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PBS: views of people with an intellectual disability

“I feel like just a normal person now”: An exploration of the perceptions of people with intellectual disabilities about what is important in the provision of positive behavioural support

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Keywords: Positive Behavioural Support; Service user views; qualitative

Abstract

Background: There is a growing evidence base about the effectiveness of positive behavioural support (PBS) in relation to behaviours that challenge (CB). There is, however, limited research from the perspective of individuals receiving this support. The objective of this qualitative study was to obtain the views of participants with an intellectual disability about what was important to them in relation to receiving PBS.

Materials and methods: Seven participants with an intellectual disability, recruited via support organisations in the North East of England, gave their views about their support through interviews ($n = 3$) and a focus group ($n = 4$). Data were collected between April and June 2016 and were analysed using thematic analysis.

Results: Four themes were identified: the importance of being treated as a human being; the wider impact of PBS; the contrast of PBS with previous experiences of support; and the beneficial impact of positive support. PBS was valued for its wide impact on quality of life, with a reduction in CB being just one of many important aspects.

Conclusion: This study highlights the importance of including service user perspectives and quality of life indicators in research which evaluates service provision and support.

Accessible Summary

- People with a learning disability do not always get good support
- We wanted to know what they thought about Positive Behaviour Support
- They told us a lot of important things about good and bad support
- Good support included being treated as a human being, having a good and full life and being helped with behaviour and skills.

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Key words: Positive Behavioural Support; intellectual disability; challenging behaviour;
qualitative

Introduction

Many people with an intellectual disability (ID) display behaviours that challenge (CB) (Allen et al., 2013). The negative impact of CB, both for the individual and others, is well documented, including increased risk of abuse, breakdown of residential placements, staff turnover, and staff and carer stress (see Allen et al., 2013 for an overview). While positive and functional approaches to the understanding of CB have been advocated for many years (e.g. Donnellan, La Vigna, Shoultz, & Fassbender, 1988), responses have often been reactive and restrictive, including physical and chemical restraint (Allen, Langthorne, et al., 2013; Sturmey, 2009). While there has been relatively little research into the way that people with ID experience such restrictive approaches, research suggests that they are experienced as negative and punitive, rather than therapeutic. They also commonly result in the person feeling a range of strong negative emotions, such as anxiety, anger, and desperation (see Heyvaert, Saenen, Maes, & Onghena, 2015) and that there is an imbalance of power in favour of staff, with service users feeling a lack of control over their lives. Importantly, many service users considered that the environments they lived in and staff attitudes were often triggers for their CB (Griffith, Hutchinson, & Hastings, 2013).

Positive behavioural support (PBS) aims to offer an alternative approach to addressing CB. It has its roots in applied behaviour analysis, in combination with a value base derived from the principles of normalisation and person-centred approaches. It is based on the assumption that CB, such as aggression and self-injury, are functional for the individual displaying them, even if they result in negative consequences for the person and others around them (Bush & Griffith, 2017). The challenge, then, is for those supporting the person to identify those functions and offer an alternative means to meet those needs. PBS offers a multi-component framework (Gore et al., 2013) for understanding and minimising CB in the context of maximising the adaptive skills and quality of life of the individual in a

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collaborative, individualised way (PBS Coalition UK, 2015; Toogood, Boyd, Bell, & Salisbury, 2011). It aims to address the interacting psychological, biological, and environmental factors that result in CB (Lucyshyn, Dunlap, & Albin, 2002) before they occur.

PBS is supported by a growing evidence base as to its effectiveness (e.g. PBS Coalition UK, 2015 for an overview). The principles enshrined in PBS are highlighted in clinical and professional guidelines (e.g. NICE, 2015) and in guidance to providers and commissioners (e.g. Department of Health, 2014).

The impact of positive behavioural approaches on individuals with ID has been primarily assessed through measuring reductions in CB and in the use of medication, along with family and staff feedback (e.g. Carr et al., 1999; Heyvaert, Maes, & Onghena, 2010). Research into the wider impact on quality of life is rare. Only one of 14 studies examining the impact of staff training in PBS, which were synthesised by MacDonald and McGill (2013), reported on the quality of life for those with ID and found no significant improvement (Dench, 2005). Research by Crates and Spicer (2012) into the impact of staff training in PBS in Tasmania suggested that there had been increases in the community participation of, and activities undertaken by, people with ID. However, this was based on anecdotal staff feedback.

Moreover, the voices of people with ID who have received PBS in relation to their CB are almost completely absent from the academic literature. While some research exists which explores the perspectives of individuals with ID who display CB (Griffith et al., 2013), to the authors' knowledge no previous studies have focused on the perspectives of people with ID about the factors that are important to them when receiving PBS. Given both the recent investigations of restrictive and abusive practices experienced by people with ID (e.g. Department of Health, 2012) and the collaborative, person-centred nature of PBS, this is a

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significant omission. The present qualitative study aimed to address this gap by exploring the experiences of people with ID of PBS. Our research question was: what are the perceptions of people with ID about the factors that are important in providing good support (in the context of PBS).

Method

Design

Ethical approval for the study was provided by the university ethics committee of the first author's institution. In order to prioritise the participants' subjective experiences an exploratory qualitative approach was chosen based on individual interviews and a focus group (Nind, 2008). Data were analysed using inductive thematic analysis because this method was suitable for analysing both interview and focus group data, situates the themes strongly within the data and does not derive from a particular theoretical or epistemological stance (Braun, & Clarke, 2006). Our focus was on the subjective perspective of the participants, based on their experiences of PBS and was underpinned by a constructivist approach. The research team comprised three clinical psychologists/researchers who were experienced in working with individuals with ID and CB, a researcher with expertise in workforce development and two research assistants with no experience of PBS.

Participants

Recruitment was conducted via non-statutory advocacy and self-advocacy organisations in the North of England for people with ID. The study formed part of a larger project which was examining the workforce development needs of staff in relation to PBS. Previous discussions had taken place with the recruiting organisations as part of this project and there was a shared understanding of what was meant by PBS. In this context, they were

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able to identify which individuals were receiving PBS who might meet the other inclusion criteria for the study. The interview schedule and inclusion and exclusion criteria were shared with the organisations and they identified and approached individuals who they thought might be interested in participating. The inclusion criteria were individuals that: were aged 18 or over and had ID; currently displayed or had previously displayed CB; were able to give informed consent; and were experiencing positive behaviour approaches. A description of PBS in terms of its key aspects as a value based approach, based on behavioural principles that aims to assess and constructively address the function of CB for the individual was provided to the recruiting organisations. The research team did not define PBS with the participants as we were interested in their subjective perceptions of what PBS was and how they had experienced this. It is acknowledged that these perceptions and experiences may or may not be consistent with professionals' definition of PBS.

Participants either took part in a focus group ($n = 4$) or individual interview ($n = 3$), according to their preferred format. The interview and focus group schedules covered the benefits and unhelpful aspects of PBS, how outcomes in relation to PBS could be improved, and any barriers to putting PBS into practice. Of the seven participants, all were over 18 (a number of participants were not sure of their age, but it was estimated that the majority were aged between 35 and 50) and white British, and five were male. Information about the level of intellectual disability of the participants was not available, but one of the male participants had more limited communication skills and had some speech difficulties and was supported during the interview by a member of his support team. Four participants were currently in supported accommodation, one lived with parents, and the living situation was unknown for the remaining two. The history of support was not shared by all participants, but a number made reference to having previously been supported in hospital at some point in the past. The participants described having a range of behaviours that challenged that they received support

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for, including physical and verbal aggression, including fighting with and swearing at staff, extreme anxiety and agitation ('kicking off'), vandalising and destroying property and self-harm (cutting self).

Procedure

Following receiving written consent, a member of the research team used the contact details provided to arrange the individual interviews. These were organised via the participants' support organisation. The focus group session was facilitated by the self-advocacy organisation. All participants chose to have their support workers present during the interviews. Both the individual interviews and the focus group lasted up to 40 minutes and were audio recorded. A semi-structured interview format was used to support the interviews and focus groups. This helped ensure that the main topics were covered, but also allowed the participant to expand on topics that were important to him/her. The participants were initially asked to tell the researcher a bit about themselves and the behaviour for which they received help. They were then asked to describe the types of help they received and the impact this had on their behaviour and other areas of their lives. There was then a focus on their views about the most important aspects of the support they received, what (if anything) could be improved and what other would need to know about them and do to be of the most help.

Analysis

The data from the interviews and focus group were transcribed and analysed as one data set according to the procedure set out by Braun and Clarke (2006). Coding took place within each data item. Codes were then brought together, analysed across the data set, and emergent, then final themes, developed and named. The analysis was conducted

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independently by two researchers and then brought together to ensure sufficient rigour. All potentially identifying information was excluded to ensure the anonymity of participants. A summary of the identified themes was fed back to participants via the recruiting organisations. No changes were requested by participants. As it was not always possible to identify which of the focus group members had made a particular point in the discussion, quotes have not been attributed to individuals in the results section.

Results

Four main themes arose from the analysis: the importance of 'being treated as a human being' as a basis for supportive relationships with all staff; the wider impact of PBS in terms of promoting 'a full and normal life'; 'contrast with restrictive practices' which compared PBS with more restrictive and negative approaches; and 'the positive impact of PBS'. These are outlined below, with their associated subthemes.

1. Being treated as a human being

In keeping with the values base of PBS, this first theme highlights the importance of being treated by staff according to basic human values. These values, in turn, formed the bedrock of supportive and trusting relationships with staff. The participants stressed the importance of staff including them in conversations, being able to talk to staff, and feeling listened to.

Supportive relationships with staff

All the participants talked of the connections and relationships they had developed with individual members of staff and how much they valued these. They talked of "getting on" and being able to have "a laugh" and joke with them: "I feel like she's a friend now

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because when she comes around she always makes me smile. She stops me looking on the black side of things”; “I’ve got a really good team, I like working with them.”

There was a sense from participants of their support staff having made efforts to really get to know them “as a person”, being reliable and responsive, “always there”, in touch with how the participant may be feeling, and sensing what they might need at a certain time. For example, if a participant felt angry or anxious, the staff member was responsive in their support: “Like he can talk to me. He can see it in my face. He just says... what’s wrong with ya?”; “Mine [support worker] only comes when I need her and it’s important.” In that way, support was tailored to their individual needs: “I’ve had a lot of help with it. Like my self-harm and things. Like the razor. I know I have to keep it in there now.”

The participants valued being treated with what they felt was respect and humanity, such as the simple gesture of staff making eye contact. Staff were often described as “nice” and “helpful”, which participants contrasted with previous experiences in a hospital setting: “The staff here treat you with respect... in the hospital they don't. Like, they err, put needles up your bum and give you tablets, like PRN tablets, makes you drowsy and stuff like that.”

Staff were seen as accessible and responsive, which was again contrasted with previous experiences: “If [I] want to tell someone straight away [what I’m feeling], I’ll just tell someone at the time. In [name of hospital] I had to go through proper channels, like my named nurse, and another nurse.”

Importance of listening and talking to regulate emotions

Within the context of a supportive relationship, the participants placed particular value on being able to talk to someone, and feeling that they were being listened to, as a way of helping them manage difficult situations and emotions. They felt able to approach staff themselves when they felt they wanted to talk, which for some was seen as a major

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breakthrough: “Yeah, listening, they both listen...Helpful. Helpful when she listens. Very helpful”; “Yeah, I talk to staff now. When I’m feeling agitated. I didn’t used to do that years ago. I just tell them I’m feeling a bit like... angry and stuff like that.”

All the participants expressed a preference for staff to proactively approach them and talk to them to find out “what’s going on” if they were finding things difficult: “Talk to me. Try and see what’s going on. See what’s wound me up and stuff like that.” Again, this was contrasted by one participant to his experiences with hospital staff: “Talk to me nice, instead of being nasty... because in the hospital they were nasty all the time. They used to wind you up... they used to, err, put you in seclusion and that would wind you up.”

Participants felt that talking would often diffuse situations which, in the past, may have resulted in episodes of CB. It enabled them to confront, rather than avoid, difficult feelings, as did other strategies for emotional regulation: “If I’m losing my temper... they just tell me to walk away, let me calm down myself.” The need to facilitate the emotional exploration and regulation of individuals who were non-verbal or who found verbal communication difficult was also recognised as important: “Yeah, you looked at the pictures and you could get your anger out. So there was a happy face and a sad face and they got it out that way.”

2. A full and normal life

In this theme, in keeping with the aims of PBS to enhance the wider quality of life of individuals rather than just focusing on a reduction in CB, the participants stressed the importance of living a full and enjoyable life. This was a life which involved meaningful activities and relationships and promoted independence. It was a life where individuals lived in the “right” environment, both physical and psychological, to meet their needs and reduce their CB.

Meaningful activities and relationships

The interview participants all talked of the value they placed on living a full life. This had two main aspects: engaging in meaningful activities; and developing and maintaining meaningful relationships with non-staff members, according to their own abilities and wishes. The former ranged from hobbies and leisure activities—“They’ve took me on walking groups, they’ve took me swimming”; “sensory room...arts and crafts... things with food, like herbs and spices... massage tonight”—to employment—“I’m, like, working now and I have a new job and I’m happy. Things are making me really happy”—and study—“Next year I’m going on a full time course... it’s at nine in the morning and on till five.”

All participants placed importance on activities that enabled them to go out into the community and live a “normal” life, in contrast to being restricted during periods in hospital: “I get to go places as well. Myself. Like my mam’s. And, erm,... Some people aren’t able to do that... So I’m quite lucky.” Through doing things outside the home and in the community, one participant felt he had been helped to “move on” and commented: “I’ve seen a whole other aspect of life.”

Participants also emphasised the importance of relationships with non-staff members as part of a positive approach to their care and support. For some, this meant maintaining strong links with family without the restrictions often found in hospital settings: “You can see your family any time. Any time. Any time I want if I want to.” Many also valued the companionship of shared living: “I like the company ‘n that. Like, I wouldn’t want to be in here by myself. I think if I was by myself I’d be smoking a lot more. Erm... I’d probably drink.”

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Participants also valued the chance to develop friendships that extended out into the community, with one talking of getting a passport and his plans to go on holiday abroad with another resident of his current home.

Independent living

Most of the participants spoke of wanting to live as independent a life as they could. One had recently moved to a self-contained flat and had been learning independent living skills: “[in previous accommodation] I used to have my own room... but now, I’m learning to be independent, like cooking, cleaning.” Another was looking forward to a time when he would not be living with his family and having greater independence and choice:

For me, when I go out places, I sometimes like to have my own independence... I’ve been living at my mam and dads for too long, nearly 30 years. I want my own, erm, breathing space. So I can go to the door and ask people if they want to come round.

Being able to go into the local community independently was also seen to be of value: “I get to go places as well. Myself.” Underpinning this was a sense of choice, which was a strong contributor to well-being; participants felt they had control and choice about what they wanted to do and that this was facilitated, rather than constrained, by their support workers.

The importance of being seen as a person first by both staff and society more widely was raised. This was expressed as wishing to be seen as “normal” and as individuals, rather than being defined by their disability: “People are people, they aren’t labels”; “People should look at you like a normal person, not a disabled person.” The negative impact of being defined in terms of disability was highlighted: “People on the streets think because you’re disabled they can take the mick out of you.”

The right environment

Participants identified both physical and psychological elements of the environment they lived in that contributed positively to their quality of life. The appreciation of the physical environment was expressed neatly by one participant: “Nice place. A very nice place, and other places... It’s good. Nice, very nice environment.” Importantly, participants felt that their current living environments suited their needs in terms of managing their behaviour that challenged both directly—“They don’t... like, restrain, because people are calm here. People don't kick off as much. I’ve never seen people kick off like”—and indirectly:

They don't have loads of staff here. They don't have many clients. That makes it easier for me to, err, talk to people. I can't live with loads of people because that agitates me... I can't live with crowded people.

The importance of predictability and security in the living environment was also highlighted, with a number of the participants mentioning ways in which support workers had given them “structure” and a “timetable”. Many participants had previously experienced being moved to different environments which could be unsettling and disruptive:

You move from the house you lived with your family... I found that stressful. Because you don't know the building, you don't know your surroundings, and the nurses... the staff in there... nah, I didn't like it. But I just had to be in there, get on with it.

3. Contrast with restrictive practices

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Whilst not explicitly asked about other types of care and support they had received, the participants frequently contrasted the positive aspects of PBS with negative experiences they had had in the past: “They put their arms around my back and shot me in. Put their knees on my head.” One participant talked of his feelings about the way staff in a previous placement had responded in a restrictive manner when he was distressed: “Very, very bad to get stuck behind the door. And stopped.” Another shared his previous negative experience of being physically restrained and put in seclusion when living in a hospital: “What’s made me unhappy is when they’ve restrained me. Yeah. I don't like getting restrained.” This response from staff served to exacerbate his behaviour: “When they restrained me. I’ve hurt staff trying to get out of the locks and stuff like that.” Participants also talked of the restrictions they previously felt, such as not being able to go out to the shop, not being listened to by staff, staff not spending time with them, and staff talking too fast. Negative memories had had a lasting impact: “That’s shut down now that place. I didn’t wanna talk about that place.”

4. A positive impact

The participants articulated some of the direct positive impact on them as a result of PBS. All participants felt that it had clearly “made a difference”. One talked of his “changing behaviour”, while another explicitly talked about a reduction in CB and the need for reactive restraint: “I don't kick off now or lose my temper or ‘owt... I’ve never been restrained here since, since, three Junes away.”

For the same participant, the impact had been more wide-ranging than just a change in behaviour: “I’ve came off my CTO [community treatment order]. That’s never happened. I’ve never came off a section or a CTO before. I get out more... I go to college.” Another participant described the positive impact of the techniques he now used to help regulate his feelings: “I’ve changed, like, err, talk to people when you feel angry. Or go to your bedroom

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and lie down”; “I’m a lot more better. I haven’t been going in low moods ‘n that. I’ve been going out... been talking to myself a lot more. I’ve been a lot more better for a month or so.”

The positive benefits were described as both emotional and practical: “That makes me happier”; “I feel like it’s a lot more... doing things for myself now that I couldn’t do years ago. And I’ve achieved that. I’ve actually achieved it.” Overall, the benefits of PBS were summarised succinctly by one participant: “I feel like just a normal person now.”

Discussion

This study aimed to explore the experiences of people with ID and CB who had received PBS. The results highlight the importance to the participants of receiving support that is value-based and which enables them to live a full and normal life. Such support was frequently contrasted by our participants with the aversive and restrictive practices that they had previously experienced. Unfortunately, such negative experiences are not uncommon (Griffith et al., 2013) and the painful memories of restrictive and punitive care described by some of our participants echo the findings of other studies (e.g. Fish & Culshaw, 2005; Hawkins, Allen, & Jenkins, 2005). Whilst humane restraint as a last resort is also a feature of PBS, our results illustrated the significant negative emotional impact that restrictive practices can have, particularly if used out with the context of a supportive, trusting, and respectful relationship with staff. Recent research has indicated that some of the factors that are important in reducing restraint and seclusion are also identified by our participants as important in PBS (Larue, Goulet, Prevost, Dumais, & Bellavance, 2018). These include a positive attitude of staff towards, and relationship with, the individual with ID, the establishment of a therapeutic environment and meaningful involvement in the person’s life and activities.

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The features of good support described by our participants are largely consistent with the value-based components identified as key to PBS (Gore et al., 2013); that is, care that enables control, communication, dignity, consistency, personalisation, and social interaction. They are also in keeping with the values that have long been seen as essential as basic human rights (United Nations, 2006) and in underpinning all services for people with ID: positive, respectful relationships, the promotion of choice and competence, and facilitating positive community presence and citizenship (Department of Health, 2009). These are also the things that people with ID have said they want out of life (Allen, McGill et al., 2013).

Our participants identified the importance of the wider impact of good support on their quality of life, going beyond a reduction in their CB to consider the positive impact of PBS on engaging in meaningful activities, such as employment and education, and on meaningful relationships with family members and friends. For our participants, PBS appeared to be achieving the wider aim of enhancing the quality of life of those who had received it (Toogood et al., 2011). This finding adds to the small research base that has considered the wider impact of PBS (Dench, 2005; MacDonald & McGill, 2013).

The research also indicated the importance of the environment, both physical and psychological, to participants' behaviour. A number of participants identified the particular features of the environment that were important in helping them manage their behaviour. These included a pleasant physical environment, stability and predictability, a calm atmosphere, and accommodation that achieved the right balance between offering the companionship of others and having sufficiently few staff and service users to avoid feeling "crowded". Previous research has also indicated the importance of both the setting and approach in relation to managing CB. Where people with CB lived together, Robertson et al. (2004) found that lower use of positive behavioural approaches corresponded with higher levels of physical restraint and the use of psychotropic medication.

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The study has a number of implications for service providers and researchers. Firstly, it adds to the small, but growing literature that indicates that the value base that underpins PBS (and all good service provision) is confirmed as important by those who receive it. This includes being treated as a human being, being included, listened to and respected. These values are not new and reflect some of the key principles of normalisation (Wolfensberger, 1972) and subsequent frameworks that were developed to evaluate good quality support, such as the 'Five Accomplishments' (O'Brien, 1992). These values are also seen as important by family carers of their adult children with ID who display CB (McKenzie, Mayer, Whelan, McNall, Noone & Chaplin, 2018).

The study also indicates that when evaluating any intervention for CB, including PBS, there is a need to go beyond a focus on the CB itself to include measures of wider quality of life and indices of success that are tailored to the personal priorities and values of the individual with ID.

The study also has implications for workforce development and research. The present study, while informed by the views of people with ID, did not include a person with ID in the research team. This is a limitation of our work and highlights the need to structure and fund research that focuses on the perspectives of people with ID, in such a way that people with ID can contribute directly as researchers (Durell, 2016). Similarly, there is a need to involve people with ID in the workforce development of those who will provide support to them in order to ensure that staff are aware of and put into practice the values and behaviours that are important to people with ID.

Limitations

The study had a number of limitations. The purposive sample was relatively small and the focus group comprised only four people, although guidance suggests that four is an

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acceptable minimum number (see Carlsen & Glenton, 2011). The participants were self-selecting and it is possible that there was a respondent bias, with only those who were positive about the support they were currently receiving electing to take part. Some of the participants chose to be interviewed individually, while others took part in a focus group. It is possible that this factor may have influenced the responses of some participants. All of the interviews differed in some respects and individual participants varied in terms of their responsiveness to open questions and ability to articulate their views. These are recognised challenges when seeking the views of people with ID (e.g. Booth & Booth, 1996). Support workers acted as helpful corroborators in this regard. All participants chose to have their support workers present during the interviews and focus group. It could be argued that this potentially inhibited the participants. However, it is acknowledged that the presence of a trusted and known person may be necessary when interviewing those with ID (Nind, 2008). Participants had very different levels of verbal ability; however, all of their views were taken into account and reflected in the final analysis. Finally, the amount, nature and quality of PBS received by participants was not known or if the type of support participants received would meet acknowledged standards of PBS. We relied on the perception of the participants in this regard because the aim of the study was to explore their perceptions of what was important in the delivery of PBS, rather than to detail the type of PBS per se. It is hoped that future research that attempts to evaluate the relationship between specific aspects of PBS (e.g. quality, duration, professionals delivering it) and outcome measures will find the results of our study helpful in informing the dimensions that people with ID consider important and the outcomes that they are most likely to value.

Conclusion

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The results of the study provide an important addition to the growing evidence base for the benefits of PBS. They also reinforce the need to include quality of life measures and service user perspectives when evaluating PBS interventions. The Department of Health (2009) makes the case for greater inclusion of people with ID in service and workforce planning, delivery, and monitoring, but this work is still in its infancy. The present study adds to the very limited research in this area.

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