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Outcomes from a community-based Positive Behavioural Support team for children and adults with developmental disabilities.

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Abstract

Background: Previous evaluations of community PBS teams have not investigated whether behaviour change is both statistically reliable and clinically significant. Very few previous studies have reported quality of life (QoL) and social validity outcomes.

Method: We collected data on 85 people referred to a specialist PBS team. We used a unique set of multiple measures and statistical change metrics to evaluate outcome.

Results: Statistically significant improvements in QoL and Health Related QoL (HRQoL), with medium to large effect sizes, were demonstrated following PBS input. Mean Behavior Problems Inventory – Short Form scores reduced from 37.74 (SD=30.54) at baseline to 12.12 (SD=12.24) at follow up, with a large effect size (d=0.84). Stakeholders reported valuing the process and outcomes of PBS, findings which support the social validity of PBS for people with developmental disabilities.

Conclusion: This study demonstrates successful PBS outcomes in QoL, HRQoL, challenging behaviour and social validity in a community setting.

INTRODUCTION

Challenging behaviours are common in individuals with developmental disabilities [DDs] (Jones et al., 2008; Bowring, Totsika, Hastings, Toogood & Griffiths, 2017). Given concern over aversive and institutional treatment models, there has been growing interest in Positive Behavioural Support (PBS) as a framework intervention model (Toogood, 2016; Kincaid et al., 2016). In the UK, the National Institute for Health and Care Excellence (NICE) has provided national guidance and advice on the design of services for individuals with DDs who may display challenging behaviour (NICE, 2018). NICE guidance includes recommending specialist community-based behavioural support teams who assess challenging behaviour and promote quality of life (QoL), utilising person-centred and skill development approaches. The primary goal of PBS is to enhance QoL, and secondly to reduce levels of challenging behaviour (Carr et al., 2002). Key components of PBS are lifestyle change, the functional assessment of challenging behaviour, stakeholder input, and social validity (Carr et al,. 2002; Dunlap & Carr, 2007; Gore et al., 2013).

Community-based PBS Teams

Davison, McGill, Baker and Allen (2015) indicated that 47% of the 46 community-based challenging behaviour services identified in the UK, described themselves as being based on the principles of PBS. A further 27% described their approach as eclectic, 20% based on behavioural models and 7% on positive psychology. Outside the UK, there has been a lack of research reports of PBS implementation by community-based teams, despite the widespread implementation of PBS in other services such as schools (Sugai & Horner, 2002).

Challenging Behaviour Outcomes

Two studies have considered challenging behaviour outcomes evaluating PBS in community teams in England via parallel, randomised, single-blind controlled trials, with incongruent results regarding challenging behaviour outcomes (Hassiotis et al., 2009; Hassiotis et al., 2018). The 2018 multi-centre study involved training selected staff in community intellectual disability (ID) teams in PBS (Hassiotis, et al., 2018), whereas the 2009 study considered outcomes from referrals to a more experienced community-based specialist behaviour team assigned at random (Hassiotis et al., 2009). In the 2018 study, findings indicated no significant reductions in challenging behaviour over 12 months as measured by the Aberrant Behaviour Checklist (ABC) [Aman & Singh, 1986]. There was also a lack of data about whether PBS interventions were actually delivered in the treatment arm of the trial (Hassiotis et al., 2018).

In the 2009 study, staff were reported as being qualified in Applied Behaviour Analysis (ABA) and the team operated using a multi-dimensional model of ABA and PBS. In this study 31 adults with ID who presented challenging behaviour received "standard treatment" from a community based multi-disciplinary team that included a range of services including nursing, medication, and adaptive skill support. Thirty-two adults with ID received this standard service plus input from the "specialist behaviour therapy team". Greater improvement in challenging behaviour measured at three and six months post randomization using the Aberrant Behaviour Checklist (ABC) [Aman & Singh, 1986] was found for the intervention group, as well as in a two year follow-up study (Hassiotis et al., 2011) . One limitation of this study is that a clear description of the multi-element intervention was not

provided, impacting on any conclusions that a PBS approach was responsible for the behaviour change described.

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Allen et al. (2011) reported preliminary outcome data for two challenging behaviour services involving 26 participants which measured challenging behaviour at the point of referral and later at discharge. In this study, there was a significant reduction in challenging behaviour scores (measured with the ABC - Aman et al. 1986) from baseline to point of discharge, although actual time scales are not specified and the reliability of the data collected was not established. Additional small studies (McLean et al., 2007), and other initial review evidence (Carr et al., 1999; LaVigna & Willis, 2012), suggests community-based PBS team input can lead to some reductions in challenging behaviour but this has largely been documented in terms of percentage change or ABC score reductions (e.g. Dunlap et al., 2010), with less focus on how meaningful that behavioural improvement has been for participants.

Quality of Life Outcomes

Neither of the Hassiotis et al. (2009; 2018) studies produced comprehensive data on QoL outcomes. Both Hassioties et al. and and Allen et al. (2011) measured QoLusing a single domain – social inclusion – from the Guernsey Community Participation and Leisure Activities Scale (Baker, 2000) Hassiotis et al. (2018) indicated no differences between study groups on the frequency of community activities, yet Allen et al. (2011) reported a statistically significant increase in community engagement. Mclean et al. (2007) assessed QoL using the Quality of Life Questionnaire (QoL-Q: Schalock, Keith, Hoffman & Karan, 1989) and found for 2 of the 5 participants there was no improvements to QoL.

As a result, research into the implementation of PBS by specialist community teams remains at the preliminary stage, with inconsistent results, and dearth of data on PBS impact on QoL (Lowe, Felce & Blackman, 1996; McLean, Grey & McCraken, 2007; Dunlap & Carr, 2007; Mckenzie, 2011). Although it has been suggested that PBS can improve QoL in some studies (Carr et al., 1999), there is currently no evidence to support this suggestion as this outcome has not been systematically included in evaluations of specialist PBS teams (cf, La Vigna & Willis, 2012).

Despite current recommendations and investment into community-based PBS teams, there are few studies that comprehensively evaluate their impacts across all aims of PBS outcomes. There are inconsistencies reported in outcome success, small participant numbers, and a lack of consistent and multiple measures to capture all of the outcome aims of PBS. We attempted to address this issue by evaluating the impact of PBS as implemented by a peripatetic specialist community-based team serving the entire population of [BLINDED]. [BLINDED], a small island located [BLINDED]. This study describes a robust set of outcome data evaluating PBS as implemented in a real world service setting. While the present study is not a randomised trial, it included one of the largest samples in community PBS evaluations and provides detailed data on implementation and outcomes. We included both QoL and challenging behaviour outcomes. For a first time in the literature, we also used a standardized method for estimating the clinical significance of behaviour change (Jacobson & Truax, 1991) in addition to statistical change as metrics for successful outcome in a community service setting. We additionally evaluated social validity to explore stakeholders' views on how meaningful the changes were in challenging behaviour and QoL.

METHOD

Participants and Setting

The present study included 93 individuals with DDs who were initially referred to the PBS team between January 2012 and December 2015. Eight were lost to follow up (due to death, relocation, or withdrawal from service), leaving 85 participants (91% retention). Participants were 39 children / young people (age up to 17 years) and 46 adults (age 18 years and older). The mean age of participants was 25.38 (SD=19.27; range 3 to 73 years) and the majority were women (68.2%). Forty had a diagnosis of ID, 32 a diagnosis of ID and autism, and 13 a diagnosis of autism and no ID. Reasons for referral, as indicated by referring agents, were: aggressive or destructive behaviour (ADB: 72.9%), ADB and self-injurious behaviour (SIB) [8.2%], ADB and stereotypy (SB) [2.4%], SIB alone (10.6%), SB alone (3.5%), or "other" behaviour (2.4%: one referral was for 'deliberate incontinence' and the other 'absconding from school'). Secondary reasons for referral, mentioned alongside the primary behaviour, included incontinence (5.9%), sleep disturbance (3.5%), and dropping to the ground (2.4%).

The total population of [BLINDED] during the data collection process was 102,700 [BLINDED]. There were no children or adults with DD placed off-island for challenging behaviour treatment during the study period.

The Positive Behavioural Support Team

The PBS team in ["BLINDED"] comprises two Behaviour Advisors and a Behaviour Advisor Assistant. All three staff are qualified at Master's level - the Behaviour Advisors have Master's degrees in Applied Behaviour Analysis and the Assistant a Master's degree in psychology. The team is part of the local publicly funded Health and Social Services (H&SS) and is fully integrated within the Community and Social Services multi-disciplinary service alongside social workers, nurses, occupational therapists, physiotherapists, speech and language therapists, psychologists, and psychiatrists. The team works with individuals of all

ages with a diagnosis of intellectual disability (IQ<70) and / or autism. The team was established in 1999 with the aim of promoting community integration for adults with ID and challenging behaviour, many of whom at that time were placed in a residential hospital which was closed in 2004. [BLINDED] has no large residential facility, and at the time of writing had no individuals placed off-island for challenging behaviour intervention.

There are a number of tasks performed by the PBS team. Casework referrals are received from many sources including parents / care-givers, individuals with DD and professionals including paediatricians, Child and Adolescent Mental Health Services, social workers, General Practitioners, and staff from education services. Following a referral for support with challenging behaviour, functional behavioural assessments are completed which inform the development of Positive Behavioural Support Plans. The PBS team also provide advisory clinics, design and deliver PBS training courses, write and review the local H&SS Positive Behavioural Support Policy and contribute to service planning and design within [BLINDED] to influence the wider implementation of PBS approaches.

Measures

Measures were all completed with a proxy informant at baseline prior to any input from the PBS team. Follow-up measures were completed once all interventions were implemented and any initial changes to PBS plans had been made. The timing of follow up measures were based on practice considerations and differed from case to case in line with the implementation of individualised plans. Time periods to complete functional assessments, produce PBS plans and implement strategies were unique to each case. This is not ideal in terms of the research design for this evaluation but it reflects practice in PBS teams.

Arrangement for the withdrawal of team support and case closure was made on an individual basis in agreement with the referring agents and stakeholders. This decision was

made collectively, usually at the point of acceptable improvement in referral problems, identified using the data measures and taking into account participant / carer views. Occasionally, stakeholders / referral agents continued to oversee implementation of key interventions that had still not been finalised (e.g. environmental adaptions / staffing changes) or alternative professionals reviewed case progress (e.g. social workers / nurses) following requests from the PBS team.

Observational or indirect data were collected for clinical purposes only where the referral or resources justified it. As this type of data was not available for every participant, it was not possible to include such data in the evaluation. In addition, the type of data tools utilised were unique to dimensions of behaviour being measured in specific cases. For the present study, it was decided to use consistent proxy measures. Finally, PBS implementation and outcome evaluation were conducted by the same team and this needs to be borne in mind when interpreting study results.

Quality of life tool (Kincaid et al. 2002). In the present study, QoL outcomes were assessed using an adapted version of Kincaid, Knoster, Harrower, Shannon and Bustamante's (2002) scale. This scale assessed 5 domains: interpersonal relationships, self-determination, social inclusion, personal development, and emotional wellbeing. These align well with the goals of a PBS intervention. The original 22-item measure had good inter-item reliability for total score and for each of the five subscales (.95 for overall quality of life and .73-.90 for each scale). However, the original measure was child-focused, used American English, and was not formatted for repeated assessments. A shorter eight item version covering the five QoL domains was developed with permission from the authors. This was primarily for ease of use, given time demands on proxy informants for completing all measures. We reduced the number of items by deleting similar ones in each domain and removing analogous ones, whilst maintaining all dimensions. For the child version, we completed readability analysis

and amended item statements to ensure scores of above 60 on the Flesch reading scale and below 8 on the Flesch-Kincaid Grade Level (Kincaid, Fishburne, Rogers & Chissom, 1975). A parallel eight question version for adults was developed which included the same questions / domains but worded items slightly differently (e.g. Question 2: Child measure: "The child / young person gets on well with family members"; Adult measure: "The person gets on well with people they live with"). Each item was measured with a five-point agreement scale ranging from 1 to 5, with a score of 1 indicating *strongly disagree* and a score of 5 indicating *strongly agree.* Proxy informants were asked to rate each statement based on the individual's life over the previous two months. The adult scale was used for individuals aged 18 and over. The child scale was used for individuals aged 17 and under. Young people who were 16 or 17 not living at home or accessing education were administered the adult scale. Participants could score a maximum of 40 on this scale with a larger score indicating higher levels of QoL. Cronbach's alpha for the eight question QoL child measure at baseline was .70 and for the adult scale .84 indicating acceptable to good internal consistency.

Health-related quality of life (HRQoL): EQ-5D (https://euroqol.org/).

To measure HRQoL the EQ-5D 3L (version 1) proxy measure was utilised. The EQ-5D is a standardised measure of HRQoL developed by Euroqol to provide a simple, generic measure of health for clinical studies (Euroqol, 1990). The EQ-5D has been used successfully in previous studies involving individuals with DDs (Jahoda et al., 2017). The EQ-5D 3L describes function and QoL across five dimensions – mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. Each dimension has three levels – no problems, some problems, and extreme problems which generates a potential 243 health states. The proxy informant rates the most appropriate statement in each dimension for that individual at that moment in time. Health states can also be converted into a summary statistic by applying a formula that attaches values or weights to each level. The present study used the

corresponding UK Time Trade Off (TTO) value set as advised by Euroqol (MVH group, 1995; Dolan, 1997). This converts one of the 243 potential health states into an index value ranging from -0.59 to 1, where 1 represents full health. Proxy informants also rated the EQ-5D Visual Analogue Scale (VAS) – a quantitative index of self-perceived health status. This records the proxy's subjective view of the individual's health status in that moment in time where 100 represents *best imaginable health* and 0 *worst imaginable health*.

Behaviour Problems Inventory – Short Form (Rojahn et al., 2012a).

The Behaviour Problems Inventory – Short Form (BPI-S) measures three of the most common challenging behaviour topographies shown by individuals with ID (Rojahn et al., 2012a). The BPI-S is a standardized rating scale, with good reliability and validity to assess challenging behaviour in individuals with ID (Mascitelli et al., 2015; Rojahn et al., 2012a, b). It has been demonstrated to have adequate to good internal consistency (Rojahn et al., 2012a, b; Mascitelli et al., 2015; Bowring et al., 2017), inter-rater agreement and test-retest reliability (Mascitelli et al., 2015), strong evidence for confirmatory and discriminant validity (Rojahn et al., 2012a, b); and confirmatory factor analysis has validated the three BPI-S subscales (Mascitelli et al., 2015).

The BPI-S comprises 30 items arranged in three subscales: The Self Injurious Behaviour (SIB) subscale (eight items), the Aggressive Destructive Behaviour (ADB) subscale (10 items), and the Stereotyped Behaviour (SB) subscale (12 items). Each item is rated on a five-point frequency scale (never = 0; monthly = 1; weekly = 2; daily = 3; hourly = 4) and a three-point severity scale (mild = 1; moderate = 2; severe = 3). Frequency and severity of behaviour are measured for the SIB and ADB subscales, and frequency alone for the SB subscale. For each item, a score is generated by multiplying the frequency and severity scores and the sum of these product scores generates a subscale score. The sum of

the three subscales gives a BPI-S total score. We asked informants to consider behaviour present in the past two months for the current study.

Data have also been published on the BPI-S to allow the evaluation of individual-level reliable and clinically significant behaviour change (Bowring, Totsika, Hastings & Toogood, 2018) using the Jacobson and Truax (1991) formulae. A clinically significant cut-off score has been established which is a score participants must cross to move from the "dysfunctional" population (those with defined challenging behaviour) to the "functional" population (those without defined challenging behaviour) [Bowring et al., 2018]. These data were utilized to explore how meaningful any behaviour change was in this study.

Social validity survey.

Social validity was measured using 6 statements about putative impact on care-givers/keyworkers (e.g. *I am more effective in preventing challenging behaviour occurring* and *there are fewer injuries / the environment is damaged less than before*), and 7 statements about the putative impact on the target individual (e.g. *People view X more positively than before* and *X is able to communicate his / her needs more effectively*). Informants rated statements on a 5-point Likert scale from 1 (*strongly agree)* to 5 (*strongly disagree)*. Social validity was measured only at follow-up. Cronbach's alpha for the total score on this 13-question measure was good at .847.

PBS Intervention

PBS allows flexibility in the assessment process in natural community settings (Carr et al., 2002). Types of data may vary, but data are always collected to guide and evaluate intervention decision making. In general, the PBS team use the following assessment approaches in completing functional assessments:

- Functional assessment interviews (e.g. O Neill et al., 1997).

- Rating scales about the function of challenging behaviour (e.g. Motivational Assessment Scale: Durand & Crimmins, 1992; Questions About Behavioural Function: Matson & Vollmer, 1995).

- Indirect data collection (e.g. episodic severity records, frequency records, Antecedent-Behaviour-Consequence records).

- Observational direct data (e.g. time sampling).

- A review of previous assessments reports (e.g. Educational Psychology reports, sensory profile assessments) and other data logs (e.g. service behaviour incident records, or daily logs).

Some challenging behaviour is complex and requires more detailed assessment to establish function. Decisions about the methods required for functional assessments were taken by the team's Behavioural Advisors. These practitioners established the likely function of challenging behaviour, and potential interventions required. Function of challenging behaviour was identified for every participant.

Once the functional assessment was completed, PBS Team staff presented results to stakeholders and used results to develop a multi-element PBS intervention plan. Plan development was a collaborative endeavour to ensure good contextual fit (Albin, Lucyshyn, Horner & Flannery, 1999). PBS plans focused on person-centred approaches that promote QoL. PBS plans included:

- A definition of the challenging behaviour.

- A shared understanding of the function of the challenging behaviour.

- Key indicators of behavioural agitation.

- Proactive strategies that are preventative: e.g. proactive management of physical and mental health; communication approaches; strategies that modify the

antecedents that evoke challenging behaviour; ABA evidenced behavioural technology such as differential reinforcement of other behaviours; strategies that promote person-centred QoL and give the individual choice, control, engagement; strategies that promote relationships and community participation.

- Proactive strategies that are developmental: e.g. teaching new behaviours; promoting skills; teaching functionally equivalent behaviours; teaching coping and tolerance skills.

- Secondary strategies: e.g. approaches to support the individual at early signs of distress: stimulus change; diversion to preferred activities; active listening; change of interactor or interactional style.

- Reactive strategies to reduce immediate risks and promote safety: e.g. first resort strategies (La Vigna & Willis, 2012) such as strategic capitulation and last resort strategies based on least restrictive approaches.

- Wider system approaches: e.g. staff / care-giver training; support for care-givers.

- Details of the review process: e.g. description of data collection requirements to evaluate progress; name of person responsible for review; scheduled date of review.

Every participant had a PBS plan which contained information and strategies in each of the areas listed above. Once the PBS plan was implemented Behaviour Advisors monitored the fidelity and impact of interventions through regular meetings with the review team and exploration of post implementation data collected. Interventions listed in PBS plans were sometimes amended depending on conclusions from these investigations. Support to implement advice was given to organisations and carers from the PBS team's Behaviour Advisor Assistant. This could involve direct modelling, training, coaching and advice, as well as practical support (e.g. to create visual tools or social stories).

Procedure

Measures were completed at baseline (after referral, as a part of the assessment phase of the PBS team's work) and follow-up by a proxy informant. A decision was made to draw data from proxy informants so as to ensure consistency in reporting for individuals at all levels of communication abilities (Chowdhury & Benson, 2011). To identify the most appropriate proxy informant, the PBS team initially discussed with the referrer the key person who knew the individual best. It was agreed that for children (aged 17 years and under) a parent / main carer should be proxy if the challenging behaviour was present in the home environment; a teacher / tutor should be proxy if the challenging behaviour was specific to an education environment; and a key-worker / carer should be proxy if the challenging behaviour was specific to a care / respite environment. If the referral was for an adult (18+ years) a parent / main carer should be proxy if the individual lived at home and the challenging behaviour was present in the home environment; a keyworker / main carer should be proxy if the individual lived in a staffed residential or accessed a day service setting and the challenging behaviour was present in this setting. If the individual lived independently, the person who had the most contact and knowledge regarding the individual acted as the proxy informant and this could be a lead professional (e.g. community nurse), support worker, or parent. In all cases, the proxy identified was expected to have continued contact with the individual during PBS team support period and be available to complete the follow-up measures.

Data were collected by PBS team practitioners directing the interventions, as a routine part of clinical practice. All data were collected in face-to-face interviews with the proxy informants. Baseline measures were completed by the individual's Mother (n=31), Father (n=2); both parents (n=7); Grandmother (n=1), keyworker/health care assistant/support worker (n=32), nurse (n=5), social worker (n=4); teacher (n=2), or respite co-ordinator (n=1). There were the same respondents at follow-up as baseline in 83 cases, with two community

nurses completing follow-up measures instead of one mother and one healthcare assistant. The mean time between baseline and follow-up was 45 weeks (SD=29.19), median=37 weeks; range 15-160 weeks.

Research ethics.

Ethical approval for the study was given by [BLINDED] and [BLINDED]. Approval to use anonymously collected service data was given by the Director of Community Services, [BLINDED]. Participants, or their consultee under [BLINDED] Law, gave consent for their outcome data to be used for research/evaluation purposes.

Approach to analysis.

Changes in mean QoL, EQ5D 3L index scores, EQ5D VAS, and BPI-S scores were calculated between baseline and follow-up. As separate child and adult tools were used for QoL, results were calculated for all participants, as well as separately for children and adults for this measure. Paired sample t-tests were used to explore change from baseline to follow-up along with standardized mean difference (d) effect sizes adjusted for repeated measurement (Dunlap, Cortina, Vaslow & Burke, 1996).

We supplemented the group-level analysis by considering whether change at an individual level was clinically meaningful and/or statistically reliable using BPI-S criteria established by Bowring et al. (2018). The number of cases where clinically significant and statistically reliable change was achieved for challenging behaviour was explored. Using baseline data from the present study, and applying Jacobson and Truax's formulae (1991), we also calculated that the total score on the QoL measure would need to improve by a score of 7.15 on the children / young people QoL scale and by 7.02 on the adult scale to represent reliable change in QoL. Therefore, we also calculated the number of participants that achieved reliable change for QoL. Minimally important differences (MIDs) in EQ5D scores

have been calculated for certain populations and health conditions (e.g. stroke patients – Kim, Kim, Jo & Lee, 2015). MIDs represent the smallest EQ5D score change that would be considered meaningful. As there is no agreed consensus for the most appropriate way to capture MIDs (Schünemann & Guyatt, 2005), and none currently exist for people with DD, reliable and clinically significant change was not considered for the EQ5D.

RESULTS

Quality of life

On average, participants were reported as having higher levels of QoL at follow-up (M=33.44; SD=3.35; 95% CI: 32.71 to 34.16) than at baseline (M=28.59, SD=.5.64; 95% CI: 27.37 to 29.80), $t(84)$=-8.60. $p < .001$, d=1.0. This indicates significant pre- to post-intervention improvement in QoL with a large effect size.

Higher levels of QoL were reported for the children / young people at follow-up (M=33.13, SD=3.32; 95% CI: 32.05 to 34.20) compared to baseline (M=28.67, SD=4.70; 95% CI: 27.14 to 30.19), $t(38)$=-7.10, $p < .001$, d=1.07. Similarly, for adults there were higher levels of QoL reported at follow-up (M=33.70, SD=3.39; 95% CI: 32.69 to 34.70) than at baseline (M=28.52, SD=6.38; 95% CI: 26.63 to 30.42), $t(45)$=-5.76, $p = <.001$, d=0.98.

A total of 21 (24.71%) participants (eight children / young people and 13 adults) demonstrated Reliable Change in QoL following PBS service input.

EQ-5D 3L / VAS

The mean EQ5D 3L index value increased from 0.52 (SD=0.30; 95% CI=0.45 to 0.58) at baseline to 0.71 (SD=0.23; 95% CI=0.66 to 0.76), at follow up: $t(84)$=-6.15, $p < .001$, d=0.72. The UK EQ5D index population norm is 0.856 (Janssen & Szende, 2014). At baseline 11

participants (12.95%) scored above 0.856; at follow up 26 participants (30.6%) scored above 0.856.

For the EQ5D VAS, the mean score on the analogue scale at baseline was 74.99 (*SD*: 17.62; 95% *CI*: 71.19 to 78.79) and at follow-up 83.15 (*SD*: 10.84; 95% *CI*: 80.82 to 85.49): $t(84)=-4.69$, $p <. 001$, $d=0.54$. The UK VAS total population norm is 82.8 (Janssen & Szende, 2014). At baseline, 36 participants (42.4%) scored above 82.8; at follow up 54 participants (63.5%) scored above 82.8. These results indicate significant positive change in HRQoL following intervention, with medium to large effect sizes. Although the comparison with total population norms follows a different method to reliable change estimation, it nonetheless suggests that, following PBS intervention, more people with DD had EQ5D index and VAS scores closer to the national norm.

BPI-S

Table 1 presents mean BPI-S scores at baseline and follow-up for the whole sample. The mean total BPI-S score at baseline was 37.74 (*SD*=30.54; 95% *CI*: 31.15 to 44.33), compared to 12.12 (*SD*=12.24; 95% *CI*: 9.48 to 14.76) at follow-up, representing a statistically significant reduction in challenging behaviour ($t(84)=9.99$, $p < .001$) with a large effect size ($d=0.84$). Across the whole sample, there were statistically significant reductions in frequency, severity and subscale scores with medium to large effect sizes.

INSERT TABLE 1

Table 2 presents the number of participants achieving reliable change in BPI-S categories using previously identified Reliable Change (RC) criteria for individuals scoring 1+ on the BPI-S (Bowring et al., 2018). In the current study, 55 people (64.71%) saw BPI-S total score reductions greater than the 10.37 RC statistic (range 11-106) representing nearly two-thirds of people referred to the PBS team. In terms of BPI-S subscales, greatest

improvement was seen in the Aggressive Destructive Behaviour (ADB) category with 54 people (65.06%) experiencing statistically reliable decreases in BPI-S ADB (scores > 6.26). For the Self-injurious Behaviour (SIB) subscale, 21 people (41.18%) saw statistically reliable improvements in self-injury, and for the Stereotyped Behaviour (SB) subscale 26 people (41.27%). There was reliable change in at least one BPI-S category for 62 participants (72.94%).

INSERT TABLE 2

Participants could only experience clinically significant behaviour change if their BPI-S baseline score fell within the clinical range, estimated in a total population study by Bowring et al. (2018). In this present study, at baseline, 69 people scored above the overall BPI-S cut-off score of 9.35, and 27 of these (39.13%) presented with clinically significant reductions in overall challenging behaviour (total BPI-S scores). Of the 50 (out of 51) people with DD who scored above the 1.88 SIB BPI-S cut off score at baseline, 19 (36.54%) experienced clinically significant reduction in SIB scores. Of the 66 (out of 83) presenting ADB above the BPI-S cut-off score of 5.69 at baseline, 41 (62.12%) experienced clinically significant reductions in ADB. Of the 52 (out of 63) people presenting SB who scored above the 5.66 BPI-S cut-off score at baseline, 19 (38%) experienced a clinically significant reduction in SB. There was clinically significant change in at least one BPI-S category for 53 participants (74 participants scored within the clinical range in at least one BPI-S category at baseline, indicating clinically significant behaviour change for 71.62%).

The relationship between score changes on the Qol scale and BPI-S were also investigated using Pearson's correlation co-efficient. There was significant evidence ($p <$ .001) to suggest an association between improvements in QoL and reductions in challenging behaviour, with a correlation co-efficient of r=-.50 indicating a moderately strong

relationship. Similarly, there was a significant association ($p < .001$) between improvements in HRQoL (EQ5D index scores) and reductions in challenging behaviour (BPI-S scores) with a correlation co-efficient of r=-.50 indicating a moderately strong relationship. There was a negative correlation also between EQ5D VAS score improvement and reductions in BPI-S total scores (r=-.28, N=85, p=.009).

Social validity survey

Table 3 presents the results from the social validity survey. For the 6 questions on the impact of interventions for the informant, such as how the intervention had improved the informant's understanding of the challenging behavior and their effectiveness to address the issues, there was evidence of meaningful outcomes (e.g., 92.94% either agreed, or strongly agreed, that they were more effective at preventing challenging behaviour occurring).

For the 7 questions regarding the perceived impact on the participants, such as how the intervention has impacted on their community presence and public perception, again there was evidence of meaningful outcomes (e.g., 74.11% either agreed, or strongly agreed, that they were viewed more positively by others than previously).

INSERT TABLE 3

DISCUSSION

The present study was an evaluation of PBS interventions as implemented in a real-world context by a specialist community team working with 85 children and adults with DD. , There was statistically significant improvement in QoL (with a large effect size). QoL improvement was large enough to be considered statistically reliable for 24.71% of participants. Similarly, for HRQoL, the group change was associated with a medium to large effect size. The results of the social validity survey add to the evidence on positive lifestyle outcomes based on subjective experiences of stakeholders. As far as we are aware, the

present study is unique in demonstrating progress in QoL, health-related quality of life, and social validity outcomes using the PBS model in a typical community environment.

BPI-S results at the group level demonstrated statistically significant reductions in overall challenging behaviour with a large effect size. Findings also indicated that 62 people (72.94%) experienced reliable improvement (reduction) in at least one BPI-S score. The greatest reliable improvements at the individual level were experienced by those with aggressive destructive behaviour (65.06% of individuals), followed by those presenting stereotypy (41.27%) and self-injurious behaviour (41.18%). Of the 85 participants, 74 (87.06%) scored in the clinical range for at least one BPI-S category at baseline. Findings show that 53 of these people experienced clinically significant behaviour change in at least one BPI-S category. This is the first study into the effectiveness of a community-based PBS team that has demonstrated clinically significant behaviour change using a standard behaviour rating tool and clearly defined criteria for improvement.

Our results demonstrated positive change in challenging behaviour and QoLThere was no person with DD who experienced reliable or clinically significant deterioration in challenging behaviour following PBS team input. One child did demonstrate statistically reliable deterioration in QoL, but at the same time demonstrated clinically significant improvement in challenging behaviour. This child's QoL score at baseline was a perfect 40 out of 40, which may have been over-estimated by proxy informants at this stage.

Although all but one person with DD was reported to have a positive reduction in challenging behaviour by the follow-up data collection point, 21 people with DD (24.71%), who had at least one BPI-S score in clinical range at baseline, did not have any clinically significant change for any of the BPI-S categories (Bowring et al., 2018). Further applied research is needed to explore why PBS may be less effective for some people, or how best to

adjust and continue PBS support until meaningful change is achieved. Further research is also needed to clearly identify independent ways to assess whether changes following PBS intervention can be considered to be clinically significant. In addition, further testing and validation of the clinical change criteria reported by Bowring et al. (2018) is needed. In particular, the Bowring et al. criteria were derived for adults with ID. The validity of these criteria for children and for those with autism, without ID, has not yet been established.

Nine (10.6%) of the 85 participants scored zero on all BPI-S items at follow-up suggesting challenging behaviour was then absent. At present, expectations about such an outcome from PBS interventions are not clear especially since the primary goal is QoL improvement. There were moderately strong correlation co-efficients reported between improvements to QoL and HRQoL and reductions in challenging behaviour. These data, and those from other evaluations, suggest that specialist PBS teams probably should continue to focus mostly on meaningful improvements in QoL coupled with clinically significant reductions in challenging behaviours. In the current study, 16 people (18.82%) with DDs were assessed as experiencing reliable change in both QoL and challenging behaviour. Ambitious outcome targets for PBS community-based teams should be established with replicable criteria such as those applied in the current research to understand change at the individual level.

In the present study, we also included a set of easy-to-use, low-cost measures and corresponding statistical change metrics that can be incorporated into further studies of community-based PBS teams. They can also be used in practice for community-based teams to evaluate the impact of their day-to-day work.

Limitations and Directions for future research

This study has a number of unique strengths in terms of the larger sample size compared to previous evaluation studies, multiple measures utilised to evaluate the impact of PBS, the statistical metrics utilised to capture the meaningful nature of behaviour and QoL change, and the evaluation of PBS in an under-studied area of service delivery.

In terms of research design, this study has a number of limitations which will need addressing in future studies. The main limitation of the existing evaluation is the lack of a comparison group and random allocation. As interventions were provided as part of the routine clinical package provided by H&SS in [BLINDED], there were no control groups or randomized allocation of treatment. Given the community setting where the PBS team was operating and the ongoing responsibilities of the service model, it would have been difficult to achieve a controlled evaluation. Waiting times post-referral were short, so not even a pre-assessment waiting period could be used as a control period. As a result of this limitation, further consideration should be given to increasing the robustness of research designs in community settings where specialist PBS teams operate. One suggestion would be to consider further randomized controlled trials like the Hassiotis et al. (2009) study with established PBS teams.

Given the single group pre-post design, it is important to acknowledge that PBS team input is only one of many variables which may determine individual case success (Davison et al., 2015). There may be additional factors that contributed to the positive results in this study. Without independent data on implementation fidelity, it is possible some other aspect of the clinical intervention process accounted for the changes described in this study. Other factors have been suggested which may impact on PBS team success, including the quality and competence of referring environments (Lowe et al., 1996), levels of available support and the motivation of mediators to implement recommended interventions (Davison et al., 2015). Specialist PBS teams can also only be as good as the mainstream services they support

(Toogood, 2016). Future studies should utilise integrity measures which evaluate PBS team activity, the quality of PBS plans (e.g. McVilly, Webber, Paris & Sharp, 2013), alongside the fidelity of their implementation (e.g., through Periodic Service Reviews; La Vigna, 1994). All these factors may mediate the impact of PBS on QoL and challenging behaviour outcomes. Further thought needs to be given to unpicking the multi-element nature of PBS input to examine at which point treatment is optimal and which elements are most important.

Caution should also be taken where services evaluate their own interventions, as in this study where proxy informants were interviewed by interventionists. Given the high scores in the social validity survey it is possible that the proxy informants were biased in favour of the intervention. Future research in this area should identify independent administrators of proxy measures and an independent evaluation of procedural fidelity.

Given the limitations in utilising proxy measures, future studies should include and describe direct (e.g., observational) data collected by PBS teams, as well as information obtained from proxy informants and directly from people with DDs themselves.

There are a lack of quality of life measures available for individuals with DD (Townsend-White et al., 2012) and existing self-report measures are not well validated (Li et al., 2013). In the present study, we opted for a short, proxy report of QoL to ensure consistency in the measurement approach. The QoL measure showed promise as a responsive, simple, pre and post intervention measure. The child version should be reviewed given the lower internal consistency score (.698 for child measure; .842 adult measure), but the PBS field would certainly benefit from a user-friendly tool. In the present study, we demonstrated that the adapted Kincaid et al. (2002) QoL measure is sensitive to change following input from community PBS teams. Similarly, the EQ5D 3L and VAS was a useful quantitative measure of health outcome. MIDs for the EQ5D measure do not currently exist

for DD populations, yet these would be useful to assess whether HRQoL score changes are meaningful. The EQ5D can also generate utility scores that can be used for the calculation of quality-adjusted life years (QALYs) [Rasanen et al., 2006] alongside economic evaluation of intervention inputs. Future research that considers an estimate of effect by PBS services on QALYs or the amount of PBS input associated with positive change would be useful. It should be noted that while the QoL and HRQoL tools included domains of QoL relevant to PBS outcomes, they did not consider wider QoL outcomes such as material wellbeing and rights (Schalock et al,. 2002). Additionally, there may be aspects of progress stakeholders were hoping to gain from PBS that are not included in the social validity measure.

We were not able to include long term follow-up in the current study. Future research should also explore whether changes in QoL and challenging behaviour are maintained over time. The measures used in this study could be appropriate and user-friendly for this purpose, as probes, at fixed time periods, to investigate the longer-term impact of PBS.

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Table 1 BPI-S mean scores at baseline and follow-up

	Baseline		Follow-up		Paired t Test	Effect size
	Mean (SD)	Range (min-max)	Mean (SD)	Range (min-max)	t	d
SIB Frequency	3.82 (4.19)	15 (0-15)	1.49 (2.17)	10 (0-10)	6.73[*]	0.60
SIB Severity	2.56 (3.08)	15 (0-15)	1.02 (1.52)	7 (0-7)	5.96[*]	0.54
SIB Total	6.34 (7.98)	39 (0-39)	1.79 (2.92)	16 (0-16)	6.17[*]	0.63
ADB Frequency	10.48 (7.91)	40 (0-40)	3.54 (3.84)	13 (0-13)	11.00[*]	0.90
ADB Severity	8.38 (6.01)	25 (0-25)	2.73 (2.86)	12 (0-12)	11.18[*]	1.00
ADB Total	19.28 (18.0)	80 (0-80)	4.13 (4.94)	20 (0-20)	9.35[*]	0.78
SB Total	12.12 (11.2)	41 (0-41)	6.20 (7.84)	30 (0-30)	7.42[*]	0.56
BPI-S Total	37.74 (30.5)	129 (2-131)	12.12 (12.4)	59 (0-59)	9.99[*]	0.84

Note. SIB=Self-injurious behaviour; ADB=Aggressive destructive behaviour;
SB=Stereotyped behaviour

[*] $p < .001$.

Table 2 Analysis of BPI-S reliable change (RC) scores

BPI-S category	Reliable Change Statistic[a]	Number of participants with Decrease in BPI-S > than RC statistic (%)
SIB Frequency	5.27	15 (29.41%)
SIB Severity	3.92	14 (27.45%)
SIB Total	7.35	21 (41.18%)
ADB Frequency	4.56	48 (57.83%)
ADB Severity	4.33	44 (53.01%)
ADB Total	6.26	54 (65.06%)
SB Total	8.35	26 (41.27%)
BPI-S Total	10.37	55 (64.71%)

Note. SIB=Self-injurious behaviour; ADB=Aggressive destructive behaviour; SB=Stereotyped behaviour

[a] RC extracted from Bowring *et al.* 2018.

Table 3 *Social validity survey results. Cells present the percentage of participants who endorsed the response*

	Strongly agree % (N)	Agree % (N)	Neither agree nor disagree % (N)	Disagree % (N)	Strongly disagree % (N)
About you					
I know more about challenging behaviour than I previously did	35.29 (30)	57.65 (49)	7.06 (6)	0.00 (0)	0.00 (0)
I am more effective in preventing challenging behaviour occurring	31.76 (27)	61.18 (52)	7.06 (6)	0.00 (0)	0.00 (0)
When challenging behaviour occurs I can manage it more effectively	30.59 (26)	62.35 (53)	7.07 (6)	0.00 (0)	0.00 (0)
Challenging behaviour now stresses me less than it previously did	12.94 (11)	55.29 (47)	30.59 (26)	1.18 (1)	0.00 (0)
I am able to cope better with challenging behaviour than before	24.71 (21)	57.65 (49)	17.65 (15)	0.00 (0)	0.00 (0)

There are fewer injuries/ the environment is damaged less than before	36.47 (31)	43.53 (37)	18.82 (16)	1.18 (1)	0.00 (0)

About X

There is less risk of X being excluded	40.00 (34)	45.88 (39)	12.94 (11)	1.18 (1)	0.00 (0)
X does more activities than s/he used to	20.00 (17)	44.71 (38)	31.76 (27)	3.53 (3)	0.00 (0)
X makes more use of the community than before	15.29 (13)	45.88 (39)	35.29 (30)	3.53 (3)	0.00 (0)
X has more (or improved) relationships with others	11.76 (10)	65.88 (56)	17.65 (15)	4.71 (4)	0.00 (0)
People view X more positively than they did previously	16.47 (14)	57.65 (49)	22.35 (19)	3.53 (3)	0.00 (0)
X is now able to communicate his/her needs more effectively	15.29 (13)	58.82 (50)	22.35 (19)	3.53 (3)	0.00 (0)
X is more independent than s/he was previously	14.12 (12)	44.71 (38)	36.47 (31)	4.71 (4)	0.00 (0)