencies that relate to evaluation of intervention effects and on-going monitoring as required for a behaviour support plan to be implemented and modified overtime. A total of nine sub-competency areas are included (with one of these, 3.4 including several distinct sub-items).

Table 1: Core Areas for the UK PBS Competencies Guide



1.	**Creating high quality care and support environments**	**2.**	**Functional, contextual and skills based assessment**	**3.**	**Developing and implementing a Behaviour Support Plan (BSP) Evaluating intervention effects and on-going monitoring**
1.1	Ensuring that services are values led	2.1	Working in partnership with stakeholders	3.1	Understanding the rationale of a BSP and its uses
1.2	Knowing the person	2.2	Assessing match between the person and their environment and mediator analysis	3.2	Synthesizing data to create an overview of a person's skills and needs
1.3	Matching support with each person's capabilities and with goals and outcomes that are personally important to them	2.3	Knowing the health of the person	3.3	Constructing a model that explains the functions of a person's challenging behaviour and how those are maintained
1.4	Establishing clear roles and effective team work	2.4	Understanding the principles of behaviour (4 term contingency); understanding the function of behaviour	3.4	Devising and implementing multi-element evidence based support strategies based on the overview and model Antecedent strategies • Antecedent strategies • Developing functionally equivalent alternative behaviour (to CB) • Increasing skills and communication • Systems change and contextual interventions
1.5	Supporting communication	2.5	Supporting data driven decision making		
1.6	Supporting choice	2.6	Assessing the function of a person's behaviour		
1.7	Supporting physical and mental health	2.7	Assessing a person's skills and understanding their abilities	3.5	Devising and implementing a least restrictive crisis management strategy • Arousal curve • Reactive strategies
1.8	Supporting relationships with family, friends and wider community	2.8	Assessing a person's preferences and understanding what motivates them		
1.9	Supporting safe, consistent and predictable environments			3.6	Developing the plan; outlining responsibilities and timeframes
1.10	Supporting high levels of participation in meaningful activity			3.7	Monitoring the delivery of the BSP (procedural/treatment fidelity/integrity)
1.11	Knowing and understanding relevant legislation			3.8	Evaluating the effectiveness of the BSP
1.12	A commitment to Behaviour Skills Training			3.9	The BSP as a live document

In addition to coverage of core assessment and support planning competencies, the framework also details those skills necessary for the establishment of supportive or capable environments for people with IDD (Area One). As has previously been described in Chapter One, evidence-based practices that support high quality of life for people with IDD in general have been incorporated within UK PBS practice (McGill et al., 2020). Supports of this nature are known to reduce the overall risk of CB (by better meeting people's needs) and so can be considered a primary tier of preventative intervention.

Secondly, and consistent with a systems-conception of PBS, the framework details three levels of competencies that span roles or functions individuals may assume within each of the three areas previously outlined (Figure 2). The levels stipulated are similar to those proposed by Denne et al. (2013) but slightly refined. As in Denne et al. (2013), the knowledge and behaviour of those in front-line positions (Level 1: Direct Contact) is given particular significance (and presented as the uppermost tier of support). It is acknowledged that Direct Contact competencies are also of relevance to those operating at other levels of a support system. The remaining levels reflect how increased levels of complexity within service delivery will typically necessitate additional competence both in terms of systems support and clinical experience, and the additional skills required by those working in these positions to support Direct Contact workers.

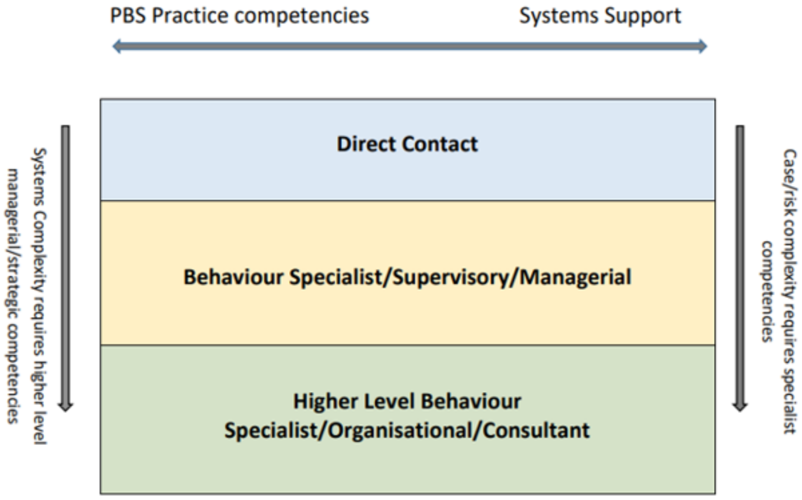


Figure 1: Levels of the UK PBS Competencies Guide

The second, ‘Behaviour Specialist/Supervisory/Managerial’, level details competencies required for anyone involved in supporting those who provide direct contact, in a supervisory and/or managerial capacity. This level also includes those who take on more advanced clinical roles, who are for instance, responsible for leading assessments and devising and guiding implementation of behaviour support plans. The final, third level of the framework details competencies expected of those undertaking ‘Specialist / Organisational / Consultant’ roles. Again, both enhanced managerial/supervisory responsibility and enhanced clinical expertise is reflected in competencies presented at this level. Those operating in these kind of roles are thought likely to be responsible for embedding PBS within services and building overall organisational capacity and/or to have expert clinical skills required to support the most complex systems and cases.

Part Two

Introduction

This study explored the perceived competencies and training needs of UK practitioners supporting children and young people with IDD via a PBS framework, with direct correspondence to the PBS Competencies Guide. This was the first study of its kind to utilise the PBS Competency Guide for this purpose. Assessing what professionals already know and are able to do, together with their views (as stakeholders) on training requirements, was considered an important step to informing a comprehensive workforce development programme to support PBS implementation with integrity.

Only one prior study could be identified where a PBS-competencies approach was taken to exploring dimensions of a workforce in this kind of way. Mankora, Chan, Lim and Penchaliah (2017) who engaged 44 allied health professionals working in the disability sector in Singapore who delivered behaviour support. The survey comprised 56 questions in total, 16 of which focussed on background demographics, qualification, prior training and experience of delivering PBS. The second part of the survey focussed more directly on participants’ knowledge and perceived competency in PBS. A total of 30 of the questions included in this section were adapted directly from items of the Behaviour Support Plan Quality Evaluation guide II (Browning-Wright et al., 2003). A further eight questions concentrated on what were described as ‘critical themes for PBS’ and reflected values and theory based components (autonomy, dignity, life quality and systems approaches). Two additional questions focussed on participants’ perceived training needs. For each of the questions in section two, participants responded using a five-point Likert scale (ranging from completely agree to completely disagree).

The study by Mankora et al. (2017) provided a useful insight into likely performance and needs of professionals supporting those with behaviour that challenges. The current study builds on this approach in a number of ways. Firstly, a focus is taken on professionals working with children and young people specifically. In addition to the overall focus of the current thesis on children and young people with IDD, it is of note that relative to adult services, PBS has been, historically, less commonly evidenced in child health services in the UK. Particular focus on the performance and needs of practitioners supporting children and young people is therefore warranted, especially given recent policy and guidance drives to ensure this population are in scope for PBS delivery.

Secondly, the work of Mankora et al. concerns a Singapore workforce and context. It is probable that some of the findings from this research have universal application but considering the particular needs of those in the UK is also necessary. A related point concerns the conception of competencies assessed. The approach taken by Mankora et al. is relatively robust but the competencies included are not as detailed or expansive as those covered in the PBS Competencies Guide. More so, these were not rooted in an appraisal of competencies corresponding to delivery of PBS as considered necessary and appropriate for PBS delivery in the UK. A final and lesser, but important point, relates to assessment of training needs. Here, Mankora et al. only included two questions regarding perceived training needs and did not appear to report on responses to these. Building effective training based on actual need arguably calls for a more detailed appraisal.

Aims

This study had three interrelated aims as follows:

1. To identify the perceived competencies of professionals using PBS to support children and young people with IDD.

A focus here was taken on professionals operating within roles equivalent to Levels Two and Three of the Competencies Guide. These are professionals in influential positions who are commonly represented within child services and teams who explicitly provide PBS and would be anticipated to have some training and expertise that corresponds to the framework. Direct Contact workers are less commonly employed within child health services. It is also notable that the majority of children with IDDs reside at home and so direct support is better represented by family carers, in addition to school staff. Both family carers and educational staff represent rather different stakeholder groups and were not included in the current study (though later chapters of this thesis do focus on the needs of carers).

The competency areas captured within Areas Two and Three of the Guide, concerning assessment, behaviour support planning, implementation and evaluation were the focus of the current study. Again these areas were considered likely core activities and responsibilities for professionals operating in UK service settings and of fundamental importance to explore. The study aimed to investigate these competencies in detail and so all of the individual competencies in these areas of the framework were included.

2. To identify the training needs of professionals using PBS to support children and young people with IDD.

Keeping the same focus, of assessment and behaviour support planning, implementation and evaluation competencies for professionals operating at Levels Two and Three of the Guide, the study aimed to identify future training needs in detail.

3. To explore the prior training, qualifications and experience of professionals with regards to perceived competencies and training needs.

The final aim of this study focussed on identifying relationships between other participant variables (including years of experience using PBS, prior PBS training and academic qualifications) and their perceived skills and training needs. Again identifying these relationships was considered important for informing a data-driven workforce development approach.

Method

Participants

The study sought participation from professionals who, at the time of the survey, worked to support children and/or young people (those aged 0-25) with intellectual and developmental disabilities through delivery of a Positive Behavioural Support (PBS) framework. Participants needed to be actively utilising PBS with this population for part or all of their role in health, social, educational, private or third sector organisations, and consider their role to be consistent with the following definition (serving as inclusion criterion):

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

This definition was created to reflect the functions of practitioners operating at a Managerial/Supervisor or Consultancy level (as opposed to direct support workers) as outlined in the PBS Competency Guide. Participants needed to be professionals only (those who receive payment in relation to their work) and not family or voluntary caregivers. Within the survey, participants were able to highlight the particular ways in which their role met this definition (e.g., working as a practitioner to do this directly, through supervision, through management responsibilities, through consultation). Participation was sought from a range of professional groups including (but not restricted to) Psychologists, Behaviour Specialists, Nurses and Allied Health Professionals.

Given the study aims, it was essential to focus on practitioners who worked with children and young people. The number of potential participants meeting this, and the other study criteria, was, however, estimated to be relatively small (compared for instance to professionals using PBS to support adults in the UK). The study, therefore, aimed to recruit a minimum of 50 participants. This corresponded to the membership number of the largest known professional network relevant to the study area (The British Psychological Society Children, Young People and Families Learning Disability Network). Whilst participation was also sought from a variety of points of contact, this number provided the best estimate of practitioners working with children and young people using PBS (explicitly) in the UK and was considered sufficient to allow an appropriate and meaningful analysis of responses.

Recruitment and Procedure

Recruitment for this study occurred over two phases. In phase one potential participants were informed about the study in connection to a forthcoming professional conference organised by The British Psychological Society Children, Young People and Families Learning Disability Network. Participants were informed about the survey ahead of the conference and provided with information and consent forms.

The rationale and structure of the survey were also presented as part of the conference proceedings by Gore who was also able to answer questions at this time. It was made clear that participation in the survey in this context remained a free choice and was not in any way a condition of conference attendance. Since the conference had a focus on the skills and training needs of practitioners in PBS this did, however, provide a potentially useful opportunity for attendees to state their views. Attendees who consented to participate were given an option to complete the survey via electronic access to a Google Forms link (see later section) at a later date, or through paper-based completion during the conference itself. In selecting the latter, participants were asked to complete the form in private during a scheduled break, place this in a sealed envelope and leave the envelope in a specified container for later collection by Gore (ensuring anonymity).

In the second phase of recruitment (shortly following the conference event) further professionals were invited to take part in the survey via advertisement in a number of professional networks, including those facilitated by professional bodies and those coordinated less formally by allied practitioners and researchers known to Gore. Participants were also recruited via social media advertisement made by Gore, his employing organisation (Tizard Centre), the PBS Academy, other third sector organisations and bodies that represent professional groups.

Participants recruited during this phase were principally informed about the study via e-mail. The e-mail included detailed information about the study (functioning as an information sheet) and invited those who would like to take part to do so by clicking on a link embedded in the e-mail that provided access to the survey as a Google Form. This structure functioned as a consent procedure, a common method in survey studies where it is considered that accessing and completing the survey is undertaken through the participant’s own choice. The names or personal details of participants were not collected including the e-mail addresses of participants as typically occurs via Google Forms (this optional function was disabled) to ensure anonymity. Google Forms automatically collates data from participant responses and can be downloaded as a spread-sheet for later analysis. Participants were also able to complete the survey by paper form if requested. In such an instance, arrangements were in place for the form to be posted to the participant with a stamped addressed envelope for its return. As with electronic access, completion of the paper-based form in itself functioned as a consent procedure.

The Survey

A bespoke survey was created for this study (appendix 1) that covered the following key question areas drawn principally from the UK PBS Competency Guide and associated resources. The survey was estimated to take no more than 15-20 minutes to complete, was designed to ensure anonymity and allow for participants to leave out items they did not wish to answer or terminate completion at any stage.

Demographics

To allow for a description of the sample, participants were initially prompted to provide their age, gender, ethnicity and professional title through open text responses. This section of the survey also required participants to detail the area of the country in which they operated and the main organisational contexts in which they were employed (e.g., health, social care, education).

Section One: Experience and Qualifications Relevant to PBS

This section of the survey concerned the participant's current role and team context, with reference to PBS supervisor/practice leader definition and recorded training and experience gained in PBS. In relation to training, participants were asked to select each form of training attended from a number of options that ranged from brief (0.5-2 day) courses in PBS or Applied Behaviour Analysis (ABA) to more formalised and extensive University based programmes in these areas. Additionally, participants were asked to record the date of their latest PBS relevant training and note any particular qualifications they had in the area. Overall experience of using PBS was assessed initially through a single question that asked the number of years a participant had worked using a PBS framework (with additional, more detailed questions that followed later in the section).

Participants who worked within a team/service context where members of that team also used PBS were asked to provide further details in that regard that included an estimation of the PBS skills and experiences of others team members. All participants were also asked to provide greater detail on their current PBS-related role. Here the main focus concerned particular activities that reflected the actual delivery of PBS in day to day work. Seven activities were provided that reflected core aspects of PBS process. The first item ('Completing assessments and creating behaviour support plans directly') primarily concerned core PBS processes that were conducted by participants themselves. The second item ('Giving staff or family caregivers support or training based on the recommendations made in a behaviour support plan you have created') highlighted some degree of stakeholder collaboration (as a subsequent phase to direct work carried out by the participant).

The five remaining work areas focussed on a range of other system-level work areas that were intended to correspond with the more strategic, supervisory and consultative competency areas of the PBS Academy framework. These included training and support to colleagues, other professionals and families to conduct assessments and develop intervention procedures, and the provision of wider organisational support and training in PBS to stakeholders. For each work area, participants were required to rate whether they never (0), sometimes (1) or often (2) engaged in these activities as part of their professional role utilising PBS.

Section Two and Three: Functional, Contextual and Skills Based Assessment and Developing, Implementing and Evaluating a Behaviour Support Plan (BSP)

The remaining two sections of the survey corresponded closely to the structure and wording of the PBS Competency Guide, spanning the assessment and behavioural support planning areas. In each case, a question that reflected the degree of knowledge or application demanded across the Supervisor and Consultant levels was generated. Participants were provided with two Likert-scale response options following each question. The first scale related to participants' own perceived skills and experience in the areas and could be rated as low (1), moderate (2) or high (3). The second scale concerned a participant's perceived need for training in this area and again could be rated as low (1), moderate (2) or high (3).

A total of eight items were included in Section Two of the survey that corresponded directly to the eight key items covered in the Functional, Contextual and Skills Based Assessment area of PBS Competency Guide. Questions are presented in Table 1 alongside the Competency Guide area headings. The Competency Guide lists nine items under 'Developing and Implementing a Behaviour Support Plan (BSP) and Evaluating Intervention Effects and on-going Monitoring.' One of these (3.4), does however include additional bullet-pointed sub areas. To capture this level of detail and allow for good discrimination in responding, a total of 12 items were therefore created for Section Three of the survey to reference these areas (see Table 2).

Table 1: Functional, Contextual and Skills Based Assessment Questions.

PBS Competency Guide Area	Survey Item (number in parenthesis refers to question number)
2.1 Working in partnership with stakeholders	(26) 2.1: Working strategically to ensure engagement with a range of stakeholders (including, the focal individual, their family and other professionals) throughout delivery of a PBS pathway

2.2 Assessing match between the person and their environment and mediator analysis	(27) 2.2: Assessing the environmental resources, strengths and training needs of staff and family caregivers and using this information strategically to support implementation of a PBS pathway.
2.3 Knowing the health of the person	(28) 2.3: Facilitating comprehensive assessment of a focal individual's physical health needs at an early stage of the PBS pathway through liaison with multiple professionals and stakeholders.
2.4 Understanding the principles of behaviour (4 term contingency), how behaviour is learned and understanding the function of behaviour	(29) 2.4: Supporting stakeholders (both staff and family caregivers) to understand behaviour of focal individuals and any interactions between this and their own behaviour in terms of four-term behavioural contingencies.
2.5 Supporting data driven decision making	(30) 2.5: Establishing and refining data-collection systems based on four-term contingencies with staff members and/or family caregivers and analysing and feeding this information back to stakeholders throughout the PBS pathway.
2.6 Assessing the function of a person's behaviour	(31) 2.6: Using a range of functional assessment tools (including observational and non-observational methods) with stakeholder involvement and analysing findings to generate functional hypotheses of challenging behaviour.
2.7 Assessing a person's skills and understanding their abilities	(32) 2.7: Supporting assessment of adaptive skills for focal individuals (including communication skills and daily living skills) with stakeholder involvement and using this information to support future skill building interventions
2.8 Assessing a person's preferences and understanding what motivates them	(33) 2.8: Supporting an understanding of the preferences of focal individuals through ongoing preference and motivational assessments and incorporating this information into Behaviour Support Plans.

Table 2: Intervention, Evaluation and Monitoring Questions.

PBS Competency Guide Item	Survey Item (number in parenthesis refers to question number)
3.1 Understanding the rationale of a BSP and its uses	(34) 3.1: Ensuring that all stakeholders (including staff teams and family caregivers) understand individual Behaviour Support Plans through training and consultation to ensure these are implemented with integrity.
3.2 Synthesizing data to create an overview of a person's skills and needs	(35) 3.2: Synthesising data from multiple functional and skills assessment sources for focal individuals and effectively communicating results to stakeholders.
3.3 Constructing a model that explains the functions of a person's challenging	(36) 3.3: Using assessment results to construct a formulation that explains the functions of an individual's challenging behaviour and

behaviour and how those are maintained	how it is maintained and communicating this effectively to stakeholders.
3.4 Devising and implementing multi-element evidence based support strategies based on the overview and model	(37) 3.4: Supporting stakeholders (family caregivers and/or staff) to understand and utilise **antecedent-based strategies** as part of an individual's Behaviour Support Plan and supporting the effective, consistent and sustained implementation of these.
3.4 Devising and implementing multi-element evidence based support strategies based on the overview and model	(38) 3.41: Supporting stakeholders (family caregivers and/or staff) to understand and **utilise skills/communication teaching** strategies as part of an individual's Behaviour Support Plan and supporting the effective, consistent and sustained implementation of these.
3.4 Devising and implementing multi-element evidence based support strategies based on the overview and model	39) 3.42: Supporting stakeholders (family caregivers and/or staff) to understand and utilise strategies that increase engagement, **choice-making** and independence as part of an individual's Behaviour Support Plan and supporting the effective, consistent and sustained implementation of these.
3.4 Devising and implementing multi-element evidence based support strategies based on the overview and model	(40) 3.43: Supporting stakeholders (family caregivers and/or staff) to understand and utilise a wide range of **options to reinforce appropriate behaviour** as part of an individual's Behaviour Support Plan and supporting the effective, consistent and sustained implementation of these.
3.5 Devising and implementing a least restrictive crisis management strategy	(41) 3.5: Ensuring a least restrictive crisis management plan is developed as part of the PBS pathway, that stakeholders implement this ethically and effectively and have the necessary understanding, resources, support and appropriate training to do so.
3.6 Developing the plan; outlining responsibilities and timeframes	(42) 3.6: Support to ensuring that all stakeholders have a comprehensive understanding of an individual's Behaviour Support Plan, understand their particular roles that relate to this and have the requisite skills, resources and training in place to deliver it.
3.7 Monitoring the delivery of the BSP (procedural/treatment fidelity/integrity)	(43) 3.7: Creating systems for monitoring and reviewing delivery of an individual's Behaviour Support Plan and providing feedback and additional support to stakeholders to facilitate implementation.
3.8 Evaluating the effectiveness of the BSP	(44) 3.8: Selecting and implementing data-based evaluation systems with stakeholders, services and organisations to assess effectiveness of interventions that have been delivered.
3.9 The BSP as a live document	(45) 3.9: Working with stakeholders, services or organisations to further develop an individual's Behaviour Support plan based on monitoring and evaluation data over the longer term.

Analysis

The survey was structured to primarily produce descriptive, quantifiable data. It was pre-determined that frequency, percentage and measures of central tendency would be calculated in relation to each item and section area for all quantifiable questions (Sections Two and Three) to allow consideration of responses at the group level. A small number of within group comparisons were also planned based on sub-group categorisation of demographic variables (including competency and training need based on prior training and experience).

Ethics

Ethical approval for this study was sought from and granted by the Tizard Centre Ethics Committee at University of Kent. In addition to issues of consent and confidentiality detailed previously, the following ethical considerations were pertinent: Firstly, participants were not offered payment or other incentives for completion of the survey. Involvement in the study was considered to largely reflect the kind of professional development activity typically undertaken by participants who were thought likely to be well motivated to express their experiences, views and needs.

The study was considered to be of benefit to participants who were working directly in the field of intellectual disability by helping to develop applications of PBS. These applications were also anticipated to be of benefit to practitioners and other researchers seeking ways to develop PBS training; to commissioners attempting to increase effectiveness of services and to families and people with disabilities who use such services. Ultimately, the research was intended to help inform how to increase availability of competent practitioners and services to deliver PBS and identify the unmet needs of practitioners in this regard. By finding more out about the skills, strengths and needs of practitioners and services the study had the potential to equip researchers, trainers and policy makers to generate more strategic and effective solutions to increasing the quality of support provided to children and young people with IDD.

Overall, it was considered that demands on participant time and resource were minimal, as the survey had been designed to be as brief as possible (estimated at 15-20 minutes). The survey also did not include any questions that were sensitive or could cause upset. The survey was instead framed positively or neutrally to allow identification of strengths and support future needs. It was agreed that findings from the study would be written up for publication and made freely available in summarised form via the PBS Academy. The principal investigator agreed to work with the PBS Academy to consider the further dissemination and use of findings to support PBS training and development

It was recognised that Gore had previously established a collaborative working relationship with some of the networks who would be approached about the study. These relationships had been marked by an equal balance of power, respect and mutual support. The majority of participants were also practitioners with professional seniority, equal to or exceeding that of the researcher and who were therefore unlikely to feel pressured into taking part. It was made clear that participation in the survey was not a prerequisite for accessing the network or any of its activities (such as conferences or workshops) with all information clarifying that participants could choose whether or not to take part and that their responses would be made in confidence.

Participants were not to be excluded on the basis of any cultural or ethnic characteristics. As a sample of UK professionals, it was anticipated that all participants would have requisite English language abilities to take part without the need for further supports/adaptations.

Results

Demographics

The survey was completed by 100 people (79 females and 21 males with a mean age of 40.06 years, SD 9.57). Of these, 52 completed online and the remainder completed a paper version. The majority of the sample (91.8%) were White British and worked in the South East of England (25.5%) or London area (23.5%), though other areas of England (35.6%), Wales (5.1%), Scotland (7.1%) and Northern Ireland (3.1%) were also represented.

Participants were most commonly recorded as being a psychologist (49.5%), behaviour analyst, behaviour specialist or behavioural advisor (18.6%) with some further participation from support workers (4.1%), nurses (5.2%), psychiatrists (5.2%), other allied health professionals (3.1%), and other non-health professionals (13.4%). Regarding work settings, 66.7% of participants had a role within the National Health Service and 18.4% within a social services setting. Participants also identified roles within educational services (10.2%), the third sector (7.1%) and private / for profit organisations (12.2%).

Training, Qualifications and Experience

A total of 33 participants reported that they had gained a training qualification relevant to PBS or ABA, at either postgraduate (n=14) or undergraduate (n=7) level or in the form of a BTEC, professional diploma (n=9) or short course certificate (n=3). A small number of participants (n=5) were Board Certified Behaviour Analysts or Board Certified Associate Behaviour Analysts. In addition, 40.6% of the sample reported having undertaken brief training (0.5-2 days) and 24% extended training (2.5-5 days) in ABA or PBS as either a standalone course or element of other professional training. Most participants (82.2%) had accessed some form of PBS or ABA training within the last 5 years or were currently accessing such training.

Over half of the sample (60%) had been working within a PBS framework for 5 years or less, with 14.7% new to the approach in the last year. The sample also included more experienced practitioners with 23.2% who had utilised PBS for between 6 and 10 years and smaller proportions beyond this (16.8%). Participants were mixed with regards to the estimated percentage of their working week in which they implemented PBS in their professional role. Only 21.1% reported using PBS all of the time with 49.4% using it half of the time or less.

Characteristics of Staff Teams and Services

The vast majority of respondents (95%) operated as part of a team, which was typically described as providing services for children and young people (0-17) and transition age young people/adults (ages 18-25) with ID (21.6%), ASC (2.3%) or both (76.1%) who display challenging behaviour (68.2%) or challenging behaviour and/or mental health difficulties (31.8%). Most respondents (70.2%) reported provision that included support for very young children (0-5 years) and a subset of services also supported adults over the age of 25 (29.7%).

Participants rarely reported being the only person in their team who used PBS (12.6%). More commonly PBS was considered to be the dominant framework used within the service (79.8% of cases) and participants typically reported that there was at least one other practitioner with skills and experience in PBS that at least equalled their own (71.1%).

PBS Related Activities

A total of 98 participants completed this section of the survey (sample modes were used to substitute missing data for three participants, all of whom had completed more than 50% of items). There was some variation between the kinds of PBS activities most commonly undertaken by participants in their role, rated as either often (2), sometimes (1) or never (0). In terms of mean ratings, participants engaged most frequently in the first two activities relating to self-completion of assessments and training based on self-completed behaviour support plans (M 1.46, SD 0.66) and support to other stakeholders based on these plans (M 1.46, SD 0.66). Lower ratings were made for three items that corresponded to supporting colleagues (M 1.15, SD .80), other professionals (M .96, SD .67) and family caregivers (M .89, SD .69) to complete assessments or create behaviour support plans. Low ratings relative to the first two activity areas were also made for the final two items corresponding to advising organisations (M .96, SD .77) and training staff teams in PBS (M 1.02, SD .79). Figure 1 displays the percentages of participants who rated each option for the seven work areas. Here it can be seen that ratings of ‘often’ were made most frequently for the first two work areas and ratings of ‘never’ were made least frequently for these areas, relative to all other items.

Visual inspection revealed data were not normally distributed. Calculation of a Friedman One-Way test revealed a statistically significant difference between these ratings, X^2 (6, N = 98) = 80.554, p < .000). Post-hoc comparisons were conducted using Wilcoxon Matched Pairs Signed Ranks tests (Table 3), noting that when using Statistical Program for the Social Sciences (SPSS), the Wilcoxon test uses the standard normal distributed Z-value to test significance. Results revealed no significant difference between both of the first two activity areas (relating to self-completion of assessments and training based on self-completed behaviour support plans) but significant differences between both of these and all remaining areas. In addition, ratings for completion of activities relating to support for colleagues within participants’ own organisation/team were significantly higher than those for supporting other professionals or family caregivers to complete assessment and behavioural support planning development work or for providing advice/consultation to other organisations.

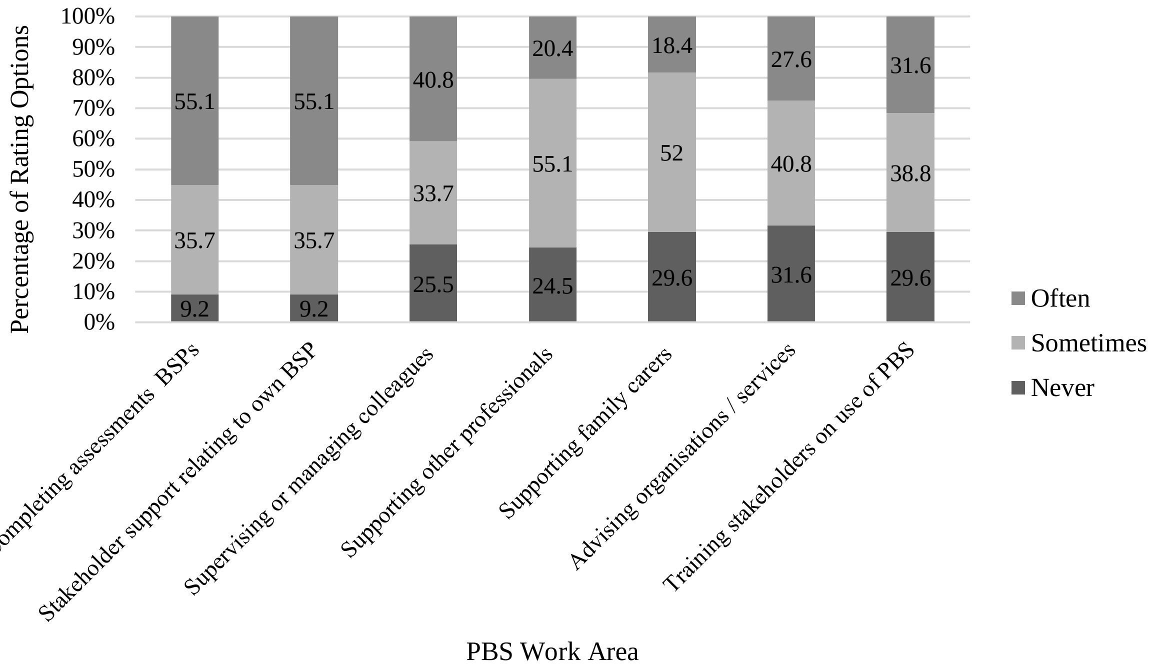


Figure 1: Percentages of Participants for Each Rating Option across All PBS Work Areas.

Table 3: Post-Hoc Comparison Results for Differences between PBS Activity Ratings.

	PBS Activity Areas					
	Training based on self-completed BSP	Supervising colleagues	Supporting other professionals	Supporting family caregivers	Advising organisations	Training staff teams
Direct assessment /BSP development	.000 (1.000)	2.983 (.003)	4.750 (<.001)	5.312 (<.001)	4.147 (<.001)	4.487 (<.001)
Training based on self-completed BSP		3.157 (.002)	4.978 (<.001)	5.233 (<.001)	4.825 (<.001)	5.130 (<.001)
Supervising colleagues			2.322 (.020)	2.709 (.007)	2.059 (.040)	1.283 (.200)
Supporting other professionals				1.178 (.239)	.014 (.989)	.625 (.532)

Supporting family caregivers	.860 (.390)	1.374 (.170)
Advising organisations		.784 (.433)

Note. First figure represents z, figure in parenthesis represents p.

Skills and Experience and Training Needs in Relation to PBS Competencies

All participants (n = 100) completed this section of the survey. As was previously the case, sample modes were used to substitute missing data for participants who had not completed an individual rating (a total of 15 participants who had missed between 1 and 3 items from a possible total of 20 items each).

The frequency of participant ratings (low, moderate and high) of perceived skill and experience in each of the assessment related competencies areas are presented in Figure 2. Data were not normally distributed. A Friedman One-Way test revealed a statistically significant difference between ratings on items overall, X^2 (7, N = 100) = 44.942, $p < .001$. Post-hoc comparisons using Wilcoxon Matched Pairs Signed Ranks tests identified that this difference was largely accounted for by higher ratings for items 2.4 (M 2.42, SD .654) (relating to support for stakeholders to understand interactions between their own behaviour and that of the focal individual), 2.6 (M 2.46, SD .658) (relating to use of functional assessment tools with stakeholder involvement to generate functional hypotheses of challenging behaviour) and 2.7 (M 2.33, SD .652) (relating to assessment of adaptive skills) relative to a number of other items, with one difference additionally found between ratings for other items (higher ratings for 2.1 (M 2.26, SD .705) compared to 2.3 (M 2.11, SD .723) (Z = 2.031. p = .042). Table 4 summarises all significant differences found between 2.4, 2.6, 2.7 and other items.

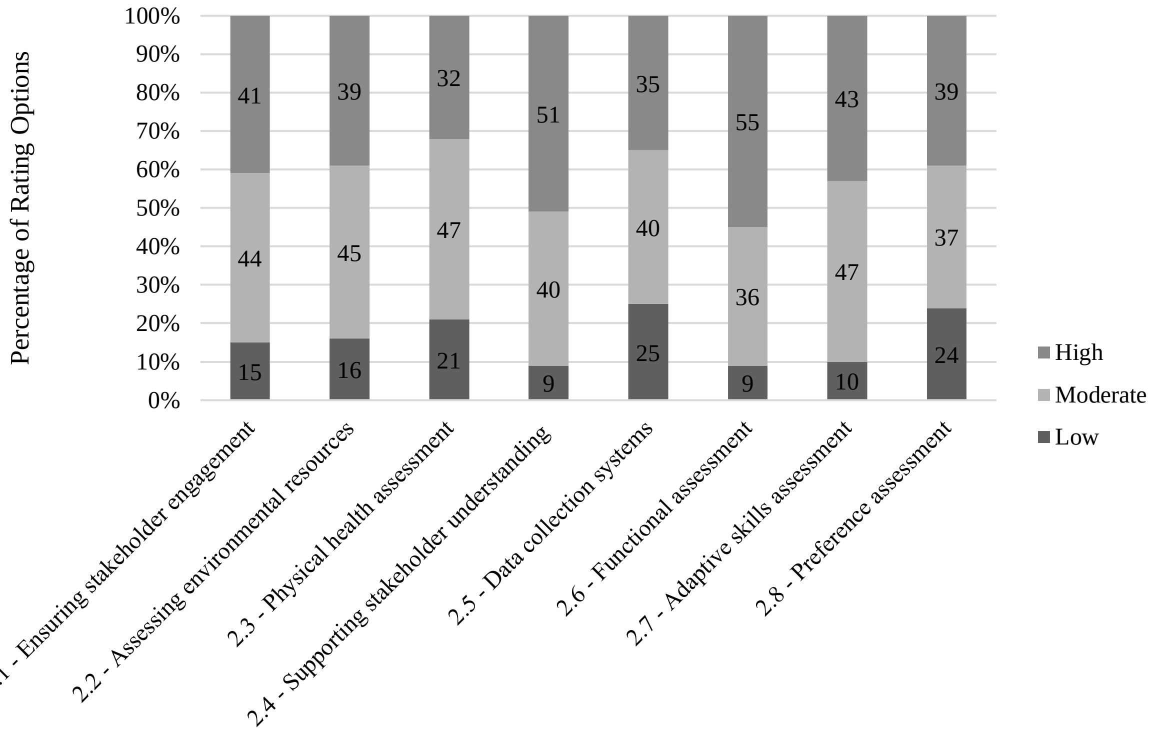


Figure 2: Participant Ratings for Skills and Experience in PBS Assessment Competencies

Table 4: Summary of Significant Differences between Items 2.4, 2.6 and 2.7 and All Other Assessment Competencies for Perceived Skills and Knowledge

	Assessment Competency Area		
	2.4	2.6	2.7
2.1 (M 2.26, SD .705)	Z = 2.596 p = .009	Z = 2.509 p = .012	
2.2 (M 2.23, SD .709)	Z = 2.872 P = .004	Z = 3.029 p = .002	Z = 3.685 p <.001
2.3 (M 2.11, SD .723)	Z = 3.710 P < .001	Z=3.924 p < .001	Z = 2.809 p = .005
2.4 (M 2.42, SD .654)			
2.5 (M 2.1, SD .772)	Z = 4.056 p <.001	Z = 4.718 p <.001	Z = 3.002 p = .003
2.6 (M 2.46, SD .658)			
2.7 (M 2.33, SD .652)		Z = 2.082 p = .037	

2.8 (M 2.15, SD .783)	Z = -3.409 p < .001	Z = 4.006 p < .001	Z= 2.604 p = .009

Frequency of ratings (low, moderate and high) concerning training needs for assessment areas are presented in Figure 3. Again, a Friedman One-Way test revealed a statistically significant difference between ratings on items overall, X^2 (7, N = 100) = 16.651, p = .02. Post-hoc comparisons using Wilcoxon Matched Pairs Signed Rank tests identified that this difference was largely accounted for by higher ratings for item 2.5 (M 2.05, SD .770) (relating to data collection systems based on 4-term contingencies) relative to a number of other items and a higher rating for item 2.8 (M 1.93, SD .807) (relating to preference and motivational assessments) compared to a smaller number of other items (see Table 5).

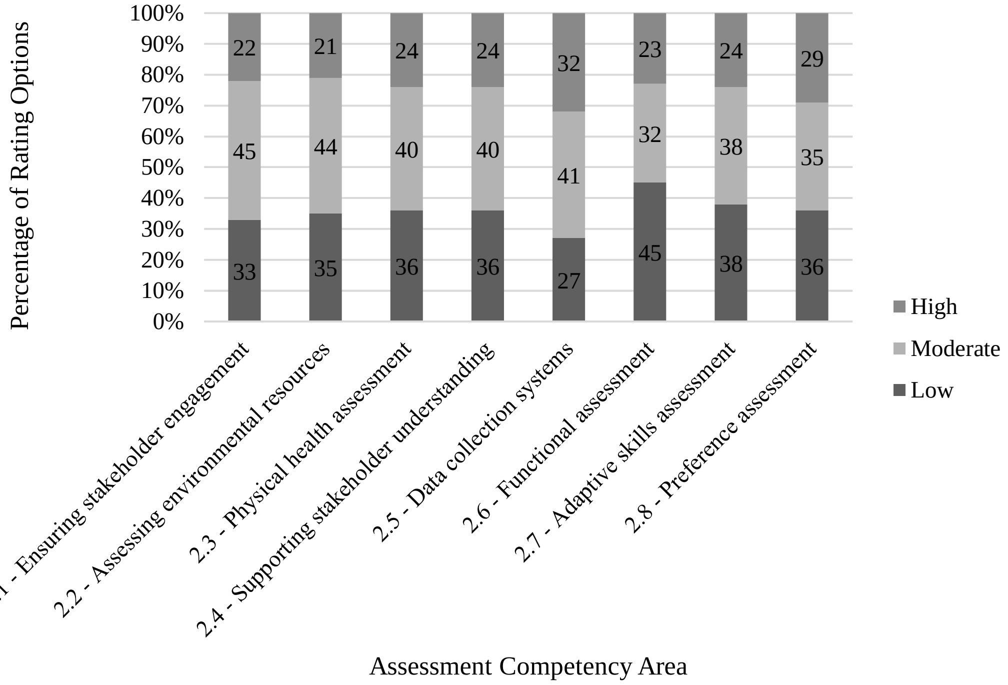


Figure 3: Participant Ratings for Training Needs in PBS Assessment Competencies

Table 5: *Summary of Significant Differences between Items. 2.5, and 2.8 and All Other Assessment Competencies for Perceived Training Needs*

	Assessment Competency Area	
	2.5	2.8
2.1 (M 1.89, SD .737)	Z = 2.173 p = .030	
2.2 (M 1.86, SD .739)	Z = 2.898 p = .004	
2.3 (M 1.88, SD .769)	Z = 1.939 p = .052	
2.4 (M 1.88, SD .769)	Z = 2.573 p = .010	Z = 3.409 p = .001
2.5 (M 2.05, SD .770)		
2.6 (M 1.78, SD .799)	Z = 4 p < .001	Z = 2.325 p = .020
2.7 (M1.86, SD .779)	Z = 2.468 p = .014	
2.8 (M 1.93, SD .807)		

Figures 4 and 5 present the frequency of participant ratings (low, moderate and high) for perceived skill and experience and training needs in each of the intervention and evaluation competency areas. A Friedman One-Way test revealed a statistically significant difference between perceived skill and experience ratings on items overall, X^2 (11, N = 100) = 145.176, $p < .001$. Post-hoc comparisons using Wilcoxon Matched Pairs Sign Ranks tests identified that this difference was largely accounted for by lower ratings for items 3.7 (M 2.03, SD .771) (relating to creating systems for monitoring and reviewing delivery of Behaviour Support Plans and providing feedback and support to facilitate implementation), 3.8 (M 1.93, SD .756) (relating to selecting and implementing evaluation systems to assess effectiveness of interventions) and 3.9 (M 2.08, SD .761) (relating to working with others to further develop Behaviour Support Plans over the longer term) relative to a number of other items. Table 6 summarises all significant differences found between items 3.7, 3.8 and 3.9.

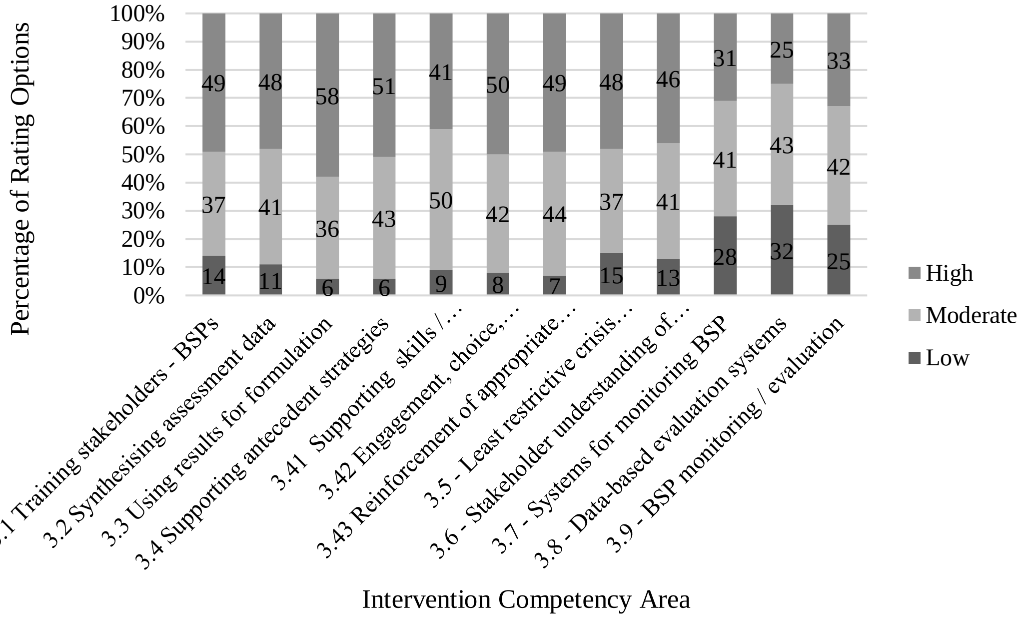


Figure 4: Participant Ratings for Skills and Experience in PBS Intervention and Evaluation Competencies

Table 6: Summary of Significant Differences between Items 3.7, 3.8, 3.9 and All Other Intervention Competencies for Perceived Skills and Knowledge

	Intervention Competency Area		
	3.7	3.8	3.9
3.1 (M 2.35, SD .716)	Z = 4.27 p < .001	Z = 4.806 p < .001	Z = 3.577 p < .001
3.2 (M 2.37, SD .677)	Z = 4.162 p < .001	Z = 5.311 p < .001	Z = 3.957 p < .001
3.3 (M 2.52, SD .611)	Z = 5.465 p < .001	Z = 6.009 p < .001	Z = 5.212 p < .001
3.4 (M 2.45, SD .609)	Z = 5.603 p < .001	Z = 5.773 p < .001	Z = 4.808 p < .001
3.41 (M 2.32, SD .634)	Z = 3.841 p < .001	Z = 4.286 p < .001	Z = 3.154 p = .002

3.42 (M 2.42, SD .639)		Z = 5.544 p < .001	Z = 4.708 p < .001
3.43 (M2.42, SD .612)	Z = 5.148 p < .001	Z = 5.667 p < .001	Z = 4.425 p < .001
3.5 (M 2.33, SD .726)	Z = 4.080 p < .001	Z = 4.904 p < .001	Z = 3.645 p < .001
3.6 (M 2.33, SD .697)	Z = 4.423 p < .001	Z = 4.774 p < .001	
3.7 (M 2.03, SD .771)			
3.8 (M 1.93, SD .756)			
3.9 (M 2.08, SD .761)		Z = 2.197 p = .028	

Additionally, lower ratings were found for 3.41 (M 2.32, SD .634) compared to 3.3 (M2.52, SD .611) (Z = 3.086, p = .002) and 3.4 (M 2.45, SD .609) (Z = 2.335, p = .020); lower ratings for 3.5 (M 2.33, SD .726) compared to 3.3 (M 2.52, SD .611) (Z = 2.773, p = .006); lower ratings for 3. 6 (M 2.33, SD .697) compared to 3.3 (M 2.52, SD .611) (Z=2.606, p=.009); lower ratings for 3.1 (M 2.35, SD .716) compared to 3.3 (M 2.52, SD .611) (Z = 2.655, p = .008); and finally, lower ratings for 3.2 (M 2.37, SD .677) compared to 3.3 (M2.52, SD .611) (Z = 2.887, p = .004) and 3.4 (M 2.45, SD .609) (Z = 4.682, p< .001).

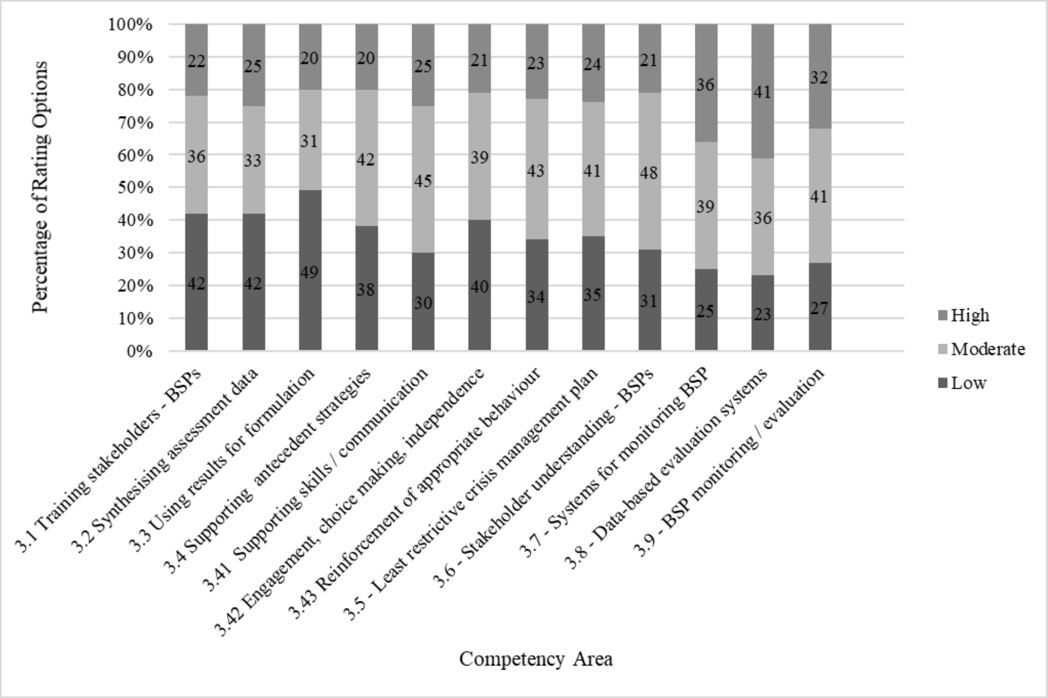


Figure 5: Participant Ratings for Training Needs in PBS Intervention and Evaluation Competencies

Regarding training needs in each of the intervention and evaluation competency areas, a Friedman One-Way test revealed a significant difference between ratings on items overall, X^2 (11, N = 100) = 92.523, $p < .001$. Post-hoc comparisons using Wilcoxon Matched Pairs Sign Ranks tests identified that this difference was largely accounted for by higher ratings for items 3.7 (M 2.11, SD .777) (relating to creating systems for monitoring and reviewing delivery of Behaviour Support Plans and providing feedback and support to facilitate implementation), 3.8 (M 2.18, SD .783) (relating to selecting and implementing evaluation systems to assess effectiveness of interventions), and 3.9 (M 2.05, SD .770) (relating to working with others to further develop Behaviour Support Plans over the longer term). Table 7 summarises all significant differences found between items 3.7, 3.8 and 3.9.

Additionally, higher ratings were found for 3.41 (M 1.95, SD .744) compared to 3.1 (M 1.8, SD .779) (Z = 2.404, p = .016), 3.3 (M 1.71, SD .782), 3.4 (M 1.82, SD .744) (Z = 2.337, p = .019) and 3.42 (M 1.81, SD .761) (Z = 2.723, p = .006); For 3.6 (M 1.9, SD .718) compared to 3.3 (M 1.71, SD .782) (Z = 2.589, p = .010); 3.43 (M 1.89, SD .751) compared to 3.3 (M 1.71, SD .782) (Z = 2.827, p = .005); 3.5 (M 1.89, SD .764) compared to 3.3 (M 1.71, SD .782) (Z = 2.637, p = .008); and finally 3.2 (M 1.83, SD .805) compared to 3.3 (M 1.71, SD .782) (Z = 2.252, p = .024).

Table 7: Summary of Significant Differences between Items 3.7, 3.8, 3.9 and All Other Intervention Competencies for Training Needs

	Intervention Competency Area		
	3.7	3.8	3.9
3.1 (M 1.8, SD .779)	Z = 3.966 p < .001	Z = 4.407 p < .001	Z = 3.377 p < .001
3.2 (M 1.83, SD .805)	Z = 3.875 p < .001	Z = 4.471 p <. 001	Z = 3.245 p < .001
3.3 (M 1.71, SD .782)	Z = 4.771 p <. 001	Z = 5.013 p <. 001	Z = 4.061 p < .001
3.4 (M 1.82, SD .744)	Z = 4.058 p < .001	Z = 2.484 p = .013	Z = 3.053 p = .002
3.41 (M 1.95, SD .744)	Z = 2.213 p = .027	Z = 2.819 p = .005	
3.42 (M 1.81, SD .761)	Z = 4.003 p < .001	Z = 4.483 p < .001	Z = 2.995 p = .003
3.43 (M 1.89, SD .751)	Z = 3.069 p = .002	Z = 3.754 p < .001	Z = 2.232 p = .026
3.5 (M 1.89, SD .764)	Z = 3.569 p < .001	Z = 4.138 p < .001	Z = 2.607 p = .009
3.6 (M 1.9, SD .718)	Z = 3.362 p < .001	Z = 3.881 p < .001	Z = 2.473 p = .013
3.7 (M 2.11, SD .777)			
3.8 (M 2.18, SD .783)			
3.9 (M 2.05, SD .770)		Z = 2.252 p = .024	

Statistical Analysis of Competency Scores

A total assessment competency score and total interventional and evaluation competency score was calculated for each participant for both skills and experience and training need ratings (the average of their ratings on all individual items). Overall there was no significant difference between participants' ratings of skills and experience for assessment based (M 2.26, SD .53) and intervention and evaluation based (M 2.30, SD .52) competencies (Z = 1.112, p =.266) based on a Wilcoxon's Matched Pairs Signed Ranks test. Participant training needs were however rated significantly higher for intervention and evaluation competency areas (M 1.91, SD .63) than assessment based areas (M 1.70, SD .45) (Z = 5.498, p = .000).

Sub groups of participants were formed based on participants who had reported using PBS for up to 5 years (n= 57) and those who had used it for more than 5 years (n = 38). Here, calculation of a Mann Whitney U test showed that participants with over 5 years' experience using PBS rated their skills in intervention and evaluation competencies (M 2.59, SD .33) as significantly higher than those who had used PBS for 5 years or less (M 2.15, SD .51) (U = 542, Z = 4.114, p < .001). Those with higher levels of experience also rated their skills and experience in assessment (M 2.53, SD .44) as significantly higher than those with lower levels of experience (2.11, SD .47), (*U* = 526, Z = 4.246, p < .001). There were no significant differences between training needs for these groups for either assessment based (*U* = 974, Z = .831, p = .406) or intervention and evaluation based areas (*U* = 921.5, Z = 1.228, p = .219).

A further comparison of total competency scores was made for a sub group of participants with the highest levels of qualification relevant to PBS/ABA (n = 24) and all other participants who responded to questions concerning qualifications (n = 73). Participants were placed in the high qualifications group if they had either a post-graduate or undergraduate degree relating to PBS/ABA or were a board certified or associate board certified behaviour analyst. Here those with increased levels of qualification rated their skills and experience in assessment based competencies as higher (M 2.4, SD .55) than those without these qualifications (M 2.2, SD .52), though this difference did not reach significance (U = 659, Z = 1.820, p = .069). Those participants with increased qualifications also rated their skills and experience in intervention and evaluation areas as higher (M 2.51, SD .54) than other participants (M = 2.23, SD, = .51), a difference which was statistically significant (*U* = 565.5, Z = 2.601, p = .009).

Finally, participants who had not gained further qualifications relevant to PBS/ABA indicated significantly higher training needs in relation to assessment areas (M 1.77, SD .45) than those with these qualifications (M 1.52, SD .41) (*U* = 584, Z = 2.450, p = .014) and significantly higher ratings (*U* = 604, Z = 2.273, p = .023) for intervention and evaluation areas (M 1.99, SD .62) relative to those with these qualifications (M 1.67, SD .62).

Discussion

The rationale for assessing and developing the skills and knowledge of professionals within the context of PBS implementation has been well established in the UK (Denne et al., 2013; Denne et al., 2015) and provided the justification and motivation for the current study. Here, it has been argued that the conceptual, technological and values-based components of PBS can only become a reality in the lives of people with IDD and their families, via effective service-delivery that organises and sustains a skilled workforce.

A variety of studies have also indicated the feasibility of training staff in PBS (MacDonald & McGill, 2013), albeit where the scope of PBS training components has been limited to a subset of relevant skills and other methodological weaknesses have often characterised outcome measurement. A more systematic and comprehensive approach to workforce development has therefore been called for (Crates & Spicer, 2012; Denne et al., 2015), giving rise to the development of the UK PBS Competency Guide.

In this study, the detailed descriptions and structuring of the Competency Guide were used to create a survey for staff working in relatively senior positions who used a PBS framework to guide their clinical support for children and young people with IDD. This was the first time the Competency Guide had been utilised in this way and the first UK-focussed study to take a competency-based approach to exploring the skills and training needs of PBS professionals. The study had three main aims as follows: 1. To identify the perceived competencies of professionals using PBS to support children and young people with IDD; 2. To identify the training needs of professionals using PBS to support children and young people with IDD; 3. To explore the prior training, qualifications and experience of professionals with regards to perceived competencies and training needs. This section of the chapter discusses the limitations, main findings and implications of the study in relation to these aims and proposes next steps for research within the thesis.

The PBS Workforce of Level Two and Three Professionals who Support Children with IDD in the UK.

As has already been discussed, a high number of psychologists and behaviour specialists participated in the study (but in a manner that may be predicted given the common service make up in the UK). Whilst to a lesser degree, several other professions did, however, also participate (including nursing and psychiatry), suggesting use of PBS by clinicians with varying backgrounds. Given PBS is intended as a common framework to support evidence and values-based practice, rather than an approach for behaviour analysts or psychologists alone (Gore et al., 2013) this was encouraging to see. Similarly, whilst the majority of respondents worked at least some of the time in the health service, there was also participation from professionals who worked in other settings. As such there was a promising suggestion of attempts to implement PBS in education, social care and third sector organisations for children with IDD. Finally, in keeping with their professional grading, it was reassuring to find that one third of participants had a formal qualification in ABA or PBS (though access to briefer training courses was most commonly identified) and amongst the sample were several professionals (making up 40 % of the sample) who had gained more than 5 years-experience utilising PBS (and most were working in teams to deliver services with others who were estimated as having equivalent or higher skills in PBS to respondents).

Taken together, based on the demographics of the sample participating, there is some good suggestion that attempts are being made to utilise PBS (explicitly) by a range of more senior professionals in different settings across the UK, where at least a portion of these have received prior training and/or have reasonable experience in the framework. Despite this, it was also noted in this section of the survey that only a small number of professionals (21%) reported actually using PBS all of the time in their work, a theme that shall be returned to later in the discussion.

The Perceived Competencies of Professionals using PBS to Support Children and Young People with IDD

Global ratings (average ratings across individual items) of competencies in assessment and intervention areas both reflected a moderate degree of perceived skill for the sample as a whole. There was no significant difference between these scores. A moderate score may be considered to reflect a relatively solid base of skills and experience regarding these core dimensions of PBS. In addition to the caveat concerning subjectivity (that these are *perceived* skills) it is however, also important to note that this rating scale might not really be regarded as interval, with differences between scores of 1, 2 or 3 being open to interpretation. At the same time, given this was a sample of higher level professionals, a higher average score of skill might be anticipated and arguably should be the ambition of a workforce development programme (see later section). Differences within the sample were identified at this global level and will also be discussed later.

Several (statistical) differences were identified between total sample ratings for individual competency areas within both the assessment and intervention, implementation and evaluation areas. Discrimination of perceived skills and experience in this way was interesting to see and suggested some validity in the way skill areas are categorised and described in the PBS Competency Guide. It would appear that different competency items map onto distinct repertoires, or at least can be understood as such by those working in the field. The potential to assess skill and experience at this fine grained level, whether in a subjective manner as in the current study or by other means (see later section) holds considerable promise for monitoring and supporting skill development in practice.

Whilst several differences were identified between perceived-competence in different areas, some were more notable, and those obtaining the lowest and highest scores can be helpfully considered further. Within the assessment areas, the highest scores were obtained for items 2.4 (relating to support for stakeholders to understand interactions between their own behaviour and that of the focal individual), 2.6 (relating to use of functional assessment tools with stakeholder involvement to generate functional hypotheses of challenging behaviour) and 2.7 (relating to assessment of adaptive skills) relative to a number of other items. Scores on these items appeared to largely account for differences within this category.

A number of possibilities may pertain to (relatively) greater skill and experience in these areas at a sample level. It is notable however, that the first two items (2.4 and 2.6) both involve stakeholder collaboration. This is encouraging given the particular emphasis on stakeholder engagement within UK definitions of PBS (Gore et al., 2013). More so, these items correspond to some kind of perception or attributional processes, in which stakeholders consider new ways of perceiving another person's behaviour and the influence of their own behaviour within maintaining interactions (Durand et al., 2012; Lucyshyn et al., 2007). It is quite possible (whilst of course not known for sure) that the broader psychological training many participants would have received afforded them particular skills in these areas. Similarly, psychologists (who made up a high proportion of the group), and perhaps other allied health professionals are frequently trained and experienced in other assessments (Scior et al., 2017). This may have related to some greater experience and perceived skill in assessing adaptive behaviour, for instance, as part of a PBS process (2.7).

Within the intervention, implementation and evaluation areas, differences in ratings of perceived skills and experience appeared to be largely accounted for by lower scores for three items in particular. Lower ratings were notable for items 3.7 (relating to creating systems for monitoring and reviewing delivery of Behaviour Support Plans and providing feedback and support to facilitate implementation), 3.8 (relating to selecting and implementing evaluation systems to assess effectiveness of interventions) and 3.9 (relating to working with others to further develop Behaviour Support Plans over the longer term) relative to a number of other items, with some differences additionally found between ratings for other items.

Again, several interpretations are possible here and any are, at best, hypotheses. It is apparent however, that unlike for assessment competencies, for intervention there appeared less perceived skill and experience in stakeholder collaboration, at least with regards one item (3.9). This items also highlights 'longer-term' work and so there is some additional possibility that this, either in the context of stakeholder engagement, or PBS work more broadly, reflects an area in which professionals generally are less experienced and feel less skilled. Further credence is afforded to this possibility when considering responses to the training needs section of this survey also.

The other two items where relatively low scores were obtained both also pertain to longer-term aspects of PBS, but rest particularly on evaluation and monitoring. As a data-based, systems approach, these aspects are critical to the implementation of PBS. Weaknesses in these areas are of some concern, since a Behaviour Support Plan, however well-conceived or written, is unlikely to be implemented or achieve its desired effect without careful monitoring and assessment of outcomes. Within these processes, Behaviour Support Plans will also typically be amended and refined as an ongoing, dynamic process. Without robust monitoring and evaluation there is a possibility that a PBS process stops at the point of handing over a report or recommendations and leaving it to others to make use of this. Given the complexity of organisational systems and the competing demands placed on stakeholders it is unlikely that this will be done in ways that are helpful (Denne et al., 2020; LaVigna et al., 2015; Lucyshyn, et al., 1997).

The Training Needs of Professionals using PBS to Support Children and Young People with IDD

Whilst there was no significant difference between global scores for perceived skills and experience, it was the case that participants rated training needs in intervention, implementation and evaluation areas as being significantly higher than for assessment areas. As with discrimination of ratings for individual competency items, detecting this difference provides helpful information for development of future training initiatives. Often PBS training is packaged or presented to provide partial or very general coverage of the framework (Carlson & Baker, 2018). The survey suggests however, that a particular focus on Intervention, Implementation and Evaluation areas may be most required for higher level professionals. Even more than this, it was also the case that within the broader assessment and intervention categories, there was some significant variation in training need dependent on individual competency areas that could further indicate specific workforce development targets. Some of these differences will also be explored within the broader discussion of heightened training need for intervention, implementation and evaluation overall.

Particular training needs in intervention, implementation and evaluation may correspond to some of the issues raised in relation to ratings of skills and experience but also the kind of training that was most commonly accessed and years of experience in which participants had been utilising the framework. As has been noted, participants had often attended quite short periods of PBS or ABA training. It is likely common practice that such courses have insufficient time to cover the full details and complexities of intervention development, implementation and evaluation (MacDonald, 2018). The logic of introductory courses will mean a typical need to provide an overall conceptual account of behaviour and then start at the beginning of a PBS pathway with most focus therefore afforded to assessment (Carlson & Baker, 2018).

It is also possible that assessment within PBS, whilst requiring practical skill and theoretical understanding is a (relatively) less complex endeavour than intervention development. Functional Assessment always needs to be individualised to the needs and circumstances of an individual and other stakeholders and can often involve technical procedures. There are however, many resources to support Functional (and other) Assessments that are less reliant on high levels of technical competence (e.g., O’Neill et al., 1997). Assessment tools (including those categorised as indirect and informant based) and guidance on their selection and use are plentiful (Madsen, Janelle, & Valdovinos, 2016) and frequently advocated for within PBS to support good contextual fit (Sugai et al., 2000). In line with this, Functional Assessment in PBS is also often presented using what are effectively mid-level terms that label common functions and present these through a metaphor of communication. Behaviour Analytic concepts connect closely to these but it could be possible for some assessment processes to be carried out with only a basic grasp of underpinning contingencies (which may indeed be a particular strength when training a large workforce and front line practitioners in particular).

Intervention design is a seemingly more complex affair. Conceptually, Behaviour Support Planning requires development of interventions that are connected closely to assessment findings and address the identified function(s) of CB (Browning-Wright et al., 2003; Toogood, 2011). In this regard PBS interventions are also typically multi-element and concern proactive strategies that both attend to antecedent events and maintaining consequences and are constructive in that they increase behavioural repertoires (with regards competing or alternative behaviours) (Sugai et al., 2000; Toogood, 2011; Willis et al., 1993). This process of translating assessment findings to intervention is one that has received attention within the PBS literature and a variety of frameworks are available (e.g., O-Neill et al., 1997). These do however, make the long-term nature of support clear, and competency in use is also typically obtained through attendance of a more in-depth training programme (e.g., Hassiotis, et al., 2018).

Some common interventions within PBS also necessitate a more sophisticated grasp and use of behavioural principles than might be required for assessment work. For instance, many have argued that development of new communication or other skills is critical to a successful Behaviour Support Plan (Browning-Wright et al., 2003; Carr et al., 2002; Durand, 1990) Using Differential Reinforcement in general or as part of specific procedures such as Functional Communication Training (Carr & Durand, 1985) requires proficiency and particular technical skill however. It is very unlikely that a brief training programme attempting to provide an overview of PBS can provide this sort of in-depth understanding or practice. Interestingly, whilst training needs were higher for Intervention areas overall, the highest training needs within the assessment category also indicated needs that corresponded to more in-depth ABA competencies. Both items 2.5 (relating to data collection systems based on 4-term contingencies) and 2.8 (relating to preference and motivational assessments) obtained higher training need ratings and concern more technical processes and behavioural concepts.

Even more than this, PBS interventions must also ensure the non-use of aversive strategies (and counter/eliminate any that already operate in an individual's life) and attend closely to other contextual variables (Horner et al., 2000). Interventions often support change at the level of a system or across multiple ecologies and may involve broader support for health and wellbeing of the individual and other stakeholders. The concepts of contextual fit, ecological and social validity (Albin, Lucyshyn, Horner, & Flannery, 1996; Dunlap, 2006) are also cornerstones of Behaviour Support Plan development and mean that any plan needs to attend closely to the reality and priorities of life for the focal person and those who support them. As such, the process of support plan development and implementation is one where long-term working with stakeholders is required (Carr et al., 2002; LaVigna & Willis, 2005).

Whereas stakeholder engagement in assessment is desirable it is arguably essential for intervention implementation since any strategies or recommendations can only occur through the behaviour of mediators (McLaughlin, Denney, Snyder, & Welsh, 2012). Despite this, PBS implementation and evaluation has received relatively less attention in PBS research, with far fewer resources to guide and structure how this is done in practice. It is apparent, for instance, that although PBS has several aims, with an overall focus of achieving life style change and enhanced quality of life, most evaluation of the framework in research has referenced a small range of outcome areas (focussed most centrally on CB and other adaptive behaviours). So at least some of the perceived training need in relation to implementation and evaluation may be a reflection of limitations in the field of PBS more generally (a theme that is returned to in Chapter Three).

Understanding and acquiring skills in intervention design, implementation, monitoring and evaluation necessitates in-depth training and resources and guidance to be available, but is also likely to be something that requires direct practical experience (MacDonald, 2018). Supporting the establishment, maintenance, refinement and evaluation of interventions is likely something that practitioners need time to rehearse and develop through opportunities and commitment to real life cases. It was notable from other responses and analysis from the survey that such occasions may not be the norm and that longer-term aspects of PBS are an area where particular training is needed. In close correspondence to the lowest perceived skills and experience, the individual Intervention competency areas where the highest training needs were indicated, all referenced this: 3.7 (creating systems for monitoring and reviewing delivery of Behaviour Support Plans and providing feedback and support to facilitate implementation), 3.8 (selecting and implementing evaluation systems to assess effectiveness of interventions), and 3.9 (working with others to further develop Behaviour Support Plans over the longer term).

Data in support of these ideas can also be drawn from the earlier section of the survey in which participants rated how commonly they engaged in a range of PBS-related activities. Here, it was most often the case that practitioners engaged in assessment and behaviour support planning activities that were either completed mostly by the individual themselves or concerned training based on these self-completed assessments and plans. These are of course core areas within most PBS pathways and so to be expected as frequent activities but it was also notable that it was far less common for participants to engage in other areas. Many of these additional areas involved more extensive work with stakeholders and long term strategies to create positive change at the level of a broader support system (such as training and supervision). Within these additional areas, participants were then most likely to complete activities relating to support for their close colleagues within their own organisation or team. They were far less likely to provide the same kind of support to other professionals or family caregivers to complete assessment and behavioural support planning development work or to provide advice/consultation to other organisations.

These were interesting findings. These particular questions (unlike in Sections Two and Three) did not map precisely onto the competency framework but some points of comparison are possible. As with skills and experience overall, it might be hoped that higher level professionals such as those surveyed, would be the people best placed to drive organisational change initiatives through systems level work. Competencies assessed were those that concerned consultants and supervisors whose main function would really be to support other professionals and stakeholders to implement and develop support strategies (in addition to holding particular expertise in core assessment and support planning themselves for more direct use during complex cases). This did not seem to reflect the bulk of what people were doing on a day to day basis.

It has already been highlighted that participants had relatively less perceived skills and experience (and higher training needs) in longer term aspects of PBS and this seems to be borne out here also. Yet, at the same time, responses to some competency questions (particularly in the Assessment category) suggested quite strong skills in working with stakeholders, skills that could be of direct relevance to supporting training and supervision that empowers others to undertake core assessment and intervention procedures. The fact that these competencies are not so clearly represented in the kind of tasks practitioners most frequently engage in could be taken as an indication that they do in fact not possess such skills. It has been noted that ratings of competence were of an inherently subjective nature.

However, it is also possible (and perhaps more so) that the activities practitioners most commonly engaged in were a reflection of other organisational demands and restrictions.

It is commonly the case that health and social care services for children with disabilities are set up with a referral system that responds to current need, or even crisis (Gore et al., 2014). Typically, cases are referred to a team or service on an individual basis and managed in that context. Practitioners (and services) will generally face pressures to minimise waiting times for children and families and permitted to only provide a set number of sessions per case, for a set period of time. It is far less typical for a service to have a border practice aim or remit to support larger systems level change. Examples of services that explicitly aim to do this (alongside other direct case work) can be found (e.g., Reid, Sholl & Gore, 2013; Iemmi et al., 2016) but they are few and far between. Practitioners may therefore find it incredibly challenging, if not impossible, to afford time to undertaking higher level change strategies and or in-depth support for stakeholders over the long-term. This creates a two-fold dilemma in that the skills and competencies practitioners already have or have been trained in, remain under-utilised, and those that they have yet to acquire fully through direct experience remain under-developed.

Prior Training, Qualifications and Experience of Health Professionals with Regards Perceived Competencies and Training Needs

The centrality of both training and experience to support skill acquisition was underscored in further analysis of participant responses based on demographic groupings. In the case of direct experience, those with more years' experience using PBS had significantly higher perceived competencies in both assessment and intervention areas relative to those with less experience (with no significant differences apparent in either of the global training scores between these groups). Hands on, practical experience is therefore suggested to be of importance in gaining expertise in PBS across all major competency areas.

There was no statistical difference between perceived assessment skills for those with the highest levels of prior training compared to those with less prior training. A significant difference was, however, found with regards intervention, implementation and evaluation skills. Here it was suggested that those with higher qualifications had higher levels of skills, supporting the hypothesis that such competencies may not be adequately developed in briefer training programmes. Those with less prior training also identified as having significantly higher future training needs than those with higher level qualifications in both assessment and intervention-based areas. This might be anticipated but gives some sense of validity to the responses made by participants throughout the survey.

Study Limitations

As discussed, this was a first study to utilise the PBS Competency Guide and to provide a detailed appraisal of PBS skills for staff in the UK. The particular focus on the UK should be underlined since PBS has been defined in slightly different ways and operates within different service structures and cultural contexts elsewhere. Findings of this study may have some relevance to these settings but this was not the intention and so any attempts to generalise beyond the UK should be approached with caution. This aside, whilst the study methodology had several strengths, was effectively unique and had pragmatic value, there were some limitations. To a large degree these reflected the financial and time resources available within a PhD.

Firstly, it is difficult to gauge the representativeness of the participant sample. A limitation of all surveys is the potential for a reporting bias whereby those who have particular experiences, needs or motivations tend to take part whilst others do not. Caution must always be exercised therefore in generalising the findings of a survey to a broader population or context. The sample was however of a reasonable size, with 100 participants taking part. Definitive numbers do not really exist concerning the number of PBS professionals (or even services) in the UK that provide PBS, but for the most part this is considered a far smaller workforce population than for adult services. It might reasonably be anticipated therefore that a sizeable proportion of the potential participant pool (operating at the professional level targeted) took part. In particular, all professionals who attended the PBS workshop event (representing the largest network for PBS professionals working with children in UK Health settings) completed the survey.

In a similar vein, it may be questioned whether the demographic variables of the sample were skewed in some way. Over 60% of respondents worked in the health service, though other settings were also clearly represented and it is certainly the case that the NHS has significant responsibility for delivery of PBS. It was also the case however that 50% of the sample were psychologists. As with the overall workforce, there is no definitive or other available data with which to compare this. It is certainly the case that psychologists would have been particularly well represented at the PBS workshop event, though this event, and other recruitment sources, were open to a range of professionals (who were also represented in the remainder of the sample).

It is also the case that Clinical Psychologists are frequent members of Child Adolescent Mental Health Services (and equivalents) in NHS settings whose training and status would be consistent with an expectation to deliver PBS at Levels Two and Three of the Competency Guide. The relatively high portion of psychologists who participated could therefore well be justified. The particular demographics of the sample are however important to be mindful of when interpreting the data and making implications for the future. Here, it is worth noting that the study did not explore the competencies of more frontline workers, who whilst less likely represented in health contexts have been established as a major priority area for workforce development. Similarly, only those who explicitly declared to be using PBS were sampled in this survey. Whether other professionals are able to utilise (and/or recognise related training needs) some of the components of a PBS framework (if by another name) is not known, but could be of value to ascertain in future research.

The particular focus of the competencies addressed in the current survey was also limited to a dominant focus on Areas One and Two of the Competencies Guide, concerning assessment, intervention and evaluation respectively. This focus was justified to be in line with the key activities most likely reflected in professional roles at supervisory and consultancy levels. The skills and training needs of participants with regards the construction and maintenance of enabling environments (Area One of the Competency Guide) were not investigated. These are, however, also critical to broader preventative intervention within PBS and require consideration in future research.

The final set of limitations to consider concern the survey methodology. Firstly, the survey contained quite a high number of relatively complex, nuanced questions. Two inter-related possibilities are relevant in this regard, in that both fatigue and misinterpretation or difficulty comprehending a question may have influenced responding. Whilst these are possibilities, difficulties of this nature were not observed. The survey had been predicted to take 15-20 minutes and during the PBS workshop event was completed within this time period (which would not suggest a particularly demanding or fatiguing exercise for professionals). The author was also present during this event and available to answer any queries should they arise. Only a very small number of participants asked a question at this time, all of which related to very minor points, and no participants reported difficulty in understanding or interpreting a question.

It was also the case that the wording of competency orientated questions had stayed quite true to wording provided in the Competency Guide. Since wording of the Guide had been created by consensus this should have been relatively clear. More so, where technical terms were incorporated into an item, these concerned concepts that would need to be known by a participant claiming skill in that area. Notably, one of the few participants who asked a question during completion of the survey stated not knowing what a 4-term contingency was, and then upon reflection realised that if not knowing, then the corresponding item should be rated as a low skill area (and high training need).

The survey, by its very nature, assessed the self-perceptions of participants. As has been argued in the introduction to this chapter, outcome measurements that assess dimensions of PBS via post-training questionnaires with staff need to be analysed tentatively. Importantly, it is recognised that the way in which individuals respond to a questionnaire does not necessarily equate to their behaviour (or practice) in other situations. Similarly, in the present study caution must therefore be exercised, with data firmly approached in the context of staff perceptions of skill and training need that may be open to subjective bias or other distortions. It is however, helpful to note that Denne, Thomas, Hastings & Hughes (2015) in their exploration of a range of measures focussed on ABA competencies, found that staff did typically not over-estimate their personal abilities or knowledge. Whilst future research may usefully investigate PBS competencies through additional methods (e.g., tests of knowledge, supervisor ratings and direct observations) the current findings should provide some important indications of what staff know, do and need.

Conclusions and Next Steps for the Thesis

Building on an appraisal of the key dimensions of PBS in Chapter One, this chapter highlighted the central importance of a skilled workforce for implementation of high quality services. As a first endeavour to utilise the PBS Competencies Guide in survey form, this study provided some important findings with regards both the strengths and needs of practitioners. The particular training needs, organisational contexts and experience opportunities for professionals drawn out from across the survey will be further discussed with reference to future research and workforce development in the final chapter of this thesis. It was however, particularly notable that skills in evaluation (as a sub-component of intervention competencies) were amongst the lowest perceived competencies for the sample in this survey, a finding that warrants particular consideration. As a data-driven approach, evaluation is fundamental to delivery of PBS, and in and of itself a core process that can support implementation. Being clear about the goals of an intervention or service development, and then evaluating the extent to which these are or are not being met, can hold both practitioners and services to account, and allow for shaping and modifications to practice in a clear and strategic manner.

Arguably, the scope of evaluation methods needs to correspond closely to the full breadth of a PBS framework. It has often been reported, however, that PBS research has tended to focus on a relatively small range of outcome areas (Carr et al., 1999; Conroy et al., 2005; O’Dell, et al., 2011). Conducting further research to enable and equip practitioners and researchers to evaluate the full breadth of possible PBS outcome areas therefore appears a priority. The next chapter (Chapter Three) of this thesis therefore focuses in detail on evaluation methods for PBS, building a consensus based framework that attempts to capture the full breadth of possible PBS outcomes to support evaluation in the UK. Evaluation and goal setting to support PBS implementation at an individual child and family carer level is further explored in Chapters Four and Five.

In addition to evaluation approaches, PBS implementation may also be enhanced by developing intervention and support approaches that better fit with the availability of resources and service structures within the UK. Continuing to support and advocate for services that can accommodate the long term working that PBS necessitates is important. Finding additional ways to deliver PBS, in briefer modalities, is likely also necessary as part of an overall systems-strategy. Doing this is not about diluting the PBS framework but about honouring contextual fit and the flexibility and ambition of PBS as an evolving science. In Chapter Five of this thesis a logic model for one such intervention programme (Early Positive Approaches to Support) is described in detail, followed by a qualitative evaluation of its use in practice.

Chapter Three: Developing an Outcomes Framework for the Evaluation of PBS[3]

Overview

Chapter Two explored the perceived skills, experiences and training needs of child-focussed practitioners who use of a Positive Behavioural Support (PBS) framework in the UK. Whilst, respondents reported perceived skills in a range of key competencies necessary for delivery of PBS (Branch & Denne, 2015), some gaps in knowledge, skills and experience were notable. Firstly, practitioners identified the greatest training need with regards 'Developing and Implementing a Behaviour Support Plan (BSP) and Evaluating Intervention Effects and On-Going Monitoring.' Within this category, practitioners reported lowest perceived competence in three areas in particular that related specifically to monitoring and evaluation (3.7 Systems for monitoring BSPs; 3.8 Data-based evaluation systems and 3.9 BSP Monitoring/evaluation).

Secondly, despite high perceived competence in areas that relate to systems-wide change (e.g., 2.1 Ensuring stakeholder engagement; 2.4 Supporting stakeholder understanding; 3.1 Training stakeholders in use of BSPs), in practice, participants' day-to-day work corresponded more closely to direct case work with individuals (whereby they typically completed assessments and behaviour support planning with this kind of focus) rather than work to support positive change at the level of a support system.

Strategically, it therefore appears prudent to identify mechanisms that both support increased knowledge and use of PBS consistent with evaluation/monitoring approaches and facilitate systems-based PBS practice. In Part One of this chapter it is argued that creation of an outcomes framework that is intrinsically connected to all definitional components of PBS,

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[3] A version of the study in this chapter has subsequently been published: Gore, N.J., Jones, E., & Stafford, V. (2020). *Building core domains for the evaluation of PBS: A consensus-based approach. International Journal of Positive Behavioural Support, 10*(1), 4-15.

for adoption in UK services, may provide a foundation to drive these developments and build enhanced service provision for children with Intellectual and Developmental Disabilities (IDD) at risk of behaviour that challenges (CB). This discussion sets the scene for a study completed to develop such a framework that is reported in Part Two.

Consistent with the second research question of this thesis (‘How can stakeholder engagement be maximised to enhance support for children with IDD and their families?) the reported study utilised a Delphi method with a panel of 10 research and practitioner experts over four rounds. An outcomes framework that comprised 162 distinct items, organised within four major levels and a number of sub-categories was generated. Potential uses of the framework and further developments are discussed in the context of research questions one (‘How can delivery of high quality PBS be supported within services?’) and two.

Part One

PBS and Outcomes

As has been described in Chapter One, PBS has evolved as a framework to support people with IDD who present (or are at risk of presenting) CB. PBS might therefore be considered an intervention for primarily reducing CB, and has indeed at times been described as such (e.g., Hassiotis et al, 2018, p161). The underlying philosophy, values-base, theoretical stance and practice of PBS are, however, far more nuanced. Principally, whilst PBS is intended to ensure reduced risk of CB over the long term, the fundamental focus of the framework concerns support for enhanced life-style and life quality (Gore et al., 2013). This overriding premise is grounded in the values base of PBS, a person-centred focus in support of social inclusion and participation, and theoretical and research-informed evidence (Carr et al., 2002).

Poor quality of life (QoL) and adversity, across a range of domains (e.g., health, wellbeing, relationships), are more common amongst people with IDD of all ages relative to the general population (e.g., Emerson & Hatton, 2014; Lunsky & Benson, 1999; Santoro, Shear & Haber, 2018). At the same time, factors pertinent to poor QoL are known risk factors for the development of CB, but when CB are effectively supported within a 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 (Carr, 2007, p4; McLaughlin et al., 2012). 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. Arguably, 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. 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).

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 & Dunlap, 2008; Clarke, Zakszeski & Kern, 2018; LaVigna & Willis, 2012; MacDonald & McGill, 2013; O'Dell et al., 2011). Although there are some notable exceptions (e.g., Lucyshyn & Zumbo 2018), evaluation of life style, life quality, stakeholder and broader system-change has, however, in the majority of cases either not been explicitly discussed (Clarke & Dunlap, 2008; LaVigna & Willis, 2012), or is highlighted as a deficit and a recommended priority area for future research (O'Dell et al., 2011; MacDonald & 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 CB, adaptive behaviour and QoL for people with IDD and QoL, knowledge and behaviour change relevant to other stakeholders (Perry et al., 2015; Summers et al., 2005; Townsend-White, Pham & Vassos, 2012; Turton, 2015).

More challenging perhaps has been the identification of measurement tools suited 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 (e.g., 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.

Part Two

Introduction

Given the limitations of prior research and the context of 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 appeared both promising and achievable. This part of the chapter reports on research to establish a comprehensive set of outcome domains for the evaluation of PBS in a 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. These aspirations built on the on-going work of the PBS Academy and the Sharland Foundation Developmental Disabilities ABA Research and Impact (SF-DDARIN) group, a related network of research active professionals supporting behavioural approaches for use with people with IDD.

Consistent with the aspiration of building consensus through a collaborative approach (and the research question two), a Delphi-Panel method was utilised (Adler & Ziglio, 1996; Linstone & Turoff, 1975) 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. 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.

Delphi studies have previously been used to good effect in the field of IDD to consult professionals' views on service design (Hemmings, Underwood & Bouras, 2009) and staff training (Wark, Hussain & Edwards, 2014); operationalise and model service quality and QoL indicators (Gomez, Arias, Verdugo, Tasse & Brown, 2015; Maes, Geeraert & Van Bruel, 2000; Petry, Maes & Vlaskamp, 2007; Swennenhuis, Vermer, Rispens, Teunissen &Wensing, 2004) and explore support and intervention for those with CB (Lemmi et al., 2016; McVilly, Webber, Sharp & Paris, 2013).

In more recent years, modification have been made to support and enhance Delphi methodology in different contexts and for differing purposes (McKenna, 1994; Turoff, 2002). In particular, Delphi studies have made increasing use of the internet as an interface for delivery (Helms et al., 2017). Delphi studies conducted online have some notable benefits in that a wider pool of participants (from differing locations) can readily take part at relatively low cost. It also provides a practical means for participants to provide responses at a time and place of their choosing (potentially between other work and personal commitments) and provides a direct way of collating data electronically (without the need to input data manually). Consequently, Delphi studies utilsiing paper resources have become less and less common (Hunter, 2012).

Method

Ethics

Ethical approval for this study was sought and approved by the Tizard Centre Ethics Committee at University of Kent, England. Issues of consent and confidentiality are detailed below.

Participants

Participants were behaviour-analytic researchers and clinicians in the field of IDD, who had a special interest, expertise and experience in PBS. A purposive sampling strategy was adopted to recruit participants. In the first instance, an invitation to participate was sent to all members of the Sharland Foundation Developmental Disabilities Research and Impact Network (SF-DDARIN). This network comprises approximately 30 behaviourally-orientated members from England, Wales, Scotland and Northern Ireland who are research active with the field of IDD. Network members share a common aspiration of enhancing the quality and implementation of research to support people with IDD. The network includes a PBS subgroup but invitation was made to all members.

Additionally, invitations were sent to a small number of individuals from Gore's professional networks, who had an established track record of research relevant to PBS but were not members of SF-DDARIN. All potential participants were contacted by e-mail. Electronic letters were distributed that provided full information and the opportunity to ask questions regarding the study. Those interested in taking part were asked to complete and return a consent form.

Twelve people expressed initial interest in taking part. Of these, 10 formed the initial Delphi Panel for Round One. This comprised an equal split of males and females, nine of whom held or had held both clinical and research positions and one of whom was a researcher. Panel members were based in England (7), Wales (2) and Scotland (1). All members had a track record of excellence in research and national development work related to PBS. Nine were members of SF-DDARIN and one was drawn from other sources. A panel of 10 also participated in Rounds Two and Three. Of these 9 had participated in the initial round and 1 had not. The demographics remained the same with an equal split of males and females. In Round Four, the panel comprised 9 participants, all of whom had taken part in previous rounds.

Delphi Process

This study comprised four Delphi rounds. All rounds for the study were administered electronically via a Google Forms interface. In each round a questionnaire was prepared and formatted onto Google Forms. A link was then e-mailed to each panel member along with instructions and any additional feedback data as relevant to that round. Participants were then able to click on the link to open and complete a questionnaire at their convenience. Questionnaires did not require participants to identify themselves and were automatically uploaded onto a database that could only be accessed by the research team.

In Rounds Two, Three and Four, participants were asked to generate (and retain) their own 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 (as a key requirement of the Delphi process) but that responses could be linked between rounds to allow for personalised feedback and consensus building.

Participants were given between two and four weeks to respond to each round. At the end of the agreed period, all participants were asked to confirm if they had taken part. It was therefore possible to determine who had participated in each round but not to match responses to individual panel members, thus maintaining anonymity.

Round One

Round One used a questionnaire that was structured to support panel members to consider the breadth of possible outcome areas relevant to PBS (appendix 2). Panel members were asked to provide open text responses in relation to a number of starter questions that prompted consideration of different perspectives, levels of implementation and key components of a PBS framework. The question areas were not considered to be mutually exclusive but to provide a range of different reference points by which members could reflect upon potential outcome areas.

By definition (Gore et al., 2013) PBS involves delivery of supports by and for a range of stakeholders. This includes the focal person/people but also other individuals who may influence the focal person’s behaviour and life and/or whose life and wellbeing is impacted upon by the behaviour of the focal person. Participants were therefore firstly asked to detail outcome areas for PBS that might be of significance for different stakeholder groups. This included people with IDD, family caregivers, staff, managers, policy makers and commissioners with a total of 12 main stakeholder groups covered. Whilst it was recognised that this line of questioning was not equivalent to direct consultation with these stakeholder groups, it was the case that panel members had considerable experience of stakeholder collaboration through research and clinical practice and were therefore well placed to explore these perspectives.

As a systems-informed framework, PBS can also be implemented at a number of different levels. The Round One questionnaire therefore also prompted panel members to reflect on outcome areas that may be relevant at different levels of a support system. Firstly, participants were asked to consider outcomes at an individual level (where the focus of support concerned a single person with IDD or related supports for individual mediators). Secondly, participants were asked about outcomes that might be pertinent when PBS was implemented at a small group level (such as classes of children with IDD; families or staff teams). The questionnaire then provided further prompting to consider outcomes relevant at an organisational level (e.g., whole service or school), local community or geographical area and at a whole population level.

The last section of the Round One questionnaire concerned the definitional features of a PBS framework and the extent to which these may relate to outcome areas during and following implementation. In line with the definition of the 10 component definition of PBS provided by Gore et al. (2013), participants were asked to consider outcomes that reflected the values, theory and evidence base and processes central to the framework. Finally, an open response section was provided in which participants could suggest any other outcome areas that had not been elicited by other questions. Evidently, domain areas relevant to each line of questioning had the potential to overlap and questions were not designed to ensure differentiated responses. Rather, the different lines of questioning were intended to provide a range of ways in which group members could engage, with the variety of questions likely to resonate with members' interests and experience to varying degrees.

Responses from Round One were analysed using a simplified Framework Approach (Ritchie & Spencer, 1994). The Framework Approach has previously been used in IDD research (Nicholson, Coyler & Cooper, 2013) and is considered to have good application to health care research (Smith & Firth, 2011). The approach offers a structured and robust method of analysing qualitative data that is particularly helpful when some categorisation of responses is prompted by the structuring of questions during interview or survey, as was the case in the current study. Framework Analysis can take the structuring of initial questions areas as a starting point for analysis but also allows for exploration of themes that emerge from the data. A basic application of this approach suited the main functions of analysis in Round One which primarily concerned a transparent organisation of panel responses, maintaining participants' original wording as far as possible (rather than the deduction of more abstract themes).

Participant responses from across all question areas prompted in Round One were analysed by the first author in accordance with the key stages required for a Framework Analysis as outlined by Ritchie and Spencer (1994). All responses were initially viewed and reviewed in tabulated form, participant by participant and question area by question area. During this first (data-management) phase of analysis initial themes and categories that emerged across participants and question areas were noted, with in-vivo codes developed over time. This connected to both the question areas structured within Round One (stakeholders, levels of implementation and key components of PBS) but also to emergent themes that were repeated across these.

An index table was then created and quotations/responses were reordered in relation to distinct outcome area items, sub-categories and higher order categories or levels (quotations are included in the reporting of results for this round). Distinct items were recorded even where these were represented by a single participant since the intention of this round was primarily to generate a wide pool of potential outcome areas (though more commonly items were reflected in the responses of multiple participants). Where possible, the wording or combination of wordings used by participants was retained to describe items and categories.

A re-examination of all responses in tabulated form was conducted as part of the Descriptive Accounts phase and a final consideration of associations between themes took place within an Exploratory Accounts phase. The final analysis structure was presented back to participants for comment during Round Two. No changes were requested at this time to the structure (higher order ‘level’ categories and sub-categories) suggesting the analysis captured the central messages and priorities of the panel.

Round Two

All items derived from the analysis of Round One responses were presented to panel members in Round Two, structured around the levels and categories that had been generated. The questionnaire used for Round Two required panel member to rate the relevance of each item as an outcome area for PBS on a three-point scale (0 = not applicable as an outcome area, 1 = applicable and 2 = highly applicable) or to indicate that the item in question was ambiguous and required further clarification. Additionally, panel members were asked to provide comment on the overall structuring and analysis of items in a free text section and to suggest any alternative approaches to organisation.

Delphi studies typically use a decision-making rule based on consensus of 80-90% of the panel. In this study, we considered consensus agreement to be made if 80% of the panel rated an item as relevant or highly relevant. Additionally, it was agreed that further clarification for an item would be provided when this was requested by 10% of the sample for items that had not reached consensus and 20% for those that had. Since the purpose of this study was to identify outcome areas rather than establish specific wording, this variation meant that clarification focused on supporting consensus regarding relevance.

Round Three

In Round Three, panel members were asked to provide further input and response to those items that had either not reached consensus or been deemed to require further clarification in Round Two. Firstly, participants were asked to provide further clarification or refine wording where possible for items that had previously appeared ambiguous. Those panel members who had rated items that had not reached consensus as applicable were also asked to provide justification as to why the item should be retained in free text responses.

The codes used by participants who had responded in this way during Round Two were presented in accompanying materials so that they could identify themselves. Finally, all panel members were able to provide free text responses that could argue for or against inclusion of these items (regardless of their prior rating in Round Two). The responses of participants in Round Three were collated and the wording of items that had been considered ambiguous refined based on participants' suggestions. The justifications and challenges provided by panel members were arranged in summary tables for each item.

Round Four

In the final round, all items that had not reached consensus and/or been considered ambiguous were re-presented to panel members in a questionnaire. Panel members were also presented with the summary tables for each item produced at the end of Round Three and a summary of group responses (mean, SD, mode and percentage agreement) for each item made in Round Two. In each case, participants were asked to rate items for a second time using the same scale as previously. The same consensus decision-making rules used in Round Two were adopted with regards item agreement and clarity.

Results

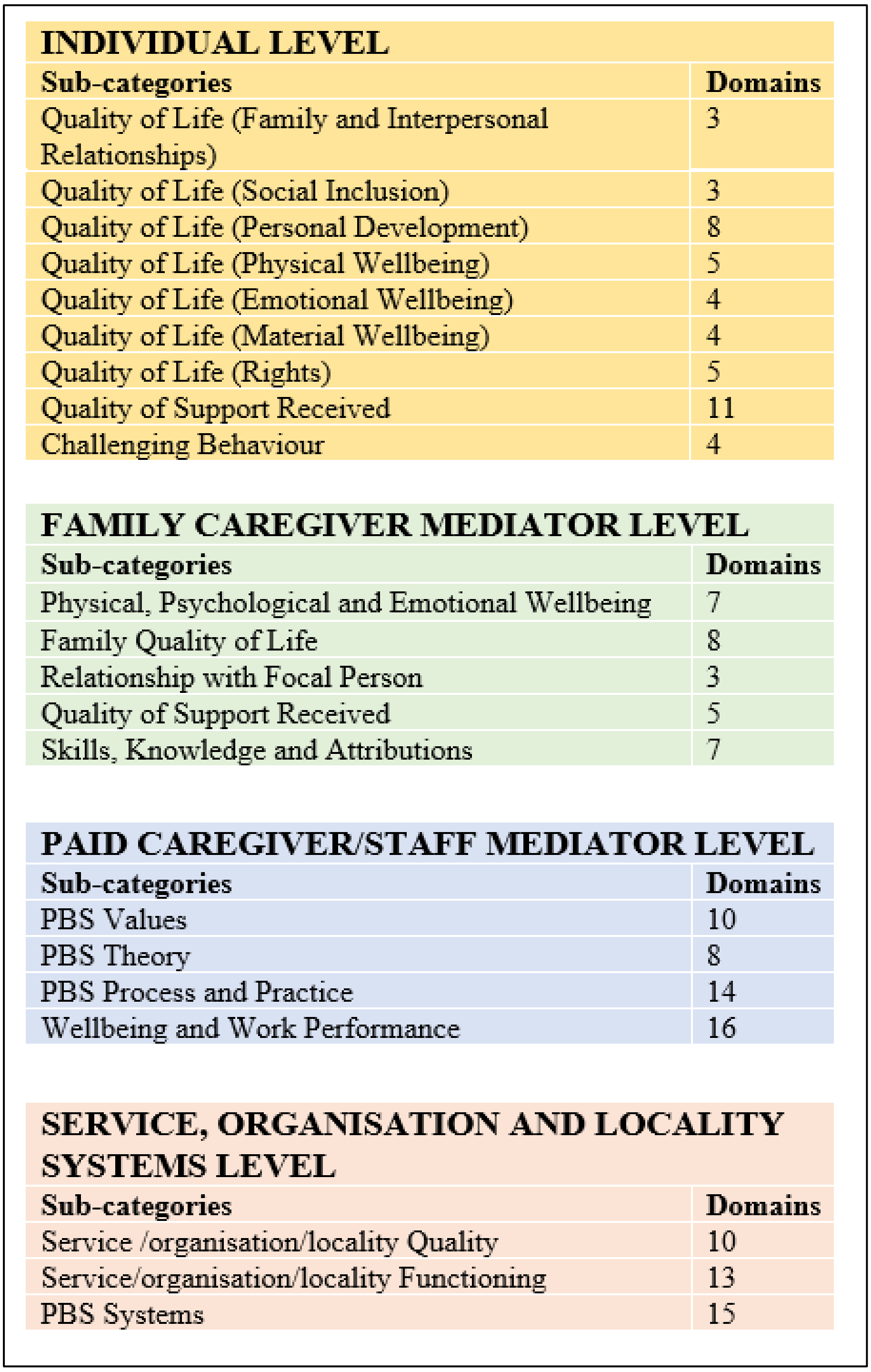
Round One

A total of 164 distinct 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 and illustrated in Figure 1.

Individual Level Category

The Individual level category concerned 48 outcome domains relating to the functioning, experience and behaviour of a focal person with IDD, which could be grouped within 3 sub-categories: Quality of Life, Quality of Support Received and Challenging Behaviour:

> *"I think people with Learning Disability would be interested in their own personal outcomes which are likely to be related to quality of life issues, health, personal relationships, employment, family and friendships, may also include specific health or behavioural challenges"*



INDIVIDUAL LEVEL

Sub-categories	Domains
Quality of Life (Family and Interpersonal Relationships)	3
Quality of Life (Social Inclusion)	3
Quality of Life (Personal Development)	8
Quality of Life (Physical Wellbeing)	5
Quality of Life (Emotional Wellbeing)	4
Quality of Life (Material Wellbeing)	4
Quality of Life (Rights)	5
Quality of Support Received	11
Challenging Behaviour	4

FAMILY CAREGIVER MEDIATOR LEVEL

Sub-categories	Domains
Physical, Psychological and Emotional Wellbeing	7
Family Quality of Life	8
Relationship with Focal Person	3
Quality of Support Received	5
Skills, Knowledge and Attributions	7

PAID CAREGIVER/STAFF MEDIATOR LEVEL

Sub-categories	Domains
PBS Values	10
PBS Theory	8
PBS Process and Practice	14
Wellbeing and Work Performance	16

SERVICE, ORGANISATION AND LOCALITY SYSTEMS LEVEL

Sub-categories	Domains
Service /organisation/locality Quality	10
Service/organisation/locality Functioning	13
PBS Systems	15

Figure 1: Levels, Sub-Categories and Domains Following in Round One

The Quality of Life sub-category included 33 domains that could be further organised into eight groupings, relating to key domains reflected in the broader QoL literature (self-determination; family and interpersonal relationships; social inclusion; personal development; physical wellbeing; emotional wellbeing; material wellbeing and Rights).

> *"Have a good quality of life, supported to make informed choices and have control…have relationships with family and friends…participate in the community…live in an enriched typical environment that meets my needs…supported to communicate…have appropriate treatment for my physical and emotional wellbeing…safe and protected from abuse."*

The Quality of Support Received sub-category contained 11 domains that concerned access to or experience of support approaches consistent with values or practices common to a PBS framework (e.g., person centred approaches); reduced experience of approaches that are counter to PBS (e.g., aversive and restrictive practices) and other areas reflecting the stability and quality of placements and support (e.g., frequency/risk of placement breakdown'.

> *"Levels of happiness or satisfaction with their support and those providing their support; environmental set-up; use of person-centred planning..."*

> *"Behaviours that challenge are understood...not subjected to restrictive practices…PBS plan is implemented consistently by the staff team…"*

The final sub-category in this level, Challenging Behaviour included four domains that concerned directly observable dimensions of CB (e.g., Frequency, severity, intensity, duration and management difficulty) and other indicators of such behaviour (e.g., school exclusions).

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

It is important to note that the responses of panel members sometimes specified a direction of change for the outcome area (for instance, a reduction in CB and restrictive practices or an increase in engagement and choice making) but on other occasions simply noted the area. Similarly, the open responses of panel members that concerned this outcome level included recognition that both the direction of change and relevance of an outcome area may vary between individuals at different times and within different contexts. It was recognised by panel members that involvement of individuals in selection of particular outcome areas would be essential in practice and that sometimes maintaining functioning or support (rather than increasing this) in a given area could be desirable. Consequently, items were summarised purely in terms of headings at this stage of analysis without imposing a fixed direction of change or prioritised ordering.

> *"For things to stay the same!"*
>
> *"People have a right to say what outcomes are important to them (not just what services assume or think are important for them). Outcomes should be developed collaboratively with people with Learning Disabilities as true partners in their own care and support."*

Family Caregiver Mediator Level Category

The Family Caregiver Mediator level comprised 30 domains that related to the behaviour, experiences and opportunities for whole families and individual family caregivers involved in supporting a focal person with IDD. As with the Individual level, items related to areas where both anticipated increases and decreases following PBS were reflected in panel members' responses or where a direction was not suggested. Maintenance (rather than change) of an area as a potentially desirable outcome and variation between priorities for caregivers were also reflected within analysis and the phrasing of items.

> *"PBS outcomes critically important for this group. They are an integral part of them! Being able to support their relative in own community with relatively easy access, being able to have family and community relationships...being able to have a say in those outcomes...being able to understand their own role in delivery of support that leads to best outcomes."*

Within this level, five sub-categories could be identified. The first two sub-categories concerned the Physical, Psychological and Emotional Wellbeing of caregivers (seven domains spanning self-management, service access, physical and emotional aspects of wellbeing) and Family Quality of Life (eight domains covering family relationships, wellbeing, and functioning together with social and community access for families).

> *"The impact of caring for someone with LD can be very challenging and can impact on family carers – their view of what is important for themselves as carers and individuals in their own right is also very relevant."*

> *"Improvement in quality of life for caregivers…good health and wellbeing, reductions in stress, for family carers to access social activity. Holidays etc. and sustain relationships…"*

The third sub-category included three domains that focussed on caregivers' Relationship with the Focal Person with learning disabilities (including their 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 domains were identified that related to the stakeholder involvement of caregivers together with their satisfaction and perceptions of professional and service support (Quality of Support Received).

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

The final sub-category, Skills, Knowledge and Attributions comprised seven domains reflecting caregiver understanding, practical and emotional responses to behaviour that challenges and supporting the needs of their relative with IDD.

> *"Better understanding of their family member; more confidence in dealing with challenging behaviour; wider range of responses to challenging behaviour; better strategies to minimise the occurrence of behaviour"*

Paid Caregiver/Staff Mediator Level Category

This category concerned mediators (including support workers, teaching staff and other professionals) who provide support to a focal person or people with IDD and focussed on increases, decreases or maintenance of paid care staff behaviour, experiences and opportunities.

> *"Support for staff; measures of staff injuries, use of restrictive practices etc.; evidence of data collection and use of that data to make decisions; evidence of on-going staff training and professional development"*

A total of 48 domains were identified, that could be thematically organised into four sub-categories. Sub-category one (10 domains) concerned staff members' knowledge, attributions and behaviour with regards to PBS Values (e.g., a commitment to supporting QoL, person centred principles and the dignity and respect of focal individuals).

> *"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 and to ensuring support is tailored to support the individual and the family and friends…commitment to non-aversive approaches…"*

The second sub-category (eight domains), PBS Theory, reflected staff understanding, knowledge and corresponding behaviour in relation to the conceptual and evidence-based elements of PBS (e.g., principles of behavioural approaches and system change) with the third sub-category (14 domains) referencing staff variables in relation to PBS Process and Practice (e.g., practical use of key behavioural and systems-based approaches within a PBS framework.)

> *"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…"*
>
> *"Increased skills in functional assessment; better quality PBS plans and interventions; greater fidelity in plan implementation; data-based decision making; data-based evaluation of intervention effectiveness."*

The last sub-category in this level comprised 16 domains that concerned the 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."*

> *"Improved job satisfaction…effective coping/support strategies; reductions in stress; reduction in injury; positive involvement in planning for the future"*

Service, Organisation and Locality Systems Level Category

The final level concerned outcome areas that focussed on change or maintenance for whole Service, Organisation and Locality Systems with 38 domains derived from panel member responses, organised within three sub-categories.

> *"For organisation, decreases in staff sickness and turnover, less use of agency staff…less difficulties in recruiting staff, organisational promotion of non-aversive approaches and commitment to no use of punishment of any kind; person-centred values evident in all support."*

Within this level, 10 outcome domains that spanned staff culture, organisational resilience, service size, inspection and stakeholder satisfaction ratings were grouped within a Service, Organisational and Locality Quality sub-category.

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

> *"Team measures of communication and consistency across support teams"*

> *"Inspections (and particularly safeguarding) ...providing services in a local community"*

A further set of 13 domains was identified and grouped within a Service, Organisational and Locality Functioning sub-category that referenced staffing variables (such as turnover, ratios and recruitment), together with items that referenced placement breakdowns, waiting list lengths and community integration.

> *"Cost-benefit analysis…individuals who move to less restrictive settings…staff turnover"*

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

The last sub-category, PBS Systems, brought together 15 domains that related to the presence of strategies and structures to support implementation, development and evaluation of behavioural procedures and other components of a PBS framework across services, organisations and localities.

> *"A clear evidence-based care pathway delivered by staff skilled and trained to deliver it…high quality clinical leadership…high quality Functional Behaviour Assessments and formulation leading to good quality support plans; outcome data in relation to quality of life, reductions in challenging behaviour and carers stress and resilience are routinely gathered and evaluated and feedback to individual services users, families, carers, health care providers"*

Round Two

Individual Level Ratings

Ratings for the Individual Level domains are displayed in Table 1. The vast majority of items within the Quality of Life sub-category (31 of the 33 domains) met the consensus criteria, with a sizeable proportion achieving 100% ratings of highly applicable (six domains) or 100% ratings of applicable or highly applicable (13 domains). Three of the domains that met consensus did however also require clarification (requested by 20% of the panel) (Sensory functioning; Experience of abuse and Experience of aversive, restrictive practices). A further two domains within this subcategory did not meet the consensus criteria (but did meet the clarification criteria): ‘Use of segregated services and institutionalised settings’ (70% of ratings as applicable or highly applicable) and ‘social image’ (50% of ratings as applicable or highly applicable).

Within the Supports Received sub-category, 10 of the 11 domains met the consensus criteria (four of which were rated as highly applicable by 100% of the sample and 3 as applicable or highly applicable). None of the items reaching consensus in this category required further clarification by the required proportion of the sample. ‘Ratio of support/teaching staff to focal person’ did not meet the consensus criteria (rated as applicable/highly applicable by 70% of the panel) but met the clarification criteria at 10%. All four of the domains within the Challenging Behavior sub-category reached the consensus criteria with ‘Frequency, severity, intensity, duration, management difficult and range of challenging behaviours’ rated most highly (highly applicable by 100% of the sample) and no items meeting the clarification criteria.

Table 1: Round Two Ratings for Individual Level

Sub-Category and Domain	Not applicable (%)	Applicable (%)	Highly applicable (%)	Acceptance criteria met (Y/N)?	Required clarification (%)	Clarification Criteria Met (Y/N)?
Quality of Life (Self Determination)						
Choice making and control	0	0	100	Y	0	N
Quality of Life (Family and Interpersonal Relationships)						
Quality of relationships with family and friends	0	0	100	Y	0	N
Number and range of relationships	0	40	60	Y	0	N
Level of contact with preferred people	0	20	70	Y	10	N
Quality of Life (Social Inclusion)						

Community participation, inclusion, integration, presence	0	0	100	Y	0	N
Use of segregated services and institutionalised settings	10	50	20	N	20	Y
Social image	0	30	20	N	50	Y
Quality of Life (Personal Development)						
Adaptive skills, competencies and levels of independence	0	10	90	Y	0	N
Engagement in meaningful activities	0	0	100	Y	0	N
Opportunities for preferred activities	0	10	90	Y	0	N
Opportunities for new activities	0	20	80	Y	0	N
Employment related skills and employment	0	50	50	Y	0	N
Communication and/or social skills (broadly)	0	0	100	Y	0	N
Functionally related communication skills	0	0	100	Y	0	N
Education attainment	10	50	30	Y	10	N
Quality of Life (Physical Wellbeing)						
Physical health status	0	30	60	Y	10	N
Positive health and lifestyle behaviours	0	20	80	Y	0	N
Access to health services	0	30	60	Y	10	N
Mobility	0	50	40	Y	10	N
Sensory functioning	0	40	40	Y	20	Y
Quality of Life (Emotional Wellbeing)						
Psychological, emotional, mental health and wellbeing difficulties	0	20	70	Y	10	N
Positive psychological, emotional, mental health and wellbeing	0	20	80	Y	0	N
Self-management and coping skills	0	10	90	Y	0	N
Access to mental health/support services	0	40	50	Y	10	N
Quality of Life (Material Wellbeing)						
Enrichment of physical environment	0	40	60	Y	0	N
Match between physical environment and individual’s specific needs	0	10	90	Y	0	N
Proximity of accommodation to community	0	60	40	Y	0	N
Proximity of accommodation to family home	0	60	40	Y	0	N
Quality of Life (Rights)						
Safety	0	10	80	Y	10	N
Respect	0	10	90	Y	0	N
Experience of abuse	0	20	60	Y	20	Y
Experience of aversive, restrictive practices	0	0	80	Y	20	Y
Access to advocacy	0	40	50	Y	10	Y
Quality of Support Received						
Staff/caregiver understanding of individuals needs and behaviours	0	0	100	Y	0	N
Staff/caregiver use of positive approaches and adherence to behaviour support plan	0	0	100	Y	0	N
Staff/caregiver use of person-centred approaches	0	0	100	Y	0	N
Quality of relationship with staff/caregiver	0	0	100	Y	0	N
Social validity of interventions received	0	10	90	Y	0	N
Costs of resources and service utilisation	0	80	20	Y	0	N
Ratio of support staff to foal person	20	50	20	N	10	Y
Frequency/risk of placement breakdown	0	10	80	Y	10	N
Stability of team support	0	40	60	Y	0	N
Staff caregiver use if restrictive, aversive practices	0	10	80	Y	10	N

Focal person injury/stress following reactive strategy use	0	10	80	Y	10	N
Challenging Behaviour						
Frequency, severity, intensity, duration and management difficulty and range of challenging behaviours	0	0	100	Y	0	N
School exclusions	0	20	80	Y	0	N
Classroom disruption	10	20	70	Y	0	N
Discipline referrals	10	60	20	Y	0	N

Family Caregiver Mediator Level Ratings

Ratings for the Family Caregiver Level are presented in Table 2. All domains within the Physical, Psychological and Emotional Wellbeing sub-category met the consensus criteria with three domains rated as applicable or highly applicable by 100% of the sample (Stress/psychological/emotional/mental health and wellbeing difficulties; Positive psychological/emotional/mental health and wellbeing and Sleep) but none rated as highly applicable by all members. No items in this sub-category required further clarification.

A total of seven domains met consensus criteria within the Family Quality of Life subcategory, with one rated as highly applicable by all panel members (Quality of family relationships) and three rated as applicable or highly applicable by all members (Family community access; Isolation; Sibling satisfaction, wellbeing and happiness). One item, ‘Marital satisfaction’ did not meet consensus, being rated as applicable/highly applicable by only 70% of the panel (and meeting the 10% clarification rule).

All three domains within the Quality of Relationship with Focal Person sub-category met consensus criteria but only one of these (Quality of relationship with focal person) was rated as applicable/highly applicable by 100% of the sample. Similarly, all five domains in the Quality of Support Received sub-category met criteria for consensus. The ‘Social/ecological validity and contextual fit of family focused interventions’ domain was rated as highly applicable by all members with three further domains rated as applicable/highly applicable by all members (Perceived quality/coordination of support; Satisfaction with training and support received and Stakeholder involvement and co-production). No items in either sub-category required further clarification.

All domains in the final Skills, Knowledge and Attributions sub-category achieved consensus ratings with three rated as highly applicable by 100% of the sample (Confidence/self-efficacy/sense of competence in responding to challenging behavior/supporting family member; Use of positive approaches to respond to relative's challenging behaviour; Understanding of focal person's needs and behaviour/causal attributions). Despite meeting consensus, two domains required clarification at the 20% rule (Use of restrictive, aversive practices to respond to relative's challenging behaviour; Positive parenting practices).

Table 2: Round Two Ratings for Family Caregiver Mediator Level

Sub-category and Domain	Not applicable (%)	Applicable (%)	Highly applicable (%)	Acceptance criteria met (Y/N)?	Required clarification (%)	Clarification criteria met (Y/N)?
Physical, Psychological and Emotional Wellbeing						
Stress, psychological, emotional	0	0	100	Y	0	N
Positive psychological, emotional, mental health and wellbeing	0	0	100	Y	0	N
Self-management and coping skills	0	10	80	Y	10	N
Access to mental health/support services	10	20	60	Y	10	N
Resilience, psychological and social	0	20	70	Y	10	N
Sleep quality	0	30	70	Y	0	N
Injury associated with challenging behaviour	0	0	90	Y	10	N
Family Quality of Life						
Quality of family relationships	0	0	100	Y	0	N
Marital satisfaction	0	40	30	N	30	Y
Family community access	0	20	80	Y	0	N
Isolation	0	20	80	Y	0	N
Sibling satisfaction, wellbeing and happiness	0	10	90	Y	0	N
Family resilience	0	20	70	Y	10	N
Engagement with valued routines/activities	0	10	90	Y	0	N

Opportunities for employment	0	70	20	Y	10	N
Relationship with Focal Person						
Access to/with focal person	0	10	80	Y	10	N
Positive perception of focal person	0	10	80	Y	10	N
Quality of relationship with focal person	0	10	90	Y	0	N
Quality of Support Received						
Perceived quality/co-ordination of support	0	20	80	Y	0	N
Involvement in planning/advocacy/service support	0	30	60	Y	10	N
Satisfaction with training and support received	0	30	70	Y	0	N
Social/Ecological validity and contextual fit of family-focused interventions	0	0	100	Y	0	N
Stakeholder involvement and coproduction	0	10	90	Y	0	N
Skills, Knowledge and Attributions						
Emotional reactions to challenging behaviour	0	10	80	Y	10	N
Confidence, self-efficacy/sense of competence in responding to challenging behaviour/supporting family member	0	0	100	Y	0	N
Perceived management difficulty of challenging behaviour	0	10	80	Y	10	N
Use of positive approaches to respond to relatives challenging behaviour	0	0	100	Y	0	N
Use of restrictive, aversive practices to respond to relatives challenging behaviour	0	10	70	Y	20	Y
Understanding of focal person’s needs and behaviour/causal attributions	0	0	100	Y	0	N
Positive parenting practices	0	20	60	Y	20	Y

Paid Caregiver/Staff Mediator Level Ratings

Ratings for the Caregiver/Staff Level are presented in Table 3. All 10 domains included within the PBS Values sub-category met consensus criteria with a high proportion of these (four domains) rated as highly applicable by 100% of the panel (Commitment and use of person-centered approaches; Commitment to non-use of aversive and restrictive practices: Commitment to increasing adaptive skills and quality of life and Commitment to supporting valued social inclusion). One domain required further clarification based on the 20% rule, whilst being rated as highly applicable by 80% of the sample (Ability to translate values into practice).

Within the PBS Theory subcategory, one domain (Knowledge and understanding of the functional model of challenging behaviour) was rated as highly applicable by all panel members, with all other items (seven domains) meeting consensus criteria and not requiring clarification. Within the PBS Process and Practice sub-category 13 domains met consensus with four rated as highly applicable by all members (Understanding and use of behaviour support plans; Adherence to/use of and implementation of behaviour support plans; Use of positive intervention support strategies; Quality of relationship/rapport with focal person). One item did not meet consensus (scoring 70%) and also required further clarification (at 10%) (Use of aversive, restrictive practices).

All domains within the final sub-category at this level, Wellbeing and Work Performance reached consensus. One domain was rated at highly applicable by 100% of the sample (Training received in PBS/ABA/challenging behavior) with the majority of other items (10 domains) rated as applicable or highly applicable by all members. One item (Resilience) was rated applicable/highly applicable by 80% of members but also required further clarification, meeting the 20% criteria.

Table 3: Round Two Ratings for Paid Caregiver/Staff Mediator Level

Sub-category and Domain	Not applicable (%)	Applicable (%)	Highly applicable (%)	Acceptance criteria met (Y/N)?	Required clarification (%)	Clarification criteria met (Y/N)?
PBS Values						
Ability to translate values into practice	0	0	80	Y	20	Y
Understanding relationships between quality of support, QoL and challenging behaviour	0	10	90	Y	0	N
Understanding a constructive approach to challenging behaviour	0	10	90	Y	0	N
Commitment and use of person centred approaches	0	0	100	Y	0	N
Collaboration with stakeholders	0	20	80	Y	0	N
Commitment to non-use of aversive and restrictive practices	0	0	100	Y	0	N
Commitment to increasing adaptive skills and quality of life	0	0	100	Y	0	N
Commitment to supporting values social inclusion	0	0	100	Y	0	N

Respect and dignity towards focal person(s) and/or vulnerable people more broadly	0	10	90	Y	0	N
Attitudes and beliefs concerning people with IDD more broadly	0	10	90	Y	0	N
PBS Theory						
Knowledge and understanding of PBS framework	0	0	90	Y	10	N
Knowledge and understanding of ABA	0	20	70	Y	10	N
Use of ABA in assessment and intervention and evaluation	0	20	70	Y	10	N
Knowledge and understanding of functional model of CB	0	0	100	Y	0	N
Causal attributions relating to reasons why person engages in challenging behaviour	0	20	80	Y	0	N
Empathy and understanding of life experiences effecting challenging behaviour	0	10	90	Y	0	N
Understanding of system-change strategies	0	40	50	Y	10	N
Knowledge and understanding of complimentary evidence-based approaches in addition to ABA	0	40	50	Y	10	N
PBS Process and Practice						
Understanding and use of functional assessment	0	0	90	Y	10	N
Quality and quantity of functional assessments undertaken	0	10	80	Y	10	N
Understanding and use of behaviour support plans	0	0	100	Y	0	N
Quality and quantity of behaviour support plans undertaken	0	0	90	Y	10	N
Adherence to/use of and implementation of behaviour support plan	0	0	100	Y	0	N
Understanding and use of data to guide decision making	0	0	90	Y	10	N
Understanding and use of evaluation methods	0	0	90	Y	10	N
Use of positive intervention support strategies	0	0	100	Y	0	N
Use of aversive, restrictive practices	10	20	50	N	20	Y
Ratio of proactive to reactive support strategies	0	10	80	Y	10	N
Stakeholder engagement activity and skills	0	10	80	Y	10	N
Appropriate use of risk assessment V risk avoidance	0	0	90	Y	10	N
Quality of relationship/rapport with focal person	0	0	100	Y	0	N
Use of active support principles and strategies	0	10	80	Y	10	N
Wellbeing and Work Performance						
Self-management and coping skills	0	20	80	Y	0	N
Stress/burnout. Psychological/emotional/mental health and wellbeing difficulties	0	20	80	Y	0	N
Positive indicators of Psychological/emotional/mental health and wellbeing	0	20	80	Y	0	N
Injury associated with challenging behaviour	0	10	90	Y	0	N
Leave/sickness relating to challenging behaviour	0	10	90	Y	0	N
Resilience	0	0	80	Y	20	Y
Job satisfaction	0	10	80	Y	10	N
Job role certainty	0	50	40	Y	10	N
CPD goals met	10	60	20	Y	10	N
Quality of working environment	0	40	50	Y	10	N
Involvement in decision making	0	30	70	Y	0	N
Motivation and morale	0	10	90	Y	0	N
Skills in practice leadership	0	30	70	Y	0	N
Use if reflective practice	0	50	50	Y	0	N
Access to supervisor and wellbeing-related support	0	30	70	Y	0	N

Training received in PBS/ABA/challenging behaviour	0	0	100	Y	0	N

Service, Organisation and Locality Systems Level Ratings

Ratings for this level are presented in Table 4. One domain in the Service, Organisational and Locality Quality sub-category did not meet consensus criteria, rated as 70% applicable/highly applicable by the panel (Inspection ratings). No items were rated highly applicable by all members, though four domains were rated applicable/highly applicable by all members (Consistency of practices across teams/services/organisations; Commitment and provision of whole staff training and professional development; Organisational resilience; Service-user/family satisfaction ratings). Two further domains required further clarification (as rated by 20% of the sample) (Service size and proximity to the community; Rates of safeguarding).

Within the Service, Organisational and Locality Functioning sub-category, five domains were rated as applicable/highly applicable by 100% of the panel (Staff turnover; Service/organisational costs; Number of breakdowns; Use of ordinary community facilities by people with IDD; Community awareness and acceptance of people with IDD; Environmental adaptations to community resources to meet needs of people with IDD). No items were rated as highly applicable by all members though a further four domains also met consensus criteria. Three items did not meet consensus and required further clarification (Ease of recruiting staff; Waiting list length; Functioning of teams/services/organisations.)

Finally, within the PBS Systems sub-category, all 15 domains met consensus criteria, with four rated highly applicable by all members (Organisational commitment to non-aversive/positive approaches; Service/organisation-wide approaches to supporting communication, choice and control and skills development; Service/organisation-wide approaches to supporting relationships and stakeholder engagement; Service/organisation-wide systems to support functional assessment and BSP development/implementation). One domain (Use of whole service/organisation reinforcement system) required further clarification, as rated by 20% of the sample.

Table 4: Round Two Ratings for Service, Organisation and Locality Systems Level

Sub-category and Domain	Not applicable (%)	Applicable (%)	Highly applicable (%)	Acceptance criteria met (Y/N)?	Required clarification (%)	Clarification criteria met (Y/N)?
Service /organisation/locality Quality						
Inspection ratings	10	40	30	N	20	Y
Safeguarding	0	40	40	Y	20	Y
Multi-disciplinary team working	0	30	60	Y	10	N
Staff discourse, culture and communication	0	10	70	Y	20	Y
Consistency of practices across teams/services/organisations	0	20	80	Y	0	N
Commitment to provision of whole staff training and professional development	0	30	70	Y	0	N
Organisational resilience	0	80	20	Y	0	N
Service-user/family satisfaction ratings	0	10	90	Y	0	N
Rates and costs of out of area/ATU service provision	10	30	50	Y	10	N
Service size and proximity to community	0	30	50	Y	20	Y
Service/organisation/locality Functioning						
Staff turnover	0	20	80	Y	0	N
Staffing ratios	10	20	60	Y	10	N
Service/organisation costs	0	50	50	Y	0	N
Local service infrastructure	0	40	50	Y	10	N
Appropriate referrals for specialist input	0	20	70	Y	10	N
Use of agency staff	20	20	60	Y	0	N
Ease of recruiting staff	20	20	50	N	10	Y
Number of placement breakdowns	0	20	80	Y	0	N
Waiting list length	20	20	50	N	10	Y
Use of ordinary community facilities by people with IDD	0	20	80	Y	0	N
Community awareness and acceptance of people with IDD	0	30	70	Y	0	N
Environmental adaptations to community resources to meet needs of people with IDD	0	50	50	Y	0	N
Functioning of teams/services/organisations	10	10	60	N	20	Y
PBS Systems						
PBS/functional model to guide practice across service/organisation/locality	0	10	90	Y	0	N
Common language/terminologies of PBS across service/organisations/locality	0	10	90	Y	0	N
Referral structure and systems that support the implementation of PBS	0	10	90	Y	0	N
Practice leadership	0	10	90	Y	0	N
Availability of staff support systems, supervision and debriefing	0	10	90	Y	0	N
Service/organisation wide systems for evaluation and monitoring support	0	20	80	Y	0	N

Implementation of tiered intervention systems	0	20	70	Y	10	Y
Use of whole service/organisation reinforcement system	0	40	40	Y	20	Y
Organisational commitment to non-aversive/positive approaches	0	0	100	Y	0	N
Organisational commitment to person centred values	0	10	90	Y	0	N
Service/organisational wide approaches to supporting communication, choice and control and skills development	0	0	100	Y	0	N
Service/organisational wide approaches to supporting health and wellbeing	0	10	90	Y	0	N
Service/organisational wide approaches to supporting relationships and stakeholder engagement	0	0	100	Y	0	N
Service/organisational wide systems to support functional assessment and behaviour support plan development/implementation	0	0	100	Y	0	N
Service/organisational wide systems for data-based decision making	0	20	80	Y	0	N

Round Two Summary

Overall, 19 items did not meet the consensus criteria and/or required clarification. Of these, six were from the individual level, three from the family caregiver mediator level category, three were from the paid caregiver/staff mediator level category and seven were from the service, organisation and locality systems level category. All 19 items were re-presented to panel members in Round Three.

Round Three

Qualitative data from Round One was initially re-examined to support revised wording of all domains that required clarification and then re-presented to panel members for feedback. Edited domains are presented in Table 5 alongside examples of justifications; queries and challenges raised by the panel in Round Three and the final version that incorporated feedback from panel members in this round. It was notable that all items received support from at least one panel member in the form of general approval:

‘Yes definitely’

‘I am happy with the clarification’

Several items also included supporting statements that provided context or rationale for the outcome area:

‘On-going 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’

Or suggested additional ways of rewording items to support clarification:

‘I think reduction isn’t enough – minimisation?’

‘Job roles, teams and conditions of service and symbolic representation of people with ID make jobs appealing and applications for posts exceed 3-1?’

Finally, challenges to inclusion of an item were made in some instances:

‘It’s a bit indirect as a PBS outcome”

‘This is very ambitions as an outcome PBS can achieve as influenced by many other variables’

Table 5: Revised Wording and Justifications gathered in Round Three

Original Domain	Initial Revised Items	Justification/Supports	Queries/Clarifications	Final revised Item
Individual Level				
Use of segregated services and institutionalised settings	A reduction in the use of services for the focal person that are separated/isolated from the community and do not reflect the principles of normalisation	'Can't achieve valued roles with reduction in segregated services'	'Whilst I'm in favour of normalisation using the term often causes problems'	A reduction in the use of services for the focal person that are separated/isolated from the community and an increase in use of services that support positive inclusion in the community
Social image	The focal person is engaged in activities and roles that are regarded positively within the cultural context	'It should be included because PBS is about implementing a value base derived from SRV' 'Also, increase in positive or socially valued behaviours will positively impact social image'	None	The focal person is engaged in activities and roles that are regarded positively within the cultural context to support a positive social image
Sensory functioning	The focal person's sensory needs (hearing and sight) are supported appropriately	'Agree'	'Would this be more than just hearing and sight?	The focal person's sensory needs (hearing, sight and all other principle functional domains) are supported appropriately
Experience of abuse	The focal person is not exposed to any forms of abusive behaviour. The focal person who has previously been exposed to abusive behaviour is supported appropriately	'Yes'	'Are these either/or? I think both need to be included' 'Person is free from abuse and abusive practices'	Person is free from abuse and abusive practices. The focal person is not exposed to any forms of abusive behaviour and a focal person who has previously been exposed to abusive behaviour is supported appropriately

Experience of aversive, restrictive practices	The focal person is not exposed to any forms of aversive / restrictive practice. Focal person who has previously been exposed to aversive/restrictive practice is supported appropriately	‘Yes’	‘Are these either/or? I think both need to be included’ ‘Person is free from aversive, restrictive practices’	Person is free from aversive / restrictive practices. The focal person is not exposed to any forms of aversive / restrictive practice and a focal person who has previously been exposed to aversive / restrictive practice is supported appropriately
Ratio of support/teaching staff to focal person	The ratio of support / teaching staff is appropriate to the focal person’s needs. There is a reduction in the ratio of teaching / support required to appropriately support the focal person in relation to quality of life and behaviour that challenges	‘Yes to first sentence’	‘I think the ratio of support needs to be appropriate to the person’s needs but I am not sure that the aim should always be to reduce the ratio’	The ratio of support / teaching staff is appropriate to the focal person’s needs.
Family Caregiver Mediator Level				
Marital satisfaction	Partner satisfaction. Family caregiver’s satisfaction with quality of their relationship with partner	‘Family relationships are often strained by the presence of challenging behaviours’	‘This is very ambitions as an outcome PBS can achieve as influenced by many other variables’	Support and behaviour needs of focal person do not impact on family caregiver’s satisfaction with quality of their relationship with partner
Use of restrictive, aversive practices to respond to relative’s challenging behaviour	A reduction in the use of restrictive/aversive practices by caregivers (reduced use of reprimands, restraint, time out etc.)	‘Yes definitely’	‘Do we need absence rather than reduction’	Minimisation the use of restrictive/aversive practices by caregivers (reduced use of reprimands, restraint, time out etc.)

Positive parenting practices	An increase in positive parenting practices (where focal person is a child in family home) such as use of behaviour specific praise and reinforcement	‘Yes definitely’	None	An increase in positive parenting practices (where focal person is a child in family home) such as use of behaviour specific praise and reinforcement
Paid Caregiver/staff Mediator Level				
Ability to translate values into practices	Staff members can articulate and demonstrate example of their own behaviour that are consistent with PBS values when supporting focal person/people (how to support choice making effectively for instance)	Agree	None	Staff members can articulate and demonstrate example of their own behaviour that are consistent with PBS values when supporting focal person/people (how to support choice making effectively for instance)
Use of aversive, restrictive practices	A reduction in use of aversive, restrictive practices by staff (restraint, seclusion, time out)	‘Yes definitely’	‘I think reduction isn’t enough – minimisation?’	Minimisation in use of aversive, restrictive practices by staff (restraint, seclusion, time out)
Resilience	Staff are able to manage demands of their role and maintain positive wellbeing over the long terms even when recognising challenges to this	‘Good’	None	Staff are able to manage demands of their role and maintain positive wellbeing over the long terms even when recognising challenges to this
Service, Organisation and Locality Systems Level				
Inspection ratings	Inspection ratings demonstrate an improvement in quality indicators that are consistent with	‘Implementation of PBS leads to better quality services which should be apparent in any inspection’	‘It’s a bit indirect as a PBS outcome’	Inspection ratings demonstrate an improvement in quality indicators that are consistent with components

	components of a PBS framework			of a PBS framework
Staff discourse, culture and communication	Staff communication and culture reflects values of a PBS framework (respectful, non-blaming, encouraging, etc.)	‘Agree’	‘Vocabulary, labelling and forms of address?’	Staff communication and culture reflects values of a PBS framework (vocabulary, labelling and forms of address that are respectful, non-blaming, encouraging, etc.)
Service size and proximity to community	The service size and proximity to the community reflects principles of normalisation and social inclusion (small, individualised and embedded within the community)	‘Yes definitely’	None	The service size and proximity to the community reflects principles of SRV and social inclusion (small, individualised and embedded within the community)
Ease of recruiting staff	It is easy to recruit staff to the organisation –people want to work there. Lots of people apply for positions that are advertised	‘I am happy with the clarifications’ ‘On-going challenging behaviour leads to poor morale and difficulty in recruitment of staff’	‘Job role, terms and conditions of service and symbolic representation of people with ID make jobs appealing and applications for posts exceed 3-1?’	It is easy to recruit staff to the organisation –people want to work there. Lots of people apply for positions that are advertised. Job role, terms and conditions of service and symbolic representation of people with ID make jobs appealing and applications for posts exceed 3-1?’

Waiting list length	Waiting lists for PBS services are managed effectively and support timely access to appropriate support	‘Well implemented PBS means that there is less likely to be crises occurring throughout an organisation; this therefore results in proactive implementation of PBS, systematically training staff over times in a panned way – with less emphasis on fire fighting.’	‘I don’t think this is an outcome’	Waiting lists for PBS services are managed effectively and support timely access to appropriate support
Functioning of teams/services/organisation	Not re-worded	‘PBS practices have a positive impact on a whole organisation, as they are based on person-centred approaches. At a service-level, the impact of PBS is to create a more pleasant working environment and better functioning team’	‘Team collaboration should improve?’	Collaboration, team working, team communications and team relationships are improved’
Use of whole service/organisation reinforcement system	In the context of a school, the use of a school-wide reinforcement system of set of principles is used (consistent with models of school-wide PBS)	‘Yes but I think this is specific to school-wide PBS as stated’	None	In the context of a school, the use of a school-wide reinforcement system of set of principles is used (consistent with models of school-wide PBS)

Round Four

The vast majority of re-presented items (17 of the 19 domains) achieved the consensus criteria during this round with 10 rated as applicable or highly applicable by 100% of members (Table 6). Two domains did not meet the consensus criteria. This comprised one domains from the Family Caregiver Mediator level category (Support and behaviour needs of the focal person do not impact on family caregiver’s satisfaction with quality of their relationship with partner) which was rated as applicable/highly applicable by 66.6% of members, and one item from the Service, Organisation and Locality Systems level (Waiting lists for PBS services are managed effectively and support timely access to appropriate support) which was rated applicable/highly applicable by 77.7% of members. The final set of domains is provided in appendix 3.

Table 6: Ratings in Round Four

Revised Domain	Not applicable (%)	Applicable/highly applicable (%)	Consensus criteria met?
Individual Level			
A reduction in the use of services for the focal person that are separated/isolated from the community and an increase in use of services that support positive inclusion in the community	0	100	Yes
The focal person is engaged in activities and roles that are regarded positively within the cultural context to support a positive social image	0	100	Yes
The focal person’s sensory needs (hearing, sight and all other principle functional domains) are supported appropriately (n = 8 for this item)	12.5	87.5	Yes
Person is free from abuse and abusive practices. The focal person is not exposed to any forms of abusive behaviour and a focal person who has previously been exposed to abusive behaviour is supported appropriately	11.1	88.9	Yes
Person is free from aversive / restrictive practices. The focal person is not exposed to any forms of aversive / restrictive practice and a focal person who has previously been exposed to aversive / restrictive practice is supported appropriately	0	100	Yes
The ratio of support / teaching staff is appropriate to the focal person’s needs.	11.1	88.9	Yes
Family Caregiver Mediator Level			
Support and behaviour needs of focal person do not impact on family caregiver’s satisfaction with quality of their relationship with partner	33.3	66.6	No
Minimisation the use of restrictive/aversive practices by caregivers (reduced use of reprimands, restraint, time out etc.)	11.1	88.9	Yes
An increase in positive parenting practices (where focal person is a child in family home) such as use of behaviour specific praise and reinforcement	0	100	Yes
Paid Caregiver/Staff Mediator Level			
Staff members can articulate and demonstrate example of their own behaviour that are consistent with PBS values when supporting focal person/people (how to support choice making effectively for instance)	0	100	Yes
Minimisation in use of aversive, restrictive practices by staff (restraint, seclusion, time out)	0	100	Yes
Staff are able to manage demands of their role and maintain positive wellbeing over the long terms even when recognising challenges to this	0	100	Yes
Service, Organisation and Locality Systems Level			

Inspection ratings demonstrate an improvement in quality indicators that are consistent with components of a PBS framework	11.1	88.9	Yes
Staff communication and culture reflects values of a PBS framework (vocabulary, labelling and forms of address that are respectful, non-blaming, encouraging, etc.)	0	100	Yes
The service size and proximity to the community reflects principles of SRV and social inclusion (small, individualised and embedded within the community)	11.1	100	Yes
It is easy to recruit staff to the organisation –people want to work there. Lots of people apply for positions that are advertised. Job role, terms and conditions of service and symbolic representation of people with ID make jobs appealing and applications for posts exceed 3-1?'	11.1	88.9	Yes
Waiting lists for PBS services are managed effectively and support timely access to appropriate support	22.2	77.7	No
Collaboration, team working, team communications and team relationships are improved'	0	100	Yes
In the context of a school, the use of a school-wide reinforcement system of set of principles is used (consistent with models of school-wide PBS)	0	100	Yes

Discussion

Overview

The aims and practices of PBS are broad and intrinsically related to person-centred values and a developmental, functional and contextual theory of behaviour (Gore et al., 2013). Whilst PBS has evolved to support people with IDD who are at risk of CB, the framework (at least at a conceptual level) concerns outcomes and mechanisms of change that relate to multiple variables beyond this focus. Fundamentally, PBS concerns the promotion of sustainable support across systems for individuals with IDD and other stakeholders that facilitate positive repertoires of behaviour and life quality (Carr et al., 2002; Horner et al., 1990). Reduction in CB is targeted and anticipated within this context, as a secondary rather than pivotal outcome of change.

PBS research has however, typically focussed on a smaller range of outcomes, with primary focus on reductions in dimensions of CB, generally accompanied by demonstrated increases in alternative or adaptive behaviours of some form. With few exceptions (e.g., Kincaid et al., 2002; Bowring et al., 2019) less attention has been systematically paid to evaluation of life quality or other changes for people with IDD, outcomes for other stakeholders or outcomes that demonstrate systems-level change following delivery of PBS. This study therefore aimed to create a consensus-based outcomes framework for evaluation in research and practice that corresponded more closely to the values, theory and practices of PBS, using a Delphi-panel method.

Findings and Relation to Prior PBS Literature

Individual Level Outcomes

Though not the primary goal for PBS, positive change with regards the occurrence of CB is critical to the framework and domains in this area were clearly identified as such by the panel. Domains within the Challenging Behaviour sub-category at the Individual level, included known impact for such behaviour in particular contexts, such as school exclusions for children with IDD, but also more global reductions in directly observable dimensions of such behaviour (frequency, severity, intensity, duration and management difficulty), reflective of the key definitional features of CB (Emerson, 2001).

Recognition of a variety of ways in which CB change may be demonstrated appeared helpful given the broad range of behavioural topographies and severities with which PBS is utilised (Carr et al., 1999; Lavigna & Willis, 2012). Items within this sub-category also made connection to the social-contextual features of CB (i.e., impact and management difficulty) thus forming helpful links to PBS principles more generally. The full range of impacts associated with CB, and central to the conceptual goals of a PBS framework were then reflected in the further domains at the Individual (and other) level(s).

Panel members recognised the centrality of QoL as an outcome area for individuals with IDD within PBS but also its multidimensional nature with respect to eight key categories, with each of these reflected in further outcome domains. The domains identified in this area corresponded well with those established through broader consensus in the field (Schalock et al., 2002). Previous examples of systematic evaluation of QoL outcomes in PBS also took a multidimensional perspective, with Fox and Emerson (2010) covering the same eight domains and Kincaid et al. (2002) including five of these (physical wellbeing; material wellbeing; social wellbeing; development and activity and emotional wellbeing).

Given the foundational association between CB and QoL in the conceptual model and framework of PBS, strong support for this category was understandable and encouraging. Consensus was readily established for the vast majority of items, with a small number of exceptions. This included two items both categorised as Rights that concerned ‘Experience of abuse’ and ‘Experience of aversive, restrictive practices’ and required further clarification before reaching consensus in round 4. Clarity here concerned both the anticipated reductions in these areas and the experience of supportive actions and systems for those who had previously experienced aversive, restrictive or abusive actions.

Quality of Life measurement for people with IDD (Fox & Emerson, 2010; Shalock et al., 2002) more commonly includes items such as civic rights, citizenship, privacy and respect within a rights category. Whilst some of these items were included by panel members, it is of interest that the Aversive/restrictive practices and Abuse domains were also categorised in this way. PBS explicitly commits to using non-aversive practices within intervention and to limit/reduce any such practices where they already exist (Gore et al., 2013; Lavigna & Willis., 2012). People with IDD who display CB are also known to be highly vulnerable to abuse and there is an emerging literature concerning trauma, CB and functional approaches (Keesler & Isham, 2017). Considering both of these areas as rights-based is a potentially helpful way of highlighting their unquestionable significance.

Following CB, adaptive and alternative skills are most generally reported as outcomes in PBS related research (Clarke & Dunlap, 2008; Clarke, Zakszeski & Kern, 2018; Conroy et al., 2005; LaVigna & Willis, 2012; O'Dell et al., 2011). Interestingly, in this study, participant responses associated with these areas did not lead to a specific sub-category. Several items were however included under the QoL Personal Development sub-category (e.g., Functionally related communication skills; Communication and/or skills broadly) and the Emotional Wellbeing sub-category (e.g., Self-management and coping skills) that did fundamentally correspond to adaptive and alternative repertoires of behaviour. Again, there appear to be some conceptual strengths to embedding these items within the broader context of QoL enhancement that may communicate helpful key messages within the PBS field.

Finally, in relation to the QoL items at the Individual Level the further comments of panel members recognised inter- and intrapersonal variability inherent in QoL measurement that has also been established as a defining conceptual feature elsewhere (Schalock et al., 2002). Participants highlighted that whilst all dimensions were within scope for change, the relative value of a domain would be both individually and contextually dependent. This finding is further explored with regards to future research in the final section of the discussion.

The last sub-category at the Individual Level concerned Support Received. Panel members identified several outcome areas that referenced the appropriateness and quality of the support environment and arrangements for a focal person with IDD. Again, intervention and strategy within PBS typically focus on creating supportive or 'capable' (McGill et al., 2020; McGill et al., 2018) environments that promote optimal life quality, and reduced risk of CB and so this was of high value. Fox and Emserson (2010) also included some items relating to these areas within their tool, but in the current study these were more expansive, with 11 items identified that related to the quality of care staff support and arrangements pertinent to the individual’s specific needs in this way (in addition to multiple other outcome levels at other levels of the support system).

Family Caregiver Mediator Level Outcomes

The impact of CB on caregivers of people with IDD is widely recognised (Dunlap & Fox, 2009/2007; Gore et al., 2014; Lucyshyn et al., 1997) and given calls within the PBS community to include more routine measurement of family outcomes, identification of items at this level was well justified and helpful. Fox and Emerson (2010) included nine items that concerned personal supports within a family context. In the current study, 30 domains that reached consensus were identified at this level.

Family caregivers are known to be at increased risk of stress and emotional difficulties (Baker et al., 2003; Hastings, 2002a; Woodman, Mawdsley & Hauser-Cram, 2015) when supporting a family member who displays CB and this was clearly represented in outcomes that formed the Physical, Psychological and Emotional Wellbeing sub-category. This included outcomes that corresponded to experience of difficult and positive mental states and the development of strategies and receipt of services to safeguard wellbeing. All of these areas have been widely researched and used as a basis for intervention within the broader IDD literature (Blackledge & Hayes, 2006; Gavidia-Payne et al., 2015; Neece, 2014; Reid, Gill, Gore & Brady, 2014), though far less commonly within the field of PBS explicitly.

Building on consideration of QoL at the Individual level, panel members also identified a variety of items that taken together related to family life quality. Prior conceptions of Family Quality of Life (FQoL) (e.g., Summer et al., 2005) have highlighted five general domains of importance: Family Interaction; Parenting; Emotional Wellbeing; Physical/Material Wellbeing; and Disability Related Support. Within the current study, the

FQoL sub-category focussed largely on family relationships (with one item relating to quality of relationships between spouses not reaching consensus), activities, community access and employment. Other domains identified in the FQoL literature were typically included elsewhere as part of another subcategory. Significantly, emotional and physical wellbeing was covered in the previously discussed wellbeing sub-category, with parenting (at least to some degree) and disability-related support further reflected within the Skills, Knowledge and Attributions and Quality of Support Received sub-categories.

A total of five outcome domains were generated that concerned the quality of supports received, at a family level, as part of PBS. These items had a different focus to the Support Received domains highlighted for individuals with IDD in that they corresponded to the needs, perspectives and experiences of family caregivers. This included both outcomes for caregivers in their own right (e.g., Satisfaction with training and support received) but largely those that concerned their role as mediators of support for their relative (e.g., Stakeholder involvement and co-production; Social validity, ecological validity and contextual fit of family focused interventions).

A further seven domains were categorised in terms of Skills, Knowledge and Attributions of families in the context of providing care and support for their relative with IDD. This included general positive parenting practices that corresponded to the parenting FQoL domain identified by Summers et al. (2005) and broader IDD behavioural literature (Totsika et al., 2014). It also included particular reference to support strategies that would be consistent with use of PBS (e.g., reduced use of restrictive and aversive practices), thus providing a helpful link to key elements of the framework beyond those captured in more general QoL measurement systems.

Finally, this level also included a small sub-set of items that were categorised as outcomes that focussed on the quality of relationship between the family and the focal person. This area is not really apparent in the FQoL domains discussed thus far but potentially of strategic significance for PBS and conceptually consistent with some of what is known regarding people with IDD and families in other literature. In the UK in particular, there is recognition at a research and policy level that people with IDD who display CB are often placed in institutions where contact with family becomes limited (either due to the geographical distances involved or other access barriers). Focussing on outcomes that concern access between caregivers and their relative with IDD is therefore clearly relevant as a goal for PBS. Other items in this sub-category concerned caregivers' perceptions of their relative and the quality of relationship. Here it is noted that child-related IDD research (Totsika et al., 2014) has demonstrated the centrality of these kind of relationship-based variables for caregivers in the context of parenting and these are also of relevance to families supporting adults with IDD (Hatton et al., 1999).

Paid Staff Mediator Outcomes

The PBS Competencies Guide for the UK (as described in Chapter Two) is structured to highlight the central roles and needs of frontline and other direct staff within organisations. This was correspondingly reflected in the 48 outcomes panel members attributed to stakeholders at this level of the system. Fox and Emerson (2010), identified a smaller subset of items that had some connection to staff when individuals are supported in group homes or supported living (nine items). The majority of these corresponded to the quality of support staff provided to an individual with IDD with only one item clearly associated with an outcome for staff members themselves (a reduction in injuries received by staff).

In this study, a total of eight outcome domains were categorised in terms of wellbeing (e.g., Self-management/coping skills; Stress and burnout) and work performance factors (e.g., Sick leave; Job satisfaction) that related directly to personal outcomes for staff themselves. There is a significant body of research that has highlighted the emotional support needs of staff in services for people with IDD and so this appears well justified. Whilst it is often unclear whether staff supporting people who display CB are at *increased risk* of experiencing stress and burnout (Hastings, 2002b; Howard, Rose & Levenson, 2009; Rose, 1995), the negative consequences of this when it does occur have been recognised (Lawson & O'Brien, 1994; Thomas & Rose, 2010).

Principally, the wellbeing of individual staff is likely to influence their interactions with colleagues and those they support which may create non-optimal environments. Consequently, a small body of research has arisen (Baker & Gore, 2019; Hastings, 2018; Smith & Gore, 2012) that has sought to develop effective wellbeing interventions for staff in services that support people with IDD whose behaviour challenges. Support for staff wellbeing has also been referenced as an appropriate and often necessary component of behavioural support plans within PBS (e.g., Singh, 2015). Monitoring (more routinely) outcomes in these areas is therefore of significance.

The remaining three sub-categories within this level concerned PBS competencies demonstrated by staff. This included both competencies that related principally to PBS Values (e.g., A commitment and use of person centred values; Respect and dignity towards focal person(s) and/or vulnerable people more broadly); Theory (e.g., Knowledge and understanding of functional model of challenging behaviour) and practices or Process central to PBS delivery (e.g., Quality and quantity of functional assessments undertaken). These categorisations readily map onto the structural definition of a PBS framework proposed for the UK (Gore et al., 2013) that is further developed within the PBS Competencies Guide.

Again, a significant body of research (particularly in the context of staff training; MacDonald & McGill, 2013) has attempted to evaluate changes in staff attitudes, knowledge and (to a lesser degree) behaviour associated with key elements of PBS. Attribution-based models formulating interactions between staff and people with IDD (alongside those concerning staff stress and emotional factors) have also been well represented in the general IDD literature (Baker, 2017; Hastings & Brown, 2002) and so these categories appear to be built on firm foundations.

Service, Organisation and Locality Systems Level Outcomes

PBS explicitly calls for assessment and intervention at the level of support systems, in recognition of the multiple social and contextual variables influencing CB. There have been some helpful formulations of these elements of PBS (e.g., Allen et al., 2013) but with some notable exceptions (e.g., McGill et al., 2018) few demonstrations of PBS actually being utilised in this way. There is a related literature concerning implementation and evaluation of other behaviourally orientated support programmes at an organisation/systems level. These include Person Centred Active Support, which concerns staff and organisation approaches to maximising engagement for people with IDD (Jones et al., 2009). Some have posited that these kind of approaches sit well within a general preventative strategy for PBS, concerning the structuring of enabling environments (McGill et al, 2018; McGill et al 2020). The need to increase ways of utilising and evaluating systems-level change for PBS is recognised as a priority (Denne et al., 2020) and is arguably of increased significance in the context of considering PBS implementation at the national level.

Systems-level outcomes were not reflected in those proposed by Fox and Emerson (2010), which, as discussed previously, focussed on outcomes following implementation of PBS for individual cases. Identification of 37 outcome domains (with one further domain not reaching consensus) concerning systems-level change following implementation of PBS by whole services, organisations or localities was therefore a definite strength of the current study. Outcomes identified in this regard included those that concerned indicators of well-functioning and quality teams (suggestive of PBS occurring at the systems-level) and evidence of systems and processes that would be associated with continued implementation and development of PBS.

Limitations

Overall, the method of delivery and recruitment strategy for this study worked well. Whilst Delphi-Panel sizes can vary considerably, panels of 10-15 are considered common and sufficient. To a large extent the panel size was also reflective of the relatively small number of potential members in the UK, where PBS research is a relatively small field. Panel members were drawn from across the UK, which was a definite strength, in addition to having recognised expertise in PBS, evidenced by membership of SF-DDARIN and other key professional networks (e.g., the PBS Academy).

The facilitation of the Delphi-process by distance via the internet also appeared to work well for the most part. Panel members were able to complete responses without incident and with anonymity maintained in this context. There were however, some caveats to this general success. Firstly, during some rounds there was a delay in data return. Despite being set a deadline for completion, participants often requested some additional time, which was typically granted. This was not possible in the final round (owing to time constraints to complete the study) when panel size reduced a little. Secondly, there was slight variation in panel membership across rounds, which again indicated some data and process limitations, though members that participated in the final round had all taken part in subsequent rounds.

Other authors have also noted that whilst having many benefits, use of the internet within Delphi studies can sometimes pose data-return issues (Helms et al., 2017).

It might be further questioned whether prior relationships and collaborations between panel members was a limitation to the study. Notably, several of the panel members had previously collaborated to create PBS resources and as a network continued to share ideas and discuss concepts pertinent to PBS. Here it could be argued that prior engagements between panel members reduced the overall possibility to generate novel ideas that had not previously been considered. It could also be possible that participants recognised the style of comments or type of concepts provided in responses by other panel members, threatening the anonymity of the panel.

Whilst its was however, certainly the case that some panel members had a history of prior engagements and group collaborations, by drawing on the authors professional networks outside of SF-DDARIN it was also possible to recruit one member where this was not the case. More so, the potential to build on the prior work and discussions of those involved in SF-DDARIN and the PBS-Academy provided a prime opportunity to ensure a consistent approach to outcome generation that reflected definitions, competencies and principles previously established for the UK and so in many ways reflected a strength of the work.

Consensus was generated across the four rounds of this study and for many items reached at an early stage. The panel, overall, appeared satisfied with the initial thematic structure and categorisation of items following Round One and of the 164 items identified all but 19 met the consensus criteria. Following further refinement and argument in relation to items in Round Three, all but two (162) met consensus criteria in the final round. In this light, the 80% (of ratings as acceptable or highly acceptable) criteria might be considered a little lenient, with a higher percentage-based rule being better suited to discriminating responses.

Delphi-studies do however, frequently take an 80% cut-off and the intention of the current study was to prompt generation of a wide pool of outcome areas, rather than limit or prioritise within these. In addition, it was apparent that consensus was often achieved at rates higher than 80%, with 100% agreement being reported for at least some items in most categories.

Finally, the initial Round One questions appeared to function well in their aim of encouraging participants to reflect broadly. This included consideration of different contexts and delivery modes for PBS but also a consideration of the perspectives of different stakeholder groups with regards outcome priorities. Panel members were all experienced in working with different stakeholders, and researching and advocating for their needs, rights and strengths and so well placed to make these considerations. It is however, recognised that this was not the same as asking or engaging directly within these stakeholder groups and that items generated in this study fundamentally concerned the perspectives of researchers. A response to this particular limitation is addressed latter in the discussion.

Conclusions and Next Steps for the Thesis

Chapter Two established the fundamental importance of a skilled workforce to support high quality delivery of PBS and identified a particular need to support competencies in areas of evaluation and outcome monitoring for practitioners in the UK. At the same time, literature reviews have included recommendations that future PBS research addresses a broader range of outcome measurements. In particular, the need to consider routine measurement beyond CB at an individual and family level, and to consider outcomes for systems-level intervention, has been a reoccurring theme as described previously. This study provided a useful first step in developing a framework for the evaluation of PBS that corresponded to the breadth of outcome areas central to values and evidence based practice. Further clinical and research implications of this work are discussed in the final chapter of the thesis.

The current study relied on detailed consultation with a relatively small and homogenous participant sample (typical of the Delphi-panel methodology). Engaging specifically with researchers and PBS professionals was a useful first strategy but there is also a pressing need to gauge the views and perspectives of a wider-range (and number) of stakeholders. The current study prompted consideration of multiple stakeholder groups but this is not equivalent to direct participation. Further research is therefore required that focuses on involvement of other professionals, family caregivers, and people with IDD themselves (an aspiration that is also recognised in Research Question Two for this thesis: ‘How can stakeholder engagement be maximised to enhance support for children with IDD and their families?’)

Whilst some greater stakeholder engagement was afforded in a subsequent study by Gore et al. (2020) to develop a core set of outcome domains for PBS (detailed in Chapter Eight, with domains provided in appendix 4), a further research question concerns ways that those for whom PBS delivery is focussed identify and select personally meaningful outcome areas. This includes family caregivers and people with IDD as prompted within Round One by panel members, yet little research has concerned exactly how stakeholders might best be supported and engaged in outcome selection procedures. Chapters Four and Five therefore respond to this limitation and explore the development and utility of a novel interview method to support PBS goal and outcome selection for family caregivers and children and young people with IDD.

Chapter Four: Making it Meaningful: Caregivers Goals and Priorities for PBS[4]

Overview

In recognition of both the limited scope of outcome measurement in prior research, and the particular need to support practitioners in evaluation-based competencies, Chapter Three utilised a consensus building approach to develop a Positive Behavioural Support (PBS) outcomes framework. The framework had several strengths in that it reflected the needs and perspectives of multiple stakeholder groups and comprised a broad range of outcome domains of relevance to PBS evaluation across different contexts and levels of a support system. It was however, noted that further work should be afforded to support direct engagement in outcome selection with stakeholders for whom PBS is the most direct focus, with particular recognition of people with Intellectual and Developmental Disabilities (IDD) themselves and family caregivers.

In response to these conclusions, and with direct relevance to Research Question Two ('How can stakeholder engagement be maximised to enhance support for children with IDD and their families?'), this chapter reports on a study that aimed to explore a method, and the process, of engaging family caregivers to identify individualised, personally-meaningful goals for their child's PBS. A related study concerning goal-selection by children with IDD is reported in Chapter Five. By considering use of the identified procedures as part of a clinical pathway, these studies also respond to Research Question Three ('How can proactive support for children with IDD and families be enhanced in the early years?')

Within a data-based intervention, goals and outcomes should be closely linked, with selection of goals determining the focus of support and monitoring and evaluation of

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[4] A version of this chapter has subsequently been published: Gore, N.J., McGill, P., &Hastings R.P. (2019). Making it Meaningful: Caregiver Goal Selection in Positive Behavioural Support. *Journal of Child and Family Studies, 28*(6), 1703-1712

outcomes aligned to both prompt and test the extent to which targets are achieved (LaVigna, & Willis, 1992). Goldiamond (1974) (in discussion of the constructional approach which forms part of the philosophical basis for PBS as discussed in Chapter One), argued that if individuals themselves are helped to identify the focus for their support they are most likely to pick those areas where change would make a meaningful difference, that fit with their circumstances and be motivated to engage in related strategies. Very little PBS or behaviourally orientated research has, however, been conducted to support stakeholders in this regard. In practice, it is therefore possible that the focus for support is often selected or influenced by someone other than the person who will be receiving that support, thus reflecting *their* needs and priorities and demands, rather than those of the individual(s) in question.

Introduction

Background

Positive Behavioural Support for people with IDD increases skills and opportunities and alters environments in accordance with individual needs and aspirations, to increase Quality of Life (QoL) and reduce occurrence or impact of behaviours that challenge (CB) over the long term (Carr et al., 2002; Horner et al., 1990; Gore et al., 2013; Kincaid, et al., 2016). PBS strategies should therefore be highly individualised, rich in ecological validity and linked to socially and personally meaningful outcomes (Carr 2007; Carr et al., 2002; Gore et al., 2013).

To support these principles, PBS demands close collaboration between clinicians and other stakeholders (Albin et al., 1996; Carr et al., 2002; Dunlap et al., 2008; Gore et al., 2013; Luchyshyn et al., 2007; Lucyshyn et al., 1997; McLaughlin et al., 2012). In the case of children, this typically means working in partnership with family caregivers as informants for assessment and agents for behaviour change since they are likely to know the child best, be experiencing the impact of behaviour that challenges most keenly, and be highly motivated to invest in positive change strategies (Dunlap & Fox, 2009/2007; Gore, et al., 2014; Luchyshyn et al., 1997). The behaviour of caregivers is also frequently interconnected with that of their child (Gore, Brady & Hastings, 2014; Guralnick, 2017; Hastings et al., 2013) and will therefore need to be considered in assessment and behaviour support planning at a systems level.

There has been a growing body of family-focused PBS research over the past three decades, (e.g., Durand et al., 2012; McLaughlin et al., 2012), with 20 single case studies known as of 2015 (see Lucyshyn et al., 2009) and others having followed since (e.g., Chu, 2015; Lucyshyn, Miller, Cheremshynski, Lohrmann & Zumbo, 2018). In addition to the other core features of PBS, and drawing on eco-cultural theory (as outlined in the first chapter to this thesis), this body of literature places particular emphasis on the critical role of families. Within family-centred PBS, caregivers are viewed as co-collaborators (Dunlap et al., 2001; Minke & Anderson 2005) when planning, designing and implementing systems of support T(Wang, McCart & Turnbull 2007). The majority of these studies have however, been conducted in non-UK countries. Whilst partnership working with family stakeholders is also a key component of the UK definition of PBS, in practice, in the UK, caregivers supporting children with disabilities who display CB, still largely report feeling marginalised, ill-informed, and not listened to (Griffith & Hastings, 2013; James, 2012; Mitchell & Slopper, 2001). Enhancing efforts in this area is therefore paramount, for UK research, with stakeholder engagement required at all stages of a PBS pathway if support is to be fully aligned with the needs, aspirations and life quality of individuals and families.

The initial identification of goals for support, prior to functional assessment and intervention would seem to mark the earliest clinical encounter between practitioners and families in a PBS pathway. Meetings and interactions during this period might well serve to set the scene for working relationships and determine the strength of joint planning that follows. In the general mental health literature, idiographic goal planning tools used at these times and to establish outcomes for later evaluation are typically valued by professionals and families for such reasons (Ebrooke-Childs, Jacob, Law, Deighton, & Wolpert 2015; Fuggle et al., 2016; Jacob, Edbrooke-Childs, Holley, Law & Wolpert, 2016; Mulligan, John Coombes & Singh, 2014) and recommended for use in all Child, Adolescent and Mental Health Services in the UK (Law, 2011; Wolpert et al., 2012). Although collaborative goal selection is intended as a key feature of PBS during intervention, little research attention has been given to the empirical study of goal selection in collaboration with key stakeholders.

Limited research in this area contrasts considerably with the strong emphasis afforded to collaborative goal selection in early constructional approaches to behaviour change that underpin PBS. In particular, ‘The Constructional Questionnaire’ (Goldiamond, 1974) was developed to support individuals to select and work towards positive behavioural change in line with personally valued life areas most likely to support contact with naturally occurring sources of reinforcement. Whilst conceptual accounts of PBS frequently reference constructional approaches (Gore et al, 2013; LaVigna & Willis, 2012), use of the Constructional Questionnaire is largely absent in contemporary PBS research and few practical tools have been developed that utilise corresponding principles to support goal selection.

One exception to this trend has been the development of ‘Positive Goals for Positive Behavioural Support’ (PGPBS) by Fox and Emerson (2010; 2001), a goal-based outcome tool that allows selection from 38-items relating to key QOL domains (Schalock, 2002), adaptive skills and other outcomes theoretically achievable via delivery of PBS. The tool appears clinically valuable, but again there are no recorded uses of it within research, beyond a small-scale pilot study assessing basic psychometric properties (Fox & Emerson 2001).

Most notably, whilst the tool provides a useful set of possible goal areas, little is known about the way in which caregivers select from amongst these to generate unique goals and the factors that influence this. Since implementation of goal-based tools would occur within the context of early engagement and relationship development, consideration of these features appears fundamental for effective practice.

Initiating and sustaining engagement with stakeholders necessitates development of a relationship that family-centred practice defines as mutually respectful, trusting and honest (Dunst et al., 1994). Here, quality of parent-professional relationships has been found to mediate interactions between service provision and family QoL (Summers et al., 2007) and so in turn would be predicted to mediate the effectiveness of goal selection procedures. In particular, responding appropriately to caregivers' emotional needs appears critical to the success of family-professional partnerships (Brotherson et al., 2010; Dempsey et al., 2009; Dunlap & Fox, 2007) and good quality CB support more broadly (Crnic et al, 2017; Local Government Association & NHS England, 2014). Challenging behaviour greatly increases the risk of emotional difficulties for caregivers (Baker et al., 2003; Hastings, 2002; Woodman et al., 2015) and is likely to be having greatest impact around the time families are first seeking support from services. Ensuring a combination of sensitive, interpersonal support and effective goal selection methods during these first encounters is therefore called for.

Study Aims

This study drew on domains that corresponded to the individual and family caregiver mediator levels of the outcomes framework developed in Chapter Three and other relevant measures in the literature to develop a new method of goal selection and investigate its use with caregivers of children with IDD. The study aimed to examine the utility of a novel method for supporting caregiver goal selection that, if helpful, could be used as part of future clinical pathways. Key to this aim was an investigation of psychological and emotional processes involved in how caregivers identified goals, together with their needs and experiences at this time of early engagement. This chapter reports on the process of goal formation by caregivers illustrated by themes that arose during interview to inform research and clinical practice concerning both PBS and goal selection more broadly.

Method

Ethics

Ethical approval was granted via a National Research Ethics Service committee in South-East England with Research Sponsorship provided by the University of Kent.

Participants

Participants were recruited primarily from two Learning Disability (i.e., Intellectual Disability, ID) Child and Adolescent Mental Health Services. Information was also distributed via a national support network for family carers facilitated by a charity for people with severe IDD. Finally, the study was advertised via Gore’s professional social media and organisational website. All potential participants were sent information packs, given an opportunity to discuss the study and asked to return consent forms. All participants received a summary report detailing the key areas they had identified in the interview, and the goals and priorities they had generated to help guide future support and engagement with services.

Participants (10 females, 2 males) were parents/guardians of children with IDD and CB awaiting service support. Participants 4a and 4b were from the same family and interviewed together. Participants’ children were 4-15 years, diagnosed with Autism Spectrum Conditions (ASC) and/or ID. Caregivers identified a range of CBs that their child displayed at the time of recruitment. Participant details are presented in Table 1.

Table 1. Participant Details

Participant	Gender	Relationship	Child	CB
1	Female	Mother	Female (9 years): ASC and Pathological Demand Avoidance	VB; PA; SI; PD;T;
2	Female	Mother	Male (9 years): Down Syndrome, ID and hearing impairment	VB; PA.
3	Female	Mother	Female (12 years): Moderate ID, Reactive Attachment Disorder and William's syndrome	PA; SI; PD;
4a 4b	Female Male	Grandparent Grandparent	Female (10 years): ASC, Foetal Valproate Syndrome and ID	VB; PA; T.
5	Female	Mother	Male (10 years): Down Syndrome, ID, hearing impairment, ASC	VB; PA; SI; T;
6	Female	Grandparent	Male (9 years): ASC	VB; PA; PD; T.
7	Female	Mother	Male (10 years): ASC	VB; PA; SI; T.
8	Female	Mother	Male (5 years): ASC, ID and epilepsy	VB; PA; SI; T.
9	Female	Mother	Female (4 years): Global developmental delay, ASC and chromosome deletion long arm C10	PA;
10	Female	Mother	Male (12 years): ASC and severe ID	VB; PA; SI; T;
11	Male	Father	Male (10 years) with ASC and severe ID	VB; PA; SI; T.

VB (verbal behaviours); PA (physical aggression); T (tantrum); SI (self-injury); PD (property damage)

Procedure

Interviews were arranged at times/places convenient to participants, audio-recorded and transcribed in anonymous form. Interviews were designed to take approximately 90 minutes and were based on a semi-structured protocol and card selection procedure, to support and explore caregiver goals in the context of valued life areas and the impacts of CB. The structuring of questions drew upon Goldiamond's (1974) constructional questionnaire to allow exploration of both desirable and problematic behaviours for children and adults and the interplay between these and wider systems of support. Question areas covered in the interview comprised five key areas: Quality of Life (QoL) for caregivers and their family; QoL for their child; CB for their child; adaptive behaviours for their child and positive and negative aspects of caregiver behaviour.

The interview was further structured using a card-selection procedure. Each question area began with a card selection task in which participants chose from a range of word-based cards those of greatest relevance, concern or priority. Use of card selection to initiate interviews has previously been effectively employed in research with families of children with IDD (Mitchel & Sloper, 2003) and to identify valued life domains in Acceptance and Commitment Therapy (Flaxman, Bond & Livheim, 2013; Hayes et al., 1999).

In this study, card selection was facilitated through Talking Mats (TM) (Murphy, 1998), an augmentative communication tool that enables people to organise and express their views. TMs are typically used with people with communication difficulties and involve placement of visual symbols to indicate thoughts or feelings. Use of TMs in this study, using written stimuli with language competent adults was novel. The method was chosen due to its potential to prompt and record in-depth discussions in a manner that could be openly shared and explored with caregivers.

Separate mats were used for each question area, divided into three columns that provided a scale of frequency, concern, or priority/value. Following card placements, participants were invited to select goals/priorities for future support. For instance, participants were asked to sort cards relating to different types of CB and then identify behaviours they would most like to change for their child or to sort cards relating to the value of different life areas and then select priorities for the future (See figure 1).

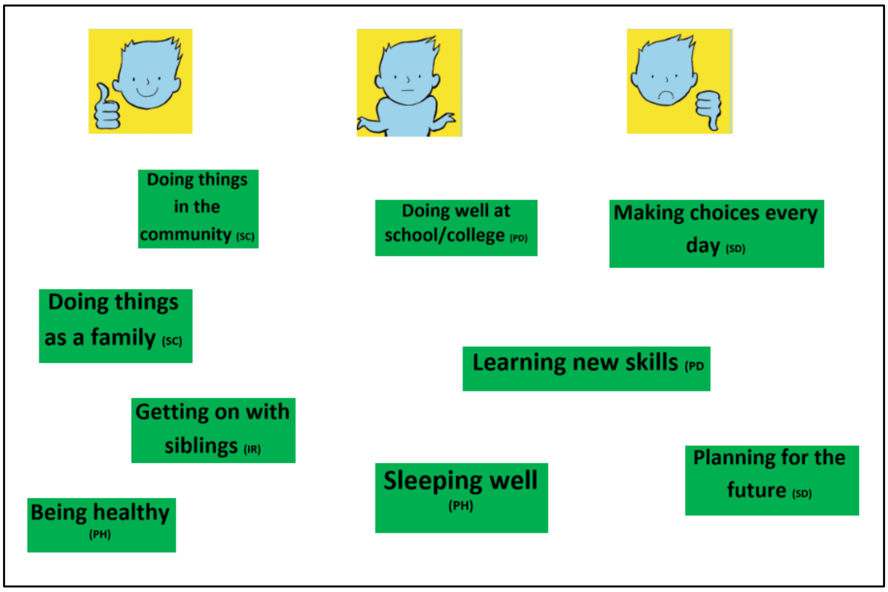

Figure 1: Example of Card Selection Procedure (Child QoL)

Card-stimuli included items that corresponded to items from the outcomes framework developed in chapter three supplemented by a range of further sources including items from family PGPBS (Fox & Emerson, 2010), FQoL (Hoffman, Marquis, Poston, Summers & Turnbull, 2006), child behaviour (Goodman, 1999), and parenting-style questionnaires (Arnold, et al., 1993). Overall, items corresponding to 8 major categories were covered in each of the first 2 mats corresponding to QoL domains for caregivers and their child; 22 individual items were covered during both the third and fourth mats corresponding to CB and adaptive behaviour for children; and 24 during mats relating to positive and negative caregiver behaviours (See Table 2 for example items use for each TM). Blank cards were also always provided so that responses were not restricted.

Table 2: Example Stimuli used with Talking Mats

Talking Mat	Example Stimuli
Family Caregiver Quality of Life	Doing things as a family; Feeling part of a community
Child Quality of Life	Being healthy; Making choices everyday
Adaptive Behaviour	Sharing; Trying new things; Waiting

Challenging Behaviour	Pulling own hair; Hitting others; Screaming
Positive Caregiver Behaviour	Doing things together; Giving choices; Praising and rewarding your child
Negative Caregiver Behaviour	Shouting at your child; Smacking; Arguing with your child

It is important to note that the card selection task was primarily a means of initiating a fuller discussion. In all sections additional questions (building on the responses of participants) were asked to explore the area further, consider relationships between concerns, values and behaviours identified across interview areas and to help understand the variables and processes that influenced items participants prioritised or selected for future goals. Within this process, the interviewer endeavoured to be mindful at all times of the emotional needs of participants and aimed to provide a non-judgemental, supportive context for discussions and to maintain a close working relationship. In a small number of instances, it was not possible to complete all TMs (corresponding areas were however still covered in discussion).

Data Analysis

A Framework Approach (Ritchie & Spencer, 1994) was used for analysis to support an exploration of the process of goal formation and the psychological and emotional dimensions that related to this. During data-management stages, transcripts were read multiple times by Gore who noted initial themes and categories with the structure of the interview (using NVivo software). In-vivo codes relating to each question area and broader discussions were generated. Emergent themes were recorded in an index table for each question, with quotations and examples listed accordingly. During the second, descriptive-accounts stage, transcripts were re-examined to identify overlap between themes and seek further supporting evidence for these, ensuring those that remained were grounded in data and captured participants' experience.

Finally, associations and patterns between themes were investigated (the exploratory accounts stage).

Results

Overall, two themes emerged during discussions of goal selection concerning caregiver/family QoL ("Being realistic" and "Most important"); two in relation to children's QOL ("What's going on?" and "Getting perspective"); three in relation to CB ("Does do that," "Just naughty children" and "For us it's negative"); two in relation to children's adaptive behaviour ("Has it in him" and "Good at that") and five in relation to caregiver's own behaviour ("Did that right," "End of my tether," "A kind of spiral," "What's needed" and "It's hard but you do").

QoL for Caregivers and Family

Being realistic

All participants identified goals and priorities for personal/family QoL that included interpersonal-relationships (10 participants), social-inclusion (5 participants) self-determination (5 participants), physical-health (9 participants), emotional-wellbeing (7 participants), personal-development (6 participants), rights (6 participants), and material-wellbeing (8 participants). There was considerable variation between what was/was not considered an important goal-area between families. Final placements were personal and varied:

> *'Rights respected, Hmm, this is what I deem important first, yes absolutely' (Participant-9)*
>
> *'Rights being respected (laughing) I couldn't give a shit what other people think!' (Participant-1).*

The processes by which final placements and priorities were selected were however, psychologically complex. Initial choices typically reflected what participants perceived as possible given current circumstances and prior experiences; selecting what might be considered ‘realistic’ rather than what was of greatest value. Early placements were often made with hesitation that referenced poor support and complexity of child needs and behaviour.

> *‘Being invited to lots of birthday parties once upon a time would have been something I would have wanted and expected but now it’s being realistic and that’s beyond something he could really cope with’ (Participant-10).*

The interviewer respected all items initially placed by participants but also attempted to communicate an appreciation of current circumstances and explore the potential of these to influence what was selected.

> *‘That is very understandable. It seems where you placed that area really reflects how difficult things are. But I get the feeling there is some sadness or frustration? That in an ideal world you might want something different?’ (Researcher).*

As interviews progressed, caregivers made increasingly fine-grained discriminations, to clarify QoL domains of greatest importance, often changing selections accordingly and contacting emotions of sadness or frustration:

> *‘This one for how actually is and here for how would want it to be’ (Participant-8)*
>
> *‘We never go out together and that is important. That’s gone and has changed our lives dramatically. A massive, massive loss.’ (Participant-11)*

Most important

In the later discussions concerning caregiver and family QoL, participants increasingly reflected on items in accordance with their personal/fundamental value and meaning.

> *'Personal development, that's what life is all about really isn't it and in amongst all the bad things that have happened to us I have a little niche.'*
>
> *(Participant-3)*

At these times significance of domains was commonly linked to aspiration for caregivers and their family, expressed with a sense of vitality. Caregivers highlighted goals for what they wanted to happen, rather than what they had previously experienced or considered possible.

> *'Everyone in family accessing and being part of and included in things, just because he's got a disability I don't feel we should be excluded from anything I don't think he should have to fit in necessarily with everyone else, why should he, why can't they adapt why has he got to change?' (Participant-2)*

QoL for Children

What's going on?

QoL goals and priorities that caregivers identified for their child spanned interpersonal-relationships (eight participants), social-inclusion (four participants) self-determination (six participants), physical-health (seven participants), emotional-wellbeing (six participants), personal-development (seven participants), rights (seven participants), and material-wellbeing (four participants).

> *'Would dearly love to have that friendship but these kind of children never make friends they sort of stay back in some way. She was bullied last year' (Participant-4a).*
>
> *'He wants to be included but the he might do the wrong thing but he really does want to be with everybody' (Participant-5)*

As with the initial mat, inviting caregivers to reflect on areas of importance for their child required exploration (though for different reasons) and was often met with initial uncertainty.

> *'She does see things differently to how we see them, and she puts things into perspective differently and it is quite hard to figure out what's going on up there.' (Particpant-4a).*

A useful strategy, initiated by one caregiver when reflecting on these items (and utilised in subsequent interviews), focused on discriminating areas perceived as important for a child's life based on the caregiver's understanding of their needs and those based on the child's own preferences/desires:

> *'I would say she enjoys it but doesn't understand the significance and importance of it so these things are all the things that are hugely important to her but she doesn't know' (Particpant-3).*

Getting perspective

Through further discussion, caregivers were able to identify goal areas of importance and demonstrated meaningful ways to attune with their child's perspective. An increasingly empathic stance flowed well from earlier discussions regarding areas of importance for caregivers' own lives and often provided fresh insights into a child's needs and aspirations:

> *'Actually because in some ways she does like to be in, to have things a certain way, and in certain places and times and I suppose that is actually about her feeling in control of certain situations and so actually thinking about it I would bring that there.' (Participant-9).*

CB for Child

Does do that

Participants readily identified and discussed CB displayed by their child and appeared to find the TM structure helpful in this regard:

> *'It's reassuring actually because you have created a list of several challenging behaviours and when you see ones she does you obviously feel there are other children doing those things as well.' (Participant-9).*

Just naughty children

Impact of supporting a child with CB was poignant and participants recounted many negative experiences with services, the public, and family that had caused lasting upset and pain:

> *'Sometimes I'm in tears when we're at home and I'm thinking I wish we had of gone but my husband's saying you know what you'd have been like – would have been on edge.' (Participant-2).*
>
> *'Another mum turned round and called him an effing little retard in my hearing. I cried for a week' (Participant-5).*

For us it's negative

Final goals selected by caregivers were varied but included a focus on verbal behaviours like screaming/shouting (participants 1, 2 and 5); physical aggression (participants 2, 6, 7, 9 and 11); self-injury (participants 7, 8 and 11), and tantrums or other/idiosyncratic behaviours (participants 2, 3, 5 and 10).

> *'That one I said about the verbal coz that's quite constant, that taps away at you like water torture…every time you sit down……makes u really tense and unable to cope if she does get violent coz if it's been going on for 2 hours' (Participant-1)*

> *'So many but scratching at school and carers. Recently bit one of his carers and she lost all the ….nerve damage down her arm sort of thing and had to have a cast…and that's awful' (Particiapnt-11)*

Whilst some variation was attributable to individual differences in children's behaviour, goals typically corresponded to the impact a given behaviour had on QoL areas caregivers had prioritised. Goals to reduce frequency/severity of a behaviour, were linked to positive impacts predicted for both family and child QoL if even small reductions could be achieved:

> *'Even if we could move it [CB] to half the table, at least I could put some of the green [QoL] things back on.' (Participant-3).*

> *'Not get into that escalation point where he's trying to scratch or kick you, his life would improve dramatically, and so would ours.' (Participant-11).*

Adaptive Behaviour for Child

Has it in him

Participants seemed to find discussion of strengths and challenges within the same interview helpful, and a contrast to other discourses surrounding their child:

> *'It's always what the child isn't doing or does badly, they don't say, like when you pick them up from school its always like he hit this child or he didn't go to assembly. Not he spent this long in assembly or he did this today and everything, I don't get any of that I always get the bad point.' (Participant-2).*

> *'If you knew how many professionals had judged me or my children' (Participant-3).*

Good at that

Considering both strengths and difficulties in adaptive behaviour seemed to enrich caregivers' understanding of the needs and potential of their child. For some this involved expanding or reframing:

> *'Struggling to understand, just make sense of life, but of course he can't make sense of life because of his autism, so I do understand, but it's hard.' (Participant-6).*

For others, reflecting on positive aspects of their child's behaviour gave voice to a more balanced and hopeful perspective:

> *'And as much as it's difficult with him doing all this touching I am proud of how he is and that he's loving and smiley most the time.' (Participant-8).*

Participants often appeared re-energised and motivated when identifying these behaviours/characteristics and the interviewer was able to share in the joy and enthusiasm that was generated:

> *'Friendly, very, right up there. We went for a swimming lesson and the bloke said he's very sociable isn't he?! Wanted to say hello to everyone in the pool. That's his main strength being friendly' (Participant-2).*
>
> *'We're seeing real progress she's able to put a toothbrush into her mouth and able to spoon-feed.' (Participant-9).*
>
> *'That's incredible, so important to be aware of that as something to build on!' (Researcher).*

Final adaptive behaviour goals were strategic in nature and linked closely to prior elements of the interview. These included a focus on coping skills (participants 1, 3, 4, 8, 10 and 11); skills to support independence (participants 2, 7 and 9), and social-interaction (participants 1, 2, 3, 5, 6). Participants described with optimism how support in chosen areas could build upon a child's strengths or emergent skills, maximise QoL and/or reduce CB:

> *'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' (Participant-3).*

> *'If relationships and understanding for sharing then it would deal with his need to take it out on her or whatever and so her relationship with him would be better because she wouldn't feel that scared of him so then maybe she would share better as well herself and it all goes round full circle' (Participant-7).*

> *'Waiting, listening to others are skills that if develop enable you to function better in the world so would pick those out……..doing things yourself – those kind of and independence skills important as gets older, being calm, being aware of emotional state….cluster those together' (Participant-10)*

Caregiver Behaviours

Did that right

Building upon prior discussions, caregivers highlighted a range of positive parenting practices they engaged in:

> *'He loves watching me cook and he got the masher out the drawer and one of those moments and he started mashing for me and I got him to hold it and that and all off his own back' (Participant-11).*

At these times participants reflected on relationships between their own positive parenting, prevention of children's CB, and development of adaptive behaviour:

> *'I'll help a bit and give him encouragement and motivation and talk to him with respect, you can avoid it'. (Participant-5).*
>
> *'The more you do take him out really the more you extinguish that kind of need. I do see a link between the two, the more you can give him those experiences the less there seems to be the need [for CB].' (Participant-10).*

As with adaptive behaviour, caregivers emphasised opportunities to highlight their own strengths to be refreshing and empowering:

> *'You think "yes I've done something right" because an ASD child never tells you when you're doing something well.' (Participant-1)*

End of my tether

Subsequently, caregivers were also able to talk about less helpful parenting behaviours. Participants did this openly and appeared to find the structure of the mat and the development of a trusting relationship with the interviewer helpful:

> *'I do shout when at the end of my tether, when gone on all day and I'm like I've had enough now and "stop it!" (Participant-2).*
>
> *'Horrible feeling but that completely broke my heart and made me feel awful and I certainly haven't said it to many people but just couldn't be around him.' (Participant-7)*

A kind of spiral

Participants often identified interrelationships between their behaviour and that of their child. Here, episodes of CB both increased the likelihood parents acted with an authoritarian style and decreased the likelihood they could engage in positive practices.

> *'I can remember doing it because he got into this kind of spiral'. (Participant-10).*

> *'When child just full of rage and not responding to you it does all go pear shaped and wave arms about and end up threatening and that's definitely the biggest'. (Participant-7).*

> *'I will shout at him but sometimes shouting doesn't work because that's why he shouts back.' (Participant-6).*

For some, these responses evidently arose in the context of broader demands and stresses of caring in an unsupportive community:

> *'So she started pulling their hair and the child got very upset, as did the mother of course, because she wouldn't let go of her hair, and then we became negative with her because we were in front of other people and you want to be seen to be taking a stand.' (Participant-9)*

Finally, whilst noting factors that influenced interactions with their child, participants often observed in heartfelt ways disparity between the value they associated with previously identified life areas and aspects of their own behaviour:

> *'The others are not huge emotional expenses for me but I don't want to shout or argue with her, I end up feeling shit afterwards. Why should I be arguing and shouting at a 12-year old? I don't want to do that' (Participant-3).*

What's needed?

The impact of these interactions, QoL and wellbeing was salient within discussions that ultimately informed meaningful goal selection. Particular goals for changing unhelpful caregiver behaviour included a focus on shouting, losing temper/arguing with their child (participants, 1, 2, 3, 5 and 7); restraining or ignoring their child (participant 9), and letting their child 'have whatever they want' (participant 1).

> *'Try not to shout – do occasionally but better to whisper as gets more attention and why raise your own blood pressure' (Particpant-5)*
>
> *'I would rather not let her do what she wants – I don't like that – it's really hard because you are going against all your natural parenting instincts' (Participant-1).*

Caregivers also selected goals based on positive parenting practices they currently used less often or experienced difficulty using, including engaging in preferred/new/individual activities with their child (participants 1, 2, 7 and 9); finding new ways to support/communicate with their child (participants 1, 3, 6 and 9), and listening or being more patient towards their child (participants 4 and 5). These goals were grounded in consideration of other QoL goals and aspirations for their child's development, with caregivers evidencing rich insight into relationships between all of these:

> *'Listening – yes but I've got to try and listen more – because he can't communicate as such I really should take the time and stop the washing machine or tumble dryer and pay attention' (Participant-5).*
>
> *'Goal might be to spend a happy hour at a children's birthday party, you almost need to break down what are the things that are required to have that success? And talk about that. Those kinds of conversations I find really useful. What's needed coz then you feel successful because you've only set yourself up for that.' (Participant-9)*

It's hard but you do

Throughout closing discussions of goals, participants often described their personal resilience and determination for the future. Here, themes of hope, commitment and endeavour juxtaposed poignantly with the struggle and impact of ongoing adverse experiences:

> *'I'm sure that is why people like me are given children like N – because you cope with it and you get it and understand it. It's hard but you do'* (Particpant-8).

> *'So I have learnt to be resilient so I don't blame myself all the time when things don't go to plan. How am I going to get back and pick myself up and go onto the next stage because there will be something else (Participant-3).*

Acceptance of difficulties, hand in hand with a determination to maximise on opportunities and potential positive developments were a frequent feature of these dialogues. In this context personal and psychological growth were both recognised and valued as unexpected outcomes of supporting a positive family life in exceptional circumstances. At these times the role of the interviewer became one of stepping back and allowing participants space and time to reflect on all of the areas previously discussed within the more structured stages of the interview process:

> *'And that sounds a bit different somehow, the way you are describing that' (Researcher).*

> *'I am saying that if you hold onto this idea, this concept that being in control of your life is critical then you are going to struggle to live with someone like C in your family. I think that to kind of learn to accept and adapt and all of those things requires you to be flexible and in order to be flexible you have to almost surrender some of that control and it is kind of learning to take control of the things that you can and accept some of the things that you can't, and be a bit open minded I suppose'* (Participant-10).

These discussions served to generate an alternative narrative to the earlier discussions of difficulty and struggle, by highlighting times and contexts in which caregivers presented as strong and resilient. This appeared both a positive aspect of interviews in and of itself but also functioned to empower and motivate caregivers to identify and drive forward goals for the future.

Discussion

In this study caregivers of children with IDD and CB were interviewed to explore processes by which personalised support goals reflective of a PBS framework could be formed. A TM-interview approach was used to provide a structured and comprehensive framework for consideration of goal-areas and ensure close attention to interpersonal interactions. A qualitative approach supported the exploratory aims of the study and allowed the richness of accounts and process to be captured.

As a first study using the TM method in this way, there were however, inevitably some limitations. Firstly, participants represented a subset of families who, whilst demonstrating considerable need, were able and motivated to engage in interviews. Care needs to be taken in generalisation of findings to different families in different situations. Secondly, whilst the study demonstrated an effective method to help caregivers identify personally meaningful goals, utility and effectiveness of using these within a clinical pathway remains to be tested.

Participants’ children presented with a range of CB and, as in prior research (Griffith & Hastings, 2014; Herring et al., 2006), impact of this on QoL and wellbeing for caregivers was evident. Timely and effective professional support (Brown et al., 2011; Griffith & Hastings, 2014; McConkey et al., 2013) and favourable, social-ecological contexts (McConnell, Savage, Breitkreuz, 2014; McConnell, Savage, Breitkreuz & Sobsey, 2016;) can offer considerable protection for families raising a child with such behaviour. By nature of their involvement, participants were however yet to access appropriate professional input and additionally reported low levels of social support and resource overall. In parallel with prior research (Baker et al., 2003; Hastings, 2002; Herring et al., 2006; Griffith & Hastings, 2014; Pozo, Sarria & Brioso, 2014; Werner, Edwards & Baum, 2009), the negative impact of CB on family life and wellbeing was therefore highly evident in participants' responses and emotional states throughout interviews.

Family-focused research emphasises centrality of relationship building throughout clinical encounters (Brotherson et al., 2010; Dunst, et al., 1994) and this was experienced as critical within interviews. Here, use of TMs and an emotionally-sensitive dialogue helped not only prompt consideration of goal-areas but normalised areas of difficulty, setting the scene for a non-judgemental, enquiring discussion. Caregivers viewed some discussions as 'therapeutic' and at times interactions reflected elements of values clarification work outlined in psychotherapeutic models of behaviour change such as Acceptance and Commitment Therapy (Flaxman et al., 2013; Hayes, Strosahl & Wilson, 1999). Without fostering a trusting respectful relationship and recognising and responding to emotions that arose, it would seem likely that areas selected by participants would have fallen short of highlighting true priorities.

Ultimately, when supported in this way, all participants were able to select goals that could inform future assessment, intervention, and outcome monitoring. The TM-interview approach therefore appeared a helpful method for facilitating goal identification and may have good utility as part of a PBS pathway. The diversity of goals/priorities identified spanned the majority of domains included by Fox and Emerson (2010) but also reflected additional items included for each starter mat reflected in outcomes identified in chapter three and other measures in the literature. Importantly, caregivers' goals were conceptually coherent (relating to interplay of several maintaining factors), strategic (focussed on discrete changes to generate multiple positive changes), and high in social validity (related closely to change in areas of personal importance/worth).

Complex psychosocial contexts, together with biological factors and interactions between individuals, their environment and those who support them, are at the heart of conceptual models of CB in PBS (Hastings et al., 2013; Lucyshyn et al., 2004). It was therefore of note that caregivers were able to openly discuss and identify interconnections between their own behaviour, behaviour of their child, and other social and contextual variables. Notably, these insights informed goal selection, were obtainable within a first meeting, and could be constructed and elaborated during a relatively brief interview. The fact that caregivers can generate hypotheses of this nature as part of goal selection (when a supportive framework is used) highlights both their expertise and the potential to draw on this more routinely as part of early engagement in clinical practice.

Enhancing motivation and empowering caregivers to facilitate future change also appeared to be a strength of the TM-interview approach. In addition to a focus on valued life areas, caregivers welcomed the opportunity to discuss and appreciate strengths of their child, successful parenting behaviour and the connection between these and desired outcomes. This mirrored the approach taken by Goldiamond (1974), highlighting that ‘no one starts out from scratch’ (pp.76). Caregivers appeared to find this alternative to problem saturated discussions helpful and evidenced a constructional approach to goal selection as a result.

Finally, within the context of the interview, caregivers often evidenced considerable personal resource (at times bolstered by social support) and examples of strength and determination. Caregivers’ accounts in this area appeared closely connected to the definition of parental resilience posited by Gavidia-Payne et al. (2015) as a capacity to deliver competent, quality parenting to children despite adverse personal, family and social circumstances.

Gavidia-Payne et al. (2015) highlighted how child and family characteristics, social connectedness, parental wellbeing, family functioning and self-efficacy may influence parental resilience and these were areas that resonated with corresponding themes in the current study. It is also likely that, to at least some extent, certain of these variables, such as self-efficacy, were activated within the interview, promoting a sense of caregiver empowerment likely to facilitate future change (Patterson, 2002).

Conclusions and Next Steps for this Thesis

In conclusion, goal-selection is a fundamental process to supporting outcome monitoring, treatment effectiveness and stakeholder engagement. Whilst goal-selection has been studied and advocated for within general mental health literature for children and families, it has previously received little research attention within the context of goal section for caregivers of children with IDD, as part of the empirical study of PBS. The TM-interview structure used in the current study highlighted the strengths and processes of engaging with caregivers of children with particularly complex needs to form personally meaningful goals and has good potential to support effective partnership working in applied settings.

The current study began to explore Research Question Two with regards the engagement of stakeholders within PBS, in a manner that might also support high quality service delivery (Research Question One). At the same time, themes and experiences relating to partnership working, wellbeing and resilience (Gavidia-Payne et al., 2015) identified during interviews have provided some guidance for advancing the third research question (‘How can proactive support for children with IDD and families be enhanced in the early years?’). These areas will be returned to within the context of an intervention programme for early years support presented in Chapters Six and Seven.

As has previously been noted, stakeholders for PBS, in theory, include people with IDD for whom support is focused. Direct engagement with people with IDD as part of a PBS pathway is however rare in practice (Kruger & Northway, 2019; Wehmeyer, Baker, Blumberg & Harrison, 2004) and typically not a feature of PBS research. The next chapter therefore continues to build on practical methods of supporting goal and outcome selection with a focus on direct engagement with children and young people with IDDs at risk of CB.

Chapter Five: I do it quite a lot: Children's Goals and Priorities for PBS[5]

Overview

Chapter Four presented a study that focused on developing and exploring use of a goal selection procedure with family caregivers, with implications for increasing stakeholder engagement and effective outcome monitoring as part of high quality PBS delivery in services. This chapter extends an exploration of Research Question Two ('How can stakeholder engagement be maximised to enhance support for children with Intellectual and Developmental Disabilities (IDD) and their families?') to explore engagement of children and young people with IDD in such a process (with some further relevance to Research Question Three: 'How can proactive support for children with IDD and families be enhanced in the early years?')

The voices of children and young people with IDD have largely been absent from behavioural research and complexities of communication as well as behaviours that challenge (CB) present a barrier to engagement in practice. Yet keeping children at the heart of decision making to shape their own support is consistent with the person centred foundations of PBS. This chapter therefore reports on a fourth empirical study that utilised a Talking Mats methodology paralleling the interview process completed with family caregivers. Both quantitative data (pertaining to the extent to which children could engage with the procedure) and qualitative data (exploring their goals and priorities for support) are presented, with implications for supporting high quality service delivery through engaging with children and young people as active stakeholders, discussed in conclusion.

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[5] A Version of the study in this chapter has subsequently been published: Gore, N.J., McGill, P., Hastings, R.P. (2021). Personalized Goals for Positive Behavioural Support: Engaging Directly with Children who have Intellectual and Developmental Disabilities. *Journal of Child and Family Studies*. ISSN 1062-1024

Introduction

Background

Children with IDD typically present with a range of difficulties concerning communication and adaptive skills; often experience physical health problems and encounter psychosocial adversity, all of which place them at increased risk of behaviours that challenge (CB) relative to their peers (Gore et al.,2014; McClintock et al., 2003; Totsika et al., 2011a; 2011b). Positive Behavioural Support (PBS) incorporates and builds upon the concepts and applications of behavioural science (Baer et al., 1969), human rights and values-based approaches to provide a framework of evidence-based practice for those at risk of CB (Carr et al., 2002; Gore et al., 2013; Horner et al., 1999; Kincaid et al., 2016). PBS recognises that CB develops within the context of biological and psychosocial aspects of disability and via interactions between an individual, people around them and their environment to serve important functions (Hastings et al., 2013).

Based on this understanding, PBS seeks to enhance skills, opportunities, environments and interactions in ways related to an individual's specific needs and aspirations and reduce risk of CB over both the short and longer term. Development of socially and personally valued adaptive behaviours and improvements in life quality, should therefore be both a focus of outcomes in PBS and the means through which desired outcomes are brought about, in addition to changes in CB (Carr, 2007). Committing to and demonstrating the full breadth of approaches and values integral to PBS in this way remains, however, a challenge for the field (Clarke & Dunlap, 2008; Kincaid et al., 2002). Maximising opportunities for people with IDD themselves to determine the focus of behavioural support may be one key way in which the values of PBS can be better actualized in practice. Building on more general calls to address what are frequently missing voices in IDD research (Farrell

& Krahn, 2014), this study therefore aimed to develop and explore a goal-selection procedure for direct use with children who have IDD and are in need of behavioural support.

Person-centred planning (Kincaid & Fox, 2002) and stakeholder involvement (Luchyshyn et al., 2007; McLaughlin et al., 2012) are considered fundamental to supporting the kind of socially valid outcomes and practices that PBS demands (Dunlap, 2006). These approaches have relevance throughout a pathway of support but are perhaps most critical during early planning stages to identify goals that are grounded in the strengths, hopes and concerns of all involved (Dunlap & Fox, 2007), and give direction to future assessment, intervention and outcome monitoring that may follow. In the case of children, person-centred activities and other PBS procedures should typically involve engagement with professionals and family caregivers who know the child well and whose own behaviour may require support as part of a multi-component plan (as discussed and explored in chapter four). Children with IDD themselves are, however, very seldom consulted directly within a PBS pathway (Kruger & Northway, 2019; Wehmeyer, Baker, Blumberg & Harrison, 2004) and little behavioural technology has developed to support their inclusion in this way, with two possible exceptions.

First, preference assessments are well established in the field of Applied Behaviour Analysis (Virués-Ortega et al., 2014) and are often used within PBS to identify reinforcing stimuli. Here, views of other informants do not always correspond to an individual’s observed preferences regarding functional reinforcers (Green et al., 1988; Parsons & Reid, 1990), underlining the fundamental importance of direct engagement with the focal person during such procedures. Secondly, some attempts have been made to advance student-directed functional assessments, where both convergence (Kinch Lewis-Palmer, Hagan-Burke & Sugai, 2001; Reed, Thomas, Sprague & Horner, 1997; Wehmeyer et al., 2004) and divergence (Murdock, O’Neil & Cunningham, 2005; Stage et al., 2006) between responses of students and other informants have been reported. Whilst demonstrations of student engagement, these functional assessment procedures have largely used verbal communication methods alone and been utilised primarily with children with minimal/no degree of intellectual disability. In addition, and fundamentally, both preference assessments and functional assessments have a different focus and scope to goal selection, and so represent necessary but incomplete opportunities for children with IDD to shape their own behaviour support.

Outside of PBS, several attempts have been made to gain perspectives of children with varying levels of intellectual disability and/or autism. This includes studies relating to evaluations and indicators of service quality (Aston, Lynn & MacLeod, 2014; Boyden, Muniz, & Laxton-Kane, 2012; Mitchell & Sloper, 2001; 2003; Preece & Jordan, 2010) with at least some examples and guidance available to support interviews with children with significant communication difficulties (Bedoin & Scelles, 2015; Mitchell & Sloper, 2001). We could find only one study on children's perspectives (Boyden et al., 2012) with a connection to their CB. Boyden et al.'s service evaluation included interviews with children with a history of CB, following input from a mental health service. Further to this, a study by Byrne and Hennessy (2009) explored views of children with IDD in relation to vignettes depicting behaviour of a fictional peer. Neither of these studies was conducted within the context of personalised goal formation for a child's own/current behaviour prior to provision of support.

Aims of the Study

The PBS framework and related research to date have therefore prompted but not adequately addressed ways to support direct engagement with children with IDD as active stakeholders in their own behavioural support. To address this research and practice gap, this study utilised an augmentative communication method supportive of low verbal ability to explore the utility of a person-centred goal selection process for children with IDD who displayed CB. It is suggested that such an approach could provide a way to help children and young people identify skills, needs and aspirations and highlight areas of both dissatisfaction and importance for their own life; information that may be of critical importance to structure effective support arrangements (e.g., scheduling of activities) and guide future functional assessment, behaviour support planning, and outcome monitoring processes. The study had two aims: 1. To develop and test the utility of a goal selection procedure of this nature, and 2. To describe goals and priorities expressed by children and explore processes involved in the identification of these.

Interviews were facilitated using Talking Mats (TMs), a versatile and structured, visually-based communication tool that enables people to organise and express their views (Murphy & Cameron, 2008; Murphy, 1998). Whilst other augmentative approaches exist, and may also be helpful in engaging children with IDD (Romski, Sevick, Barton-Hulsey & Whitmore, 2015), TMs appeared a particularly promising starting point for exploring children’s priorities and goals in the current study. From a research perspective, TMs have previously been used to good effect in studies ascertaining views of children with IDD without CB regarding a range of topics (Mitchell & Sloper, 2001; Small, Raghavan & Pawson, 2013). From a pragmatic and clinical perspective, TMs also have strengths in that they can be used to support people with even low levels of receptive communication ability (those with 2-word receptive understanding); are low cost and can be used without the need for extensive prior training with children.

Method

Ethics

The National Research Ethics Service committee in South-East England granted ethical approval for this study. Parental consent for the involvement of all participating children and young people was gained and care was taken to check for the child's assent in taking part in the study procedures (see below).

Participants

This study recruited children and young people who had a diagnosed IDD that related to multiple domains of need and who were currently exhibiting CB. Criteria for recruitment also required: families of children and young people to be seeking or awaiting service support in relation to their child's behaviour but not yet in receipt of this (thus indicating a high level of need, and providing a timely context for exploring goals for future support); children and young people to have receptive language ability (as estimated by their caregivers) at a two-word level (i.e., able to follow instructions including two information carrying words in context) as required for engagement with the communication method utilised in the study (see below).

Participants were recruited primarily from two Learning Disability (i.e., Intellectual Disability, ID) Child and Adolescent Mental Health Services. Information was also distributed via a national support network for family carers facilitated by a charity for people with severe IDD. Finally, the study was advertised via Gore's professional social media and organisational website. Participants recruited for the study (see Table 1) were 14 children (10 males, 4 females with mean age 9 years, range 4-15 years) with IDD who displayed differing forms of CB. Children's expressive communication abilities varied, with some using largely verbal methods and others utilising symbol or sign-based systems. Some of the participants recruited were the children of caregivers who took part in the related study reported in Chapter Four and the focus of interviews at that time. Participation from four of the children (Scott, Peter, Max and Billy) concerned involvement in the current study only.

Table 1: Participant Characteristics

Name	Age (years)	Sex	Diagnoses	Communication	Behaviour that Challenges
Billy	5	Male	*ASC	Verbal	TA; NC
Laura	9	Female	Pathological Demand Avoidance; ASC	Verbal	VBC; PA; SI; DP; TA; NC
Natasha	12	Female	Moderate *ID; Reactive Attachment Disorder	Verbal	VBC; PA; SI; DP
Edward	9	Male	Down Syndrome; Severe ID	Limited verbal; Makaton	VBC; PA.
Stephen	10	Male	Down Syndrome; ID; ASC	Limited verbal; Makaton	VBC; PA; SI
Peter	15	Male	ASC; Severe ID	Verbal	PA; SI; DP
Emily	10	Female	ASC; ID; Foetal Valproate Syndrome	Verbal	VBC; PA; TA
Max	10	Male	ASC; ID; Foetal Valproate Syndrome	Verbal	PA; TA
Scot	8	Male	Cri de Chat Syndrome; ID	Non-verbal; PECS	SI
David	9	Male	ASC	Verbal	VBC; PA; DP; TA
Ben	10	Male	ASC	Verbal	VBC; PA; SI; TA.
Richard	5	Male	ASC; ID	Non-verbal; PECS	VBC; PA; SI; TA
Alison	4	Female	ASC; Global Developmental Delay	Non-verbal; PECS; gestures	PA; NC
Joseph	10	Male	ASC; Severe ID	Limited verbal; Makaton	VBC; PA; SI;

Interview

Interviews were conducted using a Talking Mats (TM) approach. All TMs consist of a set of symbols relevant to a subject area. Individuals are asked semi-open questions in relation to each symbol and invited to place this on an area of the mat corresponding to their views, feelings, or experiences. Typically, TMs are divided into two columns to indicate items an individual favours or experiences frequently and those they do not like or seldom experience. Depending on communication level, a middle column can be introduced to a TM, allowing interviewees to indicate items they are not sure of, that happen occasionally, or they like to some extent. In all cases, placements are used as a starting point for further communication exchanges.

In this study, TMs were used to guide interviews structured around six topics that covered preferred activities, adaptive and challenging aspects of children's own behaviour, their caregiver's behaviour, and life quality domains. The topic areas related to the breadth of goal areas and intervention approaches conceptually possible within a PBS framework and paralleled those utilised in chapter four when interviewing caregivers. Interviews aimed to support participants to consider a range of possibilities for their future support and to identify areas that were personally meaningful. For instance, we asked children 'tell me about asking for help. Is that something you do a lot or something you do not do?' in relation to the adaptive behaviour topic. The interviewer (Gore) then handed the corresponding stimulus card to the child to place on an area of the mat that reflected their thoughts/perspective.

As is a standardised element of the TM approach, at the end of each mat the researcher verified interpretation of a child's responses by feeding back placements that had been made, and checking these corresponded to the child's views. The interviewer allowed each child to change or clarify placements at this time and add any other stimuli of their choosing (blank cards were available as is customary in TM procedures). Additionally, and specifically to this study, following placements and discussion, the interviewer asked children to identify one-two items they would like support for in the future.

The TM procedure and full range of stimuli for each mat were manualised to ensure a replicable methodology for both clinical and research settings. Table 2 presents all topics and sub-categories depicting the number and array of stimuli prepared. Physical/non-electronic TMs were used (a piece of carpet approximately 40 cm by 30 cm) with a pre-prepared set of line-drawn symbols. Interview topics were ordered in level of increasing complexity (as indicated) to support children's early engagement. Within session discussions were supported where possible by verbal communication, signing (e.g., Makaton), and gestures.

Table 2: Interview Topics and Stimuli

Topic Area	TM Stimuli	Examples
Things you enjoy (preferred)	20 (12 x home based activities; 8 x community activities	Drawing
Things you do (adaptive)	22 (12 x social skills; 5 x daily living; 5x coping skills)	Sharing
Other things you do (challenging)	21 (8 x aggressive behaviours; 7 x self-injurious behaviour; 6 x other behaviours)	Kicking others
Things your parent does (positive)	12 (3 x social; 6 x joint activities; 3 x support strategies)	Helping you
Other things your parent does (unhelpful)	12 (3 x positive punishment strategies; 6 x negative punishment strategies; 3 x other)	Shouting
Things that are important (life quality)	8 (community engagement; physical health, emotional health; relationships; self-determination; personal development; material; rights)	Relationships with others

Procedure

Preparation sessions (30-50 minutes) were completed with each participant's caregiver to ask about their child's communication and behavioural needs prior to interviews. The sessions were used to help plan and organise the main goal-selection interviews for children and young people. Following discussion, individualised plans were created for each child to minimise the likelihood of CB within interviews and manage this safely if it should occur. In all cases, it was agreed interviews would be terminated following any CB or indication that the child did not assent to continue. Preparation sessions were also completed with children. In half of the cases, this involved a preliminary visit to a child's home or school (30-40 minutes) during which the researcher engaged in preferred activities with the child. In all other cases, equivalent additional time was built into the start of interview sessions. These sessions allowed the researcher to develop rapport and further gauge participants' communication abilities, as recommended in prior research interviewing children with IDD (Bedoin & Scelles, 2015).

The main goal-selection interviews with children were arranged at a time and place convenient to families, and completed within 1-2 sessions of 30 to 60 minutes. The interviewer proactively offered breaks to children during sessions. In breaks children completed preferred activities (jointly with the researcher or alone, as preferred by the child). Interviews were typically conducted alone with the child. In a small number of instances, caregivers sat in a different area of the room but were asked not to contribute to the interview. Time with children was limited to two sessions and so interviews were ended at this point even if all mats had not been attempted. Interviews were also ended where the researcher judged remaining mats to be too complex for the child (based on prior responses). Interviews were video-recorded and later transcribed/analysed in an anonymized form. All participants received an accessible summary report detailing the goals/priorities they had generated within interview that could be used as a starting point for behaviour support planning after the study.

Data Analysis

A TM was considered completed if children were able to make valid placements of stimuli relevant to the given topic area. A discrete-response coding system was devised for the current study to verify the validity of children’s responses. Researchers viewed videos of participants one TM at a time. Placements were recorded for each stimulus presented and a confidence rating of high or low was then made based on an estimation of the validity of the child’s response. The observed position of stimuli on a mat following a participant’s response was used to code placements (i.e., the area/column depicting stimuli that was favoured/experienced frequently or not, liked/seldom experienced, or partially liked/experienced). Low confidence ratings were made if placements appeared motivated by acquiescence; were contrary to other communications (e.g., the child said ‘don’t like’ and placed the item in the highly preferred column); where the child was highly distracted (e.g., placement appeared non-intentional), or where placements appeared motivated by a sensory stimulation function (e.g., lining items up to create a visually reinforcing display). High confidence was assumed and rated in the absence of these low confidence indicators.

A second observer (Bradshaw) viewed videos from a randomly selected 50% of participants, in each case coding at least 50% of TMs from the interview and covering all categories of TM from the study overall. Inter-rater reliability (based on both placements and confidence ratings) was 100% (total agreements divided by total agreements plus total disagreements x 100). In addition, the second observer (a TM trainer), completed the Effectiveness Framework of Functional Communication (EFFC) (Murphy & Camerson, 2008) for each mat in their sample. This tool is commonly used in TM research and provides seven 0-4-point ratings concerning quality of communicative interactions based on the behaviour of both the speaker (child) and listener (researcher). A score of 21 out of 28 represents effective TM communication. Average EFFC ratings for TMs were 27.7 (range 25-28, with all but one TM scoring 28).

In addition to stimuli placements, any explicit goals children made at the end of each TM (goal formation was not taken as an indicator of TM completion since a child may or may not have prioritized a goal in that area) were recorded and verbal responses noted and later transcribed. Transcripts were reviewed in detail and analysed using a basic thematic approach (Braun & Clarke, 2006) in relation to each mat, across all children. Transcriptions were analysed alongside stimuli placement records to support an integration of both data sources and help further explore the manner in which children used the mat and perceived the topic area.

Results

Overview

It was possible to interview 9 of the 14 children (64%), with some variation in the mats completed on each occasion (see Table 3 for a breakdown of each child's responses and Table 4 for an overview of sample responses). Notably, whilst eight of the children completed between four and six TMs, it was only possible to complete one mat with Stephen who did not appear to understand questions attempted in subsequent stages.

Table 3: Topic areas completed in each participant interview

Participant	Topic Areas					
	Preferred Activities	Adaptive Behaviour	Behaviours that Challenge	Caregiver Positive	Caregiver Unhelpful	Life Quality
Billy	Yes*	Yes	Yes	Yes	Yes	No
Laura	Yes	Yes	Yes*	Yes*	Yes*	Yes
Natasha	Yes*	Yes*	Yes*	Yes	Yes*	Yes
Stephen	Yes	No	No	No	No	No
Peter	Yes*	Yes*	Yes*	Yes*	Yes	No
Emily	Yes	Yes	Yes	Yes	No	Yes
Max	Yes*	Yes	Yes	Yes*	No	No
David	Yes	Yes*	Yes*	Yes	Yes*	No
Ben	Yes	Yes*	Yes*	Yes*	Yes*	Yes

* Goal selected from this topic

Table 4: Mats Completed and Goals Selected

Topic Area	Talking Mat		Goals	
	Completed	Age (years) and Sex	Selected Goal	Age (years) and Sex
Preferred Activities	n = 9 (100%)*	*M:* 10 (5-15) (3 x Females)	n = 4 (44%)	*M:* 11 (5-15) (1 x Female)
Adaptive Behaviour	n = 8 (89%)	*M:* 10 (5-15) (3 x Females)	n = 4 (44%)	*M:* 12 (9-15) (1 x Female)
Behaviours that Challenge	n = 8 (89%)	*M:* 10 (5-15) (3 x Females)	n = 5 (56%)	*M:* 11 (9-15) (2 x Female)
Caregiver Positive	n = 8 (89%)	*M:* 10 (5-15) (3 x Females)	n = 4 (44%)	*M:* 11 (9-15) (1 x Female)
Caregiver Unhelpful	n = 6 (67%)	*M:* 10 (5-15) (3 x Females)	n = 4 (44%)	*M:* 10 (9-12) (2 x Female)
Life Quality	n = 4 (44%)	*M:* 10 (9-12) (3 x Females)	n = 0	

In all other cases (n=5) a variety of attempts were made to interview children via TMs but an effective strategy could not be identified. All of these children were described as having limited or no verbal communication skills. Attempts included adaptations to the format of TMs and stimuli, extended periods of introducing the approach in relation to concrete topics, and preliminary sorting/selection exercises. In some instances, children were still able to give some apparent indication of preference to presented items but could not express this in a TM interview format. For instance, Edward smiled/laughed at photographs of activities that his caregiver reported he typically enjoyed. He also stated ‘bad’ and screwed up his face when presented with a picture of a doctor. Notably, Edward had recently undertaken several painful operations.

Other than Stephen, the children interviewed completed between four and six TMs each with the later TMs (relating to parent behaviour and life quality) being completed the least. All children who completed more than one TM also selected goals during the interview (with each child selecting goals for three TMs on average). Across the sample, four to five children selected goals following each TM (with variation as to which children selected goals on each occasion), excepting the final life quality topic where no specific goals were formed by any child. Goals were selected most frequently in relation to children's own CB (by five children).

Things You Like (Preferred Activities)

All nine children completed a TM relating to preferred activities. The majority (eight) indicated relative preference for activities across three basic column areas. For instance, Laura (Figure 1) indicated she liked eight activities (including trampolines and going to the cinema), somewhat liked three (swimming, computers and crafts), and did not like four (shopping, sports, numbers, and reading). For Stephen, two column areas were used. Stephen communicated that he enjoyed five activities (gardening, computers, church, TV, and swimming).

Figure 1: Things You Like (Laura)

When positioning activities to indicate high preference, children referenced both liking and/or being skilled at the activity:

'I love that' (Natasha)

'[Scooter] - yes I'm really good at that' (Emily)

Three of the children also gave a rationale for placing items in the middle column that either discriminated particular aspects of the activity or highlighted conditions that determined whether it was enjoyed:

'If food shopping down here.' 'Toy shopping! Then down here.' (Laura)

'I like games but not puzzles' (Peter)

'Erm…well I like the park but sometimes when it's raining like today, um, it gets really slippery' (Max)

There were two notable examples in which children also highlighted unique activities they enjoyed which were not included in the pre-prepared stimuli but were added to the mat as part of the interview process:

'I like using keyboards and doing the news' (Peter)

'One thing you haven't got here is Lego.' (Ben)

All children referenced preferred activities they currently accessed and those they were not accessing. Two children also referenced a regularly accessed activity that they did in fact not enjoy:

'I love gardening; I go to gardening club at school' (Billy)

'[Cinema] - Granny's said she not going to take me there anymore.' 'Upset, it makes me feel upset.' (Laura)

> *'Gardening – well I do it quite a lot but I don't like it at all' (David)*

When asked if they would like to do more of any activities, four children selected items they would like to increase in the future. This included swimming (two children), games (one child), and music and computers (one child). For one child, it was also possible to specify a particular aspect of the activity he wanted to do in even more detail:

> *'Yeah, more swimming. Tomorrow I am going to swimming lesson and I been to leisure centre, that's where I like to go, and at half-term I gone under water two times and I know how to go fast – just lean back' (Max)*
>
> *'So is it the leisure centre pool, the one with the slide where you want to go to more?' (Researcher)*
>
> *'Yes.' (Max)*

Things You Do

Eight children completed a TM focused on adaptive aspects of their behaviour. Here, all, children placed items across different areas of the mat (including the middle column) to indicate personal strengths and needs. For instance, Emily expressed strengths in relation to six areas (including being friendly and polite, looking after herself, and waiting for things), that she was somewhat good in relation to four (sharing, trying new activities, being funny, and asking for help) and not so good at four (including keeping calm, and working hard). All eight children appeared to take pleasure in highlighting their strengths, for example:

> *'[Helping other people] - I do that a lot, like help with my mum's shopping' and 'well Chris has crutches at my school. Got him pencils or a chair' (Natasha)*
>
> *'[Being Funny] - really good at that, always telling jokes and pulling the silly faces' (Emily)*

Two children were also open about areas they found more difficult and shared something of the struggle they experienced in relation to these:

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

> *'I don't like asking for help.' 'I don't like sharing that often.' (Max)*

Three children also reflected on the variability of their behaviour, discriminated between particular aspects of a given behaviour, or recognised that they responded differently dependent on the context. For instance, when presented with an item relating to 'asking for help', Natasha indicated she did do this when at school. She was then asked about 'asking for help at home' at which point she shook her head. Natasha was then given a second card to symbolise 'asking for help at home', which she placed in the right hand column to indicate something she did not do. Two other children communicated further details or distinctions about their behaviour verbally:

> *'Can I put it in the good and bad? Because I'm good at half it and half not – like one and one and one and one' (Peter)*

> *'[Being loving] Well I do like being loving but I don't like being kissed.'(Max)*

Four children highlighted one or more area they would like to develop strengths in, or be supported for by others. These related to skills in emotional regulation such as keeping calm or being brave (three children) and/or other social interaction and self-determination skills including asking for help and trying new things, making choices, and waiting (two children).

> *'I'm bouncing with fun coz going to see them but this half is not that sure because going somewhere I've not been, well have been but get a bit scared, so that's what' (Emily)*

Other Things You Do

Eight children completed a TM focussed on CB. One child required some initial support to clarify he was being asked to place items in relation to things he did/did not do, rather than things he liked.

> *'I don't like getting angry and upset' (Max)*
>
> *'Arr yes – I see – but is it ever something you do, even if you don't like it?' (Researcher)*
>
> *'er…yeah.' (Max)*

All other children appeared to understand questions asked during this TM from the outset and openly shared a range of behaviours that they displayed. This included Max, who once clear about the focus of the mat, indicated he often pinched himself, became angry and upset, or displayed a tantrum; never hit himself, pinched or bit others; and engaged in a further six behaviours on some occasions (including screaming, breaking things, and kicking others).

Every child reported that they displayed some CB either often or sometimes that included topographies identified by their caregiver at recruitment. Two children indicated behaviours they displayed that had not previously been highlighted by their caregiver. For instance, Emily noted 'yes I do, do that' in relation to an image of self-biting (though no forms of self-injury had previously been indicated by her caregiver).

> *'Ooh I do that always, pull [sister's] hair if she hurts me.' (Peter)*
>
> *'Sometimes throw my duvet off the bed, sometimes even tip the sofa when I'm mad' (Ben)*

In the context of placing stimuli on the mat, three children referenced an emotional state that accompanied or preceded the behaviour, using their own terms to do this:

> *'Have a freak out' '[pulling hair] - when I'm stressed I always do that' (Ben)*
>
> *'Sometimes I do that because I got angry' (Laura)*
>
> *'[Bite-self] - yes always, when I'm angry and stamp my feet like that' (Peter)*

At other times children commented on the behaviour of other people that provided context or motivation for their CB, with three salient examples:

> *'Getting cross – sometimes, when some people are naughty to me.' 'Sometimes [brother] is stroppy, he winds me up.' (Billy)*
>
> *'Kicking people yeah sometimes because they like bully me to get me very angry and I have to fight them back but I don't really want to but because they've got me angry' (David)*
>
> *'[shout or scream] - I do that a lot when want my daddy' (Laura)*

Finally, in one instance a child discussed insight into her self-injurious behaviour indicative of a non-social function:

> *'[Pinching-self] - I do that if I hurt and it stops for a sec - and I give myself a bang – when I got pains' (Laura)*

Five children selected goals in this mat to reduce one or more of the behaviours they had highlighted. For Peter, this included finding ways to less often head-bang, bite and scratch himself; for Ben to have fewer 'freak outs'; and for David to kick and shout less. One child identified a goal that also gave some indication of the underlying function this may have served:

> *‘Pulling Daddy’s arm, not hurting Daddy, but I don’t want him to go’ (Laura)*

Things Your Parent Does

Eight children completed a TM focused on parent behaviour. Separate mats were completed in relation to positive aspects of parenting and unhelpful aspects in three cases. Owing to time restrictions, a combination of these stimuli were presented on the same Mat on a further three occasions and only positive items were covered in two cases. In all cases, children selected their primary caregiver as the focus for questions and appeared to understand that they were now being asked to think about the behaviour of that person as opposed to their own behaviour.

Children who took part in this phase of the interview identified several positive behaviours they perceived their parent to display. These included joint activities such as drawing, cooking, or playing (seven children); help and assistance (eight children); social interactions like talking, listening, and laughing together (seven children); and giving praise and rewards (four children).

> *‘[Looking after you] - we do that – helps me having my blood test – holds my hand, squeezes it very tight.’ (Emily)*

> *‘[Helping you] Yes. that’s what mums are for’ (David)*

All of these children also indicated behaviours of this nature that their caregiver did not display, and in two instances gave further comment or rationale to explain placements they made. For example:

> *‘We don’t do much together.’ (Ben)*

In addition to positive parenting practices, all children presented with relevant stimuli identified and communicated less positive/unhelpful behaviour their caregiver did/did not display:

> *'[Shouting] - Arr… sometimes. These two should go together like shouting "go to your room."' (David)*
>
> *'Holding me, like in a bad way? No she never does that.' (Ben)*

Items selected by children as displayed often or sometimes by their caregiver included reprimands and shouting (four children); negative punishments such as taking away preferred items or ignoring (four children); restraints or smacking (one child); and arguing in front of children (three children). One child also engaged in more detailed discussion of his experience of one of these behaviours:

> *'[Caregiver arguing with other people] - I can't get through them. That's Daddy, Mummy argues with Daddy.' (Billy)*
>
> *'Is that you?' (Researcher)*
>
> *'Yes trying to get through them.' (Billy)*

Children's goals related to altering aspects of caregiver behaviour, and were identified in four cases. Positive parent behaviours that children wanted to increase comprised favoured activities with a caregiver such as playing (three children); cooking or drawing (three children) together with having more praise, rewards (two children); and cuddles (one child).

> *'More playing, building castles' (Billy)*
>
> *'[Rewarding and praising you] definitely that – I'd feel on cloud nine' (Ben)*

Four children selected behaviours they would like their caregiver to reduce, including: arguing with others (one child); reprimands, smacking, and removal of/restrictions to preferred items and activities (three children).

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

Things that are Important

Four children (three females and one male) completed a TM focusing on life quality domains. In all other cases, we did not present this mat due to time restrictions (three cases), or because we believed (from experience in the rest of the interview) that the topic was too complex for the child (two cases).

One child (Emily) indicated 'doing things in the community' was somewhat important (with all other items selected as highly important), and one child (Laura) positioned items across all three columns on the mat. Two children indicated all items presented were highly important while one emphasised extra-high importance for relationships with friends and family by placing the corresponding card completely off the board to the left-hand side.

> *'Friends and family very important – I'll put them right over there' (Natasha)*

> *Two children also provided some account of why an area was so important to them:*

> *'[Physical Health] - Really important if got tummy ache like I've got now since April they always say need to keep healthy, keep fit – and my periods are really bad, makes me feel sad.' (Emily)*

> *'[Personal Development] - When I achieve something I've been working on for a long time that's important.' (Laura)*

Discussion

Prior research interviewing children with IDD (e.g., Aston et al., 2014; Mitchell & Sloper, 2001) has not focused on children's own CB, and the small number of attempts to include young people directly in PBS-procedures beyond preference assessments have largely used verbal methods alone and/or focused on those with no/low levels of IDD (Kinch et al., 2001; Murdock et al., 2005; Stage et al., 2006; Wehmeyer et al., 2004). This study developed and explored a process of engaging directly with young people with a range of IDD and a history of CB to identify personal goals and priorities for future support.

Strengths

It was possible to interview nine participants where, as in prior research (Mitchell & Sloper, 2011; Small et al., 2013), Talking Mats (TM) was a useful method for approaching complex and sensitive discussions. These children seemed to understand the TM framework and used it with fluency and creativity to express their views and experiences and select goals for support; evidenced by both the variety of placements and accompanying questions and statements. Whilst it was not possible to cover all topic areas with all children it was noteworthy that no interviews were terminated due to CB. Children overall appeared happy and confident to work with the researcher in the context of proactive supports.

The study also created a new coding system and established high inter-rater reliability for coding of participant responses (integrated with a basic qualitative analysis of any verbal responses). In conjunction with a manualised protocol, and use of the EFFC (Murphy & Cameron, 2008), this represented a robust methodology. Taken together, the findings of this study suggest it is possible to directly engage at least some children with IDDs and CB as stakeholders in research and in person-centred exercises, with implications for research, practice and policy as will be discussed.

Limitations and Future Research

Notwithstanding the strengths of this study there were some limitations. Firstly, repeating TMs with children to further examine reliability was not possible in our timeframe, but would allow for further exploration of stability (or contextual variability) in children's responses with the potential to strengthen TM procedures in the future. Similarly, this study did not make comparisons to other data or responses obtained from other sources or informants. Related research (as discussed in Chapter Four) has explored the use of a similar goal-selection tool with family caregivers and so such considerations could be readily investigated in the future (and will be further explored in the final discussion chapter of this thesis). Here it should, however, be recognised that differences in the responses of caregivers and children that may be found are not necessarily indications of poor reliability and may rather reflect differences of opinion or experience.

Secondly, it was not possible to complete interviews with five children, all of whom had limited verbal skills or were non-verbal. A variety of supplementary methods were attempted, but a reliable method of communicating via TMs could not be identified for this latter group. However, the endeavour to engage with children did appear valuable in terms of building rapport and establishing a working relationship with children and families. Developing further methods to support direct involvement in goal formation for children with more severe communication impairments is still needed, and the utility of other augmentative communication approaches (Romski et al., 2015) in this context presents a clear opportunity for future research.

Finally, we did not go on to demonstrate use of goal-based information to develop assessment and PBS interventions, which would form a logical focus for future research. Participants were provided with individual reports detailing their priorities and goals, and it could be reasonably hypothesised that this kind of information could support development of effective interventions, linked to outcomes high in social validity (Dunlap, 2006). In line with many person-centred approaches (Carr et al., 2002), this study initially asked children to indicate activities they enjoyed and select those they would like to access more in the future. Children's placements and selections were highly individualised and in practice would provide useful information to structure systems of personal support and scheduling of activities (with the life quality domains that were identified by a smaller number of children also being of strategic value in this regard).

As a first study focused on direct engagement with children with ID who displayed CB, the mid-section of interviews that prompted consideration of children's own behaviour was of particular interest. Here, children identified both CB and adaptive behaviours they displayed. Children appeared to welcome the opportunity to discuss strengths in adaptive areas, and were open and forthcoming when discussing CB. Byrne and Hennessy (2009) found children with moderate IDD made plausible attributions regarding a peer's CB. Children's comments in the current study also highlighted insights regarding causal and maintaining factors, but in this case with reference to their own behaviour. These included actions of other people and reference to emotions that accompanied instances of CB in children's lived experience. Furthermore, when identifying behaviours they struggled with, some children also specified aspects of CB or adaptive behaviour they would like support to change in the future. Information obtained was rich and personal. Such data would not typically be derived within traditional PBS procedures but would seemingly have great value when developing goals for future assessment and behaviour support planning.

Behaviour that challenges is known to often occur within a social context, reinforced by the behaviour of caregivers (Hastings et al., 2013), and so children were also supported to consider aspects of a caregiver's behaviour during interviews. Again, the majority of children interviewed identified and communicated behaviour a caregiver did and did not engage in. Behaviours spanned areas that would and would not usually be considered positive/helpful for children's development, and on at least some occasions were selected by children as a goal area for future support. There are few prior examples of individuals who display CB being invited to comment on the behaviour of those who support them, and again this is not a typical aspect of PBS. Studies that have focussed on this area (Evans & Gore, 2016; Griffith, Hutchinson & Hastings, 2013) have typically interviewed adults with IDD through verbal means about their general perspectives on behaviour of paid caregivers. Children in the current study were asked about more specific parent behaviours, and given the opportunity to use these as a basis for developing goals. Again, incorporating this novel data source into behaviour support planning could have unique potential to bring about change at the level of the caregiver system.

Conclusions and Next Steps for this Thesis

In conclusion, this study provides initial evidence of the potential for direct engagement with children/young people with IDD through a structured process to identify priorities and goals for future behavioural support. Future research is required to consider further communication methods that accommodate the needs of an even greater diversity of children and to explore use and elaboration of information and goals derived through procedures of this nature in later stages of assessment and intervention planning. In addition, future research should examine whether outcomes (changes in CB, improved life quality, and increased consumer satisfaction) of PBS interventions are improved as a result of consulting directly with people with IDD.

A number of research questions remain regarding procedures for engaging children and young people directly in PBS work. Future research and clinical implications of the current study are discussed further in Chapter Eight. Some further research conducted by Gore in this regard has also now been completed and will be referenced further in the final discussion chapter, along with details of a subsequent experience to train a service to utilise the goal selection procedure. Chapters Six and Seven now return to themes concerning partnership working with families of young children with IDD to maximise stakeholder engagement and support high quality, proactive support in the early years in response to the third research question (How can proactive support for children with IDD and families be enhanced in the early years?)

Chapter Six: Early Positive Approaches to Support (E-PAtS): A Logic Model

Overview

Providing proactive supports to families of children with IDD in the early years is critical given the range of difficulties these children and their families are likely to encounter and the heightened risk of behaviours that challenge (CB) and caregiver stress, even when children are very young (Totsika et al., 2011a; 2011b) (as discussed in Chapter One). The human and cost benefits of early intervention in health education and social care more broadly have also long been recognised and commitment to ensuring delivery of early support is now widely embedded in national and international policy and guidance (Cooper, et al., 2014; Department of Health, 2012b; Local Government Association, & NHS England., 2014; World Health Organisation, 2012; World Health Organisation, 2008). This includes recognition of early years support for people with intellectual and developmental disabilities (IDD) yet often the needs of this group remain marginalised (The Challenging Behaviour Foundation & Council for Disabled Children, 2015; Wodehouse & McGill, 2009; Sapiets, Totsika, & Hastings, 2021).

At the same time, interviews within Chapter Four highlighted the importance of partnership working and the capacity, insight and motivation of caregivers to both recognise and meet the complex needs of their child when equipped with informed and sensitive support from others. Ensuring provision of timely and organised supports, attuned to the particular needs of families raising a child with IDD is therefore a key priority for professionals and services. Responding to both research questions Two (‘How can stakeholder engagement be maximised to enhance support for children with IDD and their families?’) and Three (‘How can proactive support for children with IDD and families be enhanced in the early years?'), Chapters Six and Seven explore one such programme of support called Early Positive Approaches to Support (E-PAtS)

E-PAtS has been developed since 2012 (prior to and throughout the period of PhD) under the leadership of Gore, through partnership working with a community of family caregivers, professionals and researchers. E-PAtS was founded upon values and theoretical assumptions common to the Positive Behavioural Support (PBS) framework but over time has incorporated an increasingly holistic approach to child development and caregiver wellbeing at a family-systems level. Recent developments to the programme have been further influenced by the exploration of literature and empirical work contained within this thesis. This has facilitated the development of a detailed programme logic model, which is the focus of this chapter. An initial qualitative evaluation of E-PAtS delivery follows in Chapter Seven.

Introduction

Logic Models

Logic models are increasingly used to formulate and guide the design, implementation and evaluation of intervention programmes and some helpful examples have begun to emerge in the field of IDD (Scott, Denne & Hastings, 2018). In simple terms, logic models provide a visual representation of a programme's rationale, assumptions and conceptual underpinnings and make explicit how fundamental features of the programme operate to achieve intended outcomes. Logic models can also helpfully include information relating to potential risks and enablers to support successful implementation. Logic models are particularly helpful when working with multiple stakeholders as a means of consolidating a shared understanding and as a dynamic communication aid to shape development, thinking and action over time (McLaughlin and Jordan, 1998; Shakma & Rodriguez, 2015; Van Loon et al., 2010).

A Logic Model for E-PAtS

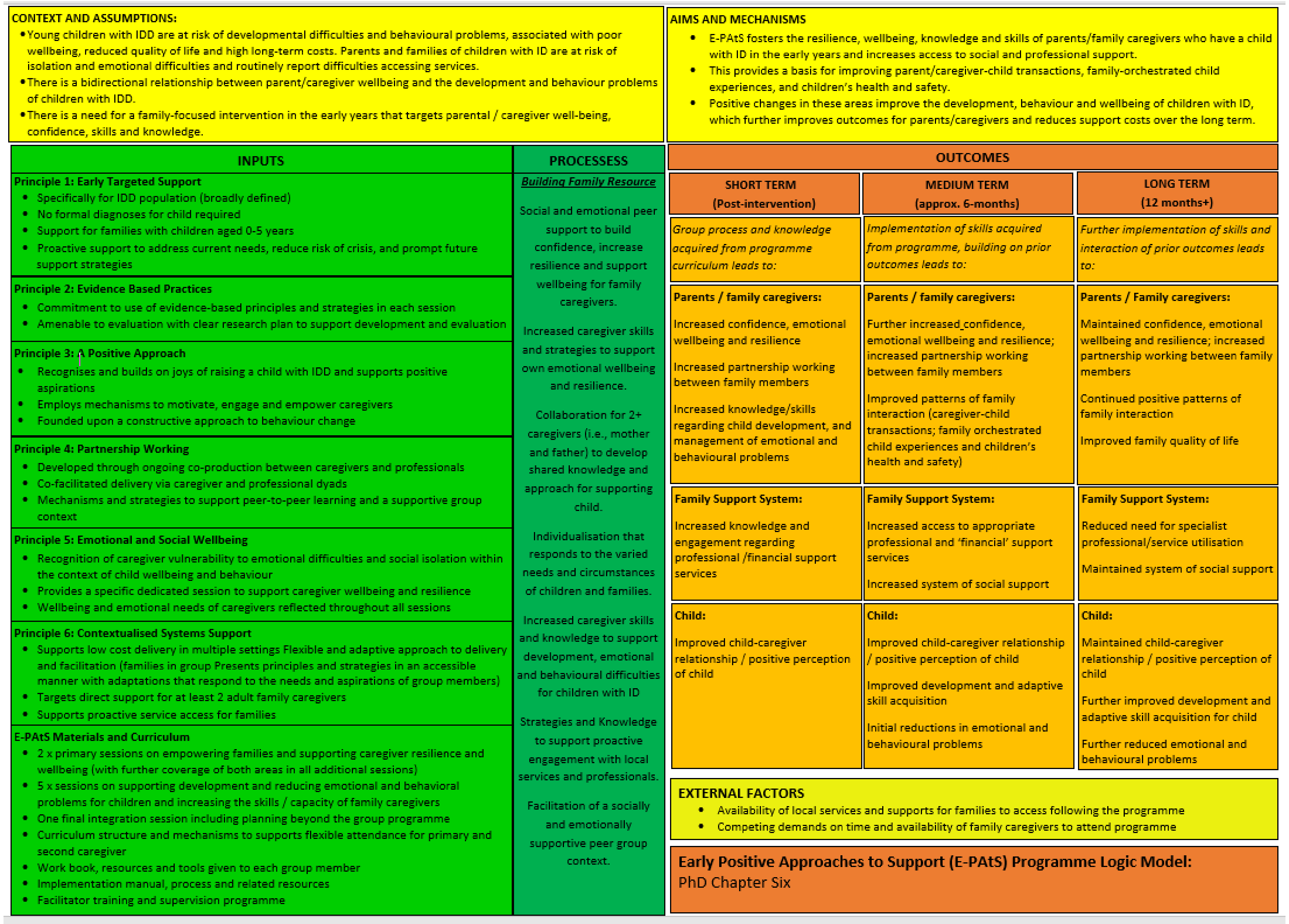
E-PAtS has been developed through an iterative process of co-production, incorporating new ideas and ways of working over time. Creation of a detailed logic model therefore appeared timely and conducive to furthering positive contexts of support for families. The E-PAtS logic model, developed throughout the time period of this thesis, is presented in Figure 1. This summarises the contextual considerations, theoretical assumptions, aims and mechanisms of the programme, linked to predicted outcomes over the short, medium and longer term. The model includes six (design) principles that specify key conceptual, practical and values-based inputs to the programme. This chapter discusses major aspects of the logic model in turn, beginning with a review of relevant literature to describe the theoretical underpinnings and evidence-base, relating to both the context and assumptions, logic model aims and mechanisms, and predicted outcomes. This is followed by a description of the key programme design principles and an overview of materials and curriculum.

The E-PAtS Logic Model

Context and Assumptions

'Young children with IDD are at risk of developmental difficulties and behavioural problems, associated with poor wellbeing, reduced quality of life and high, long-term costs.'

Whilst often referred to collectively, children with IDD represent a diverse group of individuals with varying levels of need, strengths and attributes (Emerson, & Einfeld, 2011). This group includes children with mild to profound Intellectual Disabilities (ID), those diagnosed with Global Developmental Delay (GDD) and those who have a diagnosis of Autism (AAIDD, 2013; WHO, 2018). The environmental circumstances of children with IDD also span multiple socio-economic contexts, across the globe (Carr & O'Reilly, 2016a; Emerson, 2012a; Iarocci & Petrill, 2011).



CONTEXT AND ASSUMPTIONS:

- Young children with IDD are at risk of developmental difficulties and behavioural problems, associated with poor wellbeing, reduced quality of life and high long-term costs. Parents and families of children with ID are at risk of isolation and emotional difficulties and routinely report difficulties accessing services.
- There is a bidirectional relationship between parent/caregiver wellbeing and the development and behaviour problems of children with IDD.
- There is a need for a family-focused intervention in the early years that targets parental / caregiver well-being, confidence, skills and knowledge.

AIMS AND MECHANISMS

- E-PAtS fosters the resilience, wellbeing, knowledge and skills of parents/family caregivers who have a child with ID in the early years and increases access to social and professional support.
- This provides a basis for improving parent/caregiver-child transactions, family-orchestrated child experiences, and children's health and safety.
- Positive changes in these areas improve the development, behaviour and wellbeing of children with ID, which further improves outcomes for parents/caregivers and reduces support costs over the long term.

INPUTS

Principle 1: Early Targeted Support
- Specifically for IDD population (broadly defined)
- No formal diagnoses for child required
- Support for families with children aged 0-5 years
- Proactive support to address current needs, reduce risk of crisis, and prompt future support strategies

Principle 2: Evidence Based Practices
- Commitment to use of evidence-based principles and strategies in each session
- Amenable to evaluation with clear research plan to support development and evaluation

Principle 3: A Positive Approach
- Recognises and builds on joys of raising a child with IDD and supports positive aspirations
- Employs mechanisms to motivate, engage and empower caregivers
- Founded upon a constructive approach to behaviour change

Principle 4: Partnership Working
- Developed through ongoing co-production between caregivers and professionals
- Co-facilitated delivery via caregiver and professional dyads
- Mechanisms and strategies to support peer-to-peer learning and a supportive group context

Principle 5: Emotional and Social Wellbeing
- Recognition of caregiver vulnerability to emotional difficulties and social isolation within the context of child wellbeing and behaviour
- Provides a specific dedicated session to support caregiver wellbeing and resilience
- Wellbeing and emotional needs of caregivers reflected throughout all sessions

Principle 6: Contextualised Systems Support
- Supports low cost delivery in multiple settings Flexible and adaptive approach to delivery and facilitation (families in group Presents principles and strategies in an accessible manner with adaptations that respond to the needs and aspirations of group members)
- Targets direct support for at least 2 adult family caregivers
- Supports proactive service access for families

E-PAtS Materials and Curriculum
- 2 x primary sessions on empowering families and supporting caregiver resilience and wellbeing (with further coverage of both areas in all additional sessions)
- 5 x sessions on supporting development and reducing emotional and behavioral problems for children and increasing the skills / capacity of family caregivers
- One final integration session including planning beyond the group programme
- Curriculum structure and mechanisms to supports flexible attendance for primary and second caregiver
- Work book, resources and tools given to each group member
- Implementation manual, process and related resources
- Facilitator training and supervision programme

PROCESSESS

Building Family Resource

Social and emotional peer support to build confidence, increase resilience and support wellbeing for family caregivers.

Increased caregiver skills and strategies to support own emotional wellbeing and resilience.

Collaboration for 2+ caregivers (i.e., mother and father) to develop shared knowledge and approach for supporting child.

Individualisation that responds to the varied needs and circumstances of children and families.

Increased caregiver skills and knowledge to support development, emotional and behavioural difficulties for children with ID

Strategies and Knowledge to support proactive engagement with local services and professionals.

Facilitation of a socially and emotionally supportive peer group context.

OUTCOMES

SHORT TERM (Post-intervention)	MEDIUM TERM (approx. 6-months)	LONG TERM (12 months+)
Group process and knowledge acquired from programme curriculum leads to:	*Implementation of skills acquired from programme, building on prior outcomes leads to:*	*Further implementation of skills and interaction of prior outcomes leads to:*
Parents / family caregivers: Increased confidence, emotional wellbeing and resilience Increased partnership working between family members Increased knowledge/skills regarding child development, and management of emotional and behavioural problems	**Parents / family caregivers:** Further increased confidence, emotional wellbeing and resilience; increased partnership working between family members Improved patterns of family interaction (caregiver-child transactions; family orchestrated child experiences and children's health and safety)	**Parents / Family caregivers:** Maintained confidence, emotional wellbeing and resilience; increased partnership working between family members Continued positive patterns of family interaction Improved family quality of life
Family Support System: Increased knowledge and engagement regarding professional /financial support services	**Family Support System:** Increased access to appropriate professional and 'financial' support services Increased system of social support	**Family Support System:** Reduced need for specialist professional/service utilisation Maintained system of social support
Child: Improved child-caregiver relationship / positive perception of child	**Child:** Improved child-caregiver relationship / positive perception of child Improved development and adaptive skill acquisition Initial reductions in emotional and behavioural problems	**Child:** Maintained child-caregiver relationship / positive perception of child Further improved development and adaptive skill acquisition for child Further reduced emotional and behavioural problems

EXTERNAL FACTORS
- Availability of local services and supports for families to access following the programme
- Competing demands on time and availability of family caregivers to attend programme

Early Positive Approaches to Support (E-PAtS) Programme Logic Model:
PhD Chapter Six

Figure 1: The E-PAtS Logic Model

Whilst the needs of children with IDD are not homogenous, some key domains in which difficulties (at some level) are relatively common are apparent, especially in the early years. Firstly, by definition, children with IDD typically struggle to learn every day or adaptive skills that may support independence or agency/self-determination (AAIDD, 2013; Tassé et al., 2012; WHO, 2018). Young children with IDD therefore generally present with a delay in the context of key developmental milestones (Vlasblom et al., 2019). Whilst there is variation in how caregivers perceive and respond to developmental difficulties, many feel ill-equipped to support their child's development through typical parenting approaches alone and without additional support (Douglas, Redley & Ottmann, 2017; Douglas, Redley, & Ottmann, 2016; Gallagher, Phillips, & Carroll, 2010; Plant & Sanders, 2017; Willingham-Storr, 2014).

Caregiver concerns regarding children with IDD are notable in relation to two areas in particular. Firstly, children with IDD are often slow to acquire social and communication skills, both in terms of understanding the communications of another person, and in terms of expressing their own needs and desires (Carr, & O'Reilly, 2016b; Chadwick, et al., 2019) and this is often the earliest concern raised by caregivers who contact services and whose children are later diagnosed with an IDD (Hess & Landa, 2012; Kozlowski, Matson & Horovitz, 2011; Romski, et al., 2015). Secondly, caregivers of children with IDD often encounter difficulty (and associated distress) in supporting their child to sleep, an area that has further negative impact on children's health and wellbeing and the wellbeing and functioning of caregivers (Bonuck & Grant, 2012; Kirkpatrick, et al., 2019; Krakowiak, et al., 2008; Priday, et al, 2017; Quine, 2001).

Developmental difficulties in and of themselves therefore present a challenge for a child and their family. In combination with a range of other factors and processes, these difficulties do however, also contribute towards the development of CB amongst children with IDD and are known risk factors for such behaviour (Hastings et al., 2013; McClintock et al., 2003). As a theoretical basis for PBS, Hastings et al., (2013) conceptualised both biological and psycho-social variables of this nature as broad contextual events that collectively increase vulnerability to the development of CB.

Given propensity to need in these areas, relative to typically developing children, those with IDD are therefore at increased risk of developing CB including aggression and self-injury, even from a very young age (before the child is five) (Totsika et al., 2011a). Such behaviours are known to persist, without appropriate support, and have a widespread negative impact on the life of the individual and those who care for them (Murphy et al., 2005; Totskia et al., 2011b). Consequences include physical harm, with children who display CB also at increased risk of restrictive and abusive treatment from others and reduced quality of life at both an individual and family level (Adams & Allen, 2001; Allen, et al., 2006; Allen, Hawkins, & Cooper, 2006; Emerson and Einfeld, 2011; Menon, Baburaj, & Bernard, 2012; McGill, et al., 2006; McGillivray & McCabe, 2006; McQuire, et al., 2015; Unwin & Deb, 2011).

'Parents and families of children with IDD are at risk of isolation and emotional difficulties and routinely report difficulties accessing services.'

As with their children, families raising a child with IDD are diverse in terms of resources, needs, situation and constitution, and report both positive and challenging experiences and outcomes associated with their child and family life (Hastings & Taunt, 2002; Hubert, 2010; Kenny & McGilloway, 2007; Plant & Sanders, 2017). Family caregivers have provided rich accounts of the positive gains associated with raising a child with IDD, in terms of insight, opportunity and personal growth (Griffith, & Hastings,2014; Hastings, Beck, & Hill, 2005). Relative to caregivers of typically developing children, caregivers raising a child with IDD are, however, also known to be at increased risk of experiencing stress and emotionaldifficulties (Baker et al., 2003; Hastings, 2002a), with these differences notable even when children are under the age of five years (Tosika et al., 2011b).

In the early years (and sometimes beyond), caregivers also often report challenging emotional experiences that relate to the birth, diagnosis and early interactions with their child and others. Reactions vary between families and over time (Poehlmann, Clements, Abbeduto & Farsad, 2005) but caregivers often describe an initial grief-type response, as they adjust to the apparent loss of the child they had expected, the realisation of the child who is now theirs to raise, and the consideration of what this may mean for their future lives (Blacher, 1984; Feniger-Schaal, & Oppenheim, 2013; Foley, 2006). Again, the availability and nature of social support but also the attitudes and support of professionals and society appear to be critical features in determining caregivers' experience and wellbeing in the early years (Brotherson et al., 2010; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Summers et al., 2007)

Research has demonstrated that some of the variance in caregiver wellbeing is closely associated with the type of difficulties a child presents with, whereby CB appears to particularly and reliably predict emotional distress (Baker et al., 2003; Hastings, 2002a; Woodman, et al., 2015). In addition to characteristics of the child however, availability of environmental and psychological resources has also been found to influence the wellbeing of caregivers and promote positive outcomes (Brown, et al., 2011; Dunlap & Fox, 2007; Dunlap & Fox, 2009; McConkey et al., 2013). This includes the personal coping strategies and styles adopted by caregivers (e.g., active coping, psychological acceptance and mindfulness) (Glidden & Natcher, 2009; Lloyd, & Hastings, 2008; Resch et al., 2012; Totsika & Hastings, 2009).

In addition to personal and psychological coping, access to and utilisation of sources of social and professional support have also been found to predict emotional wellbeing for caregivers (Brotherson et al., 2010; Crnic et al., 2017; Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Summers et al., 2007). In relation to this later area it is, however, recognised that families of children with IDD often report isolation from peers and extended family and encounter barriers to accessing the community, particularly (though not solely) when their child presents with CB, that is closely connected with feelings of stress (Davies & Honeyman, 2013; Emerson, 2001; Griffith and Hastings, 2014; Singer, 2006; Turnbull & Ruef, 1996; Zablotsky, Bradshaw, & Stuart, 2013).

Overall, delivery and receipt of specialist services that meet the needs of families who have a child with IDD is still relatively rare within the UK (Galpin et al., 2018; Griffith et al., 2011) and unmet needs were highlighted by many families when interviewed in Chapter Four of this thesis. Families of children with IDD often describe very negative experiences and a sense of "battling" against the system (Griffith & Hastings, 2014) and access to services and professionals is known to be very limited for children with IDD. For example, a secondary analysis of UK population-based data by Toms, Totsika, Hastings and Healy (2015) found that less than 30% of parents of children with an ID and a diagnosable mental health difficulty had access to mental health services in the preceding 12 months. Both children with IDD and their parents therefore face significant inequalities in this regard.

'There is a bidirectional relationship between parent/caregiver wellbeing and the development and behaviour problems of children with ID.'

Behaviour that challenges and caregiver stress often go hand-in-hand. Significantly, whilst CB amongst children with IDD presents a risk to the wellbeing of caregivers, caregiver stress, through its influence on parenting behaviour, is also a known risk factor for the development of CB in children, and known to influence interactions between children and caregivers more broadly in the context of child development (Neece et al., 2012; Hastings et al., 2013; Lucyshyn et al., 2004; Totsika et al., 2014). Several psychological models have highlighted the dynamic interplay between the behaviour and wellbeing of caregivers and their children with IDD in this way, but two models have been particularly influential.

Firstly, the conceptual model of CB outlined by Hastings et al., (2013) describes operant processes of social reinforcement, whereby caregiver responses to CB may provide reinforcing consequences that (inadvertently) serve to maintain the behaviour over time. Related literature has demonstrated that responses of this nature are more likely for caregivers who are experiencing emotional difficulties in response to the behaviour (Totsika et al., 2014). These processes, alongside other sources of reinforcement, within the context of bio-psycho-social vulnerabilities as outlined earlier, underpin typical conceptions of PBS.

Outside of the field of PBS, The Developmental Systems Model (DSM) created by Guralnick (Guralnick, 2001; 2005a), also provides a framework for understanding and supporting the early development of children with and without IDD (Guralnick, 2005b; 2017) and has also been particularly influential in supporting an analysis of child and caregiver relations in this way. Within the DSM, and consistent with thinking that underpins Family Systems Theory (Dunst, & Trivette, 1988; Trivette, Dunst & Hamby, 2010) Family Patterns of Interaction, within both a Couple and Parent-Child Subsystem, are considered the central processes that determine developmental outcomes for children, and wellbeing for children and families. Here, it is further recognised, that Family Characteristic Stressors (e.g., caregiver stress) and Child Stressors (e.g., needs of a child with IDD), in combination with availability of family and material resources determine the nature and quality of Family Patterns of Interaction that are critical to child development and behaviour. Parallels are also notable here with regards broader literature concerning coercive caregiver-child interactions

(Eddy et al., 2001; Patterson, 1982) and corresponding applications within the IDD field (e.g., Lucyshyn et al., 2004).

‘There is a need for a family-focused intervention in the early years that targets parental / caregiver well-being, confidence, skills and knowledge.’

Prior research, discussed thus far, has highlighted the needs and challenges faced by families raising young children with IDD and that early-years support has been advocated for in a variety of policy publications over the past ten years. There is, however, a limited range of evidence-based, family focused, interventions available that are specific to families raising a child with IDD and provide a comprehensive coverage of their needs. Intervention programmes that aim to equip family caregivers with the parenting skills and knowledge to support their child with IDD (most typically referred to as ‘parenting interventions’) that may (or may not) also consider caregiver wellbeing were the focus of a systematic review by the National Institute of Clinical Excellence (NICE) to inform the Mental Health Problems in People with Learning Disabilities clinical guideline (NICE, 2016).

A total of 15 randomised controlled trials (RCTs) of parenting programmes involving parents of children with ID were identified. With one exception (an RCT of an individual-family delivered PBS intervention for young children with intellectual disability and severe behaviour problems (Durand et al., 2013) these programmes were not developed specifically for parents of children with IDD. Rather, they were adapted from mainstream parenting programmes (e.g., Stepping Stones Triple P: Tellegen & Sanders, 2013). All of these programmes also had a primary focus on achieving reductions in problem behaviour for children that was already impacting in significant ways, and the vast majority did not focus on very early years (preventative) support for families.

A range of other early interventions focused directly on the particular aspects of behaviour and learning of children with IDD, often with a skills building focus, have been demonstrated to good effect using other research methodologies (Eldevik et al., 2010). These studies and interventions have typically been implemented by professional mediators and/or without support at a family-systems level. At the same time, other interventions have been developed and researched that are specific to supporting positive outcomes for family carers of children with IDD themselves, with regards wellbeing/mental health (Dykens et al., 2014; Singer et al., 2007) but without additional detailed coverage of child-specific strategies and support. Finally, a variety of psycho-education interventions for caregivers, offering varying focuses and partial coverage of the needs of children/young people or adults with IDD, service access or basic information on caregiver wellbeing also exist (Hsieh, Hsieh, & Lee, 2016; Lunsky et al., 2017; Picard et al., 2014; Taylor et al., 2017; DaWalt, Greenberg, & Seltzer, 2018).

It is undoubtedly the case that the examples discussed thus far have the potential to provide helpful elements of support at varying points of a care pathway. There is evidently a gap, however, in a group programme that brings together a systems-approach, bespoke to families of children with IDD in the pre-school period, access to which is not contingent on the prior development of behaviour difficulties. Such a programme could be of particular value as a universal offer to families and consequently, there is a great need to both develop further interventions and research their use in practice.

Aims and Mechanisms and Outcomes

Families of children with IDD, particularly in the context of CB, have tended to report dissatisfaction with service provision and remain vulnerable to poor outcomes (Galpin et al., 2018; Griffith et al., 2011; Wodehouse & McGill, 2009). Such dissatisfaction has included limited overall availability of services; lack of services that are specifically attuned to the needs of children with IDD and the timing of service provision. A ‘post-code lottery’ is often described whereby provision of support is subject to considerable local variation, with cost often a mitigating factor for services and prior diagnosis a pre-requisite for user access. Families have often reported that critical support in the early years was therefore absent and / or any support that later became available did so in the context of crisis or at a point when a difficulty had impacted significantly on family and child QoL (Grifith & Hastings, 2014; The Challenging Behaviour Foundation & Council for Disabled Children, 2015; Wodehouse & McGill, 2009).

Whilst useful and evidence-based practices exist, these have typically not been organised into a low cost, coherent and strategic system of support that can be routinely implemented across different settings, for families of children with IDD specifically, to address the range of factors and processes relevant to their needs in the early years. E-PAtS was developed in response to these continuing areas of need drawing upon a range of behaviourally-orientated theoretical models with the aim of increasing positive outcomes for caregivers, families and children with IDD.

E-PAtS includes content that is largely typical within a PBS framework (e.g., information and resources concerning functional assessment and behaviour support planning), but also aims to support access to appropriate services (as a focus for the first session and an element of all following sessions), proactively address other areas of developmental difficulty for children (three dedicated sessions), and, critically, bolster emotional resilience for families (in both a dedicated session and throughout the programme). Prior research has highlighted that each of these later areas present as frequent and ongoing challenges for families and children with IDD and are therefore priority areas to consider in a comprehensive support programme.

Since these areas are also known risk factors for the development of CB, E-PAtS has the potential to operate as a preventative CB intervention by providing early, constructive and proactive supports. For instance, CB is conceivably less likely to develop if caregivers are equipped with the necessary skills and knowledge to support communication and other adaptive skills for their child (Allen et al., 2013; McClintock, et al., 2003). Similarly, caregivers who are less stressed are likely better able to engage in positive parenting practices and less likely to engage in coercive practices associated with maintenance of child CB (Ho, Perry & Koudys, 2021; Neece et al., 2012; Totsika et al., 2014).Whilst addressing these areas makes conceptual sense in relation to PBS, intervening in this manner has not been a typical feature of the PBS framework and little PBS research exists to guide how best to advance and organise such an approach in practice. In addition to theoretical models that concern PBS traditionally (e.g., Hastings et al., 2013), E-PAtS therefore also draws on concepts and practices in other evidence-based areas of behavioural psychology.

Consistent with the theoretical underpinnings of the DSM and broader literature relating to caregiver stress, E-PAtS hypothesises that fostering a foundation of emotional resilience for caregivers and building material resources via service access, increases the potential for positive Patterns of Family Interaction. These mechanisms of change are predicted, in turn, to increase the likelihood of positive development for children with IDD and reduce the potential for development and maintenance of CB, further reducing risks and improving other life quality outcomes for families over the longer term. These aims correspond to the categorisation and predicted ordering of outcomes depicted in the E-PAtS logic model, with positive changes hypothesised to occur principally for caregivers in the short-term (in relation to knowledge, confidence, wellbeing and family relationships) with improved Patterns of Family Interaction predicted to emerge in the mid-term and changes in child development and behaviour occurring longer-term.

Design Principles

The E-PAtS logic model includes six (design) principles that specify conceptual, practical and values-based inputs to the programme building upon the context, assumptions and mechanisms as discussed. The first of these, concerns a specific focus on families of children with IDD in the early years and breadth of access requirements (Principle One: Early Targeted Support for Families of Children with Intellectual and Developmental Disabilities). The second, a commitment to use of evidence-based practice and further development of programme evidence over time (Principle Two: Evidence Based Practices).

The third principle (A Positive Approach) concerns the constructional approaches taken to skill development; an aspirational approach to family outcomes and fostering of motivation. The co-production of E-PAtS with regards the initial development and ongoing refinements, the co-facilitation approach and peer discussion processes is captured within the forth principle (Partnership Working and Peer Empowerment). Both the explicit content and focus on wellbeing in session two and the ongoing social and emotional support hypothesised by the peer-to-peer and facilitator approach comprises the fifth principle (Emotional and Social Wellbeing). Finally, the sixth principle (Contextualised Systems Support) depicts the flexible delivery of materials by facilitators in accordance with group members' needs, strategies to support engagement at a family systems-level and the organisational implementation process developed for E-PAtS.

'Principle one: Early Targeted Support for Families of Children with Intellectual and Developmental Disabilities.'

E-PAtS has been developed specifically for families of young children with IDD, rather than through adaptation of a mainstream-parenting programme, in response to the particular needs, experiences and aspirations of families who have a child with IDD. The contextual considerations of E-PAtS, mode of delivery and methods of facilitator training are designed to meet the needs of families with children who have a broad range of needs, and provide early support to the IDD population at large. E-PAtS may therefore be considered ‘targeted’ in relation to the general population but effectively ‘universal’ with respect to the IDD population (Allen et al., 2013). E-PAtS is intended to be implemented by services as a first offer to all families raising child with IDD to provide a firm foundation for the future. Following E-PAtS, it is likely that some families (i.e., those in more challenging circumstances and/or supporting children with more complex needs), will require additional forms of support. Within a tiered service provision, E-PAtS can therefore be conceptualised as a form of primary prevention.

E-PAtS deliberately avoids narrow inclusion criteria and aims to support families of children who may have mild to profound levels of IDD and who may have a range of accompanying complexities of need. The flexible and adaptive delivery of E-PAtS (see later principles) aims to support good contextual fit, through individualisation of programme curriculum, in ways that respond to the varied needs and circumstances of children and families, and capitalises on the learning that can be achieved through embracing such diversity.

E-PAtS aims to provide sensitive, timely and effective intervention in the early years, and focuses on provision of support to families with a child aged 0-5years. This corresponds to the pre-school period in the UK but more broadly to what is recognised as a critical period for child development and a time of particular need for caregivers. Connecting with families at this time is intended to allow for development of proactive supports and resources that maiximise the likelihood of positive outcomes and safeguard against difficulties, for both the child and family. Even at this early stage, however, families are often already experiencing significant difficulties in aspects of their child’s development or behaviour, that are starting to impact on wellbeing and life quality. Support provided by E-PAtS in this period is intended to respond to immediate needs and provide short-term benefits as well as supporting longer-term positive gains and reducing further development of difficulties.

The E-PAtS programme recognises the diversity of the IDD population and the practical, and sometimes political, factors that relate to delayed diagnosis of IDD amongst children. Programme attendance therefore does not require that children have been formally diagnosed with IDD prior to their family accessing the programme, rather that IDD is suspected and a later diagnosis likely. This ensures that families who are in need of support can access the programme as soon as possible and that acquiring or waiting for a diagnosis does not serve as a barrier to this. Ultimately, E-PAtS aims to provide support to as many (potentially) at risk families as possible, as early as possible, to maximise positive outcomes and reduce the likelihood of difficulties, rather than waiting for such difficulties to arise and require more complex intervention.

'Principle Two: Evidence Based Practices.'

E-PAtS is committed to delivery of evidence-based strategies and principles at all times to ensure families of children with IDD can readily access and utilise the best quality information and support available. This includes grounding in fundamental research from behavioural psychology and research that is specific to the needs and circumstances of people with IDD and their families. Evidence-based approaches are synthesised within the content of each session to support emotional wellbeing (e.g., Blackledge & Hayes, 2006; Pergolizzi et al., 2020; Reid et al., 2015), sleep (e.g., Priday et al., 2017) communication and adaptive skills (e.g., Ho et al., 2021) and a positive approach to behaviours that challenge (e.g., Carr et al., 2002; Durand et al., 2013). These approaches also, inform the way in which facilitators provide support to group members and informs the E-PAtS implementation process (see below). Evidence-based practices utilised within E-PAtS have been drawn directly from an in depth review of available research and theory in the field as previously summarised (Gore et al., 2014) and from on-going consultation and input from academics and specialist practitioners in the field (see partnership working).

In addition to a grounding in current evidence based practices, E-PAtS has been designed within a research context with aspiration and clear mechanisms for supporting further evaluation to inform future development. E-PAtS is fully manualised (including manuals for sessions, facilitator training and implementation) and has created 3 fidelity checklists, all of which guide delivery in practice but also support robust testing. E-PAtS encourages implementers to gather some outcome data during each programme delivery and provides a questionnaire for use in the final session as a minimal requirement. E-PAtS has a commitment to developing and actioning a research agenda over time to build an evidence-base for programme delivery.

'Principle Three: A Positive Approach'

E-PAtS responds to the particular needs and challenges faced by families of children with IDD, through a fundamentally positive orientation that celebrates and builds on the potential joys of raising children with IDD. As previously discussed, it is known from research (though not always emphasised) that many caregivers report positive experiences and perceptions of their child with IDD that are functionally related to their own wellbeing and behaviour (Hastings & Taut, 2002). E-PAtS therefore aims to hold balance between a realistic appreciation of challenges caregivers and people with IDD may face, and encouragement for families to maximise joyful experiences. Within E-PAtS, caregivers are gently supported to be aspirational, with the aims of the programme described primarily in terms of support for life quality (or ‘getting the best life for you and your family’) with reduced risk of potential difficulties a consequent, but secondary, outcome.

E-PAtS is built on an assumption that caregivers and children with IDD can experience rich, meaningful and satisfying lives, even in the context of considerable demands, given appropriate opportunities, resources and support, and that some potential difficulties can be reduced through practical strategies. Motivation for families to proactively address areas of difficulty and move towards desired futures is strongly supported by this view, alongside a related message that caregivers (in a supportive context) have the inherent insight, skills and power necessary to determine such outcomes. The assumptions of E-PAtS are considerably different to a deficit model that centres on inadequacy of caregiver (i.e., parenting) skills. In E-PAtS, caregivers are considered the solution, not the problem, with the role of the programme and work of facilitators being to nurture personal strengths and qualities in ways that empower.

The content and structuring of E-PAtS sessions are also built on a positive, constructional approach that is consistent with this standpoint. Each session highlights and validates particular areas of risk or need for families and children, but places an overriding focus on proactive strategies to support the development of positive outcomes. Positive reinforcement strategies are used throughout all sessions in a manner that responds to the particular circumstances and goals of caregivers to help build resource, and increase development of positive skills, strategies and experiences. This includes, empowering caregivers to take an assertive approach to securing service support for their family and to develop self-care strategies through commitment to values-based behaviour change. It also includes supporting caregivers to understand and utilise constructional approaches with regards their child’s development and wellbeing. Precision teaching, total communication and positive behavioural approaches are the foundations of key sessions concerning children's sleep, communication and adaptive skill development together with support for CB.

'Principle Four: Partnership Working and Peer Empowerment.'

E-PAtS has been co-produced through ongoing partnership work between family caregivers of children with IDD and professionals over an eight-year period (to date), ensuring materials and methods of delivery are grounded in evidence-based practices as previously described but also closely aligned to families' needs, and that relevance and appropriateness is maximised to support engagement. This element has been reflected in both the initial development of programme curriculum, modifications made following early piloting work and builds on literature and experience concerning partnership working (Bovaird,2007; Dew et al., 2013; Dunlap & Fox, 2007; Dodds, & Singer, 2017; Gore & Umizawa, 2011; Shilling et al., 2013; Solomon, Pistrang, & Barker, 2001). Throughout this period, E-PAtS developers have consulted, and continue to consult, with a range of family caregivers (including mothers, fathers and grandparents) to support development and refinement of programme content and process.

In addition to driving programme development, co-production and partnership working is integral to how E-PAtS is delivered. E-PAtS is routinely co-facilitated by a (paid) family caregiver of a child with IDD working in partnership with a professional and this has been a fundamental aspect of the programme since its initial conception. A relatively small number of peer-led programmes have been created in the IDD field but those that have (Gore & Umizawa, 2011; Santelli, Poyadue, & Young, 2001) (and peer-led programs more broadly; Shilling et al., 2013) have suggested particular strengths in relation to supporting engagement and positive outcomes.

Whilst professionals will undoubtedly bring useful experiences and critical knowledge to a programme such as E-PAtS, this is likely to be only part of what is needed. E-PAtS recognises that family caregivers bring a different and very valuable type of expertise and knowledge, that which is gained through direct, lived experience (Ainbinder et al., 1998; Shilling, Bailey, Logan & Morris, 2015; Shilling et al., 2013). Through this, caregivers are considered to be best placed to really understand the joys and challenges associated with raising a child who has a disability and to know what works best in practice. Co-facilitation therefore has the potential to maximise both contextual fit and social validity, both of which are cornerstones of PBS (Albin et al., 1996; Carr et al., 2002; Lucyshyn et al., 2002).

Whilst the curriculum of E-PAtS provides key information and resources, learning within sessions is promoted principally through peer-led discussions and sharing of experience and ideas. Meeting and working with peers who are experiencing similar challenges, and being supported by a facilitator who is also a caregiver, is intended to establish shared social norms and build inspiration and insight for group members. As in other peer-support programmes, group context provides the conditions for open dialogues and as such is hypothesised as key to supporting confidence and self-determined behaviour change for group members (Dew, Collings, Dowse, Meltzer & Smith, 2019).

'Principle Five: Emotional and Social Wellbeing'

Sensitivity and support for the emotional needs of caregivers is fundamental to the E-PAtS model and reflected in both programme content and the manner in which facilitators engage with and support group members. A central aim of E-PAtS is to validate the emotional vulnerabilities and needs of caregivers, support service access in relation to these and to empower group members to develop self-management and social support systems that reduce current difficulties and foster resilience in the context of child rearing (Peer & Hillman, 2014).

Founded on learning from research concerning partnership working (Brotherson et al., 2010; Dempsey et al., 2009; Dunlap & Fox, 2007; Dunlap & Fox 2009; Dunst, Trivette & Johanson, 1994; Summer et al., 2007) E-PAtS aims to establish an emotionally and socially supportive group context at all times and facilitation by family caregivers has multiple advantages in this regard. It is likely that caregivers who are experiencing emotional difficulties may feel more at ease when with other caregivers, and trust support and advice from those who have ‘walked in similar shoes’. The therapeutic benefits and group processes of normalising difficult experiences and emotional distress are key features of most third-wave behavioural approaches to supporting wellbeing. These modes of interaction are actively harnessed within the E-PAtS programme curriculum, and built upon through facilitator training and supervision in therapeutic competencies. Facilitators are therefore well placed to ensure the emotional needs of caregivers are recognised and responded to sensitively and constructively, and that supportive relationships are maximised between group members.

E-PAtS also includes a dedicated session that focusses entirely upon emotional wellbeing for caregivers, connecting closely to coping-research in the field of IDD (Glidden & Natcher, 2009; Lloyd, & Hastings, 2008; Resch et al., 2012; Totsika & Hastings, 2009) and structured around the philosophical dimensions and practices of Acceptance Commitment Therapy (Blackledge & Hayes, 2006; Hayes, 2004; Hayes, Strosahl & Wilson, 1999; Pergolizzi et al., 2020; Reid et al., 2015). Within the ACT model, periods of emotional distress are normalised as shared human experiences, arising through an interaction between an individual, their environment and a complex (behaviourally defined) language system and perpetuated by reduced engagement in valued life areas (a process of experiential avoidance).

E-PAtS assumes that these processes are shared by caregivers of children with IDD but that vulnerability to experiencing emotional distress is increased, given the exceptional circumstances and challenges with which they are faced.

Consistent with ACT, E-PAtS assumes that emotional distress can be reduced, and wellbeing increased, through non-judgemental sharing of experiences in a supportive group context, psychological acceptance, and support to engage in personally meaningful and enriching life areas. E-PAtS further assumes that peer support is an important mechanism to facilitate personal behaviour change in this regard and that these therapeutic processes have benefits in the short-term and longer-term. Within Session Two (Supporting You and Your Child) caregivers are firstly supported to reflect upon the potential to experience emotional distress when supporting a child with IDD and to consider the value of establishing systems of support in this regard from an early stage. Facilitators take a non-judgmental stance throughout the session to help explore and normalize shared emotional experiences and foster psychological acceptance. Being present with, and appreciating shared difficulties, is structured to reduce a sense of shame and isolation and support emotional validation.

Careful facilitation of this process also creates a foundation for caregivers to consider new ways of supporting their own wellbeing in the future that focus primarily on commitment and engagement in valued life areas. This session therefore also supports caregivers to identify and plan for realistic and meaningful steps they can take in everyday life, that reflect personal values and ambitions, and help maintain and build emotional resource over the short and longer-term. Caregivers are provided with a range of materials that can be used to help implement and maintain self-generated goals and strategies, together with resources and guidance concerning other systems of social and professional support.

E-PAtS Sessions Three to Eight focus predominantly on supporting family caregiver knowledge and confidence in responding to child-focussed areas of difficulty (that are also associated with poor outcomes for caregivers and families of young children with IDD). Further consideration and support in relation to both building systems of family support and safeguarding the emotional wellbeing of caregivers is, however, still included as an integral component of these sessions. In each case, caregivers are supported to consider the emotional impact or experience they may encounter when interacting with their child and to generate and plan for strategies that will safeguard their wellbeing at these times.

'Principle Six: Contextualised Systems Support.'

As has been discussed, E-PAtS is underpinned by a systems approach (Guralnick, 2005b; 2017) to supporting behavioral change and building resilience that is strategically organized within an implementation process and manual. E-PAtS takes a contextualized, family-focus that recognizes the interplay between caregiver and child behavior and the diversity of families likely to access the programme.

Whilst E-PAtS is fully manualised, facilitators are trained to identify and respond to the particular needs, circumstances and aspirations of group members on a family-by-family basis. Rather than delivering routine or static information, facilitators aim to co-produce dynamic sessions and bespoke solutions for families through partnership working with group members, centralized around frameworks and guidance provided by the programme. E-PAtS is therefore continually modified or adapted in subtle ways to provide good contextual fit and maximize social validity for families whilst maintaining integrity to its underlying structure and evidence-based content.

All families who express interest in attending E-PAtS are also invited to attend an individual, supportive preparation session/interview with facilitators or other professionals from the host organisation prior to the delivery of programme curriculum as a standard part of E-PAtS. This session is intended to help prepare caregivers for the programme, ensure it fits with their current needs and expectations and identify and proactively resolve any barriers regarding attendance and engagement. Caregivers also have opportunities throughout the programme to highlight any other factors that facilitators could address to support their engagement in the programme.

Particular attention is paid to family engagement at the couple sub-system level. E-PAtS aims to routinely engage with two parents or family caregivers through both direct attendance of the programme, and the operation of several further mechanisms and processes. This aim recognises the benefits of developing shared knowledge, responsibility and approaches to supporting a child within a family system (and the potential conflicts or increased challenges to effective child support when this is not possible). Single caregivers are fully supported to attend E-PAtS programmes (and frequently do), but provision is always made for up to two family caregivers (this may be two parents or a parent and other adult family member/close family friend) from the focal child's home to attend. The E-PAtS group process is designed to accommodate the interpersonal support needs of parent/caregiver dyads and the collaborative facilitator stance of the E-PAtS group process also models the value and possibility of a supportive and shared/co-caregiver approach to supporting children.

In situations where only one caregiver is present in the family system or only one caregiver is able to attend a programme, materials provided as part of E-PAtS can be used to help share key messages and learning with others in the support system outside of sessions. E-PAtS provides all families with a suite of resources and tools organised within a personalised workbook. This allows information gained from sessions by one family caregiver to be discussed, shared, and utilised with a secondary caregiver or other professionals whether or not they are able to attend any or all of the programme sessions directly. In this way, secondary caregivers and others in the support system are still able to engage with the E-PAtS programme and experience, and potentially contribute towards, positive outcomes for themselves and their family.

In addition to engagement with the family system, E-PAtS is responsive to the demands and potential for positive change at a broader services system level. This includes actions to facilitate proactive service access for families following attendance of E-PAtS (a central focus of Session One: Working Together and an element of each subsequent session). Notably, local adaptations of E-PAtS materials are made prior to each delivery at a new host organization, whereby facilitators and host professionals incorporate details of local services, resources and pathways into programme materials using manualised frameworks and guidance.

E-PATS is also designed to be deliverable and integrated in multiple health, educational and social care settings and by facilitators with a range of skills and backgrounds (rather than only by costlier professionals with higher-level qualifications). The co-production of E-PAtS explored carefully the length and number of programme sessions that would be acceptable and feasible to both families and service providers to ensure good contextual fit. Whilst ideally provided over 8 consecutive weeks, E-PAtS sessions can also be combined into a smaller number of extended workshops to provide flexible delivery possibilities that facilitate delivery across settings. To date, E-PAtS groups have been piloted across inner-city, small town and rural settings, in third sector, health and early-years education contexts, with professional co-facilitators that include nurses, support workers and pre-school/nursery practitioners.

Finally, E-PAtS is not a commercial enterprise and the programme has been produced with the intention of maximising low-cost delivery opportunities to provide widespread support to families. The programme (including all manuals and resources) is therefore provided free of charge for use by facilitators who have attended a group-based training programme under a no-cost licence agreement.

Materials and Curriculum

Sessions

The E-PAtS curriculum comprises eight 2.5-hour group sessions (see Table 1), delivered to small groups of caregivers (generally four-eight families, with provision for two adult caregivers per family to attend) at times of day determined by the provider in accordance with the needs and preferences of caregivers. All sessions are fully manualised and include a range of supporting materials that cover proactive access to service-support (Session One), positive approaches to supporting CB (Sessions Six and Seven) and constructive approaches to supporting sleep, communication and adaptive skills (Sessions Three, Four and Five) for children. All sessions include consideration and support for caregiver wellbeing but this is also explored in-depth during a dedicated session (Session Two). The final session (Session Eight) serves an integrative function, allowing for all learning to be synthesised and for families to plan next steps.

E-PAtS is designed as a cohesive programme curriculum rather than a menu of choices with the expectation that family caregivers attend all sessions whether or not they or their child is currently displaying a difficulty in the topic area. This is based on a premise that families who attend the programme and their children are at increased risk of experiencing difficulties across all topic areas sometime in the child’s development, but that this could be reduced through early intervention and proactive support. Second, it is considered that participating family caregivers will contribute towards the group process mechanisms, with the potential to support other group members in relation to one or more of the curriculum areas and that this may have benefits for both the caregiver in question and other group members.

Table 1: E-PAtS Sessions

Session	Topic	Example Content	Examples of Evidence-Based Procedures
One	**Working Together** (group formation and access to support services	Establishing a safe space; Sharing information on locally available services; Developing assertiveness skills	Normalising and Acceptance (ACT, Hayes et al., 1999)
Two	**Looking After You** and Your Family (focussed support for caregiver wellbeing)	Sharing and normalising difficult emotional experiences; Identifying and planning for values-based, wellbeing strategies	Acceptance and Values-based behaviour change (ACT, Hayes et al., 1999)
Three	**Supporting Sleep** (Sleep for children)	Understanding sleep stages; Developing bedtime routines; Supporting better sleep for children	Function-based behavioural interventions to supporting sleep (Jin, Hanley & Beaulieu, 2013)
Four	**Interaction and Communication** (communication for children)	Exploring a communication partnership model; Identifying how children communicate key needs	Creating communication passports (Millar & Aitken, 2003)
Five	**Supporting Active Development** (development of adaptive skills)	Maximising engagement in everyday activities; Task analysis, prompting and positive reinforcement	Positive reinforcement, task-analysis and shaping (see Cooper, Heron, & Heward, 2019)
Six	**Supporting Challenges 1** (supporting behaviours that challenge)	A functional model of challenging behaviour; Choice making, predicating the world and sensory needs	Discussion to learn about a functional account of behaviours that challenge (Hastings et al., 2013)
Seven	**Supporting Challenges 2** (supporting behaviours that challenge)	Using knowledge of the arousal curve to guide support; Developing proactive interventions	Functional Assessments, and developing behaviour support plans (O'Neil, et al., 1997)
Eight	**Bringing it Altogether** (final integrative session)	Planning for the future; Celebrating successes and achievements	Acceptance and Values-based behaviour change (ACT, Hayes et al., 1999)

Materials

Family caregivers are given opportunities to rehearse and develop strategies and skills within sessions but are not assigned targets or activities to complete following sessions. This dimension of E-PAtS is based on the assumption that families will likely present with a range of different needs and circumstances and may need to develop family support systems and personal resource as a pre-requisite to implementing self-management and child-focused strategies. For instance, it may be more appropriate for a family to first build some emotional resource and social support for themselves before implementing strategies to support their child's sleep. This may be possible for some participants within the time frame of programme delivery but is predicted to occur more typically following programme completion.

To support this process, all caregivers are provided with a workbook that accompanies E-PAtS. The workbook allows families to collate resources and learning gained across the programme and takes the form of an elaborated communication passport or person-centred profile. Within the workbook, caregivers are able to compile bespoke information and details relating to their child's strengths and needs and to highlight the best ways in which they can be supported. By completing the workbook throughout the programme, families create a resource based on their knowledge and experience, combined with evidence-based practices to inform broader systems of family and child support in the future. The workbook also contains sections that focus on the caregivers' own wellbeing. Group members are able to use the workbook in flexible ways and choose to share content with other members of their support system to facilitate a shared and consistent approach.

Facilitator Training

E-PAtS facilitators (both professional and caregiver facilitators) are typically recruited and employed via host organisations using job descriptions and recruitment materials provided by the programme that focus on both lived and professional experience. E-PAtS is also intended to be deliverable and integrated in multiple health, educational and social care settings and by facilitators with a range of skills and backgrounds (rather than by costlier professionals with higher-level qualifications only).

A training programme and manual for training mixed groups of caregiver and professional facilitators to deliver E-PAtS has been developed as part of the E-PAtS programme. Facilitator training is organized and delivered in an emotionally and practically supportive context, modeling delivery of the E-PAtS programme itself, to help facilitators build on existing knowledge and experience and gain both confidence and competence in programme delivery. Training always occurs in mixed groups to support the development of partnership working and explore the dynamics of group settings.

The five days of training are guided by a manualised curriculum comprising 1.5 days of teaching in relation to the evidence base, theory and ways of working that underpin E-PAtS; 1.5 days teaching regarding the programme curriculum for E-PAtS, and 2 days of tutoring practice-based demonstration regarding curriculum delivery, group process, and co-production in the delivery of E-PAtS. Facilitators need to be able to demonstrate necessary skills and understanding of E-PAtS during the final training session, prior to implementation, and receive 2-3 supervision sessions from the trainer (in addition to any supervision with the host organisation) during their first delivery of the programme.

Implementation

In addition to session protocols and facilitator training, E-PAtS delivery is guided by a manualised implementation process by which providers are supported to organise sessions and resources and support practitioners and families in a manner suited to their local context, needs and opportunities. This includes guidance for facilitators to schedule sessions and adapt materials to fit with local arrangements and the individual supportive preparation session for families ahead of programme attendance.

Conclusions and Next Steps for the Thesis

This chapter has provided a theoretical account and description of the E-PAtS programme, incorporating key ideas and practices from PBS but also other behavioural, family-focused and therapeutic models in response to Research Question Three (How can proactive support for children with IDD and families be enhanced in the early years?) E-PAtS offers one way to provide a combination of practical and emotional support to families at an early stage, the need for which has been drawn out in other chapters of this thesis (particularly with regards Chapter Four). However, whilst the theoretical and conceptual basis of E-PAtS has been outlined, the actual utility of this within service delivery and potential benefits to families is of critical concern. The next chapter of this thesis therefore reports on a qualitative exploration of the experiences of families who attended E-PAtS sessions as part of an early UK pilot.

Chapter Seven: Early Positive Approaches to Support: Family Views and Experiences

Overview

Chapter Six introduced the Early Positive Approaches to Support (E-PAtS programme) and outlined a detailed logic model that has evolved during the time span of this PhD and been refined and influenced by the exploration of literature and studies contained therein. Chapter Seven presents the methodology and findings from a qualitative evaluation of E-PAtS groups piloted across Northern Ireland and England in collaboration with colleagues who form part of the E-PAtS programme team (a summary of roles taken throughout is provided in appendix 5). Findings from the study are discussed in the context of the E-PAtS logic model and broader implications for stakeholder engagement and early years, proactive support to increase the quality of service delivery to children with Intellectual and Developmental Disabilities (IDD) and their families.

Introduction

Background

E-PAtS is grounded in available IDD research and behavioural theory and was developed under the leadership of Gore through a co-production model in recognition of limited and inconsistent support for families of children with IDD in the UK. E-PAtS was designed as a bespoke group support programme intended for use as a primary element of comprehensive service provision. As has previously been described (Chapter Six), E-PAtS is considered suitable for all families of young children with IDD in the early years, addressing issues for caregivers (in terms of wellbeing, service access, knowledge and confidence) and their child (in terms of development, behaviour and wellbeing) that may already be being experienced, or will be likely to emerge during the course of the child's development. The programme is co-delivered by a trained family carer facilitator and a professional facilitator across eight group sessions. The context and assumptions, aims, mechanisms and outcomes for E-PAtS have been synthesised in the form of a detailed logic model.

E-PAtS has therefore been developed through a robust approach and is closely aligned with key theoretical and evidence-based approaches in the field. As has been demonstrated with regards the NICE review process (see Chapter Six), utilisation of intervention programmes and uptake at a national level must, however, be built on a high quality programme of research concerning delivery of the intervention itself. In the longer term, the effectiveness of the E-PAtS programme should be subject to evaluation using a fully powered randomised controlled trial design (as the gold standard test of effectiveness required to inform policy development). Exploring the ways in which the particular combination of E-PAtS materials, delivery mechanisms and group processes are experienced by family caregivers, and the extent to which this is reflective of the intended programme mechanisms, is, however, an important additional step. Findings from such research have the potential to help inform and refine the design of both the E-PAtS intervention and quantitative group-based research going forward, and is a typical expectation of major funders.

Aims of the Study

This study concerned an initial evaluation of E-PAtS groups delivered in the UK. A qualitative approach was taken to allow a detailed investigation of caregivers' views, building on both the methodologies utilised in earlier chapters of this thesis (Chapters Four and Five) and consistent with the co-production elements of E-PAtS. The study had the following main aims: Firstly to explore family caregivers' overall experiences of attending an E-PAtS group and associated outcomes for themselves and their family; Secondly, to investigate processes and mechanisms that operated in E-PAtS groups from the accounts of family caregivers.

Method

Ethical Approval

Ethical approval for this study was sought and gained from the Tizard Centre Ethics Committee within the context of a larger evaluation (that also included a smaller sample of pre-intervention interviews not reported here). All caregivers who showed interest in attending E-PAtS groups were also invited to take part in the study, but this was not a condition of programme access. Families were provided with information sheets about the study, given opportunities to discuss any questions and asked to complete a consent form if happy to take part.

Intervention

Sites

Intervention delivery occurred at two main sites by trained E-PAtS facilitators, hosted by a third-sector organisation that supports people with intellectual disability, including children and young people, and their families. Site one (in Northern Ireland) delivered interventions between 2017 and 2018 and site two (in the North of England) between 2018 and 2019.

Facilitators

Facilitators were identified at each site by project managers already employed by the service, with support from E-PAtS trainers and in accordance with job descriptions and processes outlined in E-PAtS manuals. All E-PAtS professional facilitators had prior practical experience supporting children or adults with intellectual disabilities and their families and relevant training or qualifications in this area. All E-PAtS family carer facilitators had significant practical experience caring for a relative with IDD and strong verbal communication skills. During selection, all E-PAtS facilitators demonstrated empathy with families and an understanding of issues facing family carers. They also demonstrated that they could work in partnership with a co-facilitator, had some systems and resources available to manage their own emotional wellbeing and had good organisational skills.

All facilitators attended, and successfully completed, a five-day E-PAtS group training programme prior to delivering an E-PAtS group and received supervision from an E-PAtS trainer during delivery of their first group (as is a standardised aspect of E-PAtS training). All training was conducted in group format for both family carers and practitioner facilitators within a 2-month period and covered areas as outlined in Chapter Six. A cohort of 10 facilitators were trained at the Northern Ireland site by Gore (January 2017) and a smaller cohort of four facilitators were trained at the England site (August 2018) by a colleague (Bradshaw) who was trained by Gore to undertake this role over a four-day period (and supervised by Gore during this training delivery).

Group Members

Family caregivers were also recruited to E-PAtS groups at each site by project managers employed by those services with support from E-PAtS trainers and in accordance with manualised implementation processes outlined in E-PAtS materials. This process included providing written information about the E-PAtS programme and an opportunity to meet with a service representative to discuss the particular circumstances of a family. At this time, families were able to ask any further questions and, through discussion, determine whether the programme was suited to their particular needs. The E-PAtS manual also highlights the potential for this discussion to inform any particular support arrangements families may need to facilitate their engagement with the programme. All families were asked to commit to at least one family member attending all sessions (with opportunities for up to two adult carers from a family to attend a group per child).

Northern Ireland

A total of 46 caregivers from 37 families were recruited to E-PAtS groups in Northern Ireland. The majority were female and mothers (36) but the sample also included fathers and one grandfather. Further demographic information was collected on 38 of these participants via a structured demographics questionnaire administered to families as part of the broader programme implementation and evaluation. Families described themselves as White British, White Irish, Irish or English (97%) and married (49%) or cohabiting (23%).

There were 38 children with disabilities represented in families recruited to E-PAtS groups in Northern Ireland. Families were invited to complete a demographic questionnaire about their child, with all families providing some information (a small amount of missing items across the sample). On average, each family had one child (range 1-5). Nine families had more than one child with IDD (with one family having two children 0-5 and attending E-PAtS in relation to both of these simultaneously). Children were more often male (62%) with an average age (at the start of the study) of 34 months (age 2-50 months).

Whilst all children had developmental difficulties, 11% did not have a formal diagnosis. Across the remainder, the most common diagnoses were Down Syndrome (32%), Global Developmental Delay (26%) and Autism (18%) with smaller number of other diagnoses also reported (Severe Learning Disability, 11%; Other Genetic Disorders 11%; Language Delay or Social Communication Disorder and 8% Spina Bifida, 3%).

Families at the Northern Ireland site attended one of five groups (with an average group size of 9 people, range 4-12) that were delivered during 2017-18. Retention to these groups was high, with only four caregivers (9%) (representing three families) who started the course dropping out. For three of these carers, child illness or new and competing work commitments were reported as a reason. The other carer asked to be moved to a future group with parents of a similar age to herself.

England

A total of 17 caregivers from 16 families were recruited to E-PAtS groups at the England site. This included three fathers (one of whom attended only some sessions), one grandfather and 13 mothers. At least some data were collected on 16 of these carers via the demographic questionnaire (with a small amount of missing items across the sample). Most group members described themselves as White British or White Irish (80%) with the remainder identifying as Polynesian (n=1), African (n=1) and British Pakistani (n=1). Group members were more often married or cohabiting (77%).

There were 16 children represented in families recruited to E-PAtS groups in England. At least some data were collected on all of these children via the demographics questionnaire (with a small amount of missing data across the sample). On average, each family had two children (range 1-4). Two families had two children with IDD. Most children for whom group members were attending E-PAtS were male (62%) with an average age 40 months at the start of the intervention (age 9-75 months). A high proportion (47%) of children had a diagnosis of Global Developmental Delay, with diagnoses of Down Syndrome (27%), Autism (20%) and other Genetic Syndromes also common (13%). One child had a diagnosis of Cerebral Palsy, one had a diagnosis of Attention Deficit Hyperactivity Disorder and one had no diagnosis.

Two E-PAtS groups were delivered at the England site and retention was high, with only three caregivers who started the course dropping out (18%). Two of these parents dropped out after week two, following a break in the programme to take into account the school half-term week. The remaining parent did not attend the first group session due to personal difficulties and did not attend any further sessions.

Research Participants

All carers who were due to attend E-PAtS groups were invited to take part in the evaluation, with information provided ahead of the start of the group. Participants who consented to interview were recruited through collaboration between E-PAtS trainers (Gore and Bradshaw) and project managers employed within services at the Northern Ireland (n=25) or England site (n=10), with 35 taking part overall (all of whom had completed the E-PAtS programme). The majority of participants were female (96% in Northern Ireland and 80% in England), White British or White Irish (96% in Northern Ireland and 90% in England) and birth parents or grandparents (94% overall) (with one foster parent and one adult sibling also taking part). Age of participants was also similar across sites with an average age of 36.9 years (range 26-44 years) in Northern Ireland and 38.8 (range 26-50 years) in England.

The focal child for whom participants were attending E-PAtS (n=25 in Northern Ireland and n =10 in England) was most commonly male in both England (70%) and Northern Ireland (72%) with similar ages on average at the start of intervention delivery (England months, range 26-50 months; Northern Ireland 37 months, range 2-42 months). Children of participants had a variety of diagnoses which most commonly included Global Developmental Delay (32% in Northern Ireland and 60% in England), Down Syndrome (32% in Northern Ireland and 40% in England), Autism (20% in Northern Ireland and 30% in England) or another genetic conditions (16% in Northern Ireland and 10% in England). A small proportion of children had no formal diagnosis (16% in Northern Ireland and 10% in England). Key characteristics of participants and their children largely reflected the available demographics of the wider pool of families who had attended E-PAtS sessions at both sites (see Table 1).

Table 1: Comparison of Participant characteristic and demographics of families taking part in E-PAtS groups at each site.

	Northern Ireland Intervention (n=46)	Northern Ireland Evaluation (n=25)	England Intervention (n=17)	England Evaluation (n=10)
Female Carers (%)	97	96	76	80
White British or White Irish carers (%)	97	96	80	90
Child Average Age (months)	34	37	40	39
Male Children (%)	62	72	62	70

Interviews

Participants were invited to take part in either a small focus group (Northern Ireland n = 19 across 4 groups; England n = 6, in one group) or individual interview (Northern Ireland n = 6; England n = 4) as best suited their needs and preferences within a two-month period following the E-PAtS intervention. A semi-structured format was used to explore participants' experience of the group, any changes they experienced following attendance and their feedback for the future development of the programme. The interview protocol was devised by Gore in collaboration with Bradshaw and included the following question areas as a starting point for broader discussions:

1. Family carers’ views of the training. What went well/did not? How satisfied were they with the content, delivery and timings? Was it worthwhile? Did they feel more informed? What could make it better?
2. Family carers’ engagement with services prior to, during and following the programme
3. Child needs and behaviour (sleep management, communication, eating, disruptive behaviour, anxiety, antisocial behaviour) prior to, during and following the programme.
4. Child skills and proactive behaviours (waiting, communication, self-help) prior to, during and following the programme
5. Family carers’ emotional well-being and confidence (stress, anxiety, depression) prior to, during and following the programme.
6. Broader family impact (family functioning, siblings, parental relationships)

All interviews were conducted by Bradshaw, under supervision and with support from Gore. Interviews were 45-60 minutes and arranged at a time and place most suited to participants, with some interviews taking place via telephone to accommodate a caregiver’s circumstances. All interviews were audio-recorded and later transcribed in anonymous form.

Analysis

Following transcription, a thematic analysis was conducted based on the six steps described by Braun and Clarke (2006) and corresponding with Boyatzis (1998). Whilst a Framework Approach had been utilised in other studies completed for this thesis, this approach was deemed most appropriate given the relatively early stage of intervention development and selected to support greater flexibility in data analysis and exploration of detailed personal accounts. Transcripts from both sites and across focus groups and individual interviews were treated as one data set throughout analysis to identify overarching themes. Transcripts were initially read by Bradshaw who highlighted ideas and noted comments and reflections from the perspective of interviewer. Bradshaw and Gore then discussed these reflections over a series of meetings and began to group initial broad themes and consensus from across the transcripts. Bradshaw then revisited the transcripts and sought evidence of responses that either confirmed or were inconsistent with these themes based on a framework created by Gore. Gore then explored these categorised notes and devised a refined set of themes and subthemes. These were later discussed with Bradshaw during a second series of meetings. Following further re-reviewing of all transcripts, and identification of supporting quotes, the final analysis was formed. The final presentation of results and connective narrative (as presented in this chapter) was authored by Gore. This collaborative approach to analysis was considered to offer a robust methodology and support reflexivity whereby assumptions and biases of either interviewer or programme developer could be challenged. Team-based approaches to qualitative analysis have received increased attention in the social sciences during recent years (e.g., Cascio, Lee, Vaudrin & Freedman, 2019) and build upon the concept of 'Dependability' (i.e., consistency of judgement), considered a critical component of thematic analysis by Boyatzis (1998).

Results

Overview

Three major themes were identified ('Our Group, Going Through It Together'; 'Evolving Emotions', and 'Positive Approaches'). In each case, three further sub-themes were identified that captured the social and emotional experiences, learning, reflections and outcomes reported for participants and their families. Quotes are used to illustrate themes with participants indicated by number where an individual interview (e.g., PC1) and location (e.g., L1 for Northern Ireland or L2 for England). A further code (FG) is used to reference quotes from a focus group.

Our Group: Going Through It Together

The first major theme concerned participant experiences of being in a group with other family carers as part of E-PAtS. Social dynamics, the nature of a safe group and processes of engagement and co-creation were reported throughout all interviews, providing a foundation for learning and emotional support.

Feeling Normal

Participants emphasised the fundamental value of spending time with other family carers as part of an E-PAtS group, and noted how infrequent opportunities to do this at other times in their lives had been. Participants described how just being with others in and of itself was powerful:

> *'You never get a chance to meet with other parents and the fact that you are actually in a room with other parents for that length of time was good, erm and bringing together' (PC8 L1)*

It seemed particularly important, however, that participants were with not just other parents in general, but carers of children with IDD:

> *'That's what I like about the whole thing, as everyone was in the same position' (FG L2)*

And for some participants, this is what had attracted them to E-PAtS in the first place:

> *'Half the reason of coming along was coz there were going to be parents like me' (PC2 L2)*

Participants reported a sense of belonging and feeling normal; that this was a group for them:

> *'I found the camaraderie in the sense of, you belonged, you know, your group, and everybody' (FG L1)*

> *'It makes you feel normal' (FG L1)*

Saying the Unsayable

Being with other people with shared experiences appeared central to helping participants feel secure in reflecting and expressing their thoughts and feelings openly.

> '*People understand you, you don't have to explain yourself. It is nice to come to and be with a group of people who get you.' (FG L1)*

Understanding without judgement or the need for explanation was held in contrast to many other social situations; an unspoken and supportive connection, typically absent from interactions with people who did not have lived experience of children with IDD:

> *'I thought if you communicated really well with other people they would understand but they don't.' (FG L1)*

> *'Unless you have been through it, you don't understand' (FG L1)*

This group context allowed people to 'say the unsayable'. Participants reflected on how important it was to talk to other people who 'just get it' and have lived experience without worrying about their reactions. Participants felt able to talk about how they really felt when attending E-PAtS sessions:

> *'It isn't that I am not pleased that my friend has a new baby but I am sad too' (FG L1)*

> *'I can't say these things to my mum or my friends because they would be worried about me' (PC L2)*

Experts by Experience

Shared peer-experience also appeared to create a foundation for how participants related to, drew upon and contributed to learning within E-PAtS sessions. Participants acknowledged and appreciated how raising a child with additional needs resulted in high levels of expertise and unique insights regarding what works in practice.

> *'The best advice does come from someone who understands and has been through it, is going through it' (FG L1)*

Participants recognised and underscored the supportive role of facilitators with expertise and experience of children with disabilities. Co-facilitation by a parent-carer was, however, particularly valued and highlighted throughout interviews. Family-carer facilitators were recognised as someone who had direct experience of the information being presented and the reality of using this to support a child with additional needs. Information provided throughout E-PAtS sessions was seen as relevant and genuine:

> *'Because he knew exactly how we felt and yes he even thought what we…I know we all go through a different things and all our children are different, it's just nice to hear from someone view who goes through them struggles every day' (FG L1)*

> *'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' (FG L1)*

Peer-to-peer discussion was seen as the main means through which information was accessed and new knowledge generated. Participants spoke about being able to both give and receive information and the co-creation of strategies:

> *'Coz you learn such a lot from your peers as well, and especially all kinds of things about accessing services. You learn from other people that, about what's available. You see lots of people sharing, have you tried this? Have you looked there?' (PC1 L2)*

> *'You can always give that wee bit of advice to someone, maybe it's turned a lightbulb on. Where no matter what condition your child has or developmental or any of that, everybody was able to take that wee bit of advice from each other, or give' (FG L1)*

This dual role of both helping others and being helped by others was seen as empowering and motivating:

> *'But when you know people have been through it, you kind of like, you see light at the end of the tunnel' (PC2 L2)*

> *'It makes you feel like, you're not a bad parent, and everybody else is in the same boat as me' (FG L1)*

Evolving Emotions

The second major theme centralised on emotional experiences, appraisals and steps to supporting wellbeing for caregivers. Exploring and sharing thoughts and feelings in a non-judgemental group, gaining new knowledge and finding ways to take practical steps towards self-care were evidenced across interviews. This theme connected both to how participants came to view themselves as experts and how they became equipped to establish the supports they needed.

Building Support with Confidence

This theme related to how participants gained knowledge about support that was available and how best to access and utilise this. For some, E-PAtS had helped develop an understanding about why additional support might be important and to accept, without self-judgement, that this was a key aspect of raising a child with additional needs. In the context of a supportive peer group, seeking support was seen as both OK and necessary for caregivers:

> *'I am like [child]'s main sort of carer, but sort of just gave me that perspective to sort of just stand back and go right hang on a minute, maybe I don't need to do so much, maybe I need to go and speak to people that help' (FG L1)*

> *'I now understand why you claim benefits. I understand why a parent needs to have extra funding for this and I understand that [name of child] is going to cost me more money to get him swimming lessons' (PC2 L2)*

For others, it had evidently been very difficult to find out what support was available in the past, prior to attending sessions. For these families, being part of E-PAtS had started to fill the knowledge gap:

> *'I never knew half the stuff that me and [child] or me and [sibling] were entitled to until I came here and then I found out that you are entitled to so much more' (FG L1)*

> *'Out of the blue you got a child with special needs. You start off knowing absolutely nothing about any of the support... or of what you need to do as a parent so yes I am just learning all the time. So coming to this group has really accelerated that process for me' (PC1 L2)*

In addition to knowledge gained about what was available, participants reported learning about what they needed to do to access services. Participants talked about being prepared for setbacks, the need to be assertive and how group membership had bolstered this attitude:

> *'There is other parents in the same position and they have opened their mouths and you learn. You learn if you don't fight, you don't get really and it actually is the way it is in the community' (PC1 L1)*

They described how E-PAtS had provided them with the knowledge of what was available, but more so the confidence to raise issues and to persist until action was achieved:

> *'Probably give me more confidence to speak up for him you know and to go you know this isn't right, he should be getting this, he should be getting that you know' (PC1 L1)*

> *'It gives you confidence, like I can take on the education board now, I am not afraid to… because they gave you the advice, this is the way you speak to them and now I am ringing them every day… not just the education board, anybody' (FG L1)*

Caring for Myself So that I can Care for Others

Across all interviews, participants described how a greater understanding and appreciation of the need to look after themselves had arisen through attendance of E-PAtS. As with establishing and accessing other forms of support, this was viewed as an essential act of caregiving if participants were to be able to look after someone else:

> *'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)*

> *'What I took away was more from the point of view that I need this or consider myself and take a step back and that not to obsess so much about [child] and so I get myself time' (FG L1)*

Participants often described coming to the E-PAtS groups itself as 'me' time:

> *'It was an excuse to get out of the house for an evening and to have, as sad as it is, to have a bit of me time' (FG L1)*

It was clear that prior to group sessions participants had tended not to prioritise their own wellbeing and that multiple practical and psychological barriers had perpetuated this and a belief that a good parent should put their child first. Participants described how activities and discussions during E-PAtS helped them realise how little they did for themselves and explore some of these assumptions:

> *'So when you actually put it on paper you realise more. You are like, we actually don't do nothing together is all, like our whole life is revolved around [name of child] you know, which isn't a bad thing but it isn't a good thing either because we need to be a happy couple too to look after him...it helped us all I think. I'd definitely recommend it' (PC L1)*

Participants recognised the need to make changes to support their own wellbeing but also the challenges of doing this given the complexities of their life and caregiving demands. For some this process had just begun:

> *'I feel like I've got no help, no support with my children at all. It's just me and my children at all times...I think I need some kind of stress release, something to make me feel good about myself...I am just trying to find a way.' (PC L2)*

At other times, participants had already found new and different ways to start better looking after themselves having attended E-PAtS. Here, participants described carving out small opportunities to rest, socialise and relax in ways that connected to their needs, interests and circumstances.

> *'[name of child] goes to nursery and with her sister in the mornings and usually I would go back home and I'd tidy up and maybe I think I'd get the table ready for when they come home and have dinner...one day, well quite a few, I've just gone and I've just watched TV I've just sat there and I've just relaxed and I've had a coffee and I have. Just something that I wanted to do' (FG L2)*

Just taking time for oneself, in whatever form appeared the critical step, whether this was time alone:

> *'Just wanting a bit of me time, and I felt that was brilliant... even just painting my toe nails or just having a half hour nap and chilling time, and I wouldn't have even thought if doing that if I hadn't have been on that course' (FG L1)*

Or with others:

> *'So I went for a night out with my niece and the whole night I didn't think about you know going back, and you know, waking up early with kids, you know about owt like that. I just thought, I am having a really good time' (FG L2)*

Both a stance towards self-care and finding practical ways to commit to opportunities to support oneself in daily life was associated with a range of positive outcomes for participant's wellbeing and sense of self:

> *'Felt like yourself again' (P2 L1)*

> *'Not just [name of child's] mum or the person with the kid who constantly cries so I felt like me. It were really good' (FG L2)*

Doing a Good Job

Participants described a range of ways in which their self-perceptions regarding caregiving and parenting expertise had evolved throughout sessions. Being able to speak openly in a supportive group, and share experiences without judgement seemed to help give participants confirmation that they were doing the right things:

> *'It was more for me that, because you beat yourself up so much with having a child with an additional needs thinking, can I do more can I, is there anything I am doing wrong? So, just going to it really give me that confidence that I am not doing anything wrong, just they are going through this wee time, but it is harder for them, they are frustrated you know?' (FG L1)*

And that they were getting it right for their child:

> *'You feel positive because you're not doing it wrong, you're just doing it the way that the child's understanding it mightn't be somebody else's cup of tea but it works for you so you do it' (FG L1)*

Participants reported that following E-PAtS, they felt more confident about their parenting abilities:

> *'It's helped me understand that I'm actually a good mum. It's given me that confidence you know? When you used to think, oh my god, you are in melt down, thinking I'm doing an awful job and I have then days when I think I wish I could help them more, I wish I could do more for my children. But this has helped me get that, that confidence. I am really doing a good job' (PC3 L2)*

Not least because they had also gained some new strategies:

> *'I didn't feel very confident about being able to parent a child especially as he is our first with additional needs. So I feel more confident in my parenting abilities in that sense... but now I feel there are strategies that I can use which has just made me feel more confident in general.' (FG L1)*

Positive Approaches

The final major theme drew together the increased understanding, new knowledge and strategies participants had gained through attendance of E-PAtS and the manner in which these were utilised in family life to support positive developments and outcomes.

Opening Another Window

Participants reported multiple examples of new knowledge that had emerged throughout the E-PAtS sessions that both built on prior skills and expertise and connected to areas of particular concern and their personal circumstances. For many, attending E-PAtS had helped to increase an understanding of why their child might respond in particular ways which allowed them to make helpful changes:

> *'I like the functions, I swear by them now so I do and being the detective...it just opens another window for you, you know, something you never knew about, like why is he behaving like this, and if you can't remember then you just go back to page of the functions' (FG L1)*

Participants also described how they were continuing to build on this understanding over time. Here there was recognition of a need for perseverance but confidence that a reason (or reasons) could now be sought by drawing on evidence-based strategies in the context of everyday caregiving:

> *'Be persistent and keep going, no matter how long it takes, coz it's worth it in the end' (FG L2)*
>
> *'Sort of stepping back when he getting, stepping back thinking right 'what is it here that triggered this?' (FG L1)*

New knowledge and insights had also changed some of the perceptions participants had about their child's skills and abilities:

> *'I appreciate more. Like the one that we did on skills and breaking down particular activities really helped me to see how capable she is in certain things' (FG L2)*
>
> *'That it's not just that he's naughty but that there is always a reason' (FG L2)*
>
> *'I learnt about when they are chatting gibberish that they are trying to communicate something' (FG L2)*

Finally, both knowledge and increased recognition of what might be possible became manifest in new ways caregivers had found to support their child. This included new and proactive strategies so that behaviours that are challenging could be avoided:

> *'The course has been helping me figure out ways to avoid being bitten by her and you know it's actually helped in a few ways' (FG L1)*

It also included developing strategies to support key areas such as communication, sleep and everyday skills:

> *'I have learnt now you know, give him a see-through cup with milk and water in it you know? I am going do you want milk or do you want water? And [name of child] actually going and choosing what he wants, whereas before he didn't have a choice, I'd just given him it... I have been able to communicate a lot better with him by choices' (PC1 L1)*

> *'And I am doing hand-over-hand with the hairbrush, hand-over-hand with the toothbrush. I never knew that.' (PC1 L1)*

> *'Sticking to a routine, going to bed, making sure lights are off, TVs are off and basically saying goodnight and leave it at that. None of this back and forth and keeping them awake type of thing...he goes to bed and he sleeps now' (FG L1)*

Family and Caregiving Interconnections

The way in which participants had come to better understand and approach caregiving and support personal wellbeing through attendance of E-PAtS also referenced the interconnected nature of parenting and family life.

> *'It's helped me to understand their behaviour a bit better and kind of look at how we work as a whole family...across the breadth of our whole family life I think it has been useful and it will continue to be useful' (PC1 L2)*

Participants described an enriched appreciation of interactions with their children and increased agency in supporting development at these times:

> *'I found the communication the best one so far, for me, and I found that, yes, that has helped, I can see, you know, much more interactive from [name of child], and she will try, and its nearly. She is still not signing or saying the words clearly but you nearly feel like she is saying more...now it's more of an attempt, it's definite, and eye-contact has helped to communicate' (FG L1)*

> *'I didn't realise because I have got four children, in the morning you are busy, so just up and you get the kids ready yourself. I just put the breakfast in his mouth but now, where now, I actually decide to say 'let's put one sock on and you do the other sock.' So I have started doing that so that's really helpful. Even feeding him, I will load the spoon but get him to put it in his mouth. I tried to calm down, break things in small pieces, small bits so that he can understand more. So yes the kids noticed, he's noticed, definitely' (PC3 L2)*

Even more so, participants recognised and emphasised interplay between their own behaviour and that of their child and the particular need to safeguard and support personal emotions in the context of behavioural challenges:

> *'The challenging behaviour definitively. Its, I have had to change the way I was dealing with it... that's where. I was so close to the kids going 'right come on' and I was getting myself so worked up and then he was getting more worked. After the*

> *course I was like you know what, take a deep breath, calm, speak to him in a low voice, get down on his level. And I see the tantrums, they have lessened' (FG L1)*

> *'Coz I am dealing with it different. I'm keeping calm you know so I have seen a bit of improvement in that sense' (FG L1)*

Finally, participants expressed the value, need and motivation to share knowledge gained with other parent caregivers:

> *'I have spoken to my husband about this and all the course and everything I have learnt so yes. I go home and do that every day so that he has that information as well' (PC3 L2)*

And wider family, helping others to understand more about why children might be behaving in certain ways and foster better relations and systems of support:

> *'Give them a sort of insight too, what you are going through. Cause even though you maybe are, all the time, they still, it's nice for them to get to know inside. It's like people saying 'och, he will grow out of it', you know? To help family understand, no they will not, this is them, this is who they are, you know? Then you got stuff to bring home and you could show family, stuff like that' (FG L1)*

> *'I showed my mum and dad because they have an awful hard time so they are. They still think it's part of his behaviour and no it isn't, there's the answers to you, for you. They still think it's down to behaviour and I am like no it isn't, there is the answers to you. You don't look at them, and this is why he is behaving like this and they understand more now' (FG L1)*

Over the Moon

Utilising new strategies and safeguarding own wellbeing during family interactions was associated with a variety of positive outcomes for caregivers and their children. Participants spoke of the joy experienced in witnessing the small steps their children had been able to take, describing these in close detail:

> *'I was initially just grasping it and then getting it into her mouth. And then just going home and watching her and helping her with those little bits. She can now do it completely on her own...that's brilliant, absolutely brilliant to see her, you know, picking up a cup and drinking and putting it down' (PC1 L2)*

Reductions in behaviours that challenge and positive changes in other areas of concern were also reported:

> *'[Child] is now in a routine. He goes to bed every night at half eight. He is now letting me brush his teeth, and he loves his shower, it's all about consistency' (FG L1)*
>
> *'He has hardly any meltdowns now, it's like communicating more with him' (FG L1)*

With recognition of resulting satisfaction, pride and esteem for both children and caregivers at the surprise of what had been achieved:

> *"You can see he's enjoying it. You know he's enjoying the fact that he can, he can make his own choices now. He's looking at me going are you serious? I get to choose here you know? He is actually really loving it." (PC4 L1)*
>
> *"The reaching. He taking the actual spoon and if I hold his hand he would never have done this. And put yogurt, he putting it up to his mouth, so it the first time I swear, I am like over the moon" (FG L1)*

> *"She sometimes woke up at 10 o'clock, midnight, depending she wanted to wake up. She could stay awake all, it was always awkward getting her back to bed. But when they were saying, 'be persistent and keep going', no matter how long it takes, coz it's worth it in the end. It's actually worth in the end" (FG L2)*

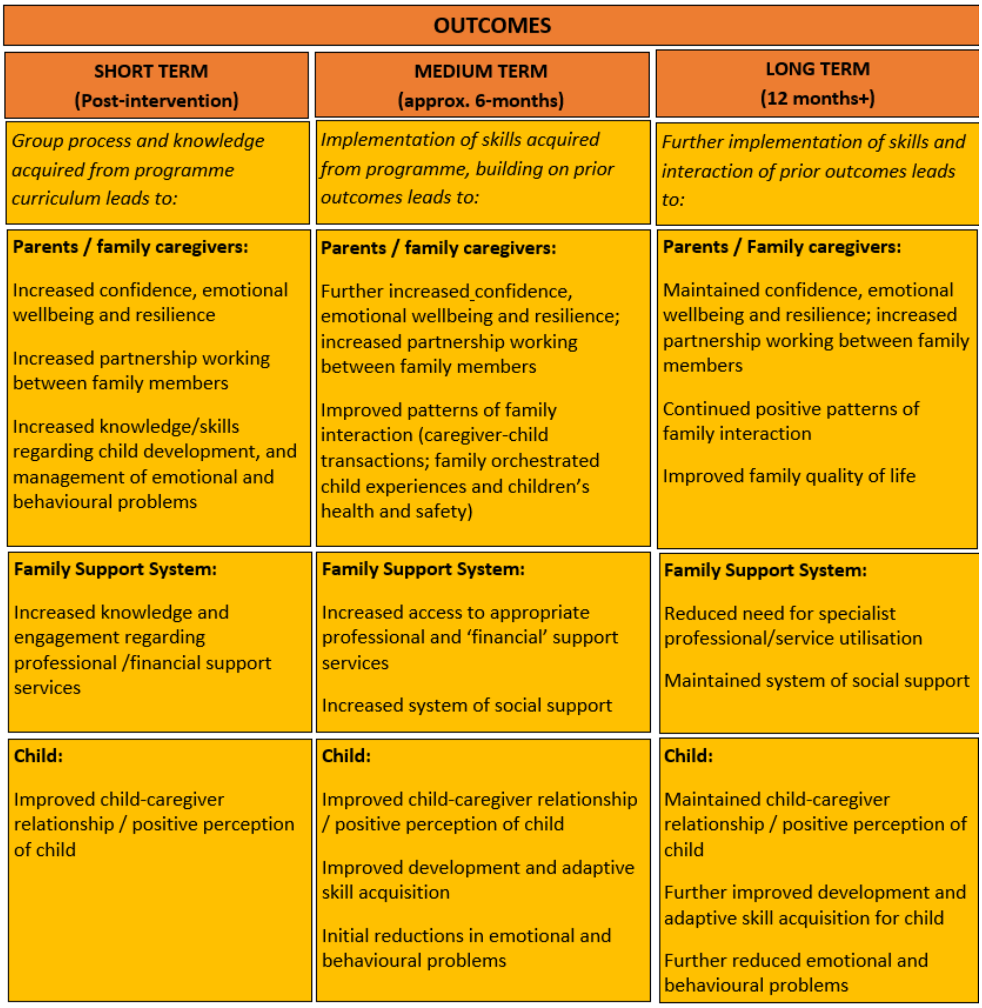
Discussion

Good quality early intervention supports for families of children with IDD in the UK are rare (The Challenging Behaviour Foundation & Council for Disabled Children, 2015; Wodehouse & McGill, 2009; Sapiets et al., 2021) despite ongoing reports of unmet need from families themselves and professional guidance advocating for provision (Local Government Association, & NHS England., 2014; Department of Health, 2012b; Cooper, et al., 2014; World Health Organisation, 2012; World Health Organisation, 2008). E-PAtS has been carefully developed through a synthesis of research and conceptual literature and, most critically, through an iterative process of partnership working between families and professionals. Over time, it has been possible to construct a comprehensive logic model for E-PAtS that attempts to distil key programme components, highlight predicted outcomes and hypothesise likely mechanisms of change.

This study was a first, qualitative evaluation of the E-PAtS programme across two implementation sites in the UK. E-PAtS programmes at these sites were accessed by 53 families and rates of attrition were very low. A total of 35 carers who had attended an E-PAtS group were interviewed following completion of the programme. Interviews aimed to firstly explore caregivers' overall experiences of E-PAtS and associated outcomes for themselves and their family and, secondly, to investigate processes and mechanisms that operated in E-PAtS groups from the personal accounts of family caregivers. These aims will be discussed in light of findings throughout the remainder of this chapter and with reference to the E-PAtS logic model. Given quantitative measurement pre and post-intervention was not conducted, inferences about the effectiveness of E-PAtS cannot be made at this time, though future recommendations in this regard are made.

Outcome and Experiences

The E-PAtS logic model predicts a number of positive outcomes as a consequence of programme attendance across the short, medium and longer-term (see Chapter Six). Consistent with Developmental Systems Theory (Guralnick, 2001; 2005a) and the reciprocal nature of parent-child transactions (Lucyshyn et al., 2014; Neece et al., 2012), the E-PAtS logic model targets primary positive change for family caregivers themselves and surrounding support contexts. This in turn is suggested to create the foundations for supporting positive patterns of interaction and outcomes for the focal child with IDD and the family more broadly. Outcome areas from the logic model are presented in Figure 1 below.



OUTCOMES		
SHORT TERM (Post-intervention)	**MEDIUM TERM (approx. 6-months)**	**LONG TERM (12 months+)**
Group process and knowledge acquired from programme curriculum leads to:	*Implementation of skills acquired from programme, building on prior outcomes leads to:*	*Further implementation of skills and interaction of prior outcomes leads to:*
Parents / family caregivers: Increased confidence, emotional wellbeing and resilience Increased partnership working between family members Increased knowledge/skills regarding child development, and management of emotional and behavioural problems	**Parents / family caregivers:** Further increased confidence, emotional wellbeing and resilience; increased partnership working between family members Improved patterns of family interaction (caregiver-child transactions; family orchestrated child experiences and children's health and safety)	**Parents / Family caregivers:** Maintained confidence, emotional wellbeing and resilience; increased partnership working between family members Continued positive patterns of family interaction Improved family quality of life
Family Support System: Increased knowledge and engagement regarding professional /financial support services	**Family Support System:** Increased access to appropriate professional and 'financial' support services Increased system of social support	**Family Support System:** Reduced need for specialist professional/service utilisation Maintained system of social support
Child: Improved child-caregiver relationship / positive perception of child	**Child:** Improved child-caregiver relationship / positive perception of child Improved development and adaptive skill acquisition Initial reductions in emotional and behavioural problems	**Child:** Maintained child-caregiver relationship / positive perception of child Further improved development and adaptive skill acquisition for child Further reduced emotional and behavioural problems

Figure 1: Outcome Areas in in the E-PAtS Logic Model

The key outcome areas referenced for family caregivers were apparent across themes with some suggestion of temporal developments and sequences as depicted by the model. It should be noted that interviews were conducted soon after completion of the programmes (within two months) and so 'longer term' changes were not appraised, and that these are qualitative reports of experience rather than quantitative evidence of effectiveness.

Participants reported several experiences that connected to perceptual, attributional and knowledge-based outcomes detailed within the E-PAtS logic model. Here, there were examples of increased empathy or appreciation of the needs of the carer's children and an enhanced or new understanding of the factors that influence child behaviour and development, referencing evidence-based principles. In each case, there appeared to be a mixture of accounts that connected these changes to group-based experiences and those that referenced continuing or later developments in home lives. Attributional and knowledge based changes have often been taken as an outcome in training for those who support people with IDD at risk of CB (MacDonald and McGill, 2003), including those for parents (e.g., Gore & Umizawa, 2011) and could be conceived as promising indicators (subjectively speaking) that group members had gained new ideas, information and insights, relevant to important dimensions of caregiver behaviour (Whittingham, Sofronoff, Sheffield & Sanders, 2009).

Increased confidence, in particular, was reported by families both in terms of self-perceptions of parenting abilities, and assertiveness to seek and secure service and social supports, captured within the Evolving Emotions sub-theme. Participants often described these shifts with reference to experiences of the group itself, with a suggestion that these may have emerged at a relatively early stage. Changes in confidence or perceived competence concerning parenting have often been taken as a key outcome in other parenting interventions (where a focus has been on behaviours that challenge) and so this was an encouraging and important finding for E-PAtS (George, Kolodziej, Rendall & Coiffait, 2014; Hames, & Rollings, 2009; Ruane & Carr, 2019). Given the difficulties families often face in accessing and engaging with services it was also significant that confidence was discussed in this context (Galpin, et al., 2018; James, 2012; Wodehouse & McGill, 2009). In addition to increased confidence to gain service and social supports (beyond those experienced within the group itself), participants reported on having gained information and knowledge about actual supports available to them. It was less clear whether at the time of interviewing new services had actually been accessed by families (with the possibility that this did not or would not occur until a later stage).

Participants also described gaining a realisation of the need for self-care and establishing a commitment towards this within the context of E-PAtS sessions. Such reports resonate with concepts of resilience in the family literature (Gavidia-Payne, et al., 2015) which was suggested to be further developed by the actions of carers following sessions and after the group had ended. Here, there were examples reported from some participants who had found new or additional ways to support their own wellbeing over time with positive emotional changes resulting from this ('I felt like me, it were really good'). Given the high rates of stress and other emotional difficulties amongst parents of children with IDD, which are known to both emerge early and often persist (Baker et al., 2003; Hastings, 2002a; Tosika et al., 2011b), facilitating enhanced wellbeing is a priority within E-PAtS. These early reports connect with outcomes reported by programmes focused solely on emotional functioning for parents exist (Borek, McDonald, Fredlund, Bjornstad, Logan & Morris, 2018; Dykens et al., 2014; Singer et al., 2007) and broader parenting programmes that have been combined with wellbeing interventions (e.g., Whittingham, Sanders, McKinlay & Boyd, 2019).

Further to continued development of family carer-focused outcomes, the E-PAtS logic model also hypothesises enhanced family patterns of interaction as medium-term outcomes. Multiple examples of changes of this nature were reported, particularly with regards parent-child transactions, with connections to the perceptual, attributional and self-care changes previously outlined. Participants described a range of positive-parenting practices to support their child's independence and skill development, and manage and avoid episodes of behaviours that challenge (Lucyshyn et al., 2004; Patterson et al., 1982) which corresponded to some of the parent-child interactions targeted in other parenting programmes (e.g., Sanders et al., 2004). These reports detailed idiosyncratic changes and bespoke solutions that connected to the particular needs and priorities of families in the group, thus demonstrating good contextual fit (Albin et al., 1996). Families often gave a sense of having developed these over time, following session attendance. There was also recognition and appreciation of ways in which participants had built on interactions with their spouse and/or other relatives. Participants shared and discussed ideas and knowledge gained from attending the programme, connecting to mechanisms that concern the couples-subsystems (see below), family systems theories (Dunst, & Trivette, 1988; Trivette, Dunst & Hamby, 2010) but also broader family quality of life outcomes (Summers et al., 2005; 2007).

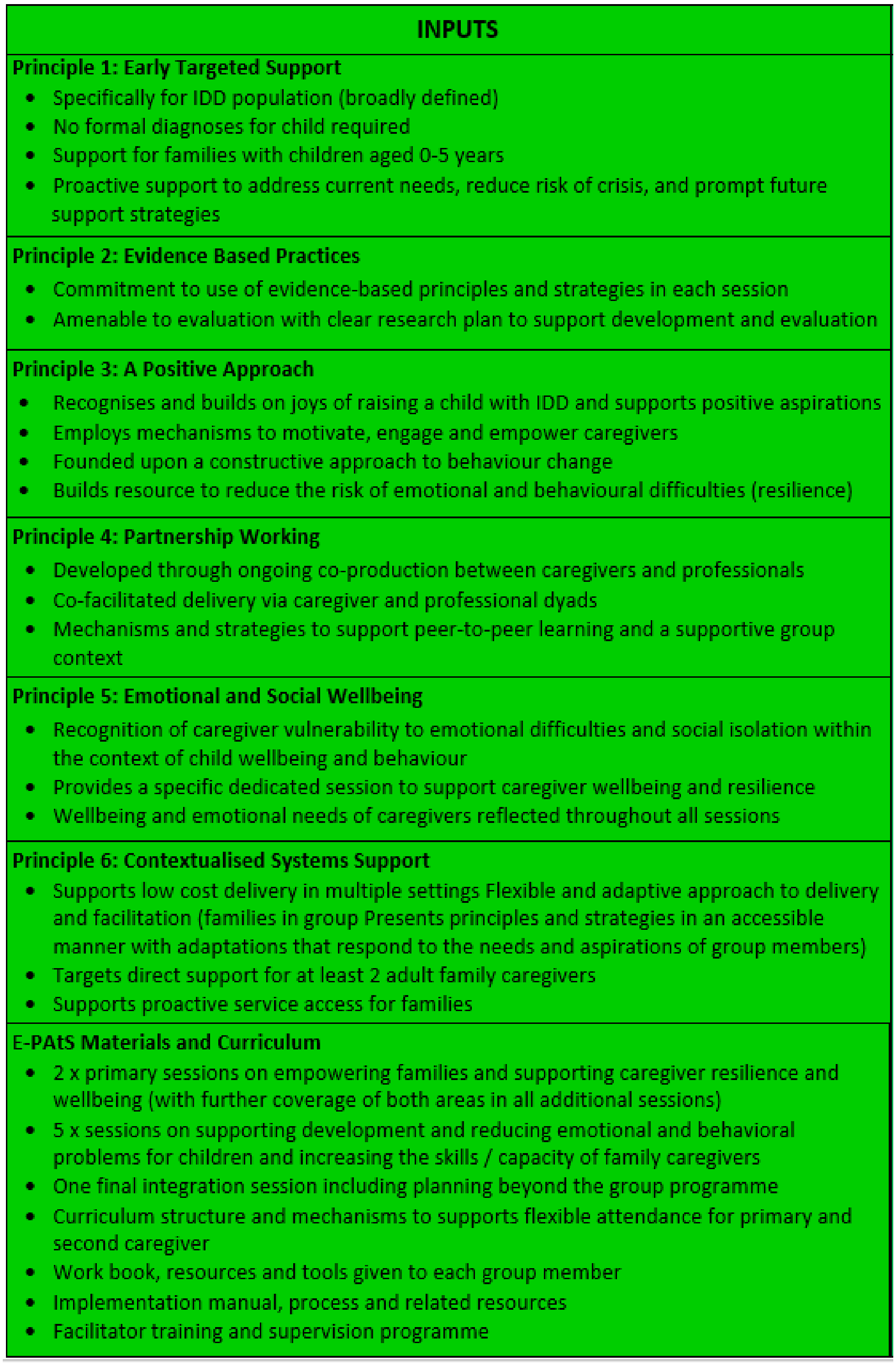
Positive changes in child development, wellbeing and behaviour are hypothesised to emerge within the medium term following E-PAtS attendance. Whilst E-PAtS does not set ‘homework’ tasks for participants, there were multiple examples ~~of ways in which~~ reported by families ~~had begun to~~ that focussed on implementing new strategies and interacting in new ways with their children by the time of interview. A wide variety of positive outcomes were reported in this context for children themselves that included reductions in dimensions of behaviours that challenge, increases in adaptive skills and communication and enhanced sleep patterns. Other parenting programmes that are focussed particularly on specific dimensions of behaviour of children have reported similar outcomes in these areas following attendance (e.g., Priday et al., 2017; Tellegen & Sanders, 2013). It is of note however, that unlike these programmes, families attended E-PAtS for a variety of reasons, at a relatively early stage and engaged with curriculum designed to cover multiple areas. Supporting change across this breadth of areas (at a sample level), with time dedicated to specific areas being relatively brief (e.g., a single session for sleep) was therefore encouraging. Furthermore, the joy, hope and increased confidence this entailed for families as captured in a qualitative evaluation, was apparent, indicating social validity, a required feature of PBS (Carr et al., 2002; Dunlap, 2006) and the longer term additional wellbeing outcomes for carers hypothesised in the logic model.

Processes and Mechanisms

The central mechanisms predicted to operate via E-PAtS parallel suggested outcomes sequences. Namely, facilitating positive change for group members (i.e., fostering resilience, wellbeing, knowledge and skills for family caregivers and increasing access to social and professional support). This in turn provides a basis for improving Family Patterns of Interaction (Guralnick, 2001; 2005a) (i.e., parent/caregiver-child transactions, family-orchestrated child experiences, and children's health and safety) to support further positive outcomes for families and their children with IDD (in terms of development, behaviour and wellbeing of children with ID) (Neece, 2014; Neece et al., 2012; Tosika et al., 2014).

These mechanisms have already been touched upon with reference to participant reports and experiences of outcome areas, but will be further discussed here to some extent. More so, the E-PAtS logic model describes 6 key input principles and hypothesises a number of processes by which these may function (see Figure 2) within the programme. Participant experiences relevant to these areas therefore form the central focus of this sub-section, allowing for a more detailed consideration of programme components.

Several elements across a variety of the key principles and logic model processes were apparent within the first theme (Our Group: Going Through It Together) that resonated with reports from families who have accessed other specialist programmes and engaged with systems of peer-support (Bovaird, 2007; Dew et al., 2013; Dodds, & Singer, 2017; Gore & Umizawa, 2011; Santelli, Poyadue, & Young, 2001; Shilling et al., 2013; Solomon, et al., 2001). Participants' feeling that this was the right group for them and that they were amongst others from similar situations was expressed clearly and can be seen to correspond to the specific focus on families of children with IDD in E-PAtS (Principle One: Early Targeted Support). Work by Borek et al. (2018) to develop a co-produced and facilitated emotional wellbeing group for families of children with disabilities reported similar findings following interviews with a focus group of six parents (a theme described as ‘meeting other parent carers, sharing and peer support in non-judgmental, empathetic setting’).



INPUTS

Principle 1: Early Targeted Support

- Specifically for IDD population (broadly defined)
- No formal diagnoses for child required
- Support for families with children aged 0-5 years
- Proactive support to address current needs, reduce risk of crisis, and prompt future support strategies

Principle 2: Evidence Based Practices

- Commitment to use of evidence-based principles and strategies in each session
- Amenable to evaluation with clear research plan to support development and evaluation

Principle 3: A Positive Approach

- Recognises and builds on joys of raising a child with IDD and supports positive aspirations
- Employs mechanisms to motivate, engage and empower caregivers
- Founded upon a constructive approach to behaviour change
- Builds resource to reduce the risk of emotional and behavioural difficulties (resilience)

Principle 4: Partnership Working

- Developed through ongoing co-production between caregivers and professionals
- Co-facilitated delivery via caregiver and professional dyads
- Mechanisms and strategies to support peer-to-peer learning and a supportive group context

Principle 5: Emotional and Social Wellbeing

- Recognition of caregiver vulnerability to emotional difficulties and social isolation within the context of child wellbeing and behaviour
- Provides a specific dedicated session to support caregiver wellbeing and resilience
- Wellbeing and emotional needs of caregivers reflected throughout all sessions

Principle 6: Contextualised Systems Support

- Supports low cost delivery in multiple settings Flexible and adaptive approach to delivery and facilitation (families in group Presents principles and strategies in an accessible manner with adaptations that respond to the needs and aspirations of group members)
- Targets direct support for at least 2 adult family caregivers
- Supports proactive service access for families

E-PAtS Materials and Curriculum

- 2 x primary sessions on empowering families and supporting caregiver resilience and wellbeing (with further coverage of both areas in all additional sessions)
- 5 x sessions on supporting development and reducing emotional and behavioral problems for children and increasing the skills / capacity of family caregivers
- One final integration session including planning beyond the group programme
- Curriculum structure and mechanisms to supports flexible attendance for primary and second caregiver
- Work book, resources and tools given to each group member
- Implementation manual, process and related resources
- Facilitator training and supervision programme

Figure 2: The E-PAtS Principles

A sense of belonging and the non-judgement that shared experience supported also appeared critical to helping establish a ‘Socially and Emotionally Supportive Group Context’ allowing carers to speak openly and discuss intimate areas of importance and concern (Saying the Unsayable). Finally, this fundamental group process appeared wholly connected to, and driven by, elements of Principle Four (Partnership Working). Initiating and sustaining engagement with caregivers necessitates development of a relationship that family-centred practice defines as mutually respectful, trusting and honest (Dunst, Trivette & Johanson, 1994). Here, quality of parent-professional relationships has been found to mediate interactions between service provision and family QoL (Summers et al., 2007) and influence the experience of family carer stress (Dempsey, Keen, Pennell, O’Reilly & Neilands, 2009). In the broader parent programme literature, parents’ perceptions of their group leaders as supportive and understanding is known to be associated with both engagement and attendance (Giannotta, Özdemir & Stattin, 2019).

The last sub-theme (Experts by Experience) highlighted how both peer-to-peer discussions, and the sensitivity and insight of facilitators with lived experience was central to supporting these kind of relationships. Within E-PAtS, achieving engagement, learning and emotional support within the group, are reflective of key dimensions identified in both the peer-led literature (Dodds, & Singer, 2017) and that concerning partnership working more broadly (Brotherson et al., 2010; Dunlap and Fox, 2007). In addition, a process that had not previously been highlighted in the logic model was suggested in this theme, whereby the act of giving advice and sharing experience with others was also (and perhaps as) important to some participants as receiving this.

The emotional and socially supportive group context processes and peer-support processes continued to be referenced within participant reports in the Evolving Emotions theme. Here, an interplay was ~~found~~ suggested between the provision of information about available services and professionals (Principle 6: Contextualised Systems Support) and the way this was facilitated through group processes to both normalise the need for support and empower carers to access this. Participants reported gaining both ‘Knowledge and Strategies’ in this area and feeling motivated and ready to seek out additional supports for themselves and their family (connecting with the third element of Principle Three: A Positive Approach that concerns engagement, motivation and empowerment). This was an interesting finding, particularly given families have called for a combination of both emotional and practical support (i.e., Wodehouse and McGill, 2009), and findings by Guralnick, Hammond and Connor (2008) that socially mediated parenting support (rather than more general social-emotional support) has the most significant impact on longer term outcomes for caregivers.

It was evident, as has been discussed in relation to outcomes, that participants experienced a number of emotional changes in relation to confidence, assertiveness and wellbeing. It is of further note that several of these experiences were referenced in relation to the content that occurs within the dedicated session of E-PAtS where wellbeing is the complete focus, the second element depicted in Principle Five: Social and Emotional Wellbeing. This related particularly to specific examples of strategies and opportunities for supporting personal wellbeing that participants had been motivated and supported to carve out for themselves in home life. Having a dedicated session concerning caregiver wellbeing, based on dimensions of ACT (Blackledge & Hayes, 2006; Hayes et al., 1999; Reid et al., 2013) therefore appears to be an important component of E-PAtS. This session is deliberately placed at an early stage in the programme to emphasise the foundational importance of self-care (as is consistent with the overriding programme mechanism of change) and this would appear to be warranted.

Notably, however, emotional changes were also referenced by participants in relation to broader group processes that were present across sessions. These may have been further supported by the programmed references to wellbeing in every session, even where the major focus concerned another area (the third element in Principle Five). Finally, peer-group support and the actions of facilitators with lived experience appeared to underpin increases in parental confidence and esteem reported in the 'Doing a Good Job' sub-theme. Again, this can be seen to reflect the constructive elements of the Positive Approach principle (Principle Three) allowing families to build upon their strengths and develop new ideas, bespoke to their particular needs and aspirations.

Whilst the aforementioned group processes also seemed to resonate with participant reports in the third 'Positive Approaches' theme, Principle Two (Evidence Based Approaches) appeared fundamental. Participants described concepts and strategies consistent with the research-informed content of E-PAtS that cut across all sessions. Both new knowledge and the application of this in daily life was reported with regards children's sleep (Priday et al., 2017), communication, skill development (Ho et al., 2021) and behaviour that challenges (Carr et al., 2002; Durand et al., 2013) in addition to self-care for group members. It was evident that developing, implementing and persevering with use of new approaches was an emotional endeavour, with Principle Five (Social and Emotional Wellbeing) and the support of peers (Principle Four: Partnership Working) of key importance in addition to the provision of information through content and materials. The positive opportunities and motivation (Principle Three: A Positive Approach) that trying something new afforded and the joy it highlighted and often led to were poignant.

E-PAtS is underpinned by a family systems approach (Dunst, & Trivette, 1988; Guralnick, 2001; 2005a; Trivette, et al., 2010). Principle Six (Contextualised Systems Support) highlights that two adult caregivers from a family are routinely invited to attend sessions. The model references a key process of supporting collaboration between caregivers to develop shared knowledge and approaches to supporting their child. To this end, E-PAtS also encourages group members to share ideas and materials from the group with other family members. A variety of participants reported on having engaged with partners and other family members (including grandparents of the focal child) in this way and the benefits this seemed to have for them. In addition to the hypothesised sharing and working towards consensus, there also appeared for some to be a sense of empowerment in which less helpful views and comments of other family could be challenged.

Finally, the Family and Caregiver Interconnections theme provided some clear illustrations of ways in which group members had reported coming to better recognise and appreciate the interplay between their own emotions and behaviour and that of their child in relation to both maintenance and change for adaptive and challenging behaviour. These examples reflected the kind of parent-child interactions fostered in other family-focused interventions (Hames, & Rollings, 2009; Lucyshyn et al., 2015; Sanders et al., 2004). Definite examples were reported of ways caregivers had found to support their own emotions at times of difficulty, and the benefits this seemed to support, which mirrored processes described in caregiver stress interventions (Neece, 2014; Reid et al., 2013). Caregivers reported on what may be conceptualised as agency, self-efficacy or locus of control in these contexts, processes which have been identified as of importance in literature concerning parenting, challenging behaviour and stress (Hastings & Brown, 2002b; Johnston & Mash, 1989; Rose, & Nelson, 2018). These reports appear to be consistent with the E-PAtS logic model but have not previously been made explicit.

Limitations

As a first study there were undoubtedly some limitations. The sample of families interviewed was relatively large for a qualitative study but was still a subset of those who attended programmes. As is common to many evaluations this poses a possible self-selection bias, with those families who took part perhaps having views or experiences that differed from those who did not participate. All findings should be taken in this context. At the same time, it is also worth noting that key characteristics of families who took part reflected available demographics for all families who accessed the programme. Additionally, it was found that the vast majority of families completed the E-PAtS programme. Dropout rates in parenting programmes are often much higher. For instance, in the context of a study concerning barriers to attendance of parenting programmes, Rostad, Moreland, Valle and Chaffin (2018) site evidence that 35 to 50% of parents typically do not attend a first session, and 50% do not complete the full intervention. Reasons for low attrition may be posited in relation to programme mechanisms (discussed below) but regardless, there is at least some suggestion that most families were motivated to attend and that programme completion was a common denominator. Outcomes and accounts of those interviewed may therefore not necessarily be unrepresentative.

Secondly, this study focussed on qualitative methods. This was considered an appropriate approach for exploring outcomes and mechanisms at this early stage in a way that had the potential to inform later outcome measurement and quantitative designs. Quantitative analysis (and the strengths that may be associated with this) was not, however, a focus of this study. Ways to incorporate quantitative measurement into future evaluations are discussed at the end of this chapter section. A similar limitation reflects the fact that data in this evaluation came directly from carers themselves and had the potential therefore to be biased by issues of recall, dissonance and social desirability (see for example, Smith, 2015). Whilst some of this bias was potentially limited by the fact that the interviewer had not otherwise met participants and was not the intervention lead, future research should also consider methods of data collection that are not dependent upon self-report. Families described a variety of detailed interactions with their child, and exploring or capturing these kind of changes through direct observation could form an interesting basis for one such study.

Conclusions and Implications

This evaluation explored the experiences of families who attended an E-PAtS group and established preliminary evidence in support of underpinning mechanisms and hypothesised outcomes. E-PAtS provides some promise as one further form of support for families and children with IDD as part of a pathway of interventions and systems that are consistent with, if not solely or wholly, reflected in the Positive Behavioural Support framework as conceptualised in the UK. E-PAtS is built on a foundation of coproduction and partnership working with families and professionals, and thus connects several of the themes explored throughout this thesis.

Findings from this first evaluation have a number of potential applications both in terms of informing future research and (consistent with the ongoing co-production component of the logic model) supporting the further development of E-PAtS as a programme. Whilst the later are discussed primarily in relation to development of E-PAtS itself, some broader implications are also apparent for development and implementation of other systems of early years support for families of children with IDDs. It is important to note that E-PAtS is not intended to serve as a complete system of support in and of itself and (whilst flexible and accommodating) may not provide the right match for all families. Rather, E-PAtS has been designed as one further element of what might be required as part of a pathway of support, providing general support as a foundation for families with a range of needs relating to children with IDD. Choice is important in any system of support and additional, specialised, intensive or alternative interventions are very likely to be required for some families throughout their child’s lifetime.

An overarching aim of the evaluation concerned exploration of reported outcomes and mechanisms hypothesised by the E-PAtS logic model. The evaluation has been helpful in reinforcing the importance of several of these. As discussed, some of these features would seem to be generalisable to the development of other programmes and interventions of support, with the benefits of partnership working, peer-to-peer support and a blend of emotional and evidence-based practical support being of value at all times. Recognising the roles various components of E-PAtS serve is also of critical importance for supporting further development of the programme. For instance, training protocols for facilitators could helpfully be enhanced to focus even further on what participants reported to be of central importance with regards group interactions and dynamics.

Given the positive outcomes and experiences typically reported by participants in this study, it would appear that further piloting of E-PAtS (and infrastructure to support delivery) is warranted. In addition to enhancing training of facilitators themselves this will need to include establishment of a train the trainers programme if availability is to be increased at greater scale. The Contextualised Systems Support principle of the E-PAtS logic model attests to sustainable yet low cost delivery across a variety of settings. Increasing the delivery of E-PAtS will therefore require ongoing work and creative solutions to stay true to this stance.

A limitation of the current evaluation was that a quantitative analysis was not part of the design. The evaluation has however, helped to underscore an understanding of the principle outcome areas for E-PAtS and time periods in which these might best be captured. This information is critical for developing future quantitative evaluations. Further proposals and actions to develop both E-PAtS at a programme level and research regarding effectiveness is presented in the next, final chapters as part of a synthesis and reflection of all studies within this thesis.

Chapter Eight: Final Conclusions and Future Directions

Overview

This (final) chapter summarises and synthesises findings, limitations and implications from each study, within the context of the three research question central to the thesis. Additional pieces of research and impact work completed by Gore, triggered by these studies, are referenced with recommendations for practice and future research in the field. The chapter concludes with consideration of future theoretical approaches to exploring implementation of high quality services and advancing the definition and scope for Positive Behavioural Support (PBS) in the UK.

Summary of Research Questions and Studies

Grounded in a review of literature, this thesis explored ways to strengthen service support for children with IDD at risk of CB in the UK, in relation to three key questions. Questions built upon the Gore et al. (2013) definition of PBS and related articles (e.g., Hastings et al., 2013) and were selected on the basis of particular strategic and practical value, in addition to the potential to generate new knowledge with conceptual implications for the field. Research questions were explored across five main studies and one further theoretical chapter.

How Can Delivery of High Quality PBS be supported within Services?

The first research question focused on delivery of PBS within UK children's services, seeking to identify particular supports and resources necessary to bolster the quality of PBS practice in ways that reflected the breadth and detail of a PBS framework. To some extent this question was considered in each of the five studies, but was given its greatest focus in Chapters Two and Three. Chapter Two (Skills, Experience and Training Needs of Service Professionals) drew on the UK PBS Competence Guide to explore the perceived competencies and training needs of UK practitioners using PBS to support children and young people with IDD. As a first endeavour to use the Competence Guide in this way, this study demonstrated the feasibility of assessing skills and training needs in a manner that allowed for fine-grained discriminations, the implications of which will be further discussed below.

It was found that the overall sample presented with moderate levels of perceived skills across competence categories, an encouraging finding with regards the capacity of the workforce, and one that might be anticipated and hoped for amongst professionals operating in the kind of senior roles that characterised participants. Particular perceived strengths for the sample were apparent with regards competencies that called for stakeholder engagement within an assessment process. At the same time, less perceived skill was notable for the whole sample with regards processes of behaviour support planning with stakeholders and the use of evaluation and outcome monitoring, with significantly greater training needs highlighted for intervention and evaluation areas compared to assessment areas. Furthermore, despite perceived competencies in working with stakeholders in a least some areas, participants were found to spend relatively little of their working time engaged in activities associated with systems level support. Differences in perceived skills and training needs were also apparent during sub-group analysis. Those with higher level qualifications had significantly higher perceived skills in intervention areas and those with more experience significantly higher perceived skills in both assessment and intervention areas. Those with lower level qualifications had significantly higher training needs in both assessment and intervention areas.

Findings from Chapter Two, with particular recognition of the need for further supporting practitioner competencies in areas of evaluation, together with limitations in prior research concerning outcome measurement more broadly, prompted further exploration of this research question in Chapter Three (Developing an Outcomes Framework for the

Evaluation of PBS). This chapter used a four-stage Delphi Panel method to identify a broad range of potential outcome domains for future evaluation of PBS, to prompt and support enhanced data-based practice, and drive quality of future service delivery. The outcomes framework developed by the end of this study comprised 162 distinct outcome domains (corresponding to the needs and priorities of different stakeholders and the definitional dimensions of PBS) that had coherence within a structure of sub-categories and four major category levels reflecting a systems wide conception of PBS (Individual; Family Caregiver Mediator; Paid Staff/Caregiver Mediator; and Service, Organisation and Locality Systems).

How Can Stakeholder Engagement be maximised to Enhance Support for Children with IDD and their Families?

The second research question concerned how best stakeholder involvement and support could be ensured and advanced within a PBS framework. Whilst professional stakeholders had been the primary focus of Chapters Two and Three, this research question was explored in relation to family caregivers and children and young people with Intellectual and Developmental Disabilities (IDD) themselves in remaining chapters. Chapter Four (Making it Meaningful: Caregivers Goals and Priorities for PBS) recognised that family caregiver engagement should begin from the earliest possible stage and that goal formation is a relatively neglected area of PBS research. The study reported in this chapter therefore concerned a method of supporting engagement and goal formation with family caregivers, with close attention to emotional and psychological variables and partnership working. Within this study, participants discussed priorities for future support with regards dimensions of life quality, their child’s skills and behaviour and their own parenting. An interview method utilising an adapted form of Talking Mats was found to be an effective approach for supporting the generation of idiosyncratic goals that connected closely to caregivers’ needs, values and circumstances. During qualitative analysis, the emotional needs of caregivers, interplay between these needs, interactions with others and the behaviour and wellbeing of their child were salient and underscored the centrality of partnership working in PBS. The author’s experience of this study connected to further research to develop a programme of support focused on the needs of caregivers and their children in the early years (Chapters Six and Seven).

A Talking Mats interview methodology was also adopted in Chapter Five (I do it quite a lot: Children’s Goals and Priorities for PBS) but with regards engagement and goal formation with children with IDD in a manner supportive of the complexity of children’s communication and behavioural needs. Whilst, conceptually, people for whom behaviour support is focussed should be considered the ultimate stakeholders in PBS, it has very rarely been the case that PBS research and practice has engaged directly with children and young people. This study did however demonstrate the feasibility of consulting with at least some children with IDD (with varying communication challenges) during the context of goal formation for PBS. Nine children within the study were themselves able to identify valued activities with eight also identifying (positive and challenging) aspects of their own behaviour, all of which had the potential to focus future support initiatives. These eight were also able to identify some aspects of their caregiver’s behaviour where they would value change, with four also being able to share priorities for support in the context of life quality domains. In addition to data concerning the selection of goals and placements of stimuli, qualitative analysis of verbal comments that occurred during interviews also highlighted the potential for positive direct engagements with children to help identify their personal needs, experiences and ambitions.

How Can Proactive Support for Children with IDD and Families be enhanced in the Early Years?

The third research question concerned the particular context of early years support. In relation to this question, and connecting with a focus on quality service provision and stakeholder engagement as expressed in questions One and Two, the logic for the Early Positive Approaches to Support (E-PAtS) programme was outlined in Chapter Six. This programme was described as being built on key principles relating to PBS but also grounded in other theoretical literature with regards child development and caregiver wellbeing. A qualitative evaluation of E-PAtS comprised the final research study in Chapter Seven (Early Positive Approaches to Support: Family Views and Experiences) with a focus on both mechanisms and reported outcomes associated with early years support. A thematic analysis was completed following interviews with 35 families, from 53 families who took part in an E-PAtS group in Northern Ireland or England. Families provided rich accounts of the experiences of being in an E-PAtS group, and reflected on changes they had personally experienced and those they had noted for their child and family.

Three major themes were identified (‘Our Group, Going Through It Together’; ‘Evolving Emotions’, and ‘Positive Approaches’) with nine further sub-themes that corresponded to social and emotional experiences, learning and reflections. These themes connected closely to outcomes hypothesised and targeted by E-PAtS (including emotional and psychological wellbeing for caregivers; family patterns of interaction and positive development and behaviour changes for children). Themes also provided insight and support for some of the mechanisms central to the E-PAtS logic model and targeted in various combinations across some other caregiver/parenting programmes and interventions. This included particular recognition of the role of peer to peer support (particularly that driven by the role of a family caregiver facilitator) within an emotionally and social supportive group context. It also connected to changes in caregiver-child interactions and relationships and interactions at a broader family systems level.

Implications of Findings for Practice

A key priority for this thesis concerned application of findings to practice settings, with research questions and studies designed within this context. This section details clinical and organisational implications of findings (whilst acknowledging limitations and the future research needs as discussed subsequently).

How Can Delivery of High Quality PBS be supported within Services?

Chapter Two: Skills, Experience and Training Needs of Service Professionals

Findings from this study may helpfully inform enhanced delivery of high quality PBS within services in a number of ways. Firstly, in a slightly adapted form, the survey itself could be utilised as a workforce auditing tool by managers or commissioners to better understand the competencies and support needs of professionals. In a further phase of development following creation of the Competencies Guide, the PBS Academy produced standards for services and individual practitioners. These provide a more global representation of what is required for PBS to operate and, used in combination with the more detailed questions from the survey, could provide a robust means of determining the extent to which PBS delivery is evidenced by the characteristics and behaviour of organisations. Although guidance for commissioners exists (e.g., Ensuring Quality Services; Local Government Association and NHS England, 2014), there is an ongoing need to ensure that procurement of services to support people with CB is driven by fidelity to a PBS model. It is far too commonly the case that services (and professionals) may report to be using PBS but operating in ways that fall short or are inconsistent with the framework. The survey structure may therefore provide one further means of assessing such assertions in detail and supporting more than delivery of PBS in name alone.

Key findings from the survey also have important implications for development of PBS training programmes. Denne, Jones et al. (2015) proposed a model for wide-scale workforce development and training that corresponded to the Competencies Guide and recognised the need for curricular that addressed the needs of different stakeholder groups working as part of a support system. Within this structure it would however, seem possible and fruitful to also develop bespoke training programmes for organisations and stakeholder groups based on the findings of this thesis. This would have considerable advantage beyond commissioning and delivery of standard training packages, especially when budgets are restricted as inevitably they are. Focusing on specific skill needs makes good economic and practical sense.

Across the survey it was found that, at a more general level, the sample had relatively greater training needs in intervention, implementation, monitoring and evaluation-based areas. For training programmes and courses operating at a more national scale (including PBS-specific programmes but also professional training courses) it is therefore important to carefully consider how training in these areas can be better supported. This may include better coverage of these components during current training programmes. It may also include development of new discrete programmes that focus, for instance, on intervention strategies or evaluation approaches and has implications for the structure/length of such programmes.

Whilst some specialist courses do exist in these areas (particularly within ABA communities), these are perhaps less targeted or available to members of a broader workforce of different professionals. In addition to the content or subject area of training, the modality with which this is designed also requires careful consideration. The survey indicated that direct experience of PBS was associated with greater, overall self-perceived skill. Creating mechanisms and opportunities for practical exercises and ongoing mentoring and supervisory support as part of training packages are therefore also likely critical. As is reflected in the overall structuring of the Competency Guide, practitioners need to both know and actually be able to ‘do’ those things central to the PBS framework.

Finally, the survey findings have some early implications for supporting better implementation of PBS in services. Notably, there was a suggestion that the day to day activities of respondents did not fully demonstrate the range or extent of skills they may have developed in PBS. One hypothesis here was that service structures and other organisational contexts largely determined how participants operated during their roles, often with a focus on more discrete case work as opposed to broader, systems-based proactive developments.

In this regard, the survey echoes suggestions that have been highlighted elsewhere (Carlson & Baker, 2018; MacDonald & McGill, 2013) that training alone, therefore, is not enough. Even a well-structured and delivered training programme in PBS will not necessarily lead to enhanced practice if professionals are unsupported, or restricted by organisations. In recent work (Denne, Gore, Hughes, Toogood, Jones & Jackson Brown, 2020) have proposed that conceptions and technologies from implementation science may provide a useful direction for future work to ensure PBS is embedded in systems. In particular, the model of implementation proposed by Fixsen et al. (2005) describes the complementary and necessary roles multiple systems play in the delivery of evidence-based practice, with training itself only one element. The Fixsen et al. model stresses that implementation depends upon:

- Practitioners that can competently deliver core implementation components defined as “the most essential and indispensable components of an intervention practice or programme”

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

Whilst a helpful frame for considering which systems elements are in place and which are in need of development, this model does not however, readily guide *how* to achieve co-ordination across or within these system elements to reach agreed outcomes. Most notably, there is currently relatively little research or practical guidance to really help understand behavioural contingencies at a systems level or inform how organisations may best be arranged to select behaviours of staff that are central to good quality PBS delivery. Service-level discussions and planning between training co-ordinators and organisational leads that attend closely to issues of implementation, should however at least be factored into workforce development initiatives as a matter of course.

Chapter Three: Developing an Outcomes Framework for the Evaluation of PBS

This study responded to the particular training and support needs identified for practitioners when surveyed in Chapter Two and recognition of the narrow range of outcomes that are typically the focus of PBS research and evaluation. The outcome framework as developed in Chapter Three is hoped to provide a useful reference to practitioners to select a variety of evaluation measurements when utilising PBS to support implementation and outcome monitoring. It would not be anticipated that all domains or levels would be attended to in all instances of practice. Rather, those domains most relevant to the context of PBS implementation might be used to structure and guide evaluation on a case by case basis, based on the clinical judgement of practitioners. Measurement within domains may then occur through direct observation but also by drawing upon other available tools and resources (e.g., Perry et al., 2015; Summers et al., 2005; Townsend-White, Pham & Vassos, 2012; Turton, 2015). By more routinely evaluating practice it may be hypothesised that practitioners will become increasingly skilled in these competency areas, which, in and of themselves, are critical to ensuring the data-based decision making that PBS demands and that drives service delivery quality (Gore et al., 2013).

In addition to supporting practitioners, it is possible that this study has implications for engaging and supporting other stakeholders. Firstly, 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 (e.g., Dunlap & Fox, 2007). In addition to supporting research and practice that focus 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 (Summer 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 by the PBS Academy (see Scott et al., 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, gives priority to the wellbeing and skills development of the workforce. Increasing evaluation 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.

Chapters Four and Five: The Process and Utility of Developing Goals for PBS through Direct Engagement with Caregivers and Children

Chapter Three created a framework for future evaluation of PBS that identified a broad range of outcome domains across four levels of a support-system but recognised further work was required to engage with stakeholders and consider how outcome selection might best be individualised in practice. The study in Chapter Four developed and demonstrated use of a goal selection procedure to guide support and monitoring within PBS through close and careful engagement with family caregivers.

Further research (as will be discussed) is required to explore the effectiveness and utility of this procedure in the context of other PBS activities. Noting the transferable strengths allied health professionals often have in other areas of assessment and the wide uptake of idiosyncratic goal tools in other clinical areas, the method developed would however appear to have good contextual fit and have considerable utility in practice. The Talking Mats method is very low cost and potentially straight forward to implement in real world settings given two key strategies. Firstly, delivery of basic training to professionals in use of the methodology. Secondly, the establishment of clear goal setting and outcome monitoring activities as part of a clinical pathway routinely offered by services.

Notably, however, this study also highlighted some of the nuances of goal selection, given the prior experiences, demands and emotional needs of family caregivers. It was evident that goal and outcome selection is not a simple matter that can readily be completed as a 'tick box' exercise. Rather time and commitment is required to establish open and respectful relationships between caregivers and practitioners (Brotherson et al., 2010; Dunst, et al., 1994). It will therefore be important to ensure any training and implementation of this process in services reflects this stance. Doing so would however, have the potential to support an increasingly family-centred culture, where stakeholder engagement and empowerment is maximised as a central strand of high quality PBS delivery from an early stage.

Direct engagement with people who have an IDD reflects the person-centred values of PBS (Lucyshyn et al., 2007; McLaughlin et al., 2012) but also a human rights agenda more broadly. For instance, in England, supporting and involving children with IDD in decision-making is recognised in law (Children and Families Act, 2014) and is a specific requirement of local authorities as part of the Special Educational Needs and Disability Code of Practice (2015).

Self-advocacy and self-directed programmes for adults with IDD are also increasingly supported within the United States and UK (DeCarlo, Bosenschutz, Hall-Lande & Hewitt, 2019; Dew, Collings, Dillon Savage, Gentle & Dowse, 2018) underpinned by principles of self-determination that are also promoted for youth with disabilities (Deci & Ryan, 1985; Wehmeyer et al., 2007). Increasing self-determination and choice-making opportunities for people with disabilities has therefore been called for more broadly in addition to the specific context of CB and PBS (Shogren, Fagella-Luby, Bae & Wehmeyer, 2004; Turnbull & Turnbull, 2000).

This study responded to Research Question Two (concerning ways to maximise stakeholder involvement in PBS) by providing one example of how professionals can actually engage with children in practice to fulfil these recommendations. The study also highlights some of the skills and resources required to do this in a meaningful way for individuals who display CB and whose views are arguably most often missing. Notably, conducting interviews took time and care, working at children's own pace and following discussion and planning with families. Whilst continuing to advocate for the central voice of children and young people, future policy should therefore also recognise and make provision for the complexities of direct engagement procedures within service training and planning. As with ongoing partnership working with families, maximising engagement with children and young people as part of PBS delivery presents as a key way to bolster the quality of PBS delivery by services.

How Can Proactive Support for Children with IDD and Families be enhanced in the Early Years?

Chapters Six and Seven: Early-Positive Approaches to Support

Early Positive Approaches to Support (E-PAtS) has been coproduced through an iterative process. Within the context of this thesis, the Logic Model for E-PAtS was formalised and the first-hand experiences of families who attended groups were explored in detail. The accounts of participants were rich and positive (connecting closely to hypothesised outcomes and mechanisms of change), and background information highlighted good retention of families who accessed the programme. E-PAtS is a non-commercial programme, intended to be low cost and fit with the needs, resources and culture of local services. Whilst ongoing research is required (and will be discussed), it would therefore seem that a good foundation has been established for continuing to develop and implement E-PAtS in (UK) services to support families and children with IDD in the early years.

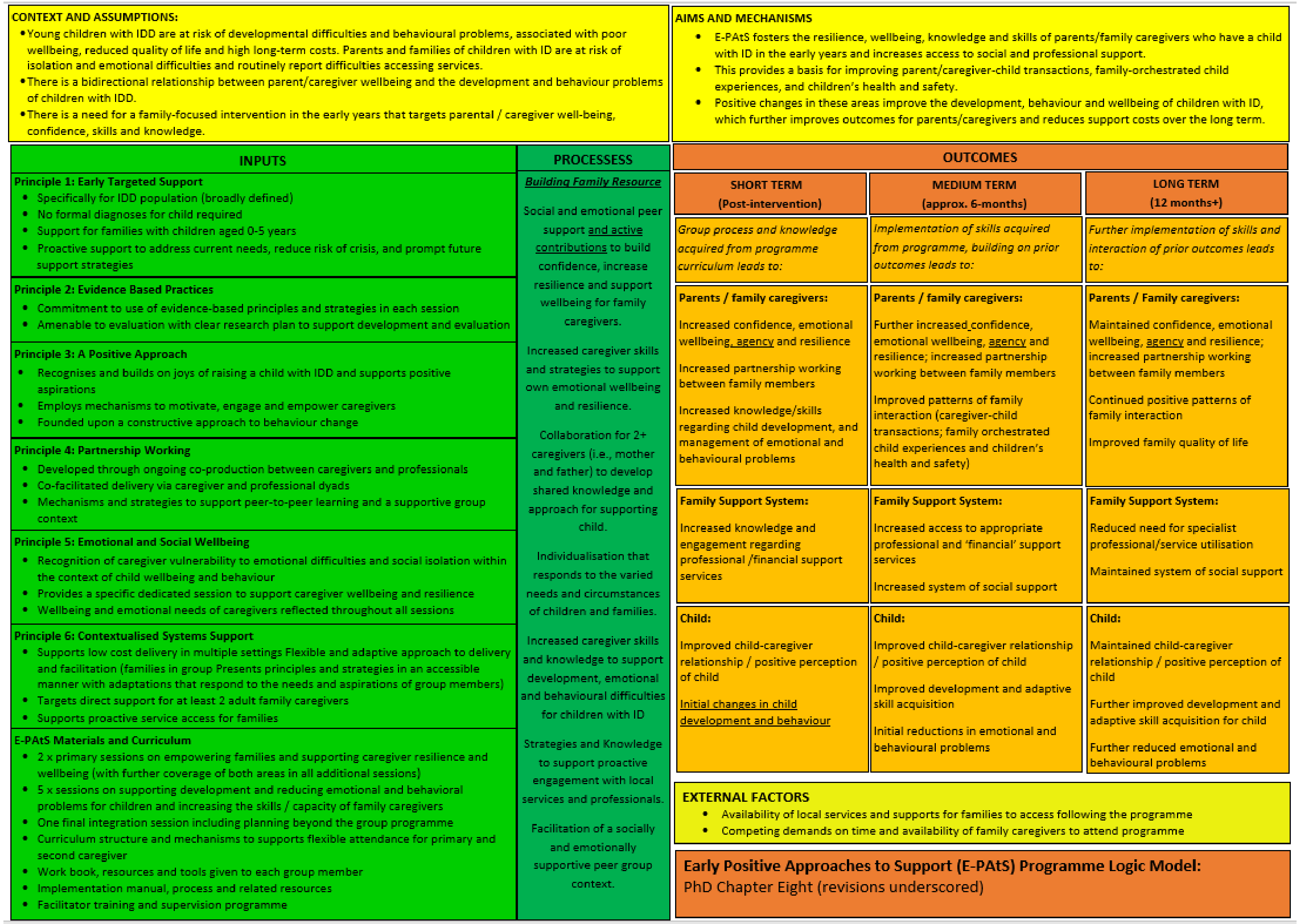
Whilst the reports of participants typically surrounded positive experiences and outcomes, the evaluation also highlighted some areas where development to improve the utility of programme mechanisms might helpfully be focussed. Firstly, it was notable that though many carers had been able to establish further ways to support their own wellbeing in home life (be it carving out time for themselves or a particular activity with others) some had not yet found a concrete way to do this. There was some suggestion that where this was the case, participants were motivated and working towards it and in time might be predicted to establish personal support strategies. Given the central importance of supporting carer wellbeing in the E-PAtS Logic Model, it is, however, important to find further ways of supporting carers to develop and implement self-care strategies and opportunities as early on as possible. One programme addition prompted by this finding, that has since been incorporated into Session Two materials, is a focus on additional support strategies for carers to utilise in ‘the heat of the moment’ when experiencing periods of intense emotion.

Secondly, discussions between group members and other relatives is an important aspect of E-PAtS and was found to occur for participants in this study. Finding further ways to support these interactions and discussions may however be helpful. In particular, the sometimes unhelpful comments of other family members were discussed in this context. Group members are likely to encounter differences of opinion and at times conflict with other family members. Incorporating further materials and exercises to support the best means of approaching such discussions would therefore seem an important further area for E-PAtS programme development.

Participant reports also highlighted some areas of potential importance for the development of E-PAtS that had not been fully appreciated in the logic model. These included a potential mechanism by which group members experience a positive emotional change (be it increased esteem, confidence, or empowerment) as a result of being able to share advice or ideas with others (in addition to receiving advice and support). This process has some resonance with the co-production components of E-PAtS and has subsequently been added to the model in this respect.

An additional potential outcome area, emerging as a consequence of enhanced interactions between carers and their child, was also referenced and has been added to a revised version of the model under the working label of ‘agency.’ Finally, the original E-PAtS model predicted that changes in child behaviour and wellbeing would be most likely to occur in the medium term (approximately 6 months following the end of the group). Yet there were a variety of reports relating to changes in adaptive and challenging behaviours in this evaluation, where participants were interviewed in the initial months following intervention.

Whilst not directly prompted within E-PAtS, there is therefore some suggestion that families may begin (through personal choice and motivation) to try new strategies during the time period of the programme itself and soon after and that this can result in some positive changes for children themselves in the shorter term. The possibility of these early child-related outcomes has therefore also been added to the revised model (Figure 1).



CONTEXT AND ASSUMPTIONS:

- Young children with IDD are at risk of developmental difficulties and behavioural problems, associated with poor wellbeing, reduced quality of life and high long-term costs. Parents and families of children with ID are at risk of isolation and emotional difficulties and routinely report difficulties accessing services.
- There is a bidirectional relationship between parent/caregiver wellbeing and the development and behaviour problems of children with IDD.
- There is a need for a family-focused intervention in the early years that targets parental / caregiver well-being, confidence, skills and knowledge.

AIMS AND MECHANISMS

- E-PAtS fosters the resilience, wellbeing, knowledge and skills of parents/family caregivers who have a child with ID in the early years and increases access to social and professional support.
- This provides a basis for improving parent/caregiver-child transactions, family-orchestrated child experiences, and children's health and safety.
- Positive changes in these areas improve the development, behaviour and wellbeing of children with ID, which further improves outcomes for parents/caregivers and reduces support costs over the long term.

INPUTS

Principle 1: Early Targeted Support
- Specifically for IDD population (broadly defined)
- No formal diagnoses for child required
- Support for families with children aged 0-5 years
- Proactive support to address current needs, reduce risk of crisis, and prompt future support strategies

Principle 2: Evidence Based Practices
- Commitment to use of evidence-based principles and strategies in each session
- Amenable to evaluation with clear research plan to support development and evaluation

Principle 3: A Positive Approach
- Recognises and builds on joys of raising a child with IDD and supports positive aspirations
- Employs mechanisms to motivate, engage and empower caregivers
- Founded upon a constructive approach to behaviour change

Principle 4: Partnership Working
- Developed through ongoing co-production between caregivers and professionals
- Co-facilitated delivery via caregiver and professional dyads
- Mechanisms and strategies to support peer-to-peer learning and a supportive group context

Principle 5: Emotional and Social Wellbeing
- Recognition of caregiver vulnerability to emotional difficulties and social isolation within the context of child wellbeing and behaviour
- Provides a specific dedicated session to support caregiver wellbeing and resilience
- Wellbeing and emotional needs of caregivers reflected throughout all sessions

Principle 6: Contextualised Systems Support
- Supports low cost delivery in multiple settings Flexible and adaptive approach to delivery and facilitation (families in group Presents principles and strategies in an accessible manner with adaptations that respond to the needs and aspirations of group members)
- Targets direct support for at least 2 adult family caregivers
- Supports proactive service access for families

E-PAtS Materials and Curriculum
- 2 x primary sessions on empowering families and supporting caregiver resilience and wellbeing (with further coverage of both areas in all additional sessions)
- 5 x sessions on supporting development and reducing emotional and behavioral problems for children and increasing the skills / capacity of family caregivers
- One final integration session including planning beyond the group programme
- Curriculum structure and mechanisms to supports flexible attendance for primary and second caregiver
- Work book, resources and tools given to each group member
- Implementation manual, process and related resources
- Facilitator training and supervision programme

PROCESSESS

<u>Building Family Resource</u>

Social and emotional peer support <u>and active contributions</u> to build confidence, increase resilience and support wellbeing for family caregivers.

Increased caregiver skills and strategies to support own emotional wellbeing and resilience.

Collaboration for 2+ caregivers (i.e., mother and father) to develop shared knowledge and approach for supporting child.

Individualisation that responds to the varied needs and circumstances of children and families.

Increased caregiver skills and knowledge to support development, emotional and behavioural difficulties for children with ID

Strategies and Knowledge to support proactive engagement with local services and professionals.

Facilitation of a socially and emotionally supportive peer group context.

OUTCOMES

SHORT TERM (Post-intervention)	**MEDIUM TERM (approx. 6-months)**	**LONG TERM (12 months+)**
Group process and knowledge acquired from programme curriculum leads to:	*Implementation of skills acquired from programme, building on prior outcomes leads to:*	*Further implementation of skills and interaction of prior outcomes leads to:*
Parents / family caregivers: Increased confidence, emotional wellbeing, <u>agency</u> and resilience Increased partnership working between family members Increased knowledge/skills regarding child development, and management of emotional and behavioural problems	**Parents / family caregivers:** Further increased confidence, emotional wellbeing, <u>agency</u> and resilience; increased partnership working between family members Improved patterns of family interaction (caregiver-child transactions; family orchestrated child experiences and children's health and safety)	**Parents / Family caregivers:** Maintained confidence, emotional wellbeing, <u>agency</u> and resilience; increased partnership working between family members Continued positive patterns of family interaction Improved family quality of life
Family Support System: Increased knowledge and engagement regarding professional /financial support services	**Family Support System:** Increased access to appropriate professional and 'financial' support services Increased system of social support	**Family Support System:** Reduced need for specialist professional/service utilisation Maintained system of social support
Child: Improved child-caregiver relationship / positive perception of child <u>Initial changes in child development and behaviour</u>	**Child:** Improved child-caregiver relationship / positive perception of child Improved development and adaptive skill acquisition Initial reductions in emotional and behavioural problems	**Child:** Maintained child-caregiver relationship / positive perception of child Further improved development and adaptive skill acquisition for child Further reduced emotional and behavioural problems

EXTERNAL FACTORS
- Availability of local services and supports for families to access following the programme
- Competing demands on time and availability of family caregivers to attend programme

Early Positive Approaches to Support (E-PAtS) Programme Logic Model:
PhD Chapter Eight (revisions underscored)

Figure 1: The E-PAtS (Revised) Logic Model

Study Findings, Limitations and Implications for Future Research

This section summarises the study limitations already discussed in preceding chapters, considers some further limitations and considers implications for future research.

How Can Delivery of High Quality PBS be supported within Services?

Chapter Two: Skills, Experience and Training Needs of Service Professionals

Whilst the current study may have some useful implications for practice, limitations were noted and further areas of research will be required to build on findings. A first consideration made in this chapter regarded the representativeness of participants, though here it was reasoned that the range of professions and settings participants operated within may be considered reasonably representative, at least for those functioning in more senior roles. The demands of the survey for respondents were also discussed in relation to the complexity of questions, but again this was considered acceptable given close correspondence to the actual Competencies Guide and observations that time to complete the survey was as predicted (i.e., approximately 20 minutes). The limitations of self-report questionnaires, concerning bias were also discussed, and the fact that the survey did not consider competencies of practitioners working at other levels of a support system nor those competencies reflected in Area One of the Guide (concerning capable environments). An additional consideration concerns limitations of sample size and complexity of statistical analysis. Whilst interesting patterns were identifiable in the current study, a more powerful regression based analysis (requiring a larger data set and beyond the scope of the current thesis) could include and explore a greater range of practitioner (and organisational) variables as predictors.

As noted, the particular focus of the survey concerned practice in services for children and young people with IDD, in the UK, amongst higher level professionals. The basic structure of the survey could however, readily be utilised (with small modifications) to explore competencies and training needs for area one of the Competencies Guide, relating to those working to support adults with IDD, and relating to those in other countries and cultures (though noting here that alternative definitions of PBS that arise from and reflect other contexts may be a better starting point in some instances). Both of these areas will be important to more fully understand (and support) the skills of workforces and inform PBS implementation, and to build larger data sets for use in more robust forms of analysis. Direct support for people with IDD is, as has been discussed, also fundamental to implementation of PBS. Exploring, in detail, the skills and needs of those working at this level of the system will also therefore be an important area for future research. Whilst the overall structuring of the survey may have some uses here, the actual questions, would, however, need attuning to the competency requirements demanded of direct support workers.

Earlier work by Denne et al. (2015) to define and assess competencies in ABA included development of a range of tools. It is likely that additional tools could also compliment use of the current survey to assess PBS competencies in ways that are not so dependent upon self-report. As with the work of Denne et al. this may include creation and testing of a direct observation tool, supervisory checklists and tests of knowledge. Each of these would represent a distinct piece of research, with further exploration required to understand how each may correspond to building an overall picture of competencies and training need. Several of the implications for practice detailed previously will also require further testing in research. It seems logical to assume that targeted training may be helpful for practitioners and services, but testing the actual feasibility and effectiveness of such training will be important.

The final major areas for future research prompted by this study concern both those competency areas where the least skills and greatest training need were noted and (relatedly) strategies and processes that support PBS implementation, so that those skills practitioners do have can be fully utilised. Several lines of argument have already been considered (in Chapter Two) that may account for relatively greater training need for practitioners in intervention, monitoring, and evaluation areas. In addition to the limitations of current training, these reasons also included recognition that at least some of these areas have received less research attention than other aspects of PBS and are also less well-resourced. In this regard, it is further noted that PBS evaluation, in both research terms and at a service-level, may be an area in particular need of further exploration.

Chapter Three: Developing an Outcomes Framework for the Evaluation of PBS

Kincaid (2018) stipulated that, by investigating a broader range of outcomes, PBS research can advance the field by answering more specific questions about utility and effectiveness. As PBS evolves, it therefore becomes increasingly important to explore outcomes 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. The domains established thus far by the current study may be helpful in organising programmes of such future research. Evaluation processes are, however, likely to be considerably enhanced by further developing the framework in accordance with the principles of PBS, to both respond to research limitations and practical considerations.

Within Chapter Three it was noted that some features of the Delphi-Panel method represented a challenge and/or limitation. This included some delays in data return and a modest panel size with some variation in membership between rounds. Here it was, however, noted that panel size was not untypical for a Delphi study and that all who participated in round four had also participated in other rounds. Prior relationships between members and the possibility of members being able to identify one another’s responses due to such familiarity were also raised whilst highlighting robust procedures employed to protect anonymity. It was also discussed that an 80% cut off, whilst again typical of many Delphi studies, supported consensus for the majority of items from an early stage (though in the context of aiming to establish a broad outcomes framework this proved helpful). A further limitation, concerned the focus of practitioners and researchers as panel members. This limitation was referenced in Chapter Three where it was noted that questions in round one to prompt consideration of stakeholder perspectives were useful but not equivalent to engaging directly with these stakeholders. This limitation was responded to in part by the focus of studies in Chapters Four and Five. It was also addressed to some extent in a follow up study (discussed below). An alternative method could however have been to carry out a number of different Delphi Panel studies, each focussed on a different stakeholder group to support development of the overall outcomes framework.

The framework developed in this study was (intentionally) broad and contains a high number of outcome areas. Part of the value of this concerns flexibility in the selection of different outcomes dependent upon context of implementation and needs and preferences of focal people and mediators. As has been discussed, it is seemingly useful to be able to select from amongst a broad range of outcome areas those that best suit a particular context or individual or group of stakeholders. It was further recognised during completion of the study, however, that some of the identified outcome areas could have more generalizable application than others and relevance across multiple contexts. Identifying a subset of core outcome areas/domains (that have more universal importance and connect most centrally to dimensions of PBS) could be particularly useful in research, policy and commissioning contexts to build and support key elements of evidence-based practice by more routinely evaluating core areas (with the potential to combine and create larger data sets over time).

How Can Stakeholder Engagement be maximised to Enhance Support for Children with IDD and their Families?

Chapters Four and Five: The Process and Utility of Developing Goals for PBS through Direct Engagement with Caregivers and Children.

Both Chapter Four and Chapter Five developed and implemented a novel interview approach to support and explore processes of engagement with stakeholders in the context of goal formation for PBS. As first studies in this area, some limitations were noted. In the case of family caregivers, it was recognised that this was a relatively small sample and that care needed to be taken in generalisation. A similar limitation holds for the second study exploring engagement with children, and findings of both studies could be bolstered through replication with a wider pool of participants in a variety of circumstances. In the case of children, this particularly concerns those with a greater range of communication challenges for whom Talking Mats is not helpful. Some work in this regard was initiated following the study and is reported later in this chapter. The child-focused study also developed a method of assessing reliability of stimuli placements that may be supportive of further Talking Mats research in other contexts also. A limitation discussed for both studies was that it was not possible within the scope of the PhD to further examine the utility of the goals and priorities identified within further pathways of support. The clinical possibilities for developing assessment, intervention and evaluation plans that correspond to goals selected appear promising. Exploring further how this might work in practice and whether this leads to enhanced forms of support and outcomes remains to be tested and is a priority area for future research.

An additional limitation, not yet discussed, concerns the lack of investigation of the extent to which priority areas and goals identified between children and caregivers were similar/different. Whilst some of the children and families in each study were related to each other this was only true in a small proportion of cases as has been described and each study was in effect carried out separately with the aim of carefully exploring engagement for each group in turn. In practice and research terms it will, however, be important to consider how goals selected by children and caregivers compare, and implications this may have for supporting families. A future research study could usefully investigate these issues, but for the purposes of this chapter some post-hoc analysis has been carried out and will now be discussed.

Of those children who selected a goal in relation to an aspect of their own CB, four had a caregiver who was also interviewed within the thesis. Table 1 presents data relating to these four children, listing CB stimuli identified as happening often or sometimes by the child themselves and their caregiver. Stimuli are arranged with corresponding items first, followed by those that were selected uniquely by either the child or caregiver. A correspondence calculation is also provided based on the number of agreements divided by the total number of agreements and disagreements multiplied by 100. Here, it can be seen that three of the child-caregiver dyads agreed on at least 50% of CB items, with one (Natasha) agreeing on 33%. For the most part, disagreements were accounted for by a greater number of items identified by caregivers (with a small number of instances in which children identified areas that were not noted by caregivers).

Table 1: Challenging Behaviour Identified by Child-Caregiver Dyads

Name of Child	Child Identified	Caregiver Identified	Correspondence of identified behaviours
Laura	Bang head	Bangs head	Agreements: 9
	Bite self	Bite self	Disagreements: 7
	Get angry and upset (Tantrum)	Tantrums	
	Hit self	Hit self	9/16 x 100 = 56%
	Scratching/pinching self	Scratching/pinching self	
	Shout and scream	Shout and scream	
	Scratch/pinch others	Scratch/pinch others	
	Throw things	Throw things	
	‘Pull’ (Hit) others	Hit others	

	Pull own hair	Bites others	
		Breaking items	
		Kicking	
		Not doing what asked	
		Persistent questions and requests	
		Running off	
		Spits	
Natasha	Get Cross (Tantrum)	Tantrums	Agreements: 5
	Run off	Run off	Disagreements: 10
	Shout and scream	Shout and scream	
	Spit	Spit	5/15 x 100 = 33%
	Throw things	Throw things	
		Kicking	
		Hitting others	
		Scratches others	
		Pinching others	
		Pull others hair	
		Not doing what asked	
		Breaking items	
		Bites self	
		Bites others	
		Slapping self	
David	Angry and upset (Tantrum)	Tantrum	Agreements: 6
	Breaking things	Breaking items	Disagreements: 6
	Hitting others	Hitting others	
	Kicking	Kicking	6/12 x 100 = 50%
	Shout and scream	Shout and scream	
	‘Slapping’ (Hit) others	‘Slapping and pushing’ (Hit) others	
	Run off	Not doing what asked	
	Swearing	Pinching others	
		Pulls own hair	
		Throwing things	
Ben	‘A freak out’ (Tantrum)	Tantrum	Agreements: 7
	Shout and Scream	Shout and Scream	Disagreements: 5
	Run off	Run off	
	‘Hurts’ (Hit) self	Hit self	7/12 x 100 = 58%
	Throws things	Throws things	
	Pull own hair	Pulls own hair	
	Not listen	Not doing what asked	
	Wave arms around	Hitting others	
		Pinching others	
		Slapping others	
		Bangs head	

Particular goal areas selected by children and adults are presented in Table 2. Here it can be seen that both David and his caregiver identified a shared goal relating to Physical

Aggression (with some slight variance in the particular topography) and David also selecting a goal about Shouting. There was also some correspondence between goals selected by Natasha's caregiver (Tantrums) and Natasha herself (who identified goals for this behaviour and all other behaviours she identified). There was no correspondence between goals selected by Laura (Physical Aggression) and those selected by her mother (Verbal CB). Correspondence between goals selected by Ben and his mother are a little harder to discern but some close connection was suggested. Here Ben selected less 'freak out' which related to tantrum behaviour that for him included physical aggression and self-injury (as explicitly selected by his mother).

Table 2: Challenging Behaviour Goals Selected by Child-Caregiver Dyads

Name of Child	Child Goal	Caregiver Goal
Laura	'Not hurt Daddy' (Physical Aggression)	Screaming and shouting (Verbal) Persistent questions (Verbal).
Natasha	Get Cross (Tantrum) Run off Shout and scream Spit Throw things	Tantrums
David	Kicking (Physical Aggression) Shouting (Verbal)	Hitting and hurting others (Physical Aggression)
Ben	'Less freak outs' (Tantrums; including aggression and self-injury)	Behaviours that hurt other people (Physical Aggression) Behaviours that hurt self (Self-Injury)

This is a small data sample only and any findings should be approached tentatively. Interpretation of correspondence also requires some consideration. Firstly, it is theoretically plausible for children and caregivers to have some difference of opinion and perspective (though this may be a more salient issue for topic areas relating to preferred activities or life quality for instance[6]). Secondly the fact that caregivers tended to identify a larger number of items may be a reflection of children's fatigue or wavering attention during interviews. Finally, finding at least some correspondence between items is seemingly very useful as a starting point for exploring the insights of the child and caregiver and as a basis for further discussion to agree shared priorities for future support (noting that even where CB goals did not correspond between child and caregiver these had at least been identified as happening by both stakeholders).

How Can Proactive Support for Children with IDD and Families be enhanced in the Early Years?

Chapters Six and Seven: Early-Positive Approaches to Support

As an early exploration of E-PAtS, the study reported in Chapter Seven utilised a qualitative approach to access the views and experiences of caregivers. Since it was not possible to interview all caregivers who had attended an E-PAtS programme at this time, selection bias was discussed as a possible limitation. It was noted, however, that the sample size was relatively large for a qualitative study (35 caregivers) and, following a basic appraisal of demographics and overall attendance, appeared to be largely representative of the characteristics of group members. Whilst a qualitative approach had strengths and fitted well with research aims, some further points for consideration might also be reflected upon.

Firstly, in Chapter Four, a Framework Approach was utilised and it might be questioned why an alternative was used for the current study. Thematic analysis was

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[6] Post-hoc analysis was not possible for these areas since caregiver interviews did not cover preferred activities and few children completed the Quality of Life Talking Mat

however selected to permit greater flexibility and in an attempt to provide in-depth accounts. The E-PAtS logic model depicts a complex array of outcomes and mechanisms and using such an approach was well suited to exploring the dynamic interplay of these variables. By contrast, Framework Analysis was a helpful starting point for exploring the structure of goal-based discussions organised around Talking Mats.

Secondly, data for this study was drawn both from interviews with individual participants and from focus groups. It was considered important to offer families flexibility with regards preferred modes for interview but synthesising across these data sources did present a challenge. Considerable care was therefore taken to ensure final themes reflected the sample at large and that supporting example quotations reflected both focus groups, individual interviews and both sites where E-PAtS was delivered.

Finally, the study adopted a team-based approach to analysis as is increasingly common in qualitative research (Cascio, Lee, Vaudrin & Freedman, 2019). Again a careful and structured set of stages guided this analysis and the approach appeared helpful in supporting dependence of data and reflexivity. Some models of co-research have however, also now begun to work more closely with participants themselves during stages of analysis, which whilst not attempted within the current study may be helpful to consider in the future.

Whilst beyond the scope of the current evaluation, a further limitation was that a quantitative analysis was not part of the design. The evaluation has, however, helped to underscore an understanding of the principle outcome areas for E-PAtS and time periods in which these might best be captured. This information is critical for developing future quantitative evaluations. Several established measures are available that relate to what appear to be the primary outcome areas for carers, including those relevant to psychological wellbeing (e.g., The Warwick-Edinburgh Mental Well-Being Scale; Tennant, Fishwick, Platt, Joseph & Stewart-Brown, 2006), and emotional functioning (e.g., The Hospital Anxiety and Depression Scale; Zigmond & Snaith, 1983). Measures also exist relevant to other possible outcomes for carers, including agency within the context of parenting interactions (e.g., the Parenting Sense of Competence Scale; Johnston & Mash, 1989) and adaptive (e.g., the Vineland Adaptive Behaviour Scales, 3rd edition; Sparrow, Cicchetti & Saulnier, 2016) and challenging behaviour or emotional difficulty (e.g., Child Behaviour Checklist; Achenbach, & Rescorla, 2001) outcomes for children. These measures should be trialled within initial pilots as pre and post group measurements and ideally for later follow up (12 months). It is important to establish whether such measures are acceptable to families and sufficiently sensitive to capture the kind of changes associated with E-PAtS. Feasibility testing should therefore be incorporated into future evaluations, with an eventual aim of building towards a Randomised Controlled Trial to test effectiveness (Arain et al., 2010).

Additionally, and in support of the Evidence-Based Practice principle of the E-PAtS Logic Model, measures should be established for routine use pre and post group delivery in general practice. Whilst the above measures may be used for this purpose, it is likely that in some cases the cost of these and more generally the demands they place on caregiver time make them less likely candidates. As a follow-on action from the current evaluation, three measurement approaches have therefore been developed for general E-PAtS delivery (allowing for ongoing service level evaluation and the potential accumulation of larger data sets over time). The first of these is a general evaluation questionnaire to be distributed to families during the final E-PAtS session. This measure aims to capture overall experiences and feedback from participants. The second is a set of measures to be used pre and post E-PAtS session with a relatively small number of scaled items in accessible language that correspond to key outcome domains. The final measure allows facilitators to support the identification of idiosyncratic goals for families attending E-PAtS and to track movement towards these goals over time (reflective of the diverse needs and priorities of families who access E-PAtS and the ambition to find bespoke solutions that meet these). Each tool will need to be further tested and refined through use but provides a range of options to support evaluation in practice without the need for additional resource or significant training.

Applications and Impact

A variety of subsequent studies, training initiatives and development projects prompted by the current thesis have been conducted following completion of the five main studies reported. Whilst by no means attending to all of the implications and limitations discussed thus far, these developments are indicative of impact in the field and will be summarised in this section.

Further Development of an Outcomes Framework for the Evaluation of PBS in the UK

Discussions concerning Chapter Three noted that identifying a subset of core outcome areas/domains (from within the broader set of 162 domains established via the Delphi Panel method) could be particularly useful in research, policy and commissioning contexts to build and support key elements of evidence-based practice (by more routinely evaluating core areas and creating larger data sets over time). In response to this possibility, a further study was undertaken, led by Gore but outside of the context of the PhD, to explore the views of a further (and larger) sample of PBS stakeholders with regards to the outcomes framework, with a focus on the identification of key items. This study also recognised that the original framework items were phrased using working terms and language that corresponded to panel members' responses. The study therefore included some initial work to refine the language and presentation of domains, in a manner that was consistent and accessible yet remained true to the themes and dimensions developed throughout the Delphi process (Gore, Jones & Stafford, 2020).

Following a series of voting exercises with 75 participants, 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 (thus maintaining the original structure of the outcomes framework established in Chapter Three) (appendix 4). Work is now underway to develop an outcome tool corresponding to outcome domains detailed for the individual level (thus further responding to the training needs identified for practitioners with regards evaluation and outcome monitoring following the competencies survey in Chapter Two).

Supporting Direct Engagement of Children, Young People and Adults in PBS

Further to completion of the study detailed in Chapter Five, a further project was conducted and published (Bradshaw, Gore & Darvell, 2018) to support engagement of children within a PBS framework. This study built upon the Talking Mats procedure, materials and conceptions developed in Chapter Three but focussed on the clinical context of Functional Assessment in a school setting. A member of the school staff (who was also a University student) was trained to carry out the Talking Mats procedure with three young people who had a history of displaying CB and presented with intellectual disabilities and communication challenges. Here, it was possible to engage with children to again explore preferred activities but also discover those factors they recognised as making life challenging (which may function as antecedent events for CB) and those that might be supportive during times of difficulty (i.e., that might serve as proactive or direct support strategies). A practical protocol has also been created combining the goal-based Talking Mats procedures and materials and those relating to Functional Assessment which has been used to provide clinical training to a specialist PBS service supporting Children and Young People in the UK.

Further to this it was possible to work in partnership with a third sector organisation that supports families of people with severe disabilities (The Challenging Behaviour Foundation) to utilise the Talking Mats method and further explore options for supporting engagement with children for whom other communication options are necessary (including structured observation methods and opportunities to draw on the expertise of family caregivers). Findings and recommendations from a demonstration project (in which Gore trained a researcher to utilise the Talking Mats procedure) are in the final stages of publication (The Challenging Behaviour Foundation, in press).

Supporting the Engagement and the Emotional Needs of Family Caregivers

In the context of work initiated in Chapter Four (Making it Meaningful: Caregivers Goals and Priorities for PBS) two further project areas are notable and have been completed during the time period of the thesis. Firstly, for a national workforce training initiative, Gore was commissioned to co-author training materials by the Royal College of Psychiatrists as part of the MindED resources housed by the Department for Health and the Department for Education (https://www.minded.org.uk). These materials were co-produced in close working partnership with a family caregiver and focused on the lived experiences and emotional needs of families in the context of supporting a relative with a learning disability. Both the content and process of this work connected closely with learning from the thesis.

Secondly, as a partnership between the Challenging Behaviour Foundation and the Tizard Centre, Gore has led on the development of a Family Caregiver Research Alliance. This alliance brings together researchers and family caregivers with a common aim of supporting one another's research skills and advancing the quality and scope of research in the field over time. Group members include a core group of family caregivers supporting relatives with a history of behaviours that challenge and academics committed to a model of partnership working. Work of the group has included a further evaluation of Early Positive Approaches to Support (E-PAtS) in which family caregivers (who did not attend E-PATS groups) were trained to conduct qualitative interviews, furthering a co-production model and creating a safe and trusting context for discussion.

Early Positive Approaches to Support

In the later stages of PhD completion (but outside the context and scope of this thesis) Gore partnered with researchers and organisations across the UK to gain funding and complete a feasibility trial of E-PAtS, building on the learning from earlier piloting work and refinement of the E-PAtS Logic Model. This was completed successfully, creating the foundation for a future full scale trial to establish effectiveness.

Since the initial pilots that formed the basis for evaluation in Chapter Seven, E-PAtS facilitators have been trained in seven further sites across the UK, two of whom were included in the feasibility trial, and all of whom have delivered groups to families and provided positive feedback to trainers. E-PAtS has also been translated into Norwegian, with trained facilitators having delivered a first group and planning for a second, and into French, with a team of facilitators in Canada now also delivering and evaluating E-PAtS in both English and French. Further E-PAtS development in Northern Ireland has been particularly encouraging with 17 facilitators having been trained and 24 E-PAtS groups having been delivered by 2020, supporting approximately 200 caregivers. The Northern Ireland Director of the organisation supporting E-PAtS delivery has reported (in a letter of support, 2020) E-PAtS to be:

> *‘A transformative programme in terms of our development of early intervention and family support. We had been searching for a programme that would meet the needs of*

> *our parents, based on the most up to date research and act as the entry point to our range of family support services.'*

And that during in-service evaluations (those conducted by the organisation):

> *'Parents consistently tell us that E-PAtS has given them a range of skills and tools to support their child's development and improve their confidence and capability as a parent. Parents also use E-PAtS to develop core support networks and we see many of the groups continue to meet and support each other as well as begin to ask for other programmes of support. The range of peer sharing and learning in E-PAtS is significant.'*

Finally, reports from the organisation underscore the value of partnership working and embedding early years, proactive support within service pathways:

> *'Conclusion: E-PAtS has been a partnership programme from the beginning.'*
>
> *'Without doubt our family support would not be as successful or effective without the E-PAtS programme. It has and continues to be an excellent example of how research expertise applied and delivered in partnership with the community can have real impact.'*

Final Conclusions: The Evolving Definition and Scope for PBS

Positive Behavioural Support has been described as an evolving science (Carr et al., 2002). In this context, and with the ambition of informing enhanced early years, service support for children with IDD and their families in the UK, this thesis approached three research questions that stemmed from the Gore et al. (2013) definition of PBS and associated publications (e.g., Hastings et al., 2013; Denne et al., 2013). At the close of this thesis, and after a period of seven years since publication of these articles, taking steps to further refine and develop a definition and scope for PBS appears valuable.

It is notable that since 2013 the use of PBS in services, reference to PBS in guidance and research publications, and debate about what PBS does, for whom and in what ways have proliferated (e.g., Scott et al., 2018; Fuchs & Ravoux, 2019). Careful consultation with a range of stakeholders and further work will be required to address the breadth of developments and issues that have arisen in this period, and inform construction of a renewed definition for PBS going forward. Some key points for consideration have however, been prompted by the studies and discussions contained within this thesis, and are summarised below by way of final conclusions and recommendations.

Other Complementary, Evidence-Based Approaches to Support Behaviour Change

Whilst ABA is considered a foundational approach within PBS, a stance towards embracing other practices and approaches has long been recognised as critical for the framework (e.g., Carr et al., 2002), and formed part of the sixth component in the Gore et al. (2013) definition. A variety of approaches were highlighted as within scope in this regard, including training, self-management or therapeutic interventions with focal individuals, their staff and family carers (Gore & Umizawa, 2011; MacDonald & McGill 2013; Smith & Gore, 2011).

Within this thesis three main strands have reflected this component. Firstly, technologies that have not been derived from ABA have been utilised at a practice-based level. Most notably the Talking Mats methodology employed in Chapter Four and Chapter Five drew on the research literature and evidence-base of Speech and Language Therapy. The second feature concerns theoretical areas. Here, aspects of Acceptance and Commitment Therapy (ACT: Hayes et al., 1999) were also utilised in Chapter Four and more centrally within construction and delivery of the E-PAtS programme in Chapters Six and Seven.

Whilst ACT has a behavioural basis, the model draws on concepts that are not so commonly utilised in ABA (i.e., Relational Frame Theory: Hayes, Barnes-Holmes & Roche, 2001), or PBS or the IDD field. The Logic Model for E-PAtS also drew to a large extent on the Developmental Systems Model (Guralnick, 2001; 2005a) which again has been created in a related but separate field. Referencing these kind of additional examples will be important for a revised definition, as will making explicit the learning that can be gained from a cross-discipline or multi-profession approach to PBS implementation.

Secondly, this thesis utilised a range of research methodologies including qualitative methods and a Delphi-Panel approach. Whilst group based designs are becoming more common in ABA research, single-case experiments are more traditionally utilised within the behavioural field. These have considerable strengths in many regards (most notably for demonstrating experimental control, replication and identifying effectiveness of discrete intervention components). At a practice level, PBS does, however, recognise and encourage the use of a flexible range of assessment procedures, which have good contextual fit and minimise demands on stakeholders (even where experimental control may be compromised to some degree). The breadth of aims and methods utilised in PBS and the fact that policy makers typically form decisions based on evidence derived from trials-based research (e.g., National Institute for Health and Care Excellence, 2015) mean that single-case experimental designs are not always optimal for research in the field and the evolution of PBS. Whilst continuing to value and utilise single case designs in certain contexts, this definitional component may helpfully also reference flexibility and development with regard scientific method to a greater degree.

Systems Level, Long-Term Implementation

Part of the sixth component in the 2013 definition reflects PBS implementation at a systems level. This also corresponds to the final, tenth component with recognition that PBS necessitates further support and guidance for stakeholders (Horner et al., 2000), together with ongoing monitoring, evaluation and refinement as part of a data-informed iterative process (LaVigna, Christian & Willis, 2005). Outcome evaluation was recognised in this thesis as a key training and support need for practitioners (in Chapter Two) which prompted the development of an outcomes framework for PBS (in Chapter Three). More closely referencing the breadth and extent of outcome dimensions relevant to PBS may be a useful element of a refined definition with work from this thesis a helpful foundation.

A further priority area to emphasise in a future definition concerns a systems conception of PBS with correspondence to tiered models of implementation. Tiered models, underpinned by a public health approach, are commonly applied with regards physical and psychological health, with lower-cost, preventative supports delivered at a broader population level, and more targeted (and often costlier) supports provided to the smaller numbers of those most at risk. Tiered models are typical within the School-Wide Positive Behaviour Support (Sprague & Horner, 2006) literature but also have resonance with the concepts of capable environments (McGill, Bradshaw, Smyth, Hurman, & Roy, 2020) that often feature in UK models of PBS across community settings (e.g., Jones et al., 1999). Arguably, these elements of PBS are not readily discernible in the 2013 definition and could helpfully be better demonstrated in the future with possible refernce to models of implementation science (i.e., Fixsen et al, 2015). A systems theme featured in Chapters Two and Three of the current thesis but also had relevance to the development and conception of E-PAtS, all of which provide helpful connections to an expanded consideration of systems-level implementation.

Stakeholder participation and prevention of challenging behaviour within the context of increased quality of life

Finally, but most significantly, PBS is built on a foundation of key values that form the initial components of the 2013 definition and to which this thesis has endeavoured to connect closely. The third component in the definition highlights the centrality of working with stakeholders to both inform and validate PBS assessment, intervention and evaluation and the need to provide support to stakeholders themselves as part of a programme of interventions. This thesis worked closely with practitioner stakeholders (Chapters Two and Three) and family caregivers (Chapters Four and Seven). In both cases, research was approached with sensitivity to the challenges faced in supporting children who present with CB and an ambition of enhancing, the skills, resources and power of stakeholders to function effectively. Enhancing conceptions and commitment to stakeholder engagement in this regard will be of critical importance to a revised definition of PBS, with recognition that PBS can only be implemented when the same person centred values and support are afforded to the behaviour and wellbeing of those who operate as mediators.

The impact of trauma experienced by caregivers in the context of both a relative's CB and the failings of support systems has received increased recognition in recent years (e.g., Keesler & Isham, 2017; Gardiner, Larocci & Moretti, 2017). The extreme circumstances many families face was contacted in Chapter Four and has been a continuing characteristic of families who have shared their past experiences in the context of attending E-PAtS groups. A continuing emphasis on the need to support wellbeing for caregivers will be important for a new PBS definition but so too will be a reinforcing message of the resilience, insight and skill of caregivers. Here, it is noted that the language of co-production and 'experts by experience' is becoming more widespread in the UK more generally and has close synergies to the concept of stakeholder engagement. Partnership working, in the context of both families and staff teams may also be a helpful additional component area to incorporate more explicitly, reflecting those dimensions of professional relationships that families have reported to be of importance (Brotherson et al., 2010; Dunst et al., 1994; Summers et al., 2007) and which were referenced in some aspects of this thesis.

Whilst conceptually, the person-centred roots of PBS and stakeholder component of the 2013 definition would support direct engagement with a person for whom behaviour support is the focus, this has rarely been a feature of PBS in practice or research. This thesis explored an initial method of engaging directly with at least some children where both behaviour and communication presented a potential barrier to doing so. Whilst a small step, this might be considered a critical one for connecting elements of a PBS framework, particularly within the context of goal formation, and should therefore receive further consideration and discussion in a future PBS definition. Attempts to support direct engagement with people with IDD are a significant challenge and one that calls for integration and use of both the technologies of ABA and other disciplines, together with close working relationships with other stakeholders. Whilst multiple strategies are needed to support successful implementation, embedding such engagement practices within systems and services has the potential to ensure PBS is delivered and monitored with integrity and sensitivity, to support life quality in both the short and longer term for children and their families.

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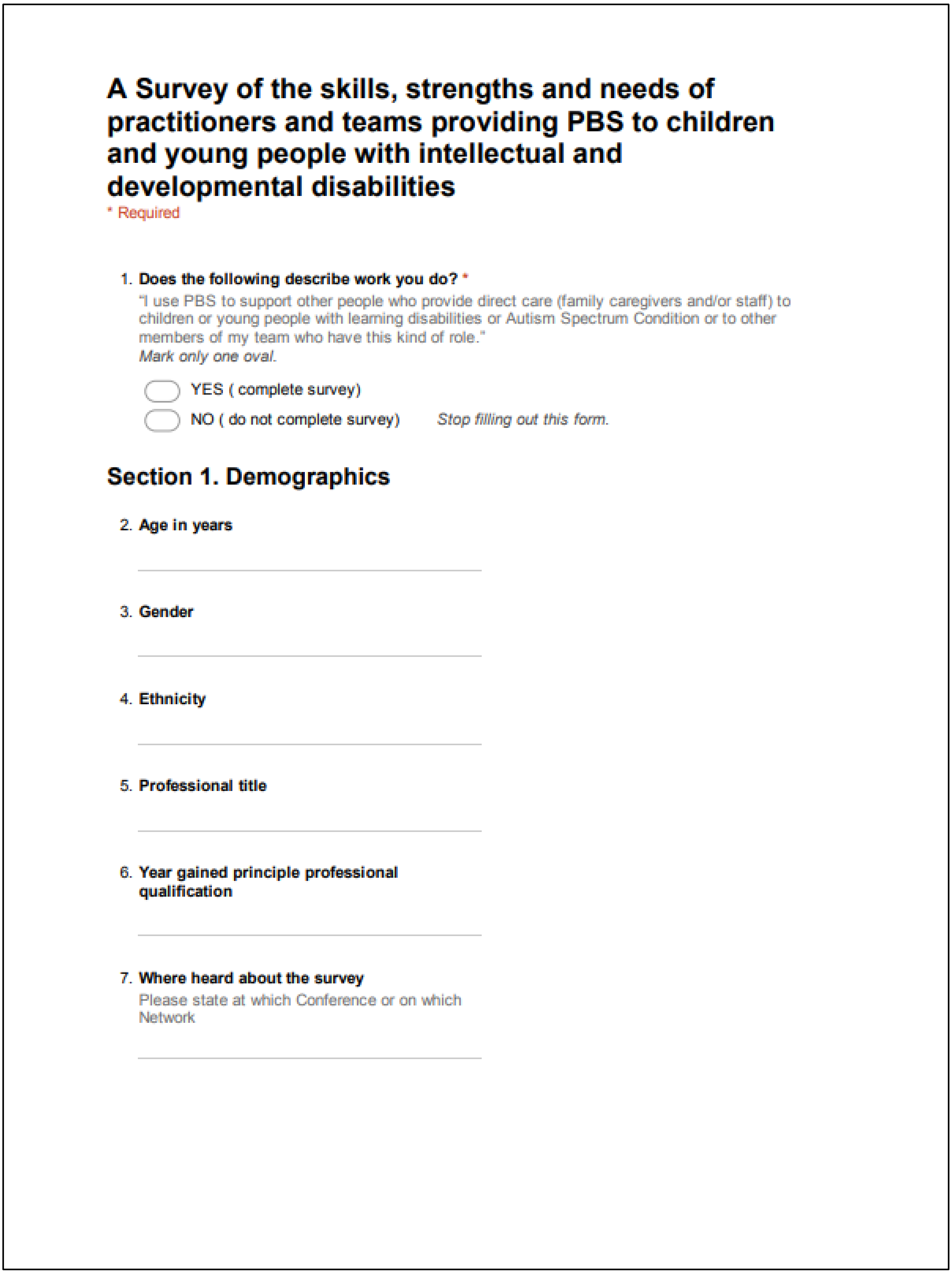
Appendixes

Appendix 1: Survey (Chapter Two)



A Survey of the skills, strengths and needs of practitioners and teams providing PBS to children and young people with intellectual and developmental disabilities

* Required

1. **Does the following describe work you do? ***
   "I use PBS to support other people who provide direct care (family caregivers and/or staff) to children or young people with learning disabilities or Autism Spectrum Condition or to other members of my team who have this kind of role."
   Mark only one oval.
   ○ YES (complete survey)
   ○ NO (do not complete survey) *Stop filling out this form.*

Section 1. Demographics

2. **Age in years**

   ____

3. **Gender**

   ____

4. **Ethnicity**

   ____

5. **Professional title**

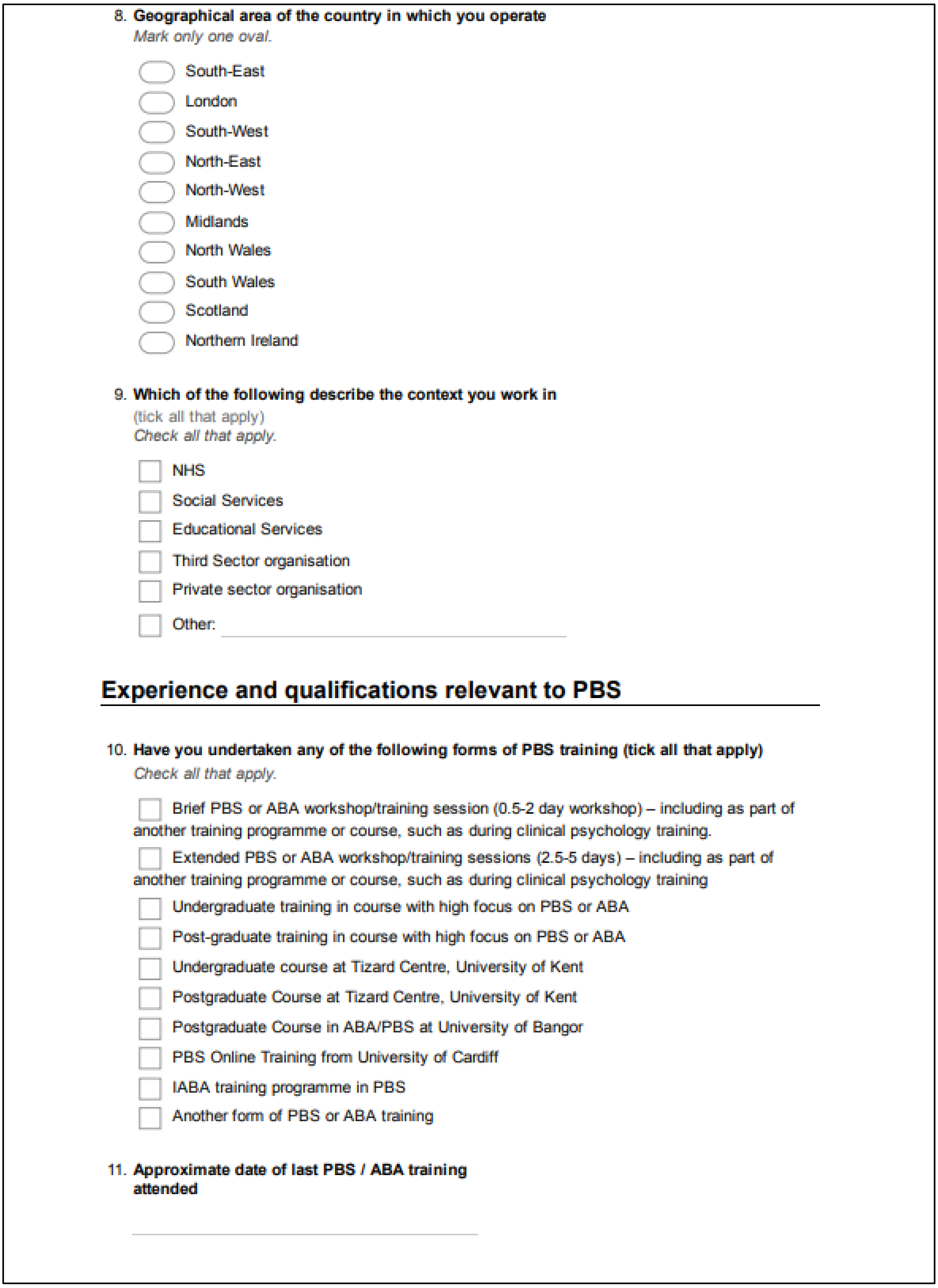
   ____

6. **Year gained principle professional qualification**

   ____

7. **Where heard about the survey**
   Please state at which Conference or on which Network

   ____



8. **Geographical area of the country in which you operate**

Mark only one oval.

○ South-East
○ London
○ South-West
○ North-East
○ North-West
○ Midlands
○ North Wales
○ South Wales
○ Scotland
○ Northern Ireland

9. **Which of the following describe the context you work in**

(tick all that apply)

Check all that apply.

☐ NHS
☐ Social Services
☐ Educational Services
☐ Third Sector organisation
☐ Private sector organisation
☐ Other: ____________________

Experience and qualifications relevant to PBS

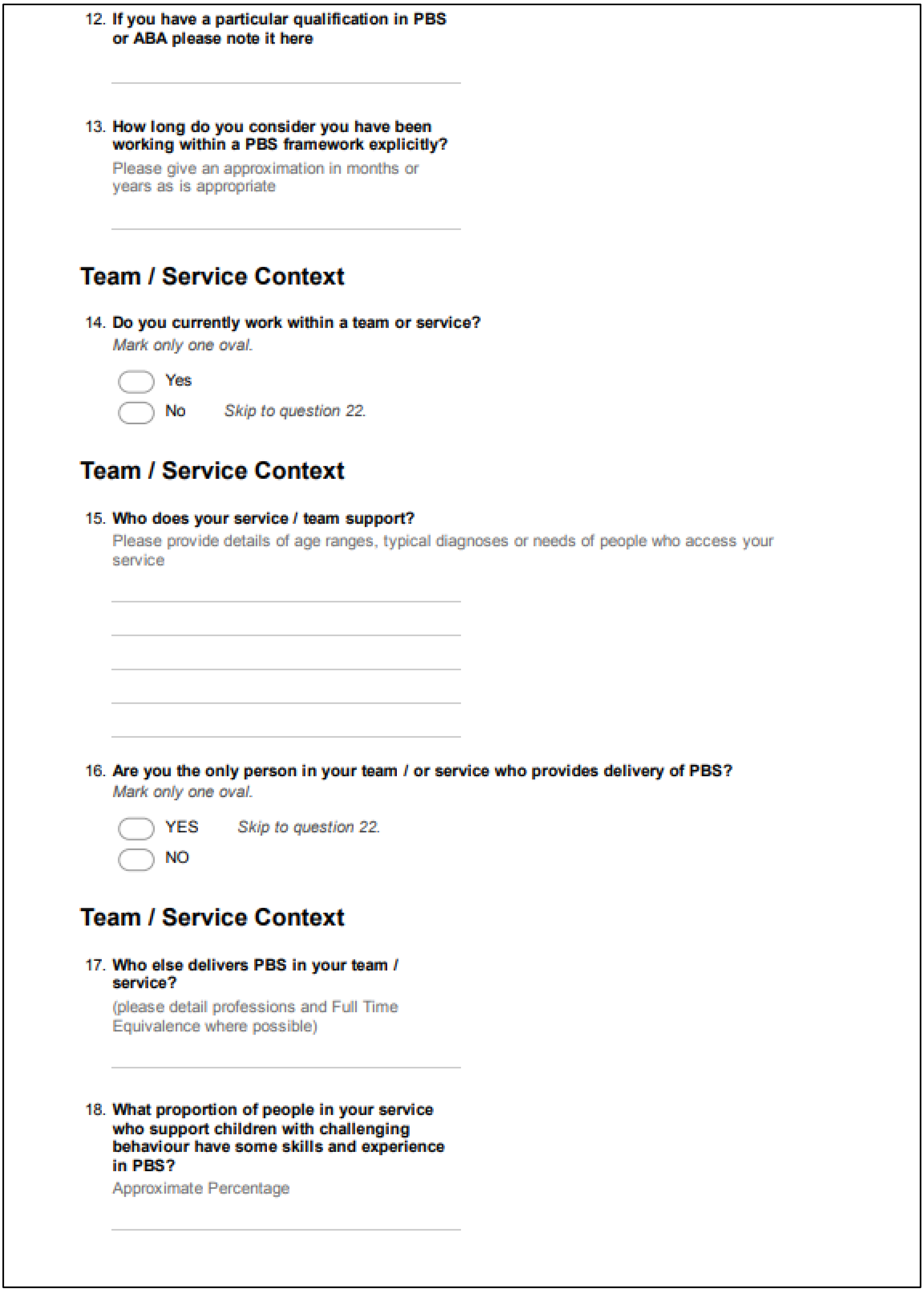
10. **Have you undertaken any of the following forms of PBS training (tick all that apply)**

Check all that apply.

☐ Brief PBS or ABA workshop/training session (0.5-2 day workshop) – including as part of another training programme or course, such as during clinical psychology training.
☐ Extended PBS or ABA workshop/training sessions (2.5-5 days) – including as part of another training programme or course, such as during clinical psychology training
☐ Undergraduate training in course with high focus on PBS or ABA
☐ Post-graduate training in course with high focus on PBS or ABA
☐ Undergraduate course at Tizard Centre, University of Kent
☐ Postgraduate Course at Tizard Centre, University of Kent
☐ Postgraduate Course in ABA/PBS at University of Bangor
☐ PBS Online Training from University of Cardiff
☐ IABA training programme in PBS
☐ Another form of PBS or ABA training

11. **Approximate date of last PBS / ABA training attended**

____



12. **If you have a particular qualification in PBS or ABA please note it here**

13. **How long do you consider you have been working within a PBS framework explicitly?**
Please give an approximation in months or years as is appropriate

Team / Service Context

14. **Do you currently work within a team or service?**
Mark only one oval.

○ Yes
○ No *Skip to question 22.*

Team / Service Context

15. **Who does your service / team support?**
Please provide details of age ranges, typical diagnoses or needs of people who access your service

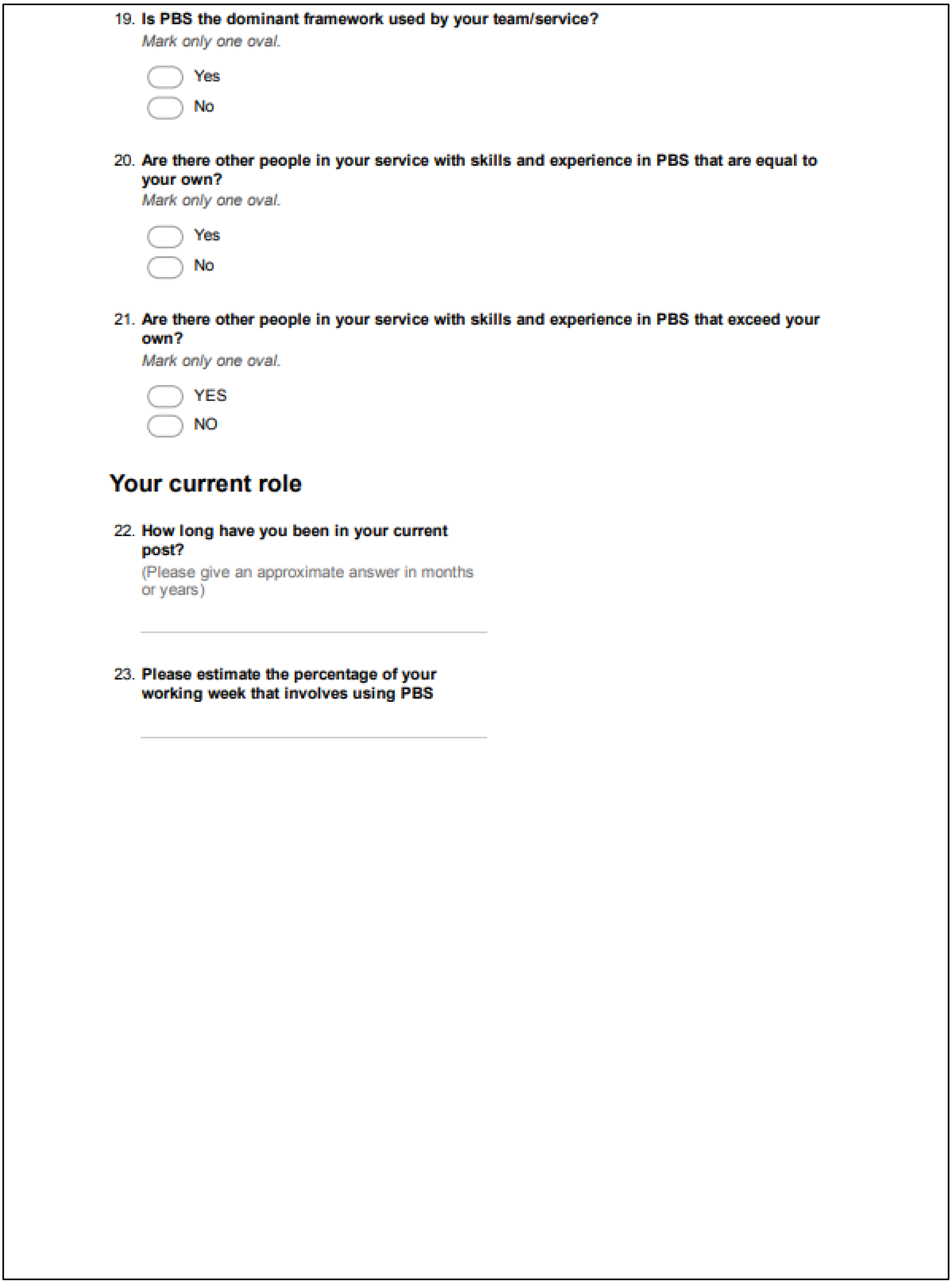
16. **Are you the only person in your team / or service who provides delivery of PBS?**
Mark only one oval.

○ YES *Skip to question 22.*
○ NO

Team / Service Context

17. **Who else delivers PBS in your team / service?**
(please detail professions and Full Time Equivalence where possible)

18. **What proportion of people in your service who support children with challenging behaviour have some skills and experience in PBS?**
Approximate Percentage



19. **Is PBS the dominant framework used by your team/service?**
Mark only one oval.

○ Yes
○ No

20. **Are there other people in your service with skills and experience in PBS that are equal to your own?**
Mark only one oval.

○ Yes
○ No

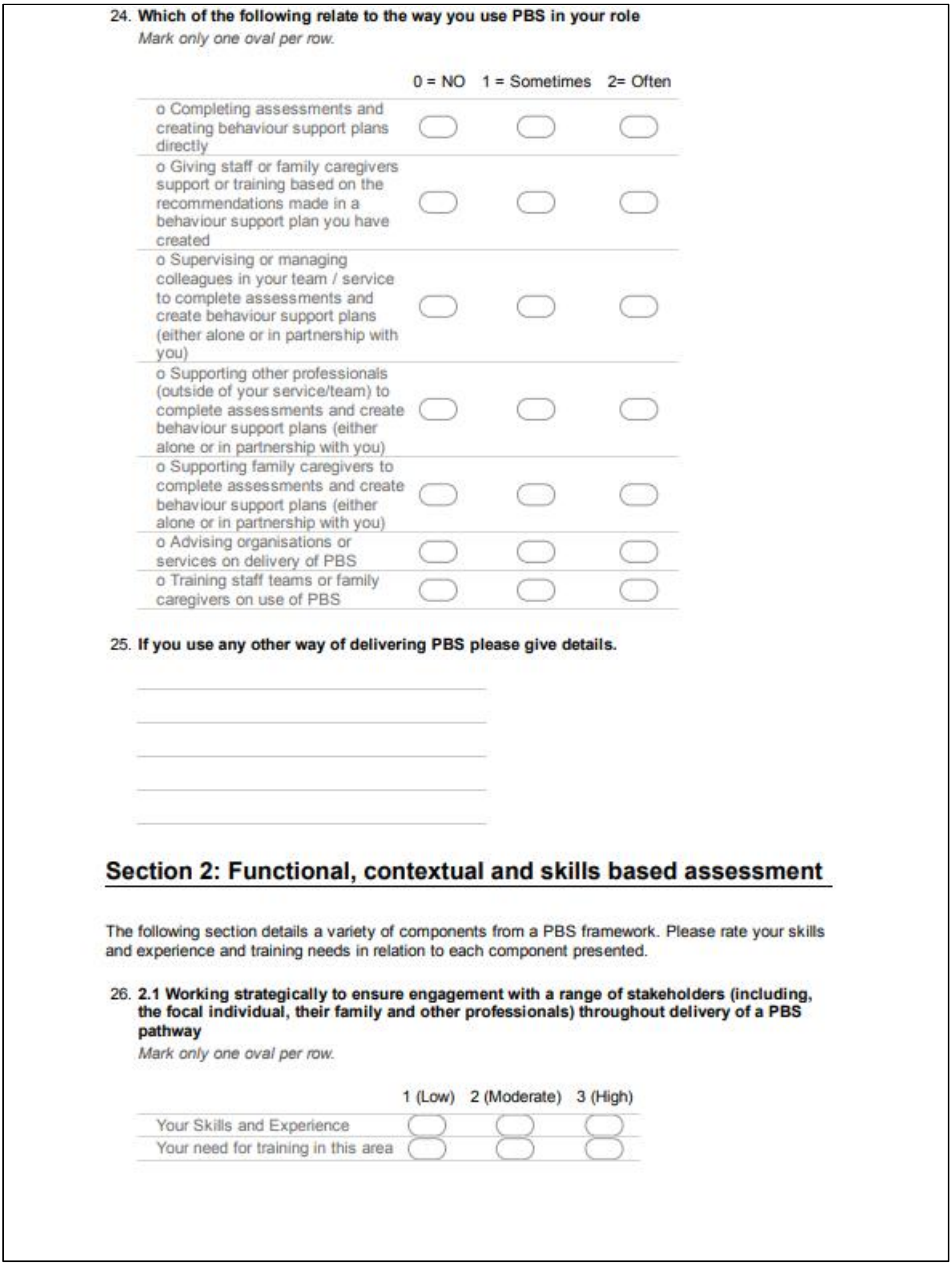
21. **Are there other people in your service with skills and experience in PBS that exceed your own?**
Mark only one oval.

○ YES
○ NO

Your current role

22. **How long have you been in your current post?**
(Please give an approximate answer in months or years)

23. **Please estimate the percentage of your working week that involves using PBS**



24. **Which of the following relate to the way you use PBS in your role**
Mark only one oval per row.

	0 = NO	1 = Sometimes	2= Often
o Completing assessments and creating behaviour support plans directly	○	○	○
o Giving staff or family caregivers support or training based on the recommendations made in a behaviour support plan you have created	○	○	○
o Supervising or managing colleagues in your team / service to complete assessments and create behaviour support plans (either alone or in partnership with you)	○	○	○
o Supporting other professionals (outside of your service/team) to complete assessments and create behaviour support plans (either alone or in partnership with you)	○	○	○
o Supporting family caregivers to complete assessments and create behaviour support plans (either alone or in partnership with you)	○	○	○
o Advising organisations or services on delivery of PBS	○	○	○
o Training staff teams or family caregivers on use of PBS	○	○	○

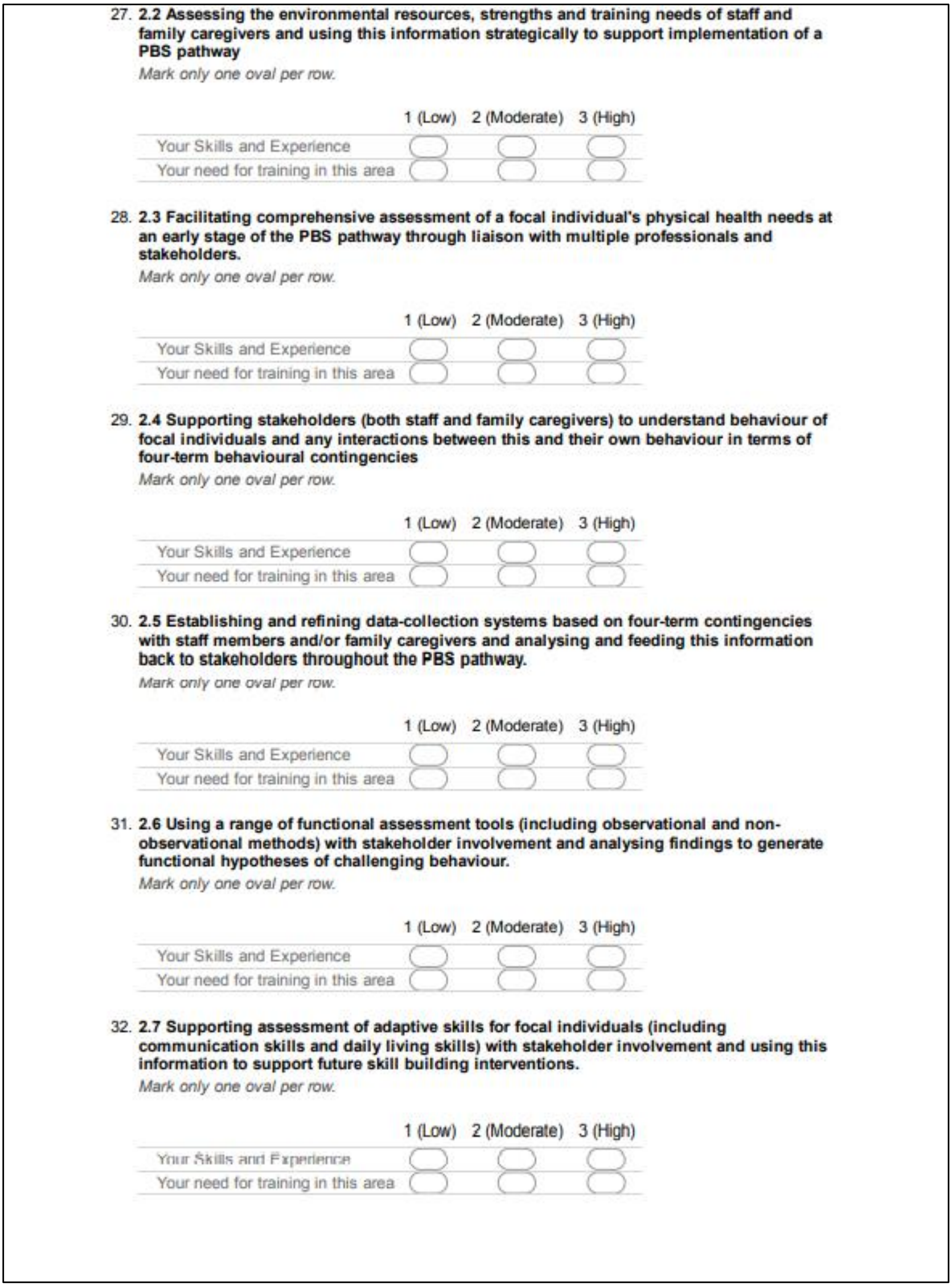
25. **If you use any other way of delivering PBS please give details.**

Section 2: Functional, contextual and skills based assessment

The following section details a variety of components from a PBS framework. Please rate your skills and experience and training needs in relation to each component presented.

26. **2.1 Working strategically to ensure engagement with a range of stakeholders (including, the focal individual, their family and other professionals) throughout delivery of a PBS pathway**
Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○



27. **2.2 Assessing the environmental resources, strengths and training needs of staff and family caregivers and using this information strategically to support implementation of a PBS pathway**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

28. **2.3 Facilitating comprehensive assessment of a focal individual's physical health needs at an early stage of the PBS pathway through liaison with multiple professionals and stakeholders.**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

29. **2.4 Supporting stakeholders (both staff and family caregivers) to understand behaviour of focal individuals and any interactions between this and their own behaviour in terms of four-term behavioural contingencies**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

30. **2.5 Establishing and refining data-collection systems based on four-term contingencies with staff members and/or family caregivers and analysing and feeding this information back to stakeholders throughout the PBS pathway.**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

31. **2.6 Using a range of functional assessment tools (including observational and non-observational methods) with stakeholder involvement and analysing findings to generate functional hypotheses of challenging behaviour.**

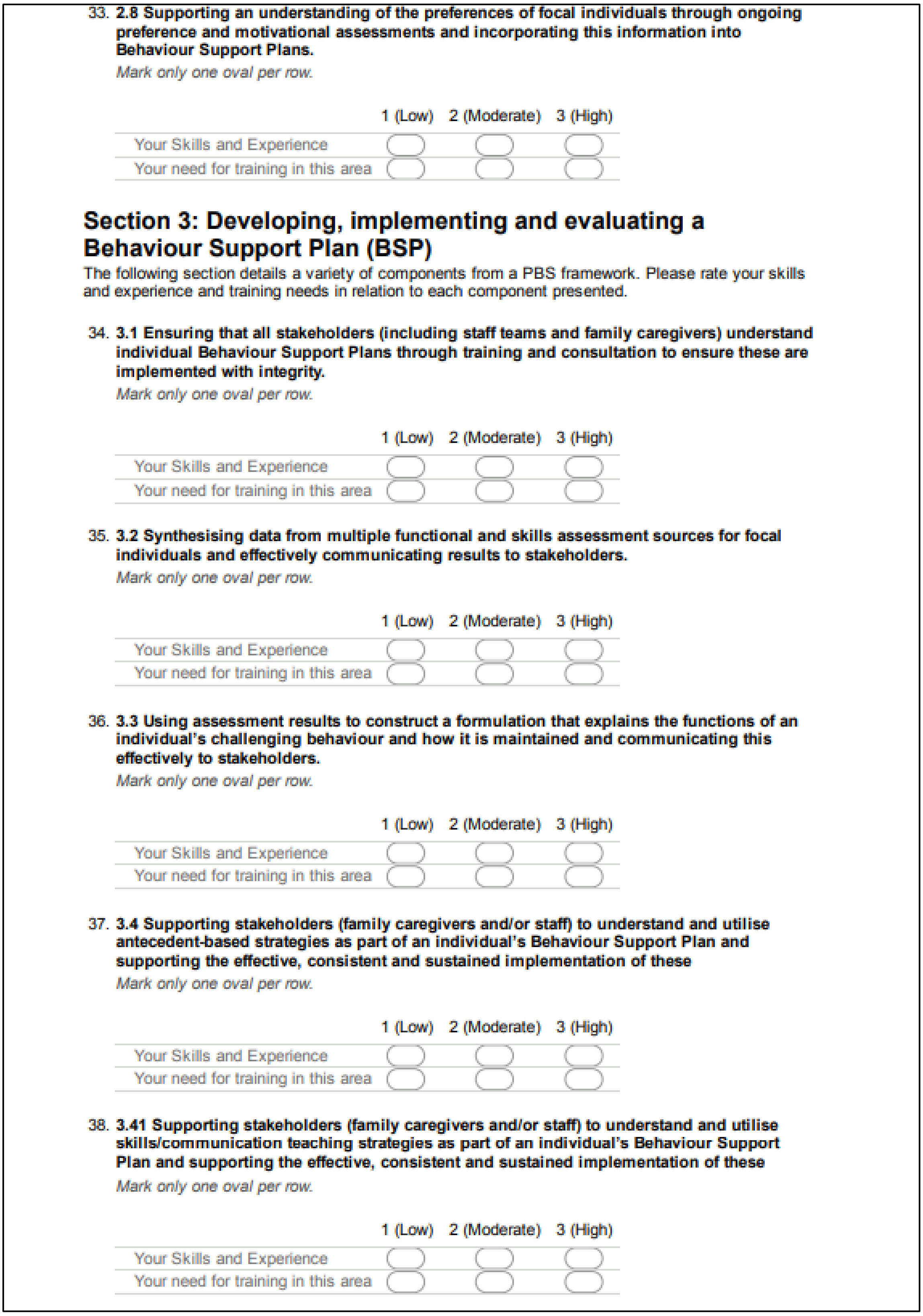
Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

32. **2.7 Supporting assessment of adaptive skills for focal individuals (including communication skills and daily living skills) with stakeholder involvement and using this information to support future skill building interventions.**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○



33. **2.8 Supporting an understanding of the preferences of focal individuals through ongoing preference and motivational assessments and incorporating this information into Behaviour Support Plans.**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

Section 3: Developing, implementing and evaluating a Behaviour Support Plan (BSP)

The following section details a variety of components from a PBS framework. Please rate your skills and experience and training needs in relation to each component presented.

34. **3.1 Ensuring that all stakeholders (including staff teams and family caregivers) understand individual Behaviour Support Plans through training and consultation to ensure these are implemented with integrity.**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

35. **3.2 Synthesising data from multiple functional and skills assessment sources for focal individuals and effectively communicating results to stakeholders.**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

36. **3.3 Using assessment results to construct a formulation that explains the functions of an individual's challenging behaviour and how it is maintained and communicating this effectively to stakeholders.**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

37. **3.4 Supporting stakeholders (family caregivers and/or staff) to understand and utilise antecedent-based strategies as part of an individual's Behaviour Support Plan and supporting the effective, consistent and sustained implementation of these**

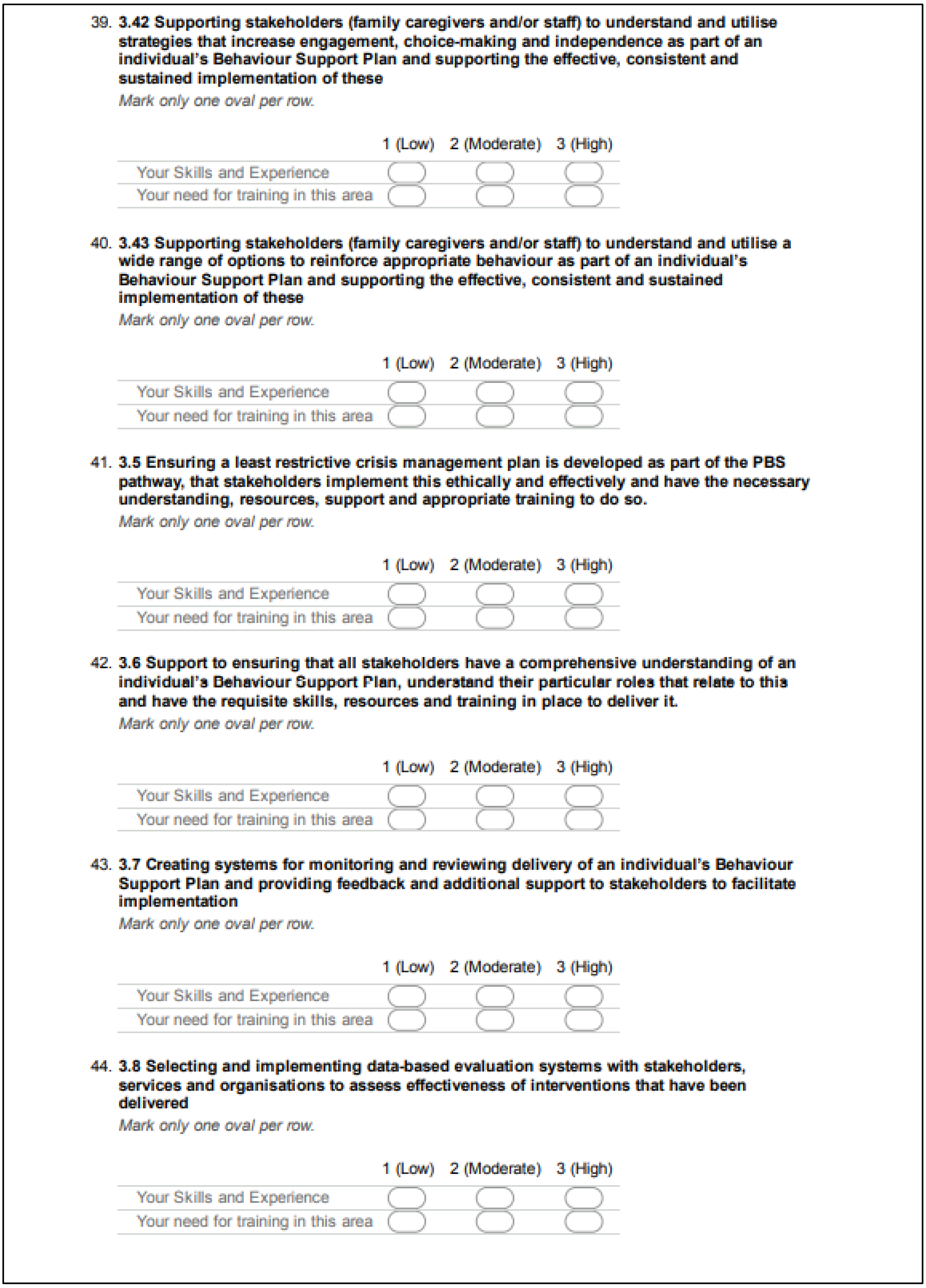
Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

38. **3.41 Supporting stakeholders (family caregivers and/or staff) to understand and utilise skills/communication teaching strategies as part of an individual's Behaviour Support Plan and supporting the effective, consistent and sustained implementation of these**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○



39. **3.42 Supporting stakeholders (family caregivers and/or staff) to understand and utilise strategies that increase engagement, choice-making and independence as part of an individual's Behaviour Support Plan and supporting the effective, consistent and sustained implementation of these**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

40. **3.43 Supporting stakeholders (family caregivers and/or staff) to understand and utilise a wide range of options to reinforce appropriate behaviour as part of an individual's Behaviour Support Plan and supporting the effective, consistent and sustained implementation of these**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

41. **3.5 Ensuring a least restrictive crisis management plan is developed as part of the PBS pathway, that stakeholders implement this ethically and effectively and have the necessary understanding, resources, support and appropriate training to do so.**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

42. **3.6 Support to ensuring that all stakeholders have a comprehensive understanding of an individual's Behaviour Support Plan, understand their particular roles that relate to this and have the requisite skills, resources and training in place to deliver it.**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

43. **3.7 Creating systems for monitoring and reviewing delivery of an individual's Behaviour Support Plan and providing feedback and additional support to stakeholders to facilitate implementation**

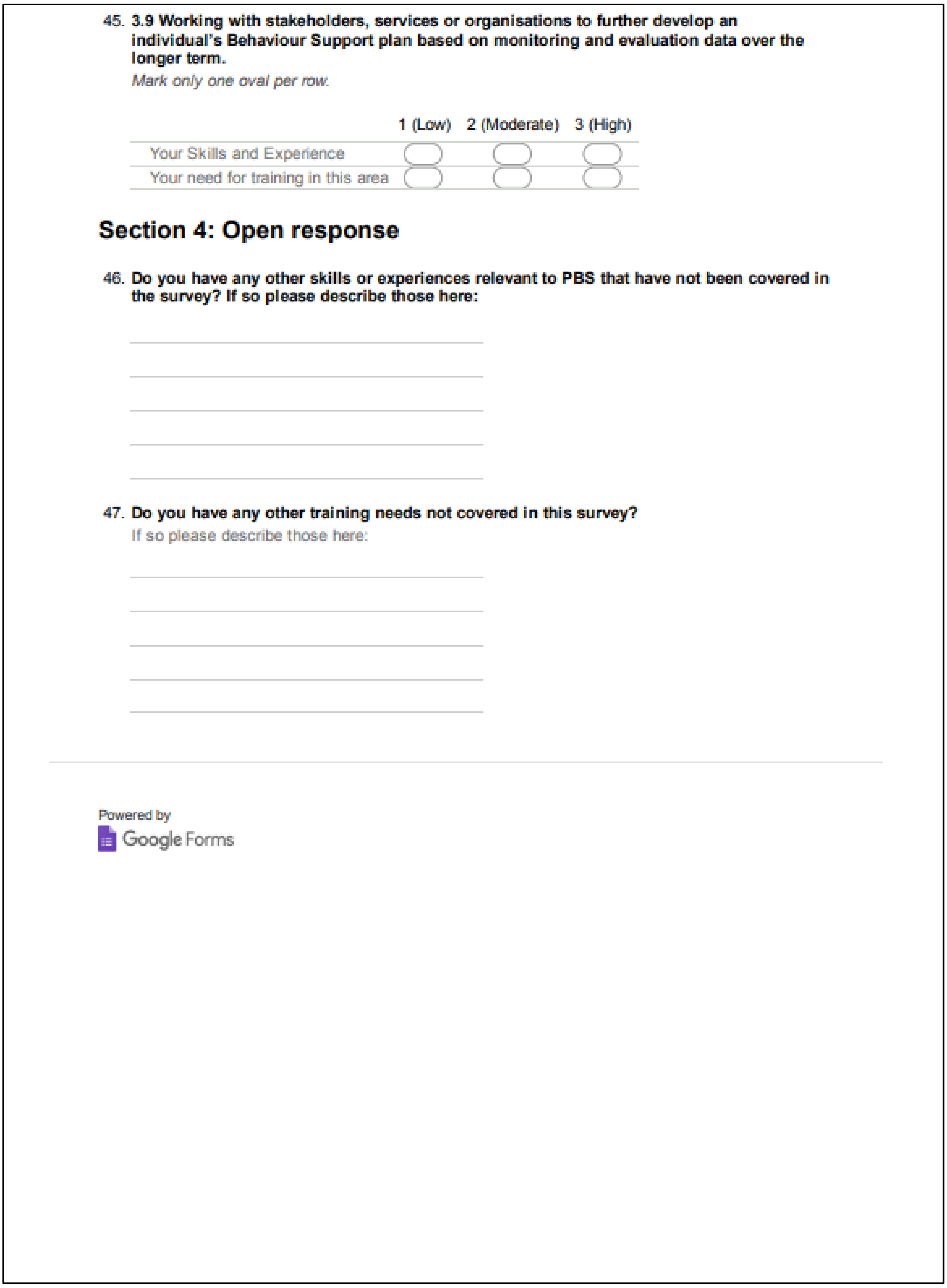
Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

44. **3.8 Selecting and implementing data-based evaluation systems with stakeholders, services and organisations to assess effectiveness of interventions that have been delivered**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○



45. **3.9 Working with stakeholders, services or organisations to further develop an individual's Behaviour Support plan based on monitoring and evaluation data over the longer term.**

Mark only one oval per row.

	1 (Low)	2 (Moderate)	3 (High)
Your Skills and Experience	○	○	○
Your need for training in this area	○	○	○

Section 4: Open response

46. **Do you have any other skills or experiences relevant to PBS that have not been covered in the survey? If so please describe those here:**

47. **Do you have any other training needs not covered in this survey?**

If so please describe those here:

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Appendix 2: Delphi Round 1 Invitation and Questions (Chapter Three)

Developing a Comprehensive, Consensus-Based Framework for the Evaluation of Positive Behavioural Support in the UK: A Delphi Study

ROUND 1

Thank you again for agreeing to participate in this study as a Delphi panel member. The first round of questions draws on dimensions and components of Positive Behavioural Support (PBS) proposed within the *autumn 2013 special edition of the International Journal of PBS and adopted by the PBS Academy within related resources*.

As is typical of early Delphi rounds, questions ask for qualitative responses to support open expression of your views and ideas. It is likely that in later rounds more discrete questions will be used that require briefer, quantitative responses.

To access the questions please click on the link below. This will take you to a google-forms document. Answer areas will expand as you type and the form will allow you to submit up to 4500 words in total (though it is not anticipated that your responses will require this). It is likely that you will want to write more for some answers than others and you can either type directly onto the form or copy and paste from Word.

It is possible that as you move through the questions you will want to change or add to your earlier responses or copy from these to later ones. If this is the case please do so. When you are happy with your answers click submit. This will send the form through to me but I will not know who it is from, so that your responses are anonymised.

I would be grateful if you could complete your responses by **12.00 Monday 5th December**. Following this I will send an e-mail to the whole group to check who has participated (assuming more than one person has taken part I still will not be able to link you to your form but need to keep a record of participation).

If you have any queries about the questions (for instance the terms used or wording) please do not hesitate to get in contact and I will try and provide further clarity (N.J.Gore@Kent.ac.uk). Thank you again and hope you enjoy it!

1. Listed below are groups of people who might have an interest in outcomes relating to PBS. Please look through the list and comment on the potential relevance of PBS outcomes for these groups. It could be helpful to consider the kind of outcomes you think people most want to know about, how they might use information about outcomes or how this might influence future behaviour. It you do not consider PBS outcomes to be relevant to a particular group please note this.

- People with Intellectual and developmental disabilities
- Family carers
- Commissioners
- Clinicians and professional bodies
- Policy makers
- Researchers / Academics
- Support staff

- Education staff and organisations
- Other social care workers and organisations
- Health care workers and organisations
- Provider organisations
- Third sector organisations
- General public / media

2. Are there other key stakeholder groups that are not covered above? If so please list these and again comment on the kind of outcomes you think people most want to know about, how they might use information about outcomes or how this might influence future behaviour.

3. Listed below are possible levels of a support system where change might be anticipated during or following delivery of PBS. In some cases sub-group examples have been provided. Please comment on the kind of outcomes that should be considered under each level of the system, and where possible in relation to each sub-group that could indicate effectiveness of PBS. If you do not consider any of the proposed levels or sub-groups to be relevant please note this.

    - Individual (people with IDD, caregivers, staff)
    - Group (families, teams, classes, service-user groups)
    - Organisation (service, school, unit, provider, family home)
    - Local community
    - Population

4. Please add any further sub-groups and alternative or additional system levels not covered above as you see fit (again, describing the key outcome areas that should be considered).

5. Listed below are three category headings that relate to key components of PBS. Please comment on the kind of outcomes that might be anticipated in relation to each of these to indicate that the framework has been implemented with fidelity.

- Values
- Theory and Evidence Base
- Process
-

6. Please list and describe any other outcome areas relevant to PBS that have not been included in your responses to earlier questions. If you have ideas for additional or alternative ways of structuring dimensions for outcome areas to those prompted in earlier questions please also describe these.

Many thanks for the time and energy you have taken to complete round 1 of the Delphi exercise. Your ideas and input are of great value. Once I have received all responses I will synthesise suggestions and comments and devise a second round of questions – watch this space!

With kind regards

Nick Gore

Appendix 3: Outcome Domains at Round 4 (Chapter Three)

	INDIVIDUAL LEVEL: Focal person with IDD
	Sub- Category QOL - Self-determination:
1	Choice making and control
	Sub- Category QOL - Family and interpersonal relationships:
2	Quality of relationships with family and friends
3	Number and range of relationships
4	Level of contact with preferred people.
	Sub- Category QOL - Social inclusion:
5	Community participation, inclusion, integration, presence
6	*A reduction in use of segregated services for the focal person that are separated/isolated from the community and an increase in use of services that support positive inclusion in the community*[7]
7	*The focal person is engaged in activates and roles that are regarded positively within the cultural context to support a positive social image*
	Sub- Category QOL - Personal development:
8	Adaptive skills, competencies and levels of independence
9	Engagement in meaningful activities
10	Opportunities for preferred activities
11	Opportunities for new activities
12	Employment related skills and employment
13	Communication and/or social skills (broadly)
14	Functionally related Communication Skills
15	Educational attainment
	Sub- Category QOL - Physical well-being:
16	Physical health status
17	Positive health and lifestyle behaviours
18	Access to health services
19	Mobility
20	*The focal person's sensory needs (hearing, sight and all other principle functional domains) are supported appropriately*
	Sub- Category QOL - Emotional wellbeing:
21	Psychological/emotional/mental health and wellbeing difficulties
22	Positive psychological/emotional/mental health and wellbeing
23	Self-management and coping skills
24	Access to mental health/support services
	Sub- Category QOL - Material wellbeing:
25	Enrichment of physical environment
26	Match between physical environment and individual's specific needs

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[7] Italics indicates reworded item

27	Proximity of accommodation to community
28	Proximity of accommodation to family home
	Sub- Category QOL - Rights:
29	Safety
30	Respect
31	*Peron is free form 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 abusive behaviour is supported appropriately*
32	*Person is free from aversive, restrictive practices. The focal person is not exposed to any forms of aversive/restrictive practice and a focal person who has previously been exposed to aversive practice is supported appropriately*
33	Access to advocacy
	Sub- Category Costs and quality of support received:
34	Staff/caregiver understanding of individual's needs and behaviours
35	Staff/caregiver use of positive approaches and adherence to BSP
36	Staff/caregiver use of person-centred approaches
37	Quality of relationship/rapport with staff/caregiver
38	Social validity of interventions received
39	Cost of resources and service utilization
40	*The ratio of teaching/support staff is appropriate to the person's needs*
41	Frequency/risk of placement breakdown
42	Stability of support team
43	Staff/caregiver use restrictive, aversive practices
44	Focal person injury/stress following restraint/reactive strategy use
	Sub- Category Challenging Behaviour:
45	Frequency, severity, intensity, duration, management difficulty and range of challenging behaviours
46	School exclusions
47	Classroom disruption
48	Discipline referrals

	MEDIATOR LEVEL: Family Caregivers
	Sub- Category Physical, psychological and emotional wellbeing:
49	Stress, psychological/emotional/mental health and wellbeing difficulties
50	Positive psychological/emotional/mental health and wellbeing
51	Self-management and coping skills
52	Access to mental health/support services
53	Resilience (psychological and social)
54	Sleep quality
55	Injury associated with challenging behaviour
	Sub- Category Family Quality of Life:
56	Quality of family relationships
57	Family community access

58	Isolation
59	Sibling satisfaction, wellbeing and happiness
60	Family resilience
61	Engagement with valued routines/activities
62	Opportunities for employment
	~~Support and behaviour needs of focal person do not impact on family caregiver's satisfaction with the quality of their relationship with partner~~[8]
	Sub- Category Relationship with focal person:
63	Access to/with focal person
64	Positive perception of focal person
65	Quality of relationship with focal person
	Sub- Category Quality of Support Received:
66	Perceived quality/co-ordination of support
67	Involvement in planning/advocacy/service support
68	Satisfaction with training and support received
69	Social validity, ecological validity and contextual fit of family-focused interventions
70	Stakeholder involvement and co-production
	Sub- Category Skills, knowledge and attributions:
71	Emotional reactions to challenging behaviour
72	Confidence/self-efficacy/sense of competence in responding to challenging behaviour/supporting family member
73	Perceived management difficulty of challenging behaviour
74	Use of positive approaches to respond to relative's challenging behaviour
75	*Minimisation in the use of restrictive/aversive practices by caregivers (reduced use of reprimands, restraint, time out, etc.,)*
76	Understanding of focal person's needs and behaviour/causal attributions
77	*An increase in positive parenting practices (where focal person is a child in family home) such as use of behaviour specific praise and reinforcement*

	MEDIATOR LEVEL: Paid Caregiver/Staff
	Sub- Category PBS Values (knowledge, attributions and behaviour):
78	Understanding relationships between quality of support, quality of life and challenging behaviour
79	Understanding a constructive approach to challenging behaviour
80	Commitment and use of person centred approaches
81	Collaboration with stakeholders
82	Commitment to non-use of aversive and restrictive practices.
83	Commitment to increasing adaptive skills and quality of life
84	Commitment to supporting valued social inclusion

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[8] Strike through indicates Item that did not reach consensus

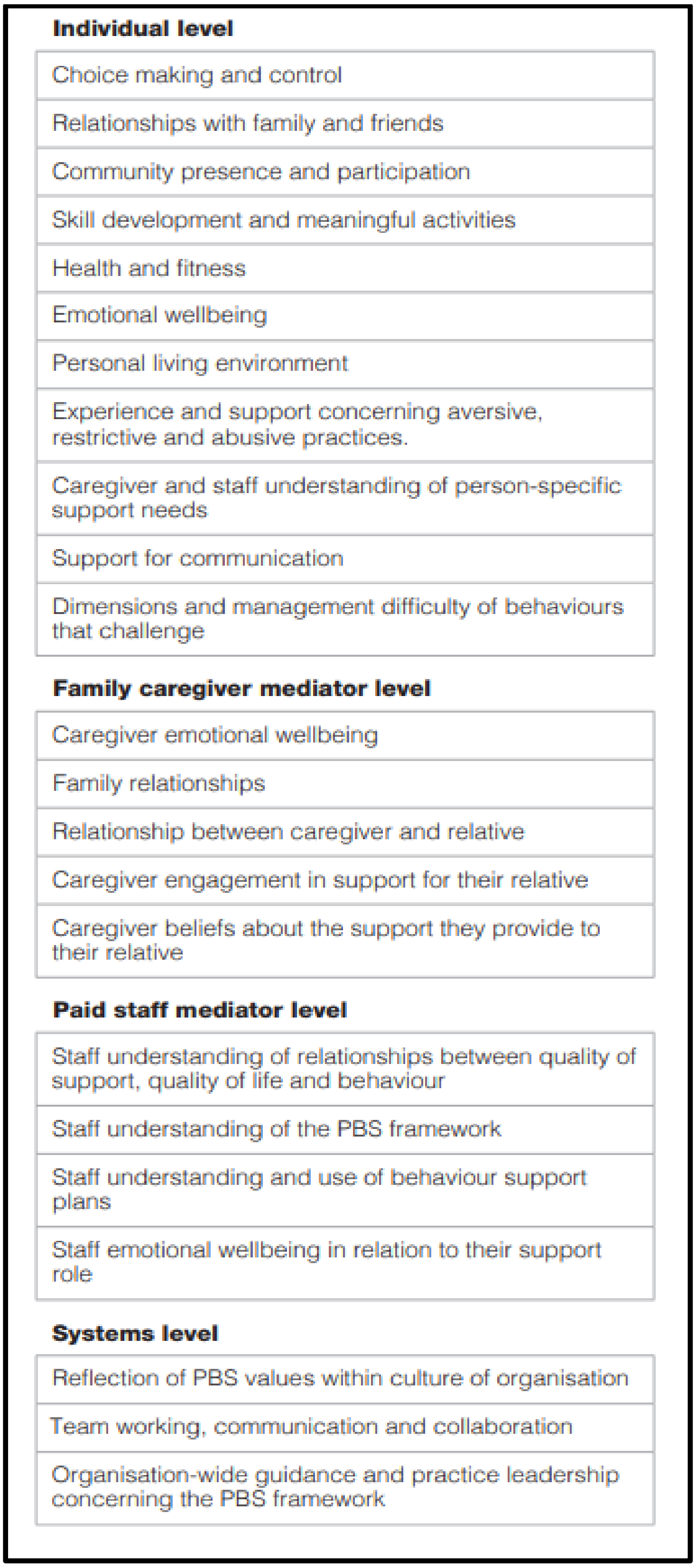
85	Respect and dignity towards focal person(s) and/or vulnerable people more broadly
86	Attitudes and beliefs concerning people with IDD more broadly
87	*Staff members can articulate and demonstrate examples of their own behaviour that are consistent with PBS values when supporting focal person/people (how to support choice making effectively for instance)*
	Sub- Category PBS Theory (knowledge, attributions and behaviour) (
88	Knowledge and understanding of PBS framework
89	Knowledge and understanding of ABA
90	Use of ABA in assessment, intervention and evaluation
91	Knowledge and understanding of functional model of CB
92	Causal attributions relating to reasons why person engages in CB
93	Empathy and understanding of life experiences effecting CB
94	Knowledge and understanding of system-change strategies
95	Knowledge and understanding of complimentary evidence based approaches in addition to ABA
	Sub- Category PBS Process and practice (knowledge, attributions and behaviour)
96	Understanding and use of Functional Assessment
97	Quality and quantity of Functional Assessments undertaken
98	Understanding and use of Behaviour Support Plans
99	Quality and quantity of Behaviour Support Plans undertaken
100	Adherence to/use of and implementation of Behaviour Support Plans
101	Understanding and use of data to guide decision making
102	Understanding and use of evaluation methods
103	Use of positive intervention support strategies
104	*Minimisation in use of aversive restrictive practices by staff (restraint, seclusion, time out)*
105	Ratio of proactive to reactive support strategies
106	Stakeholder engagement activity and skills
107	Appropriate use of risk assessment Vs risk avoidance
108	Quality of relationship /rapport with focal person
109	Use of active support principles and strategies
	Sub- Category Wellbeing and work performance:
110	Self-management and coping skills
111	Stress/burnout, psychological/emotional/mental health and wellbeing difficulties,
112	Positive indicators of psychological/emotional/mental health and wellbeing
113	Injury associated with challenging behaviour
114	Leave/sickness relating to challenging behaviour
115	*Staff manage the demands of their role and maintain positive wellbeing over the long term even when recognising challenges to this.*
116	Job satisfaction

117	Job role certainty
118	CPD goals met
119	Quality of working environment
120	Involvement in decision making
121	Motivation and morale
122	Skills in practice leadership
123	Use of reflective practice
124	Access to supervisor and wellbeing-related support;
125	Training received in PBS/ABA/challenging behaviour

	SYSTEMS LEVEL: Services, organisations and localities
	Sub- Category Service, organisational and locality quality:
126	*Inspection ratings demonstrate an improvement in quality indicators that are consistent with components of a PBS framework*
127	Rates of safeguarding,
128	Multi-disciplinary team working
129	*Staff communication and culture reflects values of a PBS framework (vocabulary – labelling and forms of address that are respectful, non-blaming and encouraging, etc)*
130	Consistency of practices across teams/services/organisations
131	Commitment and provision of whole staff training and professional development
132	Organisational resilience
133	Service-user/family satisfaction ratings
134	Rates and costs of out of area/ATU service provision
135	*Service size and proximity to the community reflects principles of SRV and social inclusion (small, individualised and embedded within the community)*
	Sub- Category Service, organisational and locality functioning:
136	Staff turnover
137	Staffing ratios
138	Service/organisation costs
139	Local service infrastructure
140	Appropriate referrals for specialist input
141	Use of agency staff
142	It is easy to recruit staff to the organisation – people want to work there. Lots of people apply for positions that are advertised. Job role, terms and conditions of service, and symbolic representation of people with ID make jobs appealing and applications for posts exceed 3-1
143	Number of placement break-downs
	~~Waiting list for PBS services are managed effectively and support timely access to appropriate support~~
144	Use of ordinary community facilities by people with IDD
145	Community awareness and acceptance of people with IDD
146	Environmental adaptations to community resources to meet needs of people with IDD

147	Collaboration, team working, team communications and team relationships are improved
	Sub- Category (V) PBS Systems:
148	Shared (PBS/Functional) model to guide practice across service/organisation/locality
149	Common language/terminologies of PBS across service/organisation/locality
150	Referral structures and systems that support the implementation of PBS
151	Practice leadership
152	Availability of staff support systems, supervision and debriefing
153	Service/organisation wide systems for evaluating and monitoring support (such as PSR)
154	Implementation of tiered intervention systems
155	*In the context of a school, the use of a school-wide reinforcement system or set of principles (consistent with models of school-wide PBS)*
156	Organisational commitment to non-aversive/positive approaches
157	Organisational commitment to person centred values
158	Service/organisation-wide approaches to supporting communication, choice, and control and skills development
159	Service/organisation-wide approaches to supporting health and wellbeing
160	Service/organisation-wide approaches to supporting relationships and stakeholder engagement
161	Service/organisation-wide systems to support functional assessment and BSP development/implementation
162	Service/organisation wide systems for data-based decision making

Appendix 4: Outcome Domains following Voting Exercises and Final Wording (Chapter Three and Chapter Eight)



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

Appendix 5: Summary of Roles taken in Evaluation of E-PAtS Programme

Role	**Researcher**	**Percentage of role undertaken**
Intervention Development Lead	Dr Nick Gore	95%
	Dr Jill Bradshaw	5%
E-PAtS Trainer Training	Dr Nick Gore	100%
	Dr Jill Bradshaw	0%
Facilitator Training	Dr Nick Gore	70%
	Dr Jill Bradshaw	30%
Evaluation Design	Dr Nick Gore	95%
	Dr Jill Bradshaw	5%
Recruitment	Dr Nick Gore	70%
	Dr Jill Bradshaw	10%
	Provider Representatives	20%
Data Collection	Dr Nick Gore	10%
	Dr Jill Bradshaw	90%
Data Analysis	Dr Nick Gore	75%
	Dr Jill Bradshaw	25%
Write Up	Dr Nick Gore	100%
	Dr Jill Bradshaw	0%