Perceptions and experiences of co-produced Positive Behaviour Support training in community-based services and organisations for children with intellectual disabilities and behaviours that challenge: A qualitative multiple case study design.

Abstract

Background: Children with intellectual disabilities can display behaviours that challenge, often associated with poor outcomes. Despite national policy commitment to co-production, little evidence is available on how such services deliver co-produced activity.

Methods: Qualitative data were collected from three services that reported co-producing Positive Behaviour Support introductory workshops. Participants' experiences and perceptions of these workshops were described through individual semi-structured interviews conducted with staff and family carers (n=24) and analysed using a Framework approach.

Results: Two main themes were represented in the initial framework. *Positives of Co-production* included the advantages of obtaining and combining theoretical and practical knowledge, including personal and professional development for those delivering the intervention. *Challenges to Implementation* included time and effort required to build a collaborative way of working, barriers to organisational support and family carers' history with services.

Conclusions: Support, funding and resources need to be made available and protected to make co-production activities meaningful.

Keywords: Behaviours that challenge; Challenging behaviour; Children; Intellectual disabilities; Learning disabilities, Community services; Community organisations; Families; Family support; Co-production; Positive Behaviour Support (PBS); Qualitative; Case studies.

Lay Summary

- Co-production is when users of services and professionals work together as equals to plan, design and deliver services.
- Little evidence is available on the experience of co-production in services for children with intellectual disabilities and behaviours that challenge.
- We carried out interviews with staff and family carers from three services that used Positive Behaviour Support workshops that had been co-produced.
- The workshops helped people improve their knowledge and skills including knowledge from trainers with lived experience. Challenges included time and effort required to build a collaborative way of working, barriers to organisational support and family carers' history with services.

Introduction

Children with intellectual disabilities can display behaviours that challenge, with approximately 1 in 5 children with intellectual disabilities in the UK who are in contact with services displaying behaviours that challenge [1]. These behaviours are associated with poor care outcomes for children and for their family carers [2]. For children, these outcomes include, physical injury, threats to personal safety, exclusion from schools, and increased exposure to restrictive practices [3]. The development of community-based services for children with intellectual disabilities and behaviours that challenge is a national priority in the UK [4], [5].

The development of services internationally is increasingly influenced by co-production. Despite initially being applied to health and social care over 50 years ago [6] and the increasing prominence of its stated importance [9], co-production remains an umbrella term without consensus as to a specific definition[7], [8]. In the UK, NHS England's (2022) statutory guidance [9] (p.24) defines co-production as: *"a way of working that involves people who use health and care services, carers and communities in equal partnership; and which engages groups of people at the earliest stages of service design, development and evaluation.".* Additional guidance emphasises that if improvements are to be made in health and social care systems, co-production methods are central [10]. The guidance

states four ways in which health and social care systems can achieve this, which include: 1) involving service users and providers in the first place, 2) working with people who have relevant lived experience, 3) working with staff, building equal and reciprocal partnerships with people who have relevant lived experience from the beginning and until the end of the co-production process, and 4) paid recruitment of lived experience partners as equal members of the workforce where decisions are genuinely co-produced[10]. Working in a co-produced way that brings together experts-by-experience and experts-by-profession has become increasingly valued in healthcare [11].

Robert et al. (2024) [7] examined models of co-production in peer-reviewed articles about co-production in the health and social care sector. Three broad types of models were identified – conceptual/theoretical, practice-oriented, and presenting a typology. Conceptual/theoretical models draw on a vast spectrum of different theories and analytic approaches [12]. Practice-oriented models focused on exploring barriers/facilitators and community organising. Typology models focused on proposing ways of organising co-production into different types, categories, or 'levels.' Generally, there is an inconsistency and a lack of specific theory underpinning health and social care co-production literature ([7], [12], [13]. Challenges to implementing co-production within health and social care services include: (i) dynamics of professional-patient relationships including hostility/reluctance to challenge traditional roles and information asymmetry [14]; (ii) issues with how co-production was conducted including being overly complex and/or time-consuming, a lack of clarity on roles, objectives and responsibilities, a lack of outcomes and/or follow-up to consultation, and inclusion of proxy groups rather than patients themselves (e.g., parents and carers rather than children or patients) [15]; and (iii) funding/commissioning processes including funding cycles, unfeasible timescales, and rigid commissioning and governance structures [16].

Co-production in health and social care tends to be associated with reports of positive outcomes, both globally [8], [14], [15] and specifically concerning service user involvement within UK National Health Service (NHS) healthcare services [12]. Some specific examples include co-production being associated with positive service user experiences and outcomes regarding patient safety [10]; and

enhanced patient care in diabetes [11], cancer care [12], [13], emergency medicine [14] and mental health [15]. However, this is caveated by the lack of common approaches to measuring co-production outcomes making comparisons between studies difficult ([8], [12] and some less commonly reported negative outcomes for some service users (e.g., feeling that their involvement was tokenistic) [15].

Co-production of the design and delivery of services with children with intellectual disabilities and behaviours that challenge, and their families and carers are explicitly recommended [17]. However, information is needed on if and how services can deliver on these recommendations. Little research has considered the role and experiences of co-production in community-based services for children with intellectual disabilities and behaviours that challenge.

An earlier stage of the current research involved a mapping exercise of community-based services for children with intellectual disabilities and behaviours that challenge in England [18]. Staff at 60 services completed an interview that included questions about what co-production was occurring within their services. Using an existing practical framework of levels of co-production [19] to organise responses, activities meeting higher levels of co-production were only found in six services, typically these activities created clear changes in the relationship between services and those accessing them (e.g. the latter taking over some of the work typically done by practitioners). Most reported activities met 'lower level' definition classifications such as participation or co-creation [20].

Our initial plans were to follow the survey stage of our research and conduct case studies about how community-based services for children with intellectual disabilities and behaviours that challenge used co-production processes to develop their overall services. This plan was constrained by the lack of higher-level co-production within identified services during the survey study [20]. However, through project partners, we were able to identify three organisations that worked in a co-produced way as defined by NHS England's (2022) [21] statutory guidance. These three organisations were all delivering co-produced Positive Behavioural Support (PBS) introductory workshops to family carers of children with intellectual disabilities who displayed behaviours that challenge.

Therefore, the aim of the current study was to explore participants' perceptions and experiences of being involved in these co-produced training workshops.

Methods

Research design

Partners involved in a study of community-based service models for children with intellectual disabilities and behaviours that challenge in England [18],identified co-production examples from their own networks, and three case study sites (one NHS service and two non-NHS organisations) were recruited. All three co-production examples were Positive Behaviour Support (PBS) introductory workshops designed for family carers. These workshops were co-designed, co-produced and co-delivered by family carers with lived experience, alongside professionals. PBS focuses on the dual goals of promoting quality of life of the person who requires support and actively working to reduce behaviours that challenge [22] (see Supplementary file 1 for a summary of case study sites in Table 1). Qualitative data were collected by using a multiple case study design approach that was informed by Yin [23] and Stake [24]. For each organisation (or case study), purposive sampling strategies were used to recruit participants from three broad groups eligible to participate if they were involved in co-designing and/or co-delivering the PBS introductory workshops: (a)family carers (those who only attended the workshops and were ***not*** employed by the organisations); (b)internal staff(included both staff with lived experience and those without lived experience); (c)external members of staff (those who were not employed by the organisations but were involved in supporting internal staff at some point during the co-production process). Case study A (CA) consisted of 10 participants; Case study B (CB) consisted of eight participants and Case study C (CC) consisted of six participants, with a total of 24 participants recruited. Table one provides a summary of the characteristics of participants.

To guide the analysis and drawing on the work by Yin [23] we examined, tested, and refined a draft proposition to guide data collection and analysis. The proposition is based on key categories in our

earlier qualitative synthesis of existing literature [25] and was reviewed by the study team and family carer advisory group before data analysis commenced and is as follows:

- Co-production of services with family carers and children with intellectual disabilities may enable more appropriate services to be developed.

Participants

Family carers were eligible to participate if they were aged 18 or over, English-speaking, they had attended the PBS introductory workshops within the two years prior to interview, and their child was up to 15 years of age with intellectual disabilities and displayed behaviours that challenge at the time the family carer attended the workshop. Eligible and consenting participants were identified by each organisations' leaders when potential participants attended the organisations' PBS workshops. The organisations' leaders provided the potential participants with a short summary about the study and an online link to complete a 'consent to contact' form via the Qualtrics platform should they wished to take part and/or to learn more about the study from the research team. A researcher then conducted a five-minute preliminary discussion with the interested family carers over the telephone. An appointment for an interview was then made with the interested family carer, which was usually followed up with an email and an attachment of a participant information sheet. The interested family carers were informed of the voluntary nature of the study and had at least 24 hours to consider taking part in the study. They were also free to ask the researcher any questions prior to taking part. A text message and an email were sent the day before the interview was due to take place to confirm their attendance. At this point, some participants had postponed the scheduled interviews, which were then conducted at another time. Some participants did not respond to further contact from the research team or contacted the research team to let them know that they were no longer available for an interview. Table 2 provides an overview of participant characteristics for those who attended an interview.

151 **Table 2** Overview of participant characteristics

Case Study A - Participant ID	**Gender**	**Profession**
CAP1	Female	Family carer PBS introductory workshop co-trainer (internal member of staff)
CAP2	Male	Professional PBS introductory workshop co-trainer (internal member of staff)
CAP3	Male	Professional PBS introductory workshop co-trainer (internal member of staff)
CAP4	Female	Family carer PBS introductory workshop co-trainer (internal member of staff)
CAP5	Female	Internal member of staff
CAP6	Female	Organisation manager (internal member of staff)
CAP7	Female	Internal member of staff
CAP8	Female	Family carer PBS introductory workshop attendee
CAP9	Female	Family carer PBS introductory workshop attendee
CAP10	Female	Family carer PBS introductory workshop attendee
Case Study B - Participant ID	**Gender**	**Profession**
CBP1	Female	PBS manager (external to organisation but involved in supporting internal members of staff at some point during the co-production process).
CBP2	Female	PBS practitioner (external to organisation but involved in supporting internal members of staff at some point during the co-production process)
CBP3	Female	Organisation manager (internal member of staff)
CBP4	Female	Family carer PBS introductory workshop co-trainer (internal member of staff)
CBP5	Female	Family carer PBS introductory workshop co-trainer (external to organisation but involved in supporting internal members of staff at some point during the co-production process)
CBP6	Female	Family carer PBS introductory workshop attendee
CBP7	Female	Family carer PBS introductory workshop attendee
CBP8	Female	Family carer PBS introductory workshop attendee

Case Study C – Participant ID	Gender	Profession
CCP1	Female	Family carer PBS introductory workshop co-trainer (internal member of staff)
CCP2	Female	Family carer PBS introductory workshop co-trainer (internal member of staff)
CCP3	Male	Internal member of staff
CCP4	Female	Internal member of staff
CCP5	Female	Internal member of staff
CCP6	Female	Service manager (internal of staff)

Interview procedures

Participants were invited to participate in individual semi-structured interviews over the telephone, on Microsoft (MS) Teams, or face-to-face with a researcher. In total, 23 out of 24 interviews were conducted via MS Teams (one interview took place over the telephone). The interviews lasted between 30 and 60 minutes. The one telephone interview was audio-recorded with consent by using an encrypted recorder and those conducted via MS Teams were recorded, also with consent, using the recording function in MS Teams. [REDACTED FOR REVIEW] carried out all the interviews and field notes were completed immediately after the interviews. An indicative topic guide (see Supplementary file 2) was used to guide interviews, exploring participants' understanding of the processes of co-production, whether and how they were involved in co-producing the PBS introductory workshops, and their perceptions and experiences of the workshops and any barriers and facilitators to working in a co-produced way. For staff, additional questions were asked related to whether and how the organisations provided opportunities for families to be involved in decision-making and co-producing the PBS introductory workshops. Staff were also asked to provide copies of relevant written documentation such as policy documents and internal papers that they could share for analysis.

Data analysis

Gale et al's [26] framework method analysis was utilised. All 24 interview transcripts were read multiple times by [REDACTED FOR REVIEW]. Transcripts were read alongside field notes that were

collected during the data collection process. Initial categories were noted within each transcript using NVivo software (version 12). A combined approach to analysis took place. Deductive (or a priori) coding was used to create codes prior to data analysis from existing literature. Inductive coding was then used to develop codes from the accounts of research participants. Once interviews were conducted and transcribed, [REDACTED FOR REVIEW] read each transcript line-by-line, identifying initial codes, with two interview transcripts double-coded independently [27]. Emerging findings were discussed with the core study team and at family carer advisory group meetings to resolve discrepancies and refine categories. To address reflexivity, prior experiences and views of both researchers [REDACTED FOR REVIEW] and [REDACTED FOR REVIEW] which may influence the analysis were discussed [28]. The participants were predominantly women and so were the two researchers [REDACTED FOR REVIEW] and [REDACTED FOR REVIEW] who analysed the data. One of the researchers [REDACTED FOR REVIEW] had prior experience of working with children with intellectual disabilities and behaviours that challenge. However, the main interviewer and researcher [REDACTED FOR REVIEW] did not have prior experience of working with children with intellectual disabilities and behaviours that challenge. [REDACTED FOR REVIEW] conducted all the interviews and it is highly unlikely that the analysis would be influenced in any way. The interviews were emotionally challenging and [REDACTED FOR REVIEW] addressed this as part of the reflexivity process. They were able to separate their personal feelings from those of participants which enabled them to acknowledge the emotional resonance of the phenomenon that is being studied, whilst maintaining methodological rigour [29].

Table 3 presents the description of categories (by using the analytical framework) that formed the basis of the cross-case analysis of the experiences and perceptions of participants from the three case studies [26].

For triangulation purposes, we conducted documentary evidence analysis on each co-production case study. None of the organisations possessed relevant written documentation in the form of policy

documents and internal papers. However, during the data collection period, two organisations provided us with some documents that acted as background information, and contextualised and corroborated interview data. In addition, at the end of the data collection period (April 2024), organisation CA developed a guide to co-production and shared this with the research team.

Results

Developing the analytical framework

Two main themes were represented in the initial framework: (a) Positives of Co-production, and (b) Challenges to Implementation. The two themes, together with descriptions of five constituent sub-themes make up the analytical framework, as presented in Table 3. The findings are reported in line with the COREQ checklist[30].

Table 3 Analytical framework

Themes	Sub-themes	Description
Positives of Co-production	Advantages of obtaining and combining theoretical and practical knowledge from a variety of sources in the development of training.	Participants' responses related to professional and lived experience being seen as important in the development of the training.
	Co-produced training leads to personal and professional development for those involved.	Participants' responses around the benefits of combining professional and lived experience within delivery of the training.

Challenges to Implementation	Time and effort required to build a collaborative way of working.	Participants' responses related to factors that enable the process of working together.
	Barriers to organisational support, including funding and resources.	Participants' responses related to whether they had the support from the organisations in which they were employed and/or from external organisations.
	Family carers' history with services	Participants' responses related to the impact of challenges they face or have faced in the past when trying to access support for their children.

By applying the analytical framework (Table 3) across the entire qualitative dataset, we looked across the three cases to understand the similarities and differences between them, as per Yin's [23] suggestions of pattern matching, explanation building and cross case synthesis. For transparency purposes, as suggested by Yin [23], we have displayed part of a matrix for all 24 participants' experiences and perceptions in working in a co-produced way across the three case study sites in Table 4 (see Supplementary file 3 for a data matrix showing categories for working in a co-produced way in three case study sites in Table 4).

(i) Positives of Co-Production

- ***Advantages of obtaining and combining theoretical and practical knowledge from a variety of sources in the development of material***

Participants from across the three case studies stated that they had accessed and gained knowledge from various sources, including family carers with grown up children with intellectual disabilities and behaviours that challenge, professionals with nursing and behaviour analysis qualifications, a peer support worker (a family carer with lived experience), national charities, academic papers, former family carer PBS workshop attendees and experts in the fields of intellectual disability and behaviours

that challenge. Accessing the information enabled the participants to create the content of the PBS introductory workshops and emphasised the need to include family carers with lived experience or family carer co-trainers to (co)deliver the contents to family carer workshop attendees. For example, a member of staff working in service A, highlighted how families' personal and professional experiences had contributed to the development of a workshop:

"…So, the group of families had an enormous amount of knowledge and experience in terms of supporting their own children and an incredible skill level in terms of both professional and personal experiences that they'd been through, which contributed to the development of the PBS workshop…" (Case study A participant 7: Internal member of staff).

However, contributions to the development of materials alone were insufficient.

- ***Co-produced training leads to personal and professional development for those involved***

Most participants emphasised the importance of having knowledge and experience when it came to people co-delivering the workshops to family carer workshop attendees. This seemed to be important both for those being trained and those delivering training. For example, a family carer trainer from service B reflected on their lived and academic experience:

"…the NHS paid for me to do a postgraduate course on PBS. They said that it would make sense if I was trained in PBS, because I was delivering PBS sessions. So, now looking back, it's great for me because I've got the lived experience and the academic stuff to back it up…"

(Case study B participant 5: External member of staff - family carer PBS introductory workshop co-trainer).

In addition, a family carer in service B highlighted the importance of learning from someone who had both lived experience and theoretical knowledge. For this participant, learning from a family carer who had older children (and therefore had been through shared experiences and come out the other side) was particularly helpful:

"…So, to have somebody like [NAME OF ORGANISATION] and [NAMES OF FAMILY CARER CO-FACILITATORS] with their experiences and their children being older, I really value the fact that they've been there for me. They've worn the T shirt and trained in the PBS approach…"

(Case study B participant 7: Family carer PBS introductory workshop attendee).

Finally, participants were aware that whilst knowledge and experience were important, family carers who delivered training also needed to have the confidence to train and the ability to share (often difficult) experiences in authentic ways, thinking about the needs of the families they were training. A family carer trainer in service A reflected:

"…So, you're talking in front of a lot of people. You've got to overcome your nerves. You have got to make it real. You have got to talk the truth. You know, you have got to say how you experience things. Otherwise, you are not being supportive in that way, because you can pick up a book and read about PBS…"

(Case study A participant 4: Internal member of staff - family carer PBS introductory workshop co-trainer).

(ii) Challenges in Implementation of Co-Production

- ***Time and effort required to build a collaborative way of working***

Collaborative working was not something that was automatic and instantaneous. Initial resistance was common. During the initial stages of co-producing PBS introductory workshops, internal members of staff from two case study sites (A and C) reported to have faced resistance to working in a collaborative way with health and social care professionals and with family carer workshop attendees. The resistance however, subsided over time, as people saw the benefit of working in a collaborative way when it came to co-producing PBS introductory workshops.

One participant (from Case study A) stated that when they began working in a co-produced way, it was challenging for some health and social care professionals to work collaboratively as this was different from their usual practice:

"…it was the first time the professionals had properly co-produced something from the beginning… and sometimes that was challenging because it was a different way of working, a different way of doing things, and sometimes, obviously there were disagreements about how we did things…"

(Case study A participant 7: Internal member of staff).

One participant (from Case study C) stated that both family carers and professionals initially struggled to collaboratively deliver co-produced PBS introductory workshops when it was first introduced to them. The participant, however, reported to have faced most resistance from professionals:

"…It was other professionals, the ones who did the referrals, they probably put more boundaries up because families didn't have any expectations. It was very different back then. There's a lot more group work that goes on now. But at that time, it was quite different, and some people really struggled to get their heads around it…."

(Case study C participant 6: Internal member of staff - service manager).

People from both case study sites (A and C) eventually accepted the idea of working in a co-produced way and at the time of interviews, referrals to these co-developed PBS workshops were being made by professionals and family carers were happy to attend the workshops.

Initial reticence from family carers may also have reflect their experiences of services, as highlighted in the next theme.

- ***Family carers' history with services***

Family carers attending workshops described the type of challenges that they had faced with regards to co-producing these. Some family carer attendees had a history of challenging experiences with

health and social care services. Because of these past experiences, family carers attendees often needed to express their thoughts and emotions before PBS workshops began. Examples of bad experiences included family carers not being believed by health and social professionals when it came to discussing the needs of their children; family carers often feeling their parenting skills were judged and they were subsequently blamed for the health and social care needs of their children by professionals. For example, a member of staff in service B reflected on the lack of understanding from professionals and the ways in which professionals might blame families for difficulties they and their child were experiencing:

"…she'd [family carer] been banging her head against a brick wall trying to get a diagnosis for her son, but getting a diagnosis can be hard, if people write you off by placing a blame on your parenting skills. Even I experience that. So, the fact is that there's often a gulf, I think, between professionals and parents…"

(Case study B participant 4: Internal member of staff - Family carer PBS introductory workshop co-trainer).

For other families, hearing about the difficulties other families were experiencing was hard. For example, when a family carer from service A was asked what she thought would be a barrier for her to take part in the co-production process of a PBS introductory workshop, she said that it was difficult to hear about the experiences of other parents that were similar to hers:

"…I find it quite hard to listen to other people's experiences because that's quite upsetting... The most challenging thing for me is saying your own experiences and hearing other people's because it hits close to home, I guess…"

(Case study A participant 10: Family carer PBS introductory workshop attendee).

- ***Barriers to organisational support***

Family carer co-trainers, peer (family carer) support workers and other staff members (health and social care) stated that having support from the organisations in which they were employed was crucial when it came to co-producing PBS introductory workshops.

There was one instance where a participant explained that, although in theory, their NHS organisation supported employing two peer support workers to co-deliver the PBS workshops to family carer attendees, but this did not come in the form of funding:

"…I do find the Trust extremely supportive from a commissioning point of view. I don't get much money from them; they haven't given us anything extra to keep the peers [PEER SUPPORT WORKERS]. …"

(Case study C participant 6: Internal member of staff - organisation manager).

In summary, co-production had led to the development of workshop materials that included knowledge and skills gained from a range of perspectives. Co-facilitation of training based on these materials needed those with both lived experience and theoretical knowledge. Family carer co-facilitators needed to have the confidence to present information and to deliver content in ways which related to their own lived experiences and considered the support needed by the participants. These collaborative ways of working needed to be developed over time (and might need careful negotiation) and organisational support (though this might not always result in the necessary resources).

Conducting co-production in a meaningful way means funding is needed. Participants spoke about the challenges of accessing funding during the initial stages of co-producing PBS introductory workshops:

"…it's having the resources to do it. It's being able to get people together and the need to facilitate it, to be able to pay people to attend the PBS workshops, to write it up, to then come back again, go over it and refine it. So, it's funding and resources to do that, they are hard to find, and we didn't have dedicated funding for it…"

(Case study A participant 6: Internal member of staff – organisation manager).

Once funding had been acquired to deliver the workshops, the funds were usually earmarked for one financial year and there was no way of knowing whether the organisations or service would receive further funds:

"…Money is always an issue. So, for a project like that is you get given a pot of money which you must spend by the end of the financial year. I think that's the problem with a lot of project work which does some brilliant work, but it can't ever be a long-term plan…"

(Case study B participant 2: External member of staff - PBS practitioner).

Discussion

When we initially looked for co-production case studies in community-based health or care services for children with intellectual disabilities and behaviours that challenge, none met accepted full definitions of co-production[18]. However, we did find the three examples of co-produced/co-delivered PBS introductory workshops as described in the current study. Thus, our findings are focused on these examples rather than providing further data about co-production in these services more generally.

From our study, there was evidence that all three organisations delivered PBS introductory workshops to family carers of children with intellectual disabilities who displayed behaviours that challenge in a co-produced way. Case studies A and B worked in a co-produced way by involving family carers with lived experience and professionals with learned experience to co-design the contents of the PBS introductory workshop. Both organisations also always co-delivered the workshops to family carers. Throughout the process, the family carers who were recruited as employees of the organisations were paid for their time. Case study C achieved working in a co-produced way by recruiting peer support workers (family carers with lived experience) to co-deliver the PBS introductory workshops to family carers. There was no evidence reported on whether (and how) co-evaluation of the workshops was conducted across the three organisations.

362 The current study suggests some experience of 'growing pains' in the practice and implementation of
363 co-production in services for children with intellectual disabilities and behaviours that challenge. The
364 'pain' relates to two key features. First, family carers typically bring a history to co-production and
365 their experience of co-produced training that is characterised by difficulties, especially a battle with
366 services for recognition and support. Such experiences are well-documented internationally for
367 families of individuals with intellectual disabilities and behaviours that challenge[28]. These
368 experiences need to be carefully considered in all co-production work. In particular, professionals
369 need to understand and empathically respond to these experiences and the likely associated distrust.
370 The second dimension of 'pain' identified in the current study is that of the process of coming together
371 to 'do' co-production and in terms of implementation of co-production including co-produced
372 training. Our findings suggest that co-production is messy and beset with challenges (attitudinal and
373 organisational). Even where the value of co-production is accepted, it is still a difficult thing to do.
374 These key challenges noted, the current study does also offer hope in terms of the experiences and
375 perceptions of co-production and co-produced training. First, significant value was placed by
376 interviewees on the contributions both from professional/theoretical and practice perspectives and
377 family carers' direct experience. It is important to note that co-production is defined in terms of both
378 perspectives coming together. Notably, however, the value of family carers' lived experiences in the
379 co-production of training, in its delivery, and in shared problem solving as a part of training was
380 recognised. Again, this is similar to other research on the experiences of stakeholders involved in co-
381 produced research and supports for families [31], [32]. The second dimension of hope is that exposure
382 "works" as identified in the findings. Coming together to work through different experiences and to
383 be in training situations bringing different perspectives helps to break down barriers and for
384 stakeholders to directly experience the added value of working together co-productively.
385 Attitudinal and organisation barriers may be addressed by clear planning and guidelines focused on
386 practicalities and learning from other co-production with family carers of individuals with intellectual
387 disabilities [33]. However, the main implication of the current research is that doing something is the

most important thing. Approaching co-production with curiosity and a willingness to learn and adapt (and be transparent when things have gone wrong), is likely to lead to a 'good' co-production experience and to act as a mechanism to challenge attitudes and make organisational process adapt to the realities of engaging in and implementing co-production.

Our study has certain **strengths and limitations**. To our knowledge, this is the first study to focus on how community-based services and organisations in England for children with intellectual disabilities work in a meaningful co-produced manner. The study benefitted from a multiple case study approach. Nonetheless, there were several limitations. We were able to interview three family carer PBS introductory workshop attendees from sites A and B. However, we were unable to interview any family carer PBS introductory workshop attendees from site C as these potential participants declined participation. However, the data emerging from those interviewed did reach saturation. Finally, the three organisations did not possess much relevant written documentation (in the form of policy documents and internal papers) that was relevant to the process of co-production, although one organisation did provide us with a document which was newly written to guide co-production towards the end of the data collection period.

Our findings also raise several important new research avenues, including what support and resources can be provided to family carers before they attend interventions (including those that have been co-produced). Professionals need to acknowledge the ways in which services have negatively impacted families and provide support for families in ways that enable them to fully engage in interventions. There is also still much to do to truly meet definitions of co-production in working with family carers and others with lived experience in services for children with intellectual disabilities and behaviours that challenge, such as ensuring that this involves co-design in addition to co-delivery. More broadly, the difficulty in finding examples of co-production suggests that this is still an implementation priority for future practice and research.

List of abbreviations

COREQ Consolidated criteria for reporting qualitative research

CYP Children and Young People

MS Microsoft

NHS National Health Service

NICE National Institute for Health and Care Excellence

NQB National Quality Board

PBS Positive Behaviour Support

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Ethics approval and consent to participate

Ethical approval was obtained from the National Institute for Health Research (NIHR) Health and Social Care Delivery Research programme (Ref NIHR 129577) and Health Research Authority (HRA). Informed written consent was obtained from all interviewees prior to the interviews, including consent to be audio recorded during the interviews. Potential participants were informed of the voluntary nature of the study and had at least 24 hours to consider taking part. Efforts were made to create a safe place for sharing experiences during all the interviews.

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Supplementary file 1: A summary of the case study sites is provided in Table 1.

Supplementary file 2: Indicative topic guide for qualitative interviews for the coproduction case studies V1.0, 15.12.2021.

Supplementary file 3: A data matrix showing categories for working in a co-produced way in three case study sites in Table 4.