Abstract
Positive behaviour support (PBS) is often used with people with learning disabilities to improve their quality of life and support a reduction in behaviour that challenges. To increase the effectiveness of a PBS intervention, it is important that the person concerned is involved in its development, which may require creativity on the part of professionals. This article presents the story of Jack (a pseudonym), an autistic young person with a mild learning disability whose behaviour that challenges had increased in frequency and severity. The author describes how he supported Jack to contribute to the development of his PBS intervention by using an accessible communication method, Talking Mats, and to engage in the PBS intervention through co-production of a video.

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BEHAVIOUR THAT challenges has been defined as ‘behaviour 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 and Einfeld 2011). It is important to understand, however, that although such behaviour may be challenging for family members, carers and service providers, it may serve a function for the person expressing it – for example, to attract attention, communicate with others or avoid demands (National Institute for Health and Care Excellence (NICE) 2015). Multiple factors may motivate behaviour that challenges in a person with a learning disability, for example excessive noise, limited opportunities for social interaction and meaningful activities, and lack of choice and sensory input (NICE 2015).

NICE (2015) recommends that support and interventions to address behaviour that challenges are individualised, and there is growing acknowledgement that people with learning disabilities should be actively involved in the development of their positive behaviour support (PBS) interventions (Breeze 2021, Gore et al 2021, Gore et al 2022). A PBS intervention can be described as an evidence-based, multidisciplinary and
person-centred intervention that aims to improve the person’s quality of life, with the additional benefit of a reduction in behaviour that challenges (British Institute of Learning Disabilities 2016, Gore et al 2022). The aim of a PBS intervention is to support the person to improve their quality of life and replace behaviour that challenges with skills that fulfil the same function, and to ensure adaptations are made to the person’s environment to ensure their needs are met and that they have opportunities to engage in meaningful activities and social interactions (Gore et al 2022).

A PBS intervention usually includes several strategies based on the outcomes of a functional assessment conducted to identify the behaviours that challenge and to make data-driven hypotheses about their function for the person (O’Neill et al 1997). Family members, carers, school staff and service providers should all be involved to help validate the hypotheses and provide contextual information that can be incorporated into the PBS intervention (Gore et al 2013). Most importantly, the person themselves should be involved (Breeze 2021, Gore et al 2022). This may be challenging due, for example, to societal barriers such as discriminatory attitudes and inaccessible environments (Barnes and Mercer 2005), personal barriers such as communication or cognitive issues and/or professional barriers such as workload and time pressures (Kruger and Northway 2019). However, some of these barriers can be overcome by using a co-production approach and considering the person as an ‘expert by experience’.

This article describes how Jack (a pseudonym), a young autistic person with a mild learning disability, was supported to contribute to the development of his PBS intervention and engage with the strategies it contained. The article discusses the assessment process, the results of the outcome measures used to determine Jack and his family’s needs and goals, and the effectiveness of implementation of the intervention. The background to Jack’s story is shown in Case study 1.

**Initial assessment**

During the initial assessment, the learning disability nurse completed the following four outcome measures with Jack and his mother. These outcome measures were completed again, by the behaviour specialist, before Jack’s discharge from CAMHS to evaluate whether his needs and goals had been met.

**Health of the Nation Outcome Scales for People with Learning Disabilities**

The Health of the Nation Outcome Scales for People with Learning Disabilities is an 18-item questionnaire, completed by a proxy respondent, that assesses the person’s quality of life (Roy et al 2002) – an important outcome of a PBS intervention. It has a high inter-rater reliability (Roy et al 2002), which is relevant in Jack’s case since the outcome measures were completed by different CAHMS professionals at the initial assessment and before discharge.

**Case study 1. Background to Jack’s story**

Jack is a 13-year-old autistic young person with a mild learning disability who lives at home with his mother and older sibling. According to his mother, Jack has ‘always’ displayed some ‘aggressive’ behaviours, often as a form of demand avoidance. Staff at Jack’s school and his respite carers have also noted long-standing behaviour that challenges but have said that it is usually of low intensity and unlikely to cause significant harm. However, a marked increase in the frequency and severity of Jack’s behaviour that challenges prompted a referral to children’s social care.

Social care staff and Jack’s family developed a care plan which included seeking a residential placement, since the family felt that the situation at home was unsafe. The care plan also recommended referral to a community paediatrician for a health assessment to rule out any physical health conditions that may be contributing to the changes in Jack’s behaviour. Since no physical health conditions were identified, Jack was referred to the local Child and Adolescent Mental Health Service (CAMHS).

A learning disability nurse working with the local CAMHS team completed an initial assessment with Jack and his mother to gather information about the family, home life and Jack’s behaviour that challenges. This included the completion of outcome measures – detailed below – to identify Jack and his family’s needs and goals and provide a way of determining whether these were met before Jack’s discharge from CAMHS. During the assessment, Jack was invited to discuss what he wanted to achieve, but he did not respond to the question and his engagement throughout the assessment was sporadic. After the initial assessment, due to the crisis nature of the situation, Jack was allocated a behaviour specialist from the local CAMHS team (the author of this article) for functional assessment and development of a PBS intervention.
Sheffield Learning Disabilities Outcome Measure

The Sheffield Learning Disabilities Outcome Measure is a measure of the parent or carer's perceptions of the child's symptoms and their ability to cope with them (Girgis 2013). Part 1 contains eight items rated on a 5-point Likert scale, from 5 (strongly agree) to 1 (strongly disagree) for five items and a reversed scoring of 1 (strongly agree) to 5 (strongly disagree) for three items, with 0 meaning 'not applicable'. This questionnaire measures the parent or carer's perceptions of the child's behaviour and diagnosis, their confidence in managing the child's behaviour, their self-efficacy, their relationship with the child, their hopes for the future, how they are coping as a family and their confidence when dealing with services such as school or respite (Girgis 2013). Only part 1 of the Sheffield Learning Disabilities Outcome Measure was used in Jack's assessment.

Behavior Problems Inventory-Short Form

The Behavior Problems Inventory-Short Form is an informant-rated questionnaire that measures the frequency and severity of three subscales of behaviour that challenges: aggressive/destructive behaviour; self-injurious behaviour; and stereotyped behaviour (Rojahn et al 2013).

Goal-Based Outcomes tool

The Goal-Based Outcomes tool encourages the person and/or their family to determine personalised goals for an intervention. Progress is then measured using a numerical scale, for example 0-10 (Law and Jacob 2015). Jack and his mother's main two goals were a reduction in Jack's behaviour that challenges and for Jack to be able to remain at home.

Functional assessment

The behaviour specialist conducted a functional assessment of Jack's behaviour that challenges in line with NICE (2015) guidelines. The data and hypotheses generated by the functional assessment were then used to guide development of Jack's PBS intervention.

Data collection

The functional assessment involved several data collection methods. The Brief Behavioural Assessment Tool (Smith and Nethell 2014) uses open questions to gather qualitative data about the person and their specific behaviours and a questionnaire to collect quantitative data relating to the function of these behaviours. This part of the functional assessment was completed with Jack's mother in an interview and identified two primary functions of Jack's behaviours: to gain access to 'tangibles' – in Jack's case food and preferred activities; and to escape a situation or avoid a demand. It also identified that Jack's behaviour that challenges at home – expressed as aggression – usually occurred around mealtimes, was more likely to occur if he was hungry or tired and often escalated rapidly. The aggression was usually expressed by a single strike with a closed fist before Jack left the room, but aggressive behaviour towards other family members could continue for up to an hour.

To gain information from school staff, the behaviour specialist used Questions About Behavioural Function (Matson and Vollmer 2007), a 25-item questionnaire. He also reviewed school incident reports involving Jack, since these can provide useful information about themes and patterns of behaviour that challenges. Findings from both sources suggested that 'escape' was the primary function of Jack's behaviour that challenges at school, with a secondary function of accessing tangibles, such as food and preferred activities, which correlated with the findings from the home environment.

NICE (2015) guidelines encourage direct observation of behaviour that challenges, so the behaviour specialist completed an observation of Jack at school. This demonstrated the way in which school staff engaged with Jack, the social and environmental factors that could negatively
affect Jack’s behaviour and early warning signs of behaviour that challenges.

**Talking Mats**
Jack’s lack of engagement in the initial assessment could have been due to his higher expressive communication abilities relative to his receptive language skills and an overestimation of his communication abilities by his family and carers (Bradshaw 2001). Therefore, the behaviour specialist used an accessible communication method, Talking Mats, to attempt to engage Jack in the functional assessment. Talking Mats is an evidence-based approach used to support people with communication issues to share their views (Brewster 2004, Murphy and Cameron 2008) and has been shown to effectively support young people’s involvement in a functional assessment (Bradshaw et al 2018).

Jack was prompted to use Talking Mats to engage in a conversation about his interests and preferred activities (Breeze 2021). Using Talking Mats involved:

- Three expression symbol cards: ‘thumbs up’ (I like this), ‘shrug’ (I’m not sure about this) and ‘thumbs down’ (I don’t like this).
- Picture and/or word symbol cards that represented ‘tangibles’ (such as food or drinks or activities) and de-escalation strategies (such as deep breathing).

Jack was asked to place picture/word symbol cards underneath each expression symbol card. Since picture/word symbol cards can predetermine the scope of the conversation (Doak 2019), the behaviour specialist included some blank cards so that Jack and his mother could suggest activities and strategies that were not represented.

Using Talking Mats helped Jack to engage in the functional assessment, which enabled the behaviour specialist to include activities and strategies that Jack had chosen himself in the PBS intervention.

**Developing and implementing the intervention**
The hypothesised functions of Jack’s behaviour that challenges were to gain access to food and preferred activities and to escape a situation or avoid a demand. Therefore, one of the strategies in the PBS intervention was to teach Jack functionally equivalent skills to develop his independence. For example, Jack was shown how to make himself a simple meal and how to use a ‘time out’ card to indicate to supporting adults that they needed to reduce their demands on him.

The PBS intervention also recommended that those who support Jack should increase opportunities for him to make choices – for example, about what he wanted to do, where he would like to go or what he would like to eat – and to increase the use of visual scheduling so that Jack knew how his day was going to be structured. Both strategies have been shown to reduce the frequency of behaviour that challenges in demand-avoidant autistic children and young people (Lory et al 2020).

A further strategy was for supporting adults to encourage Jack to engage in one of his preferred activities in a quieter area when he became unsettled or began to display early warning signs of behaviour that challenges. These activities included those Jack had identified when using Talking Mats, such as singing, trampolining and going for a walk, and those identified by family members and school staff, such as making a den.

**Coloured card system**
Jack’s preferred activities and strategies for regulating emotions were matched to a coloured card system that was already in use at his school and with which he was therefore familiar.

Symbols representing Jack’s typical emotions when feeling content or happy, alongside pictures and brief written descriptions of his preferred activities, were printed on green cards. Three other coloured cards were used to represent sections of the ‘arousal curve’: yellow for the escalation phase; red for the crisis phase; and blue for the recovery phase.
The arousal curve is a visual representation of the phases of the assault cycle (Kaplan and Wheeler 1983). Each coloured card incorporated relevant symbols depicting emotions, for example, frustration or distress, and pictures with brief written descriptions depicting corresponding activities or strategies, such as deep breathing or trampolining, that could help Jack to self-regulate and de-escalate.

Supporting adults were encouraged to help Jack use the cards to recognise his emotions and link them to an activity or strategy that could help him feel calmer. Ultimately, the aim was for Jack to be able to identify his emotions and use corresponding activities or strategies to self-regulate and de-escalate independently. However, Jack was reluctant to use the coloured cards when prompted to do so by supporting adults.

Co-produced video

Social learning theory suggests that when an individual observes a behaviour displayed by someone else they are more likely to replicate that behaviour, particularly if the ‘model’ is similar to them in physical appearance and characteristics (Bandura 1977). The functional assessment had identified that Jack enjoyed filming himself talking and then watching himself on the videos. Therefore, Jack was asked if he would like to film himself talking about and demonstrating the different emotions and activities or strategies on the coloured cards.

Jack was filmed reading each activity or strategy listed on the coloured cards and he then filmed himself demonstrating them. The footage was used to create a video in which Jack named and demonstrated each activity or strategy (for example, trampolining or performing a breathing exercise) while the corresponding words (‘trampoline’, ‘deep breathing’) and pictures appeared at the bottom of the image. Some of the strategies were abstract – for example ‘making green choices’ which meant choosing an activity from the green cards – so Jack read these out as words rather than demonstrating them.

Jack enjoyed participating in recording the video, engaged positively throughout the process and, as he filmed himself, started to verbally suggest additional activities he would like to participate in. He went on to watch the video regularly and, crucially, without being prompted. This created repeated exposure to the self-modelled strategies, which it was hoped would increase Jack’s retention of the strategies and his ability to self-regulate.

Evaluating the intervention

Outcome measure results

The four outcome measures completed by the learning disability nurse at the initial assessment (baseline) were completed again by the behaviour specialist before Jack’s discharge from CAMHS, nine months after implementation of the PBS intervention (pre-discharge).

Figure 1 shows baseline and pre-discharge scores on the Behavior Problems Inventory-Short Form. The results show that the frequency of Jack’s aggressive/destructive behaviour had significantly decreased, with a large effect size ($t(9)=3.85$, $P<0.01$, $d=1.35$), and that its severity had significantly decreased, with a medium effect size ($t(9)=2.45$, $P<0.05$, $d=0.50$) (Cohen 1988). The frequency of self-injurious behaviour and stereotyped behaviour had decreased, but was not statistically significant, and there was no change in the severity of self-injurious behaviour. However, neither self-injurious behaviour nor stereotyped behaviour was the focus of the PBS intervention.

Table 1 shows baseline and pre-discharge scores on the Health of the Nation Outcome Scales for People with Learning Disabilities, Sheffield Learning Disabilities Outcome Measure and Goal-Based Outcomes tool.

There was a decrease in the Health of the Nation Outcome Scales for People...
with Learning Disabilities overall score, demonstrating an increase in Jack’s quality of life, a reduction of behaviours directed at others from severe to minor and a reduction in mental health issues, such as anxiety, from moderate to minor. However, the difference between the overall baseline and pre-discharge scores was not statistically significant and the effect size was negligible ($t(17)=1.37$, $ns, d=0.14$) (Cohen 1988).

Among the eight items of part 1 of the Sheffield Learning Disabilities Outcome Measure, the scores for the items relating to the parent-child relationship improved with a moderate effect size but only trended towards statistical significance ($t(3)=-3.00$, $P=0.058, d=0.56$) (Cohen 1988). However, there was a statistically significant increase, with a moderate effect size, in the scores for the item relating to Jack mother’s confidence in managing Jack’s behaviour ($t(7)=2.38$, $P<0.05, d=0.53$) (Cohen 1988), as well as positive changes in the items relating to how Jack’s mother felt they were coping as a family and in how often she felt close to Jack.

Scores on the Goal Based Outcomes tool increased, suggesting that both goals were closer to being achieved by pre-discharge. The scores for the first goal showed a (subjective) decrease in aggression towards family members at home, which was a meaningful outcome for the family. The scores for the second goal suggested that parental confidence and willingness to have Jack remain at home had increased.

**Effectiveness of the implementation**

It is important to measure the effectiveness of the implementation of a PBS intervention, since there are positive correlations between higher implementation scores and reduced levels of behaviour that challenges (McClean et al 2007). A periodic service review can be used for that purpose (LaVigna 1994). In this case, an eight-item periodic service review was developed collaboratively with Jack’s family and respite care staff to monitor over time the implementation of eight strategies within the PBS intervention, which focused on the increased use of visual schedules and increasing opportunities for Jack to make choices and develop independent functional skills (Breeze and Symes 2019).

Jack’s mother, school staff and respite care staff were asked to complete the periodic service review immediately after the implementation of Jack’s PBS intervention and subsequently at two-week intervals. Each item could be scored either as ‘achieved’ (indicating that the strategy had been implemented) or as an ‘opportunity’ (indicating that the strategy had not been implemented). Scores were added up and percentages were calculated. Figure 2 shows the percentages of ‘achieved’ scores regarding implementation of the eight strategies at three points in time – immediately after implementation, two weeks after and four weeks after.
The higher percentage of ‘achieved’ scores at four weeks demonstrates an improvement in the effectiveness of implementing Jack’s PBS intervention.

Discussion
There are concerns about a lack of co-production and accessibility of PBS interventions for people with learning disabilities. The co-production aspect of interventions is often neglected (Kruger and Northway 2019), while those that do involve co-production are often designed for carers rather than for the person themselves (Ham and Davies 2018). Barriers to co-production include perceived staff time constraints and the often crisis nature of the development and implementation of a PBS intervention. However, these barriers can be overcome through the use of appropriate and accessible communication methods and person-centred approaches to planning (Breeze 2021).

Jack’s PBS intervention was collaboratively produced with his family, respite care and school staff to ensure that it was practical and realistic, which increased the likelihood of effective and sustainable implementation (Breeze and Symes 2019). The PBS intervention was regarded as effective in that it was accompanied by a reduction in the severity and frequency of Jack’s behaviour that challenges. It also improved his quality of life, although this was largely due to the reduction in behaviour that challenges rather than wider quality of life improvements, such as learning independent living skills outside the home. At the time of Jack’s discharge from CAMHS, the intervention had not had a significant effect on his wider quality of life but had enabled him and his mother to meet their two main goals – a reduction in Jack’s behaviour that challenges and for him to be able to remain living at home.

The format of the PBS intervention, specifically Jack’s co-produced videos, makes it noteworthy as it incorporates one of Jack’s special interests – filming and watching himself on the screen. This is comparable to a case study described by Ham and Davies (2018), in which ‘selfies’ were used to illustrate the facial expressions that may be seen at various points along the arousal curve. The case study described in this article built on that idea, with Jack talking through the strategies he could implement at each stage of the arousal curve. The difference was that in Ham and Davies’ (2018) case study, the intervention was designed for those supporting the person, while Jack’s intervention was designed to enable him to develop his independence and ability to self-regulate. The author would argue that this resulted in a more meaningful intervention.

Conclusion
A creative co-production and collaborative approach to developing a PBS intervention for an autistic young person with a mild learning disability can facilitate their meaningful engagement and support effective and sustainable implementation of the intervention’s strategies. Using the person’s special interests can increase their engagement. It is important to note that a PBS intervention is a working document and that simply having one in place will not result in positive outcomes. Positive outcomes can only be achieved and sustained through effective implementation of the collaboratively developed strategies detailed in the intervention.


