



Co-production within community-based services for children with intellectual disabilities and behaviours that challenge in England

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3 **Co-production within community-based services for children with intellectual disabilities and**
4 **behaviours that challenge in England**
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8 **Abstract**
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11 **Purpose:** Developing effective community-based services for children with intellectual disabilities
12 and behaviours that challenge in England is a national priority. Service design and delivery guidelines
13 state services should be co-produced with the children and families/carers accessing them. There
14 are no identified data about how well services are delivering this recommendation. This research
15 aimed to describe self-reported co-production activities within such services, and to consider how
16 well these align with co-production definitions.
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23 **Methodology:** During a mapping exercise of community-based services for children with intellectual
24 disabilities and behaviours that challenge in England, staff at 60 services completed an interview
25 including questions concerning co-production. Types of self-reported co-production within services
26 were described. We then examined how well these aligned with definitions of co-production.
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32 **Findings:** Six types of self-reported 'co-production' activities were identified via content analysis – (i)
33 service planning, (ii) recruitment processes and decisions, (iii) individual case work, (iv) resources
34 used within the service, (v) running training, workshops and groups, and (vi) the service's physical
35 environment. Very few activities met co-production definitions, typically being classified as
36 participation or co-creation.
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42 **Originality:** This is the first known assessment of how well community-based services for children
43 with intellectual disabilities and behaviours that challenge are enacting guidance that service design
44 and delivery should be co-produced.
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49 **Practical implications:** All involved in the planning and delivery of services need to better consider
50 how to implement additional activities that meet higher-level co-production definitions.
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53 **Key words:** Co-production, Behaviours that challenge, Challenging Behaviour, Intellectual
54 Disabilities, Learning Disabilities, Children, Community services
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Introduction

Approximately 1 in 5 children with intellectual disabilities in contact with UK health and social care services display behaviours that challenge (Emerson et al., 2001). Behaviours that challenge are not a medical disorder or diagnosis. Rather, they are socially defined in accordance with what behaviours are not typical within the culture people live within and which occur at a frequency, severity, and/or duration resulting in risks of harm for both the individual and those around them, as well as limiting inclusion within typical community settings. Harms to the individual can include self-injury, exclusion, poorer care outcomes, personal safety, and increased exposure to restrictive care. Harms to those around them can include physical aggression, stress and physically destructive behaviour (Bowring et al., 2019; Emerson & Einfeld, 2011; Hastings et al., 2013). Behaviours that challenge can also result in increased costs for both families and health and social care services (Einfeld et al., 2010; Lemmi et al., 2016).

It is a national priority to develop effective community-based services for children with intellectual disabilities and behaviours that challenge (NHS England, 2015; Department of Health and Social Care, 2022). The urgency of this is reinforced by persistent evidence of the abuse of children with intellectual disabilities within services, including within residential settings and concerning the use of restraint within special schools (The Child Safeguarding Practice Review Panel, 2022, 2023; Clegg and Adnitt, 2024; Titheradge and Deas, 2024).

~~National Institute for Health and Care Excellence guidelines concerning service design and delivery for people with intellectual disabilities and behaviours that challenge recommends that services and interventions should be co-produced with the children, young people and adults using services as well as their families, carers and independent advocates (National Institute for Health and Care Excellence, 2018).~~ Co-production is typically viewed as a process whereby those who provide and access services work together equally to create the service, shaping its design, development and evaluation (NHS England, 2022; Social Care Institute for Excellence, 2022). Within co-production, “professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities” (Social Care Institute for Excellence, 2022, p.6).

Co-production has been linked to more positive experiences and outcomes within health and social care services in general (Bombard et al., 2018; Palumbo, 2016; Nordin et al., 2023;) and within

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3 the NHS in the UK (Mockford *et al.*, 2012). and in specific areas where benefits have been reported
4 including emergency medicine, diabetes and cancer care (Iedema *et al.*, 2010; Peat *et al.*, 2010;
5 Tsianakas *et al.*, 2012, Kohler *et al.*, 2017). National Institute for Health and Care Excellence
6 guidelines concerning service design and delivery for people with intellectual disabilities and
7 behaviours that challenge recommends that services and interventions should be co-produced with
8 the children, young people and adults using services as well as their families, carers and independent
9 advocates (National Institute for Health and Care Excellence, 2018).
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16 We could find no existing research concerning how well services for children with intellectual
17 disabilities and behaviours that challenge are following recommendations around co-production,
18 making it difficult to know what types and quality of co-production is occurring. Some insight into
19 how well other types of services for children and/or young people are delivering co-production is
20 evident in literature reviews concerning co-production in mental health services for those aged 10-
21 25 (Jones *et al.*, 2024) and services for children and young people with special educational needs
22 (Boswell and Woods, 2021). Factors that can facilitate or be barriers to co-production include the
23 degree of support from leadership/within the organisation, resources/funding including around
24 transport and support, to what extent power is shared with those accessing services, the degree of
25 flexibility to the needs of those accessing services, and how much the time and views of those
26 accessing services are valued. There being a range of positive and negative outcomes related to such
27 factors is suggestive of variation in how co-production is being delivered.”
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38 In the current study, our aims were: i) to describe reported co-production activities within
39 community-based services for children with intellectual disabilities and behaviours that challenge in
40 England, and ii) consider how well these activities align with co-production definitions.
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45 **Method**

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48 The current study drew upon a subset of data gathered as part of a wider study, which involved
49 mapping and identifying service models for community-based services for children with intellectual
50 disabilities and behaviours that challenge in England (REDACTED FOR REVIEW). A combination of
51 latent class analysis, descriptive analysis and consultation with family carers and professionals was
52 utilised to describe how services were structured and organised (“service models”). Five service
53 models were identified - (i) Child and Adolescent Mental Health Services (CAMHS), (ii) Intellectual
54 Disability CAMHS, (iii) Children and Young People Disability services, (iv) Specialist services for
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3 children who display behaviours that challenge, and (v) broader age range services for children
4 and/or adolescents and adults.
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8 *Ethics*

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11 Ethical approval was received from REDACTED FOR REVIEW
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14 *Wider study*

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18 For the wider study, we aimed to collect service characteristic data from as many services fulfilling
19 eligibility criteria as possible. Inclusion criteria were being (i) geographically located in, and at least
20 partially drawing referrals from, England, (ii) a community-based service, (iii) an NHS, local authority
21 or other (e.g., private, charity) service commissioned by relevant public bodies at the time of the
22 survey, or a service where individual places are purchased by commissioners, and (iv) providing
23 supports for children 0-17 years of age with intellectual disabilities and behaviours that challenge or
24 providing supports to this group of children as a clearly distinct care pathway (whilst also providing
25 other services). Services were not excluded if they also provided services to individuals 18+ years of
26 age. Exclusion criteria were services being (i) inpatient services, (ii) commissioned by non-NHS or
27 local authority commissioner (e.g., solely a special school service), and (iii) not yet operational.
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37 Methods of identifying potentially eligible services included expressions of interest in response to
38 study information, local authority/local offer websites, details provided by other services,
39 suggestions from leads of NHS regional teams, finding information online, and details provided by
40 NHS staff. 161 eligible community-based services completed a survey between July 2021 and March
41 2022. See REDACTED FOR REVIEW for further service identification and recruitment details.
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46 *Procedure*

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50 All 161 services included in the wider research were invited to identify an individual to participate in
51 a short additional interview to gather further data that required discussion to fully understand,
52 including data on co-production. Staff received a study information sheet and completed an
53 informed consent form prior to the interview; consent was also reconfirmed verbally at the start of
54 each interview. Interviews were guided by an interview schedule and covered a range of topics
55 including the history of the service, future plans, staffing structure, connections to other local
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3 services and opportunities for children and families to be involved in decision-making and co-
4 production. The interview schedule included a description of co-production to orientate participants
5 to questions about this (“We are defining co-production as a way of working where service providers
6 and the people who use them work together to produce shared outcomes”). Participants were asked
7 “I wonder whether your service undertakes co-production work with children and young people with
8 learning disability and behaviours that challenge and/or their families?” Five researchers conducted
9 interviews. Interviews were conducted remotely and recorded using Microsoft Teams®.
10 Interviewers made notes of the content of participant responses during interviews using a form set
11 up in the Qualtrics® survey platform. After each interview, the interviewer checked their notes
12 against the recording for accuracy, updating notes accordingly. After accuracy was confirmed, the
13 recording was deleted.
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23 *Participants*

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26 Participants at 60 of the 161 services included in the wider research completed an interview about
27 their service between July 2021 and February 2022. Participants were those identified by each
28 service to take part, typically service managers or lead clinicians. All 60 services responded to the co-
29 production question. Six services reported they were not currently conducting co-production, with
30 the other 54 describing current co-production activities they were conducting. Reasons for not
31 undertaking co-production were discussed by four services not conducting any co-production
32 activities, and 12 services who were conducting some co-production activities - explaining why they
33 were not conducting other types of co-production activities. In terms of service models, of these 54
34 services reporting some co-production 21 were CAMHS, ten ID-CAMHS, four general child disability
35 services, 14 specialist challenging behaviour services, and five all-age services.
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45 *Analysis*

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48 Analysis focused on the subset of interview data concerning opportunities for children and families
49 to be involved in decision-making and co-production. Researcher notes from the interviews were
50 transferred from Qualtrics® to NVivo® software. Patterns within interview data were identified
51 using content analysis (Berelson, 1952; Prior, 2014). An initial deductive list of codes was developed
52 prior to coding by discussion within the research team, formalising researcher expectations of what
53 codes may have been present in the dataset. These codes were based on team knowledge of the
54 research area/literature, as well as experiences of interviewing participants. Two researchers coded
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3 all data using the initial deductive coding framework, adding codes iteratively as they arose. For
4 example, the researchers added new iterative codes to expand the breadth of co-production
5 activities reported including “resources used within the service” and “the service’s physical
6 environment” as well as building depth through adding iterative sub-codes to the deductive “service
7 planning” code about “evaluating and modifying the existing service” and “setting up the initial
8 service model”. This process was repeated until there were no further edits to the coding framework
9 being made. A third member of the research team then used the final coding framework to code a
10 random sample of 20% of the data. Inter-coder reliability was tested. There was good level of overall
11 agreement (average $\kappa=.83$) within the $>.81$ “almost perfect” strength of agreement range (Landis
12 and Koch, 1977). A Kappa coefficient of $<.6$ can be interpreted as only a moderate or lower strength
13 of agreement (Landis and Koch, 1977). Consequently, individual codes with a Kappa coefficient $<.6$
14 were discussed, and agreement reached about how to resolve such disagreement.
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25 Having established different types of self-reported co-production, we then assessed how well these
26 fitted within different definitions of co-production as detailed in a co-production guide created by
27 The Social Care Institute for Excellence (SCIE) (2022). We considered multiple definitions of co-
28 production because there is not a universally agreed upon single definition. It was therefore viewed
29 as more comprehensive to use multiple definitions encompassing different definition criteria rather
30 than opt for a single definition that would have the shortcoming of not capturing the breadth of
31 potential definitions. The SCIE guide was chosen because it was itself co-produced with people
32 drawing on care/support, support providers and SCIE staff. The guide details four ways of
33 conceptualising and categorising co-production, including defining what activities are, or are not, co-
34 production:
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- 44 • The first definition proposes three levels of co-production: descriptive, intermediate, and
45 transformative.
 - 46 ○ Descriptive co-production involves those accessing a service working together to
47 achieve individual outcomes in a way that does not challenge how the service is
48 delivered.
 - 49 ○ Intermediate co-production involves a greater degree of recognition and mutual
50 respect (e.g., involvement in recruitment and staff training).
 - 51 ○ Transformative co-production involves new relationships between service staff and
52 those accessing the service. This involves those accessing the service working in
53 equal partnership with professionals towards shared goals, having a more
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3 meaningful and powerful role within the service, and everyone who contributes
4 getting something back in exchange.
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- 6 • The second definition distinguishes between participation and co-production.
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 - 8 ○ Participation involves being consulted.
 - 9 ○ Co-production involves being equal partners and co-creators.
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- 15 • The third definition distinguishes between co-creation and co-production.
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 - 17 ○ Co-creation involves those using services working with professionals to design,
18 create and deliver services.
 - 19 ○ Co-production expands on this by having those using services take over some of the
20 work being done by practitioners.
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- 23 • The fourth definition sets out four co-production activities:
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 - 25 ○ Co-design, including planning of services
 - 26 ○ Co-decision making in the allocation of resources
 - 27 ○ Co-delivery of services, including the role of volunteers in providing the service
 - 28 ○ Co-evaluation of the service.
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33 The core research team discussed and reached agreement about how each reported co-production
34 activity could be best categorised within each of the four definitions. This was then presented to and
35 discussed with the wider research team, resulting in agreement with this categorisation. One
36 member of the research team then assessed every individual self-reported activity within each type
37 of co-production, classifying each to one category within each of the four definitions.
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43 **Results**

44 *Types of self-reported co-production within services*

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50 Six types of co-production were identified – (i) service planning, (ii) recruitment processes and
51 decisions, (iii) individual case work, (iv) resources used within the service, (v) running training,
52 workshops and groups, and (vi) the service's physical environment
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57 Service planning was the most common co-production type, being reported by over half of services.
58 This mostly concerned evaluating and modifying the existing service ($n=31$ services), most commonly
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3 via consultation with groups. This was more likely to be with pre-existing groups ($n=10$), including
4 youth groups and parent groups/forums, than with groups brought together specifically for this
5 purpose ($n=5$) (e.g., general focus groups, parent workshops). Also common was gathering input
6 through feedback processes ($n=13$) such as asking children/young people and/or families to
7 complete surveys and outcome measures, with feedback also gathered informally ($n=3$) (e.g.,
8 discussing with families). There were also some less common examples of parents being on steering
9 groups (a mixed group involved professionals and families) ($n=3$) and of people being employed in
10 roles related to co-production ($n=3$) (e.g., parents undertaking family support worker/experts by
11 experience roles and people with intellectual disabilities undertaking peer support worker roles).

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13 Engagement in 'Service planning' involving setting up the initial service model was less common
14 ($n=8$). For this, there was an equal split between consulting pre-existing parent groups or fora ($n=3$)
15 and groups brought together specifically for this purpose ($n=3$). There were also individual reports of
16 (i) children and parent groups identifying the need for a new service, (ii) parents being involved in
17 designing the business case, and (iii) contributing to stakeholder meetings for a funding bid.

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19 Similar numbers of services reported co-production relating to recruitment processes and decisions
20 ($n=25$), individual case work ($n=23$) and resources used within the service ($n=19$).

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22 'Recruitment processes and decisions' involved including children/young people ($n=16$) and families
23 ($n=12$) who had accessed the service within recruitment processes (e.g., on interview panels for new
24 staff). Some services involved children/young people and/or family carers from other organisations
25 or departments on interview panels ($n=4$) including other parts of CAMHS.

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27 'Individual case work' involved specific planning of an individual child/young person's support,
28 typically in the creation of support/care plans ($n=18$) and setting individual 'treatment' goals ($n=10$).

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30 'Resources used within the service' involved working with and/or seeking feedback from
31 children/young people and/or families to create service-related leaflets ($n=6$), videos ($n=3$), letters
32 ($n=2$), easy-read information ($n=2$), outcome measures ($n=2$), one-page profiles ($n=2$), presentation
33 slides ($n=1$), and feedback forms ($n=1$).

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35 Least commonly, services reported running training, workshops and groups ($n=5$) and impacting the
36 service's physical environment ($n=5$).

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3 'Running training, workshops and groups' involved families being involved in the planning and
4 delivery of training, workshops and groups, typically those that they had previously accessed
5 themselves.
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10 'The service's physical environment' involved children/young people and/or families being involved
11 in decisions around building decoration and the naming of buildings and/or rooms. See table I for
12 example interviewer notes for each type of self-reported co-production activity.
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16 [Table I here]
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19 *Reasons for not undertaking co-production*

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23 Services also discussed reasons for not undertaking co-production activities. This included four of the
24 six services that had reported not currently conducting any co-production activities, as well as 12
25 services that *were* conducting some co-production activities explaining why they were not also
26 conducting other types of co-production activities. Reasons mostly included either the impact of
27 COVID-19 ($n=7$) or the level of intellectual disability of those accessing the service ($n=4$), with less
28 common reasons including difficulties getting interest from families, lack of time, being a new
29 service, and rarely having staff vacancies. Similar reasons were given for there being limitations
30 within co-production activities that services were attempting, mostly that those with greater needs
31 (e.g., more severe intellectual disabilities) could not be included within existing co-production
32 activities (e.g., due to not understanding complex questioning or finding such activities distressing)
33 ($n=7$), and the impact of COVID-19 ($n=3$). Individual services also mentioned difficulties getting
34 interest from families, staffing problems, multi-agency working, lack of time and wanting to avoid
35 being tokenistic/ensuring had a meaningful impact.
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46 *Alignment with co-production definitions*

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50 Table II summarises the alignment between reported co-production activity and the four definitions
51 within The Social Care Institute for Excellence (2022) co-production guide, detailing how many of
52 each activity were classified to what within each co-production definition
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56 [Table II here]
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3 *Levels of co-production (classification definition 1)*
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6 From table II, it can be seen that Individual case work activities were all classified as 'descriptive',
7 because these concerned achieving individual outcomes in a way that does not challenge how the
8 wider service is delivered. Almost all other activities were classified as 'intermediate', as they
9 involved a relatively greater degree of recognition and mutual respect and progressed beyond
10 individual outcomes to impact the wider service. A small number of service planning activities
11 regarding evaluating and modifying the existing service ($n=3$) and setting up the initial service model
12 ($n=1$) were classified as 'transformative', as these involved a clear change in the relationship with
13 those accessing the service (e.g., undertaking peer support workers and expert by experience roles).
14 This was meaningfully different from most of the same type of activities classified as intermediate
15 (e.g., seeking feedback to evaluate the service). Additionally, three of the five services reporting
16 running training, workshops and groups had this activity classified as transformative. Again, the
17 criterion moving these into the higher classification was there being clear evidence of new
18 relationships (e.g., the family carer involved having a formal role and/or clear power to determine
19 the content and delivery of the activity). In terms of service models, of the six services with activities
20 classed as transformative, three were CAMHS, one was a general child disability service and two
21 were all-age services.
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35 *Co-production vs. participant/co-creation (classification definitions 2 and 3)*
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38 A similar pattern of classifications is evident in terms of distinguishing between co-production and
39 participation or co-creation. Most activities were classified as participation or co-creation rather
40 than co-production because, respectively, they involved those accessing the service being consulted
41 or working with professionals to design, create and deliver services. A small number of activities
42 within evaluating and modifying the existing service ($n=3$), setting up the initial service model ($n=1$),
43 and running training, workshops and groups ($n=3$) were classified as co-production. These were the
44 same activities also classified as at the transformative level of co-production. Like with classification
45 of the level of co-production, it is new relationships with those accessing the service that underpins
46 such higher classification, with these evidencing meeting co-production criteria of being equal
47 partners and co-creators and having those using services take over some of the work being done by
48 practitioners.
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58 *Co-production activity types (classification definition 4)*
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5 Activities concerning individual case work, the service's physical environment, and resources used
6 within the service did not fit into any of the four co-production activity types. All evaluating and
7 modifying the existing service activities were classified as co-evaluation, as they involved evaluation
8 of the service. All setting up the initial service model activities were classified as co-design, as they
9 involved planning of services. All recruitment activities were classified as co-decision making as they
10 could be considered to be concerned with the allocation of (staffing) resources. All running training,
11 workshops and groups activities were classified as co-delivery as they involved aspects of direct
12 service provision.
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20 **Discussion**

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23 Although staff working in community-based services for children with intellectual disabilities and
24 behaviours that challenge in England reported co-production within their services, activities meeting
25 higher-level co-production classifications (The Social Care Institute for Excellence, 2022) were only
26 found in six services. These included two services conducting evaluating and modifying the existing
27 service activities, two services conducting running training, workshops and groups activities, one
28 service conducting setting up the initial service model activities, and one service conducting both
29 evaluating and modifying the existing service and running training, workshops and groups activities.
30 Most activities reported met lower-level definition classifications, such as participation and co-
31 creation.
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40 Insight into why these specific activities met higher level co-production classifications was obtained
41 through comparing them to other activities within their respective categories, which met lower-level
42 classifications (i.e., intermediate, participation or co-creation). The persistent difference was the
43 degree to which the activity created clear changes in the relationship between the service and those
44 who accessed it, with some evidence that those accessing the service had become equal partners
45 and co-creators and had taken over some of the work typically done by practitioners. This is
46 meaningfully different from other activity of the same type categorised within lower-level
47 classifications, which tended to involve seeking feedback from those accessing the service whilst
48 maintaining their existing relationship with the service.
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57 *Implications*

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3 These findings have implications for services, staff, and policy makers, as well as for families
4 accessing services. All involved in the planning and delivery of services need to better consider how
5 to implement additional activities that meet higher-level co-production definitions. Doing so is
6 important to potentially generate more positive experiences and outcomes as observed in other
7 health and social care services (Bombard *et al.*, 2018; Iedema *et al.*, 2010; Mockford *et al.*, 2012;
8 Palumbo, 2016; Peat *et al.*, 2010; Nordin *et al.*, 2023; Tsianakas *et al.*, 2012, Kohler *et al.*, 2017) and
9 in so doing -fulfil recommendations about how to best design and deliver services (National Institute
10 for Health and Care Excellence, 2018), ~~potentially generating more positive experiences and~~
11 ~~outcomes for those accessing services (Iedema *et al.*, 2010; Peat *et al.*, 2010; Tsianakas *et al.*, 2012,~~
12 ~~Kohler *et al.*, 2017).~~ While it is the responsibility of services to implement co-production activities,
13 families accessing services should be aware that services should be offering to involve them within
14 the type of activities meeting higher-level co-production definitions.

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25 The factors resulting in activities meeting higher-level co-production definitions can inform such
26 planning and delivery. These factors include explicitly planning activities to change the relationship
27 between services and those accessing them and/or to enable those accessing services to take over
28 some of the work typically done by practitioners. Examples of this from the services interviewed
29 include those accessing the service and family carers having formal (paid) roles (e.g., peer support
30 workers, experts by experience) and the power to determine outcomes such as the content and
31 delivery of training, workshops and groups (i.e., not merely advising service staff who then lead
32 making the decision). As part of this, it is important for organisations to proactively examine and
33 reach agreement about what they understand co-production to be (The Social Care Institute for
34 Excellence, 2022), working alongside those accessing the service to actively consider what co-
35 production means within the specific context of their service.

36 37 38 39 40 41 42 43 44 45 *Limitations*

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48 There were some features of the way that data was collected that meant there was a greater chance
49 that certain types of participants/services were included than others – meaning that data may not
50 have been representative (sampling bias). Although 161 eligible services completed the survey in the
51 wider study, only 60 (37.27%) of these chose to complete the optional additional interview. It is
52 possible that services choosing not to take part in the interview may have differed from those
53 choosing to take part e.g., conducting less/more/different types of co-production (non-response
54 bias). Similarly, services themselves determined which of their staff were willing to be interviewed,
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3 meaning there may have been differences between those who volunteered to be interviewed
4 compared with those who did not (self-selection/volunteer bias).
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8 Interviews covered a broader range of topics than solely co-production, meaning that co-production
9 activity data are based on relatively brief discussion. It is possible that more in-depth data collection
10 (e.g., being the focus of interviews, additional prompts) may have resulted in more activities being
11 reported. It is also possible that more in-depth data collection may reveal additional attributes of
12 activities that could potentially result in changes to how they are classified e.g., ways that activities
13 resulted in new relationships between staff and those accessing services not evident within this
14 study's data. This relates to difficulties clearly defining co-production. Although the interview
15 schedule included a description of co-production to orientate participants to the question, there
16 may have been variance between individual participants' ideas of what co-production was/was not,
17 which could have affected responses.
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26 Co-production activities were self-reported by services, meaning they only reflect staff views on
27 what co-production is occurring, with the views of children and families accessing the service
28 missing. Only one staff member was interviewed per service, typically service managers or lead
29 clinicians, meaning their knowledge of what co-production activities were occurring may have been
30 limited by their job role e.g., speech and language therapists may have been aware of co-production
31 activities specific to their role that service managers were unaware of. Furthermore, whilst some
32 interviews included brief positive reflections on reported activities, the data did not provide much
33 insight into the impact of activities, or whether feedback received from those accessing services led
34 to changes. Such information may be important in distinguishing between different types of co-
35 production (e.g., whether activities resulted in new relationships between service staff and those
36 accessing the service). Similarly, whilst some services gave some brief descriptions of why co-
37 production was not occurring (e.g., due to the level of intellectual disability of those accessing the
38 service), the data is not of sufficient depth to allow for detailed exploration of this potentially
39 insightful topic.
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51 This study was conducted solely in England, so may not be representative of what co-production is
52 occurring in community-based services for children with intellectual disabilities and behaviours that
53 challenge within the rest of the United Kingdom, or in other countries. It also reports only what co-
54 production was occurring around when participants were interviewed (2021-2022), meaning there
55 may have been changes since this data was collected.
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Future research

Future research should build on this initial study by investigating what co-production activities are evident in a broader range of community-based services for children with intellectual disabilities and behaviours that challenge, utilising more in-depth methodologies to better understand what co-production is occurring (e.g., documentary analysis, ethnography), as well as investigating in more depth why co-production is not occurring e.g., what barriers there are to specific co-production activities. Such research should prioritise including the views of children and families accessing services to address their lack of current representation in this area. Furthermore, research should endeavour to go beyond describing co-production activities to better understand the processes underpinning how these are conducted and what makes them effective.

Research should also endeavour to consider how these findings fit within broader debates around co-production including how to make this accessible for people with intellectual disabilities and challenging/barriers for parents/carers to be involved e.g., emotional and cognitive labour (Sutherland *et al.* 2025). As higher-level definitions of co-production often have funding implications (e.g., transformative co-production involving everyone who contribute getting something back in exchange) how co-production is resourced within services would also be a productive focus for future research.

Conclusion

Except for limited examples of running training, workshops and groups, most co-production activities self-reported by community-based service for children with intellectual disabilities and behaviours that challenge did not meet higher-level definitions of co-production. There is a need for services to better plan how to implement activities meeting higher-level definitions of co-production, including working alongside the children and families accessing services to best understand what co-production means within the specific context of their service.

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Declarations

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Availability of data and materials

Interview datasets are not publicly available to protect participant anonymity.

Ethics approval and consent to participate

This study received approval from REDACTED FOR REVIEW. Informed consent was obtained from all participants and participating organisations

Consent for publication

All participants completed informed consent forms including that data from this study would be used in a non-identifiable way in publications

References

Berelson, B. (1952), *Content Analysis in Communication Research*, Free Press, Glencoe, IL.

[Bombard, Y., Baker, G.R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., Onate, K., Dennis, J-L. and Pomey, M-P. \(2018\). "Engaging patients to improve quality of care: A systematic review", *Implementation Science*, Vol. 13 a98. <https://doi.org/10.1186/s13012-018-0784-z>](#)

Boswell, N. and Woods, K. (2021). "Facilitators and barriers of co-production of services with children and young people within education, health and care services.", *Educational & Child Psychology*, Vol. 38 No. 2, pp.41-52. <https://doi.org/10.53841/bpsecp.2021.38.2.41>

1
2
3 Bowring, D.L., Painter, J. and Hastings, R.P. (2019). "Prevalence of challenging behaviour in adults
4 with intellectual disabilities, correlates, and association with mental health", *Current Developmental*
5 *Disorders Reports*, Vol. 6, pp.173-181. <https://doi.org/10.1007/s40474-019-00175-9>
6
7

8
9
10 Clegg, R. and Adnitt, J. (2024). 'Restrained and scared - the £100k schools failing vulnerable children',
11 *BBC News*, 30 August. Available at: <https://www.bbc.co.uk/news/articles/c4ge00wp9vgo> (Accessed:
12 29 June 2025).
13
14

15
16 Department of Health and Social Care (2022). *Building the right support for people with a learning*
17 *disability and autistic people*. Available at:
18 [https://assets.publishing.service.gov.uk/media/62d7df62e90e071e7cbe1ef0/Building-the-Right-](https://assets.publishing.service.gov.uk/media/62d7df62e90e071e7cbe1ef0/Building-the-Right-Support-for-People-with-a-Learning-Disability-and-Autistic-People-Action-Plan-accessible.pdf)
19 [Support-for-People-with-a-Learning-Disability-and-Autistic-People-Action-Plan-accessible.pdf](https://assets.publishing.service.gov.uk/media/62d7df62e90e071e7cbe1ef0/Building-the-Right-Support-for-People-with-a-Learning-Disability-and-Autistic-People-Action-Plan-accessible.pdf)
20
21 (Accessed: 29 June 2025).
22
23
24
25

26
27 Einfeld, S.L., Ellis, L.A., Doran, C.M., Emerson, E., Horstead, S.K., Madden, R.H. and Tonge, B.J. (2010),
28 "Behavior problems increase costs of care of children with intellectual disabilities", *Journal of Mental*
29 *Health Research in Intellectual Disabilities*, Vol. 3 No. 4, pp.202–209.
30
31 <https://doi.org/10.1080/19315864.2010.524973>
32
33

34
35 Emerson, E. and Einfeld, S.L. (2011), *Challenging Behaviour*, Cambridge University Press, Cambridge,
36 UK.
37

38
39
40 Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Mason, H., Swarbrick, R., Mason, L. and Hatton, C.
41 (2001), "The prevalence of challenging behaviours: A total population study", *Research in*
42 *Developmental Disabilities*, Vol. 22 No.1, pp.77-93. [https://doi.org/10.1016/S0891-4222\(00\)00061-5](https://doi.org/10.1016/S0891-4222(00)00061-5)
43
44
45

46
47 Hastings, R.P., Allen, D., Baker, P., Gore, N.J., Hughes, J.C., McGill, P., Noone, S.J. and Toogood, S.
48 (2013), "A conceptual framework for understanding why challenging behaviours occur in people
49 with developmental disabilities", *International Journal of Positive Behavioural Support*, Vol 3. No.2,
50 pp.5-13.
51
52

53
54
55 Iedema, R., Merrick, E., Piper, D., Britton, K., Gray, J., Verma, R. and Manning, N. (2010),
56 "Codesigning as a discursive practice in emergency health services: The architecture of
57
58
59
60

1
2
3 deliberation", *The Journal of Applied Behavioral Science*, Vol. 46 No. 1, pp.73-91.

4 <https://doi.org/10.1177/0021886309357544>

5
6
7
8 lemmi, V., Knapp, M., Reid, C., Sholl, C., Ferdinand, M., Buescher, A. and Trachtenberg, M. (2016),
9 "Positive behavioural support for children and adolescents with learning disabilities and behaviour
10 that challenges: an initial exploration of service use and costs", *Tizard Learning Disability Review*,
11 Vol. 21 No. 4, pp. 169-180. <https://doi.org/10.1108/TLDR-03-2015-0013>

12
13
14
15
16 Jones, V. R., Waring, J., Wright, N. and Fenton, S-F. (2024), "A rapid realist review of literature
17 examining Co-production in mental health services for youth", *JCPP Advances*, Vol. 4 No. 4, e12272.
18 <https://doi.org/10.1002/jcv2.12272>

19
20
21
22
23 Kohler, G., Sampalli, T., Ryer, A., Porter, J., Wood, L., Bedford, L., Higgins-Bowser, I., Edwards, L.,
24 Christian, E., Dunn, S., Gibson, R., Ryan Carson, S., Vallis, M., Zed, J., Tugwell, B., Van Zoost, C.,
25 Canfield, C. and Rivoire, E. (2017), "Bringing value-based perspectives to care: Including patient and
26 family members in decision-making processes", *International Journal of Health Policy and*
27 *Management*, Vol. 6 No. 11, pp.661–668. <https://doi.org/10.15171/ijhpm.2017.27>

28
29
30
31
32
33 Landis, J.R. and Koch, G.G. (1977), "The measurement of observer agreement for categorical data",
34 *Biometrics*, Vol. 33 No. 1, pp.159-174. <https://doi.org/10.2307/2529310>

35
36
37
38 [Mockford, C., Staniszewska, S., Griffiths, F. and Herron-Marx, S. \(2012\), "The impact of patient and](#)
39 [public involvement on UK NHS health care: A systematic review", *International Journal for Quality in*](#)
40 [*Health Care*, Vol. 24 No. 1, pp.28–38. <https://doi.org/10.1093/intqhc/mzr066>](#)

41
42
43
44
45 National Institute for Health and Care Excellence (2018). *Learning disabilities and behaviour that*
46 *challenges: Service design and delivery NG93*. Available at: <https://www.nice.org.uk/guidance/ng93>
47 (Accessed: 29 June 2025).

48
49
50
51 NHS England (2015). *Supporting people with a learning disability and/or autism who display*
52 *behaviour that challenges, including those with a mental health condition: Service model for*
53 *commissioners of health and social care services*. Available at: [https://www.england.nhs.uk/wp-](https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf)
54 [content/uploads/2015/10/service-model-291015.pdf](https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf) (Accessed: 29 June 2025).

1
2
3 NHS England (2022). *Working in partnership with people and communities: Statutory guidance*.
4 Available at: [https://www.england.nhs.uk/long-read/working-in-partnership-with-people-and-](https://www.england.nhs.uk/long-read/working-in-partnership-with-people-and-communities-statutory-guidance/)
5 [communities-statutory-guidance/](https://www.england.nhs.uk/long-read/working-in-partnership-with-people-and-communities-statutory-guidance/) (Accessed: 29 June 2025).
6
7

8
9
10 [Nordin, A., Kjellstrom, S., Robert, G., Masterson, D. and Josefsson, K.A. \(2023\), "Measurement and](#)
11 [outcomes of co-production in health and social care: A systematic review of empirical studies", *BMJ*](#)
12 [Open, Vol.13 No. 9, e073808. <https://doi.org/10.1136/bmjopen-2023-073808>](#)
13
14

15
16 [Palumbo, R. \(2016\), "Contextualizing co-production of health care: a systematic literature review",](#)
17 [International Journal of Public Sector Management, Vol. 29 No. 1, pp.72-90.](#)
18 <https://doi.org/10.1108/IJPSM-07-2015-0125>
19
20
21

22
23 Peat, M., Entwistle, V., Hall, J., Birks, Y. and Golder, S. (2010), "Scoping review and approach to
24 appraisal of interventions intended to involve patients in patient safety", *Journal of Health Services*
25 *Research & Policy*, Vol. 15 No. 1, pp.17-25. <https://doi.org/10.1258/jhsrp.2009.009040>
26
27
28

29
30 Prior, L. (2014), "Content analysis", Leavy, P. (Ed.), *The Oxford Handbook of Qualitative Research*,
31 Oxford University Press, Oxford, UK, pp.359–379.
32
33

34
35 Social Care Institute for Excellence (2022). *Co-production: What is it and how to do it*. Available at:
36 <https://www.scie.org.uk/download/22652/?tmstv=1699958786> (Accessed: 29 June 2025).
37
38

39
40 Sutherland, D., Griffin, J., Austin, D., Bjornstad, G., Bradshaw, J., Charles, M., Cooper, V., Divers, J.,
41 Evan-Jones, K., Foxwell, S., Gore, N., Minhas, S., Penfold, I., Singh, G. and Hastings, R. (2025),
42 "Developing guidance on co-producing research with family carers of people with learning
43 disabilities", *Tizard Learning Disability Review*, Vol. 30 No. 3, pp.143-153.
44 <https://doi.org/10.1108/TLDR-12-2024-0040>
45
46
47
48

49
50 REDACTED FOR REVIEW
51

52
53 The Child Safeguarding Practice Review Panel (2022). *Safeguarding children with disabilities and*
54 *complex health needs in residential settings: Phase 1 report*. Available at:
55 [https://assets.publishing.service.gov.uk/media/635914568fa8f557d066c1ad/safeguarding_children](https://assets.publishing.service.gov.uk/media/635914568fa8f557d066c1ad/safeguarding_children_with_disabilities_in_residential_care_homes_phase_1_report.pdf)
56 [with_disabilities_in_residential_care_homes_phase_1_report.pdf](https://assets.publishing.service.gov.uk/media/635914568fa8f557d066c1ad/safeguarding_children_with_disabilities_in_residential_care_homes_phase_1_report.pdf) (Accessed 29 June 2025).
57
58
59
60

1
2
3
4
5 The Child Safeguarding Practice Review Panel (2023). *Safeguarding children with disabilities and*
6 *complex health needs in residential settings: Phase 2 report*. Available at:

7
8 https://assets.publishing.service.gov.uk/media/643e82136dda69000c11df6a/Safeguarding_children
9 [with disabilities in residential care homes phase 2 report.pdf](https://assets.publishing.service.gov.uk/media/643e82136dda69000c11df6a/Safeguarding_children) (Accessed 29 June 2025).
10
11

12
13 Titheradge, N. and Deas, A. (2024). 'Special school pupils 'tortured' in calming rooms, BBC
14 investigation finds', *BBC News*, 30 April. Available at: <https://www.bbc.co.uk/news/uk-68897335>
15 (Accessed: 29 June 2025).
16
17

18
19 Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C. and Wiseman, T. (2012),
20 "Implementing patient-centred cancer care: Using experience-based co-design to improve patient
21 experience in breast and lung cancer services", *Supportive Care in Cancer*, Vol. 20, pp.2639–2647.
22
23 <https://doi.org/10.1007/s00520-012-1470-3>
24
25
26
27
28
29
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3 **Co-production within community-based services for children with intellectual disabilities and**
4 **behaviours that challenge in England**
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8 **Abstract**
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11 **Purpose:** Developing effective community-based services for children with intellectual disabilities
12 and behaviours that challenge in England is a national priority. Service design and delivery guidelines
13 state services should be co-produced with the children and families/carers accessing them. There
14 are no identified data about how well services are delivering this recommendation. This research
15 aimed to describe self-reported co-production activities within such services, and to consider how
16 well these align with co-production definitions.
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23 **Methodology:** During a mapping exercise of community-based services for children with intellectual
24 disabilities and behaviours that challenge in England, staff at 60 services completed an interview
25 including questions concerning co-production. Types of self-reported co-production within services
26 were described. We then examined how well these aligned with definitions of co-production.
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32 **Findings:** Six types of self-reported 'co-production' activities were identified via content analysis – (i)
33 service planning, (ii) recruitment processes and decisions, (iii) individual case work, (iv) resources
34 used within the service, (v) running training, workshops and groups, and (vi) the service's physical
35 environment. Very few activities met co-production definitions, typically being classified as
36 participation or co-creation.
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42 **Originality:** This is the first known assessment of how well community-based services for children
43 with intellectual disabilities and behaviours that challenge are enacting guidance that service design
44 and delivery should be co-produced.
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49 **Practical implications:** All involved in the planning and delivery of services need to better consider
50 how to implement additional activities that meet higher-level co-production definitions.
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53 **Key words:** Co-production, Behaviours that challenge, Challenging Behaviour, Intellectual
54 Disabilities, Learning Disabilities, Children, Community services
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Introduction

Approximately 1 in 5 children with intellectual disabilities in contact with UK health and social care services display behaviours that challenge (Emerson *et al.*, 2001). Behaviours that challenge are not a medical disorder or diagnosis. Rather, they are socially defined in accordance with what behaviours are not typical within the culture people live within and which occur at a frequency, severity, and/or duration resulting in risks of harm for both the individual and those around them, as well as limiting inclusion within typical community settings. Harms to the individual can include self-injury, exclusion, poorer care outcomes, personal safety, and increased exposure to restrictive care. Harms to those around them can include physical aggression, stress and physically destructive behaviour (Bowring *et al.*, 2019; Emerson & Einfeld, 2011; Hastings *et al.*, 2013). Behaviours that challenge can also result in increased costs for both families and health and social care services (Einfeld *et al.*, 2010; Lemmi *et al.*, 2016).

It is a national priority to develop effective community-based services for children with intellectual disabilities and behaviours that challenge (NHS England, 2015; Department of Health and Social Care, 2022). The urgency of this is reinforced by persistent evidence of the abuse of children with intellectual disabilities within services, including within residential settings and concerning the use of restraint within special schools (The Child Safeguarding Practice Review Panel, 2022, 2023; Clegg and Adnitt, 2024; Titheradge and Deas, 2024).

Co-production is typically viewed as a process whereby those who provide and access services work together equally to create the service, shaping its design, development and evaluation (NHS England, 2022; Social Care Institute for Excellence, 2022). Within co-production, “professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities” (Social Care Institute for Excellence, 2022, p.6).

Co-production has been linked to more positive experiences and outcomes within health and social care services in general (Bombard *et al.*, 2018; Palumbo, 2016; Nordin *et al.*, 2023) and within the NHS in the UK (Mockford *et al.*, 2012). Specific areas where benefits have been reported include emergency medicine, diabetes and cancer care (Iedema *et al.*, 2010; Peat *et al.*, 2010; Tsianakas *et al.*, 2012, Kohler *et al.*, 2017). National Institute for Health and Care Excellence guidelines concerning service design and delivery for people with intellectual disabilities and behaviours that challenge

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3 recommends that services and interventions should be co-produced with the children, young people
4 and adults using services as well as their families, carers and independent advocates (National
5 Institute for Health and Care Excellence, 2018).
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10 We could find no existing research concerning how well services for children with intellectual
11 disabilities and behaviours that challenge are following recommendations around co-production,
12 making it difficult to know what types and quality of co-production is occurring. Some insight into
13 how well other types of services for children and/or young people are delivering co-production is
14 evident in literature reviews concerning co-production in mental health services for those aged 10-
15 25 (Jones *et al.*, 2024) and services for children and young people with special educational needs
16 (Boswell and Woods, 2021). Factors that can facilitate or be barriers to co-production include the
17 degree of support from leadership/within the organisation, resources/funding including around
18 transport and support, to what extent power is shared with those accessing services, the degree of
19 flexibility to the needs of those accessing services, and how much the time and views of those
20 accessing services are valued. There being a range of positive and negative outcomes related to such
21 factors is suggestive of variation in how co-production is being delivered.”
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31 In the current study, our aims were: i) to describe reported co-production activities within
32 community-based services for children with intellectual disabilities and behaviours that challenge in
33 England, and ii) consider how well these activities align with co-production definitions.
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38 **Method**

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41 The current study drew upon a subset of data gathered as part of a wider study, which involved
42 mapping and identifying service models for community-based services for children with intellectual
43 disabilities and behaviours that challenge in England (REDACTED FOR REVIEW). A combination of
44 latent class analysis, descriptive analysis and consultation with family carers and professionals was
45 utilised to describe how services were structured and organised (“service models”). Five service
46 models were identified - (i) Child and Adolescent Mental Health Services (CAMHS), (ii) Intellectual
47 Disability CAMHS, (iii) Children and Young People Disability services, (iv) Specialist services for
48 children who display behaviours that challenge, and (v) broader age range services for children
49 and/or adolescents and adults.
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Ethics

Ethical approval was received from REDACTED FOR REVIEW

Wider study

For the wider study, we aimed to collect service characteristic data from as many services fulfilling eligibility criteria as possible. Inclusion criteria were being (i) geographically located in, and at least partially drawing referrals from, England, (ii) a community-based service, (iii) an NHS, local authority or other (e.g., private, charity) service commissioned by relevant public bodies at the time of the survey, or a service where individual places are purchased by commissioners, and (iv) providing supports for children 0-17 years of age with intellectual disabilities and behaviours that challenge or providing supports to this group of children as a clearly distinct care pathway (whilst also providing other services). Services were not excluded if they also provided services to individuals 18+ years of age. Exclusion criteria were services being (i) inpatient services, (ii) commissioned by non-NHS or local authority commissioner (e.g., solely a special school service), and (iii) not yet operational.

Methods of identifying potentially eligible services included expressions of interest in response to study information, local authority/local offer websites, details provided by other services, suggestions from leads of NHS regional teams, finding information online, and details provided by NHS staff. 161 eligible community-based services completed a survey between July 2021 and March 2022. See REDACTED FOR REVIEW for further service identification and recruitment details.

Procedure

All 161 services included in the wider research were invited to identify an individual to participate in a short additional interview to gather further data that required discussion to fully understand, including data on co-production. Staff received a study information sheet and completed an informed consent form prior to the interview; consent was also reconfirmed verbally at the start of each interview. Interviews were guided by an interview schedule and covered a range of topics including the history of the service, future plans, staffing structure, connections to other local services and opportunities for children and families to be involved in decision-making and co-production. The interview schedule included a description of co-production to orientate participants to questions about this ("We are defining co-production as a way of working where service providers

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3 and the people who use them work together to produce shared outcomes”). Participants were asked
4 “I wonder whether your service undertakes co-production work with children and young people with
5 learning disability and behaviours that challenge and/or their families?” Five researchers conducted
6 interviews. Interviews were conducted remotely and recorded using Microsoft Teams®.
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8 Interviewers made notes of the content of participant responses during interviews using a form set
9 up in the Qualtrics® survey platform. After each interview, the interviewer checked their notes
10 against the recording for accuracy, updating notes accordingly. After accuracy was confirmed, the
11 recording was deleted.
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18 *Participants*

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21 Participants at 60 of the 161 services included in the wider research completed an interview about
22 their service between July 2021 and February 2022. Participants were those identified by each
23 service to take part, typically service managers or lead clinicians. All 60 services responded to the co-
24 production question. Six services reported they were not currently conducting co-production, with
25 the other 54 describing current co-production activities they were conducting. Reasons for not
26 undertaking co-production were discussed by four services not conducting any co-production
27 activities, and 12 services who were conducting some co-production activities - explaining why they
28 were not conducting other types of co-production activities. In terms of service models, of these 54
29 services reporting some co-production 21 were CAMHS, ten ID-CAMHS, four general child disability
30 services, 14 specialist challenging behaviour services, and five all-age services.
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40 *Analysis*

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43 Analysis focused on the subset of interview data concerning opportunities for children and families
44 to be involved in decision-making and co-production. Researcher notes from the interviews were
45 transferred from Qualtrics® to NVivo® software. Patterns within interview data were identified
46 using content analysis (Berelson, 1952; Prior, 2014). An initial deductive list of codes was developed
47 prior to coding by discussion within the research team, formalising researcher expectations of what
48 codes may have been present in the dataset. These codes were based on team knowledge of the
49 research area/literature, as well as experiences of interviewing participants. Two researchers coded
50 all data using the initial deductive coding framework, adding codes iteratively as they arose. For
51 example, the researchers added new iterative codes to expand the breadth of co-production
52 activities reported including “resources used within the service” and “the service’s physical
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3 environment” as well as building depth through adding iterative sub-codes to the deductive “service
4 planning” code about “evaluating and modifying the existing service” and “setting up the initial
5 service model”. This process was repeated until there were no further edits to the coding framework
6 being made. A third member of the research team then used the final coding framework to code a
7 random sample of 20% of the data. Inter-coder reliability was tested. There was good level of overall
8 agreement (average $\kappa=.83$) within the $>.81$ “almost perfect” strength of agreement range (Landis
9 and Koch, 1977). A Kappa coefficient of $<.6$ can be interpreted as only a moderate or lower strength
10 of agreement (Landis and Koch, 1977). Consequently, individual codes with a Kappa coefficient $<.6$
11 were discussed, and agreement reached about how to resolve such disagreement.
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20 Having established different types of self-reported co-production, we then assessed how well these
21 fitted within different definitions of co-production as detailed in a co-production guide created by
22 The Social Care Institute for Excellence (SCIE) (2022). We considered multiple definitions of co-
23 production because there is not a universally agreed upon single definition. It was therefore viewed
24 as more comprehensive to use multiple definitions encompassing different definition criteria rather
25 than opt for a single definition that would have the shortcoming of not capturing the breadth of
26 potential definitions. The SCIE guide was chosen because it was itself co-produced with people
27 drawing on care/support, support providers and SCIE staff. The guide details four ways of
28 conceptualising and categorising co-production, including defining what activities are, or are not, co-
29 production:
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- The first definition proposes three levels of co-production: descriptive, intermediate, and transformative.
 - Descriptive co-production involves those accessing a service working together to achieve individual outcomes in a way that does not challenge how the service is delivered.
 - Intermediate co-production involves a greater degree of recognition and mutual respect (e.g., involvement in recruitment and staff training).
 - Transformative co-production involves new relationships between service staff and those accessing the service. This involves those accessing the service working in equal partnership with professionals towards shared goals, having a more meaningful and powerful role within the service, and everyone who contributes getting something back in exchange.

- The second definition distinguishes between participation and co-production.
 - Participation involves being consulted.
 - Co-production involves being equal partners and co-creators.
- The third definition distinguishes between co-creation and co-production.
 - Co-creation involves those using services working with professionals to design, create and deliver services.
 - Co-production expands on this by having those using services take over some of the work being done by practitioners.
- The fourth definition sets out four co-production activities:
 - Co-design, including planning of services
 - Co-decision making in the allocation of resources
 - Co-delivery of services, including the role of volunteers in providing the service
 - Co-evaluation of the service.

The core research team discussed and reached agreement about how each reported co-production activity could be best categorised within each of the four definitions. This was then presented to and discussed with the wider research team, resulting in agreement with this categorisation. One member of the research team then assessed every individual self-reported activity within each type of co-production, classifying each to one category within each of the four definitions.

Results

Types of self-reported co-production within services

Six types of co-production were identified – (i) service planning, (ii) recruitment processes and decisions, (iii) individual case work, (iv) resources used within the service, (v) running training, workshops and groups, and (vi) the service's physical environment

Service planning was the most common co-production type, being reported by over half of services. This mostly concerned evaluating and modifying the existing service ($n=31$ services), most commonly via consultation with groups. This was more likely to be with pre-existing groups ($n=10$), including youth groups and parent groups/forums, than with groups brought together specifically for this purpose ($n=5$) (e.g., general focus groups, parent workshops). Also common was gathering input through feedback processes ($n=13$) such as asking children/young people and/or families to

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3 complete surveys and outcome measures, with feedback also gathered informally ($n=3$) (e.g.,
4 discussing with families). There were also some less common examples of parents being on steering
5 groups (a mixed group involved professionals and families) ($n=3$) and of people being employed in
6 roles related to co-production ($n=3$) (e.g., parents undertaking family support worker/experts by
7 experience roles and people with intellectual disabilities undertaking peer support worker roles).
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12 Engagement in 'Service planning' involving setting up the initial service model was less common
13 ($n=8$). For this, there was an equal split between consulting pre-existing parent groups or fora ($n=3$)
14 and groups brought together specifically for this purpose ($n=3$). There were also individual reports of
15 (i) children and parent groups identifying the need for a new service, (ii) parents being involved in
16 designing the business case, and (iii) contributing to stakeholder meetings for a funding bid.
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22 Similar numbers of services reported co-production relating to recruitment processes and decisions
23 ($n=25$), individual case work ($n=23$) and resources used within the service ($n=19$).
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28 'Recruitment processes and decisions' involved including children/young people ($n=16$) and families
29 ($n=12$) who had accessed the service within recruitment processes (e.g., on interview panels for new
30 staff). Some services involved children/young people and/or family carers from other organisations
31 or departments on interview panels ($n=4$) including other parts of CAMHS.
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36 'Individual case work' involved specific planning of an individual child/young person's support,
37 typically in the creation of support/care plans ($n=18$) and setting individual 'treatment' goals ($n=10$).
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42 'Resources used within the service' involved working with and/or seeking feedback from
43 children/young people and/or families to create service-related leaflets ($n=6$), videos ($n=3$), letters
44 ($n=2$), easy-read information ($n=2$), outcome measures ($n=2$), one-page profiles ($n=2$), presentation
45 slides ($n=1$), and feedback forms ($n=1$).
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50 Least commonly, services reported running training, workshops and groups ($n=5$) and impacting the
51 service's physical environment ($n=5$).
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56 'Running training, workshops and groups' involved families being involved in the planning and
57 delivery of training, workshops and groups, typically those that they had previously accessed
58 themselves.
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3 'The service's physical environment' involved children/young people and/or families being involved
4 in decisions around building decoration and the naming of buildings and/or rooms. See table I for
5 example interviewer notes for each type of self-reported co-production activity.
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10 [Table I here]
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13 *Reasons for not undertaking co-production*

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16 Services also discussed reasons for not undertaking co-production activities. This included four of the
17 six services that had reported not currently conducting any co-production activities, as well as 12
18 services that *were* conducting some co-production activities explaining why they were not also
19 conducting other types of co-production activities. Reasons mostly included either the impact of
20 COVID-19 ($n=7$) or the level of intellectual disability of those accessing the service ($n=4$), with less
21 common reasons including difficulties getting interest from families, lack of time, being a new
22 service, and rarely having staff vacancies. Similar reasons were given for there being limitations
23 within co-production activities that services were attempting, mostly that those with greater needs
24 (e.g., more severe intellectual disabilities) could not be included within existing co-production
25 activities (e.g., due to not understanding complex questioning or finding such activities distressing)
26 ($n=7$), and the impact of COVID-19 ($n=3$). Individual services also mentioned difficulties getting
27 interest from families, staffing problems, multi-agency working, lack of time and wanting to avoid
28 being tokenistic/ensuring had a meaningful impact.
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39 *Alignment with co-production definitions*

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43 Table II summarises the alignment between reported co-production activity and the four definitions
44 within The Social Care Institute for Excellence (2022) co-production guide, detailing how many of
45 each activity were classified to what within each co-production definition
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50 [Table II here]
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53 *Levels of co-production (classification definition 1)*

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56 From table II, it can be seen that Individual case work activities were all classified as 'descriptive',
57 because these concerned achieving individual outcomes in a way that does not challenge how the
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3 wider service is delivered. Almost all other activities were classified as 'intermediate', as they
4 involved a relatively greater degree of recognition and mutual respect and progressed beyond
5 individual outcomes to impact the wider service. A small number of service planning activities
6 regarding evaluating and modifying the existing service ($n=3$) and setting up the initial service model
7 ($n=1$) were classified as 'transformative', as these involved a clear change in the relationship with
8 those accessing the service (e.g., undertaking peer support workers and expert by experience roles).
9 This was meaningfully different from most of the same type of activities classified as intermediate
10 (e.g., seeking feedback to evaluate the service). Additionally, three of the five services reporting
11 running training, workshops and groups had this activity classified as transformative. Again, the
12 criterion moving these into the higher classification was there being clear evidence of new
13 relationships (e.g., the family carer involved having a formal role and/or clear power to determine
14 the content and delivery of the activity). In terms of service models, of the six services with activities
15 classed as transformative, three were CAMHS, one was a general child disability service and two
16 were all-age services.
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28 *Co-production vs. participant/co-creation (classification definitions 2 and 3)*

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31 A similar pattern of classifications is evident in terms of distinguishing between co-production and
32 participation or co-creation. Most activities were classified as participation or co-creation rather
33 than co-production because, respectively, they involved those accessing the service being consulted
34 or working with professionals to design, create and deliver services. A small number of activities
35 within evaluating and modifying the existing service ($n=3$), setting up the initial service model ($n=1$),
36 and running training, workshops and groups ($n=3$) were classified as co-production. These were the
37 same activities also classified as at the transformative level of co-production. Like with classification
38 of the level of co-production, it is new relationships with those accessing the service that underpins
39 such higher classification, with these evidencing meeting co-production criteria of being equal
40 partners and co-creators and having those using services take over some of the work being done by
41 practitioners.
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52 *Co-production activity types (classification definition 4)*

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55 Activities concerning individual case work, the service's physical environment, and resources used
56 within the service did not fit into any of the four co-production activity types. All evaluating and
57 modifying the existing service activities were classified as co-evaluation, as they involved evaluation
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3 of the service. All setting up the initial service model activities were classified as co-design, as they
4 involved planning of services. All recruitment activities were classified as co-decision making as they
5 could be considered to be concerned with the allocation of (staffing) resources. All running training,
6 workshops and groups activities were classified as co-delivery as they involved aspects of direct
7 service provision.
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13 **Discussion**

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16 Although staff working in community-based services for children with intellectual disabilities and
17 behaviours that challenge in England reported co-production within their services, activities meeting
18 higher-level co-production classifications (The Social Care Institute for Excellence, 2022) were only
19 found in six services. These included two services conducting evaluating and modifying the existing
20 service activities, two services conducting running training, workshops and groups activities, one
21 service conducting setting up the initial service model activities, and one service conducting both
22 evaluating and modifying the existing service and running training, workshops and groups activities.
23 Most activities reported met lower-level definition classifications, such as participation and co-
24 creation.
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33 Insight into why these specific activities met higher level co-production classifications was obtained
34 through comparing them to other activities within their respective categories, which met lower-level
35 classifications (i.e., intermediate, participation or co-creation). The persistent difference was the
36 degree to which the activity created clear changes in the relationship between the service and those
37 who accessed it, with some evidence that those accessing the service had become equal partners
38 and co-creators and had taken over some of the work typically done by practitioners. This is
39 meaningfully different from other activity of the same type categorised within lower-level
40 classifications, which tended to involve seeking feedback from those accessing the service whilst
41 maintaining their existing relationship with the service.
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50 *Implications*

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53 These findings have implications for services, staff, and policy makers, as well as for families
54 accessing services. All involved in the planning and delivery of services need to better consider how
55 to implement additional activities that meet higher-level co-production definitions. Doing so is
56 important to potentially generate more positive experiences and outcomes as observed in other
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3 health and social care services (Bombard *et al.*, 2018; ledema *et al.*, 2010; Mockford *et al.*, 2012;
4 Palumbo, 2016; Peat *et al.*, 2010; Nordin *et al.*, 2023; Tsianakas *et al.*, 2012, Kohler *et al.*, 2017) and
5 in so doing fulfil recommendations about how to best design and deliver services (National Institute
6 for Health and Care Excellence, 2018). While it is the responsibility of services to implement co-
7 production activities, families accessing services should be aware that services should be offering to
8 involve them within the type of activities meeting higher-level co-production definitions.
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15 The factors resulting in activities meeting higher-level co-production definitions can inform such
16 planning and delivery. These factors include explicitly planning activities to change the relationship
17 between services and those accessing them and/or to enable those accessing services to take over
18 some of the work typically done by practitioners. Examples of this from the services interviewed
19 include those accessing the service and family carers having formal (paid) roles (e.g., peer support
20 workers, experts by experience) and the power to determine outcomes such as the content and
21 delivery of training, workshops and groups (i.e., not merely advising service staff who then lead
22 making the decision). As part of this, it is important for organisations to proactively examine and
23 reach agreement about what they understand co-production to be (The Social Care Institute for
24 Excellence, 2022), working alongside those accessing the service to actively consider what co-
25 production means within the specific context of their service.
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33 34 35 *Limitations*

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38 There were some features of the way that data was collected that meant there was a greater chance
39 that certain types of participants/services were included than others – meaning that data may not
40 have been representative (sampling bias). Although 161 eligible services completed the survey in the
41 wider study, only 60 (37.27%) of these chose to complete the optional additional interview. It is
42 possible that services choosing not to take part in the interview may have differed from those
43 choosing to take part e.g., conducting less/more/different types of co-production (non-response
44 bias). Similarly, services themselves determined which of their staff were willing to be interviewed,
45 meaning there may have been differences between those who volunteered to be interviewed
46 compared with those who did not (self-selection/volunteer bias).
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55 Interviews covered a broader range of topics than solely co-production, meaning that co-production
56 activity data are based on relatively brief discussion. It is possible that more in-depth data collection
57 (e.g., being the focus of interviews, additional prompts) may have resulted in more activities being
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3 reported. It is also possible that more in-depth data collection may reveal additional attributes of
4 activities that could potentially result in changes to how they are classified e.g., ways that activities
5 resulted in new relationships between staff and those accessing services not evident within this
6 study's data. This relates to difficulties clearly defining co-production. Although the interview
7 schedule included a description of co-production to orientate participants to the question, there
8 may have been variance between individual participants' ideas of what co-production was/was not,
9 which could have affected responses.
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16 Co-production activities were self-reported by services, meaning they only reflect staff views on
17 what co-production is occurring, with the views of children and families accessing the service
18 missing. Only one staff member was interviewed per service, typically service managers or lead
19 clinicians, meaning their knowledge of what co-production activities were occurring may have been
20 limited by their job role e.g., speech and language therapists may have been aware of co-production
21 activities specific to their role that service managers were unaware of. Furthermore, whilst some
22 interviews included brief positive reflections on reported activities, the data did not provide much
23 insight into the impact of activities, or whether feedback received from those accessing services led
24 to changes. Such information may be important in distinguishing between different types of co-
25 production (e.g., whether activities resulted in new relationships between service staff and those
26 accessing the service). Similarly, whilst some services gave some brief descriptions of why co-
27 production was not occurring (e.g., due to the level of intellectual disability of those accessing the
28 service), the data is not of sufficient depth to allow for detailed exploration of this potentially
29 insightful topic.
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42 This study was conducted solely in England, so may not be representative of what co-production is
43 occurring in community-based services for children with intellectual disabilities and behaviours that
44 challenge within the rest of the United Kingdom, or in other countries. It also reports only what co-
45 production was occurring around when participants were interviewed (2021-2022), meaning there
46 may have been changes since this data was collected.
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51 *Future research*

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55 Future research should build on this initial study by investigating what co-production activities are
56 evident in a broader range of community-based services for children with intellectual disabilities and
57 behaviours that challenge, utilising more in-depth methodologies to better understand what co-
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3 production is occurring (e.g., documentary analysis, ethnography), as well as investigating in more
4 depth why co-production is not occurring e.g., what barriers there are to specific co-production
5 activities. Such research should prioritise including the views of children and families accessing
6 services to address their lack of current representation in this area. Furthermore, research should
7 endeavour to go beyond describing co-production activities to better understand the processes
8 underpinning how these are conducted and what makes them effective.
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15 Research should also endeavour to consider how these findings fit within broader debates around
16 co-production including how to make this accessible for people with intellectual disabilities and
17 challenging/barriers for parents/carers to be involved e.g., emotional and cognitive labour
18 (Sutherland *et al.* 2025). As higher-level definitions of co-production often have funding implications
19 (e.g., transformative co-production involving everyone who contribute getting something back in
20 exchange) how co-production is resourced within services would also be a productive focus for
21 future research.
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28 **Conclusion**

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32 Except for limited examples of running training, workshops and groups, most co-production
33 activities self-reported by community-based service for children with intellectual disabilities and
34 behaviours that challenge did not meet higher-level definitions of co-production. There is a need for
35 services to better plan how to implement activities meeting higher-level definitions of co-
36 production, including working alongside the children and families accessing services to best
37 understand what co-production means within the specific context of their service.
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43 **Acknowledgements**

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48 family carer and professional advisory groups, whose input was essential throughout this project.
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51 **Declarations**

52 **Funding**

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4 and not necessarily those of REDACTED FOR REVIEW.

5 6 **Availability of data and materials**

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9 Interview datasets are not publicly available to protect participant anonymity.

10 11 12 **Ethics approval and consent to participate**

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15 This study received approval from REDACTED FOR REVIEW. Informed consent was obtained from all
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17 participants and participating organisations

18 19 20 **Consent for publication**

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23 All participants completed informed consent forms including that data from this study would be used
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25 in a non-identifiable way in publications

26 27 28 **References**

29
30
31 Berelson, B. (1952), *Content Analysis in Communication Research*, Free Press, Glencoe, IL.

32
33
34
35 Bombard, Y., Baker, G.R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., Onate, K., Dennis, J-L. and
36
37 Pomey, M-P. (2018). "Engaging patients to improve quality of care: A systematic review",
38
39 *Implementation Science*, Vol. 13 a98. <https://doi.org/10.1186/s13012-018-0784-z>

40
41
42 Boswell, N. and Woods, K. (2021). "Facilitators and barriers of co-production of services with
43
44 children and young people within education, health and care services.", *Educational & Child*
45
46 *Psychology*, Vol. 38 No. 2, pp.41-52. <https://doi.org/10.53841/bpsecp.2021.38.2.41>

47
48
49 Bowring, D.L., Painter, J. and Hastings, R.P. (2019). "Prevalence of challenging behaviour in adults
50
51 with intellectual disabilities, correlates, and association with mental health", *Current Developmental*
52
53 *Disorders Reports*, Vol. 6, pp.173-181. <https://doi.org/10.1007/s40474-019-00175-9>

54
55
56 Clegg, R. and Adnitt, J. (2024). 'Restrained and scared - the £100k schools failing vulnerable children',
57
58 *BBC News*, 30 August. Available at: <https://www.bbc.co.uk/news/articles/c4ge00wp9vgo> (Accessed:
59
60 29 June 2025).

1
2
3
4
5 Department of Health and Social Care (2022). *Building the right support for people with a learning*
6 *disability and autistic people*. Available at:

7
8 [https://assets.publishing.service.gov.uk/media/62d7df62e90e071e7cbe1ef0/Building-the-Right-](https://assets.publishing.service.gov.uk/media/62d7df62e90e071e7cbe1ef0/Building-the-Right-Support-for-People-with-a-Learning-Disability-and-Autistic-People-Action-Plan-accessible.pdf)
9 [Support-for-People-with-a-Learning-Disability-and-Autistic-People-Action-Plan-accessible.pdf](https://assets.publishing.service.gov.uk/media/62d7df62e90e071e7cbe1ef0/Building-the-Right-Support-for-People-with-a-Learning-Disability-and-Autistic-People-Action-Plan-accessible.pdf)

10 (Accessed: 29 June 2025).
11

12
13
14
15 Einfeld, S.L., Ellis, L.A., Doran, C.M., Emerson, E., Horstead, S.K., Madden, R.H. and Tonge, B.J. (2010),
16 "Behavior problems increase costs of care of children with intellectual disabilities", *Journal of Mental*
17 *Health Research in Intellectual Disabilities*, Vol. 3 No. 4, pp.202–209.

18
19
20 <https://doi.org/10.1080/19315864.2010.524973>
21

22
23 Emerson, E. and Einfeld, S.L. (2011), *Challenging Behaviour*, Cambridge University Press, Cambridge,
24 UK.
25

26
27
28 Emerson, E., Kiernan, C., Alborz, A., Reeves, D., Mason, H., Swarbrick, R., Mason, L. and Hatton, C.
29 (2001), "The prevalence of challenging behaviours: A total population study", *Research in*
30 *Developmental Disabilities*, Vol. 22 No.1, pp.77-93. [https://doi.org/10.1016/S0891-4222\(00\)00061-5](https://doi.org/10.1016/S0891-4222(00)00061-5)
31

32
33
34
35 Hastings, R.P., Allen, D., Baker, P., Gore, N.J., Hughes, J.C., McGill, P., Noone, S.J. and Toogood, S.
36 (2013), "A conceptual framework for understanding why challenging behaviours occur in people
37 with developmental disabilities", *International Journal of Positive Behavioural Support*, Vol 3. No.2,
38 pp.5-13.
39

40
41
42
43 Iedema, R., Merrick, E., Piper, D., Britton, K., Gray, J., Verma, R. and Manning, N. (2010),
44 "Codesigning as a discursive practice in emergency health services: The architecture of
45 deliberation", *The Journal of Applied Behavioral Science*, Vol. 46 No. 1, pp.73-91.
46

47
48 <https://doi.org/10.1177/0021886309357544>
49

50
51
52 Iemmi, V., Knapp, M., Reid, C., Sholl, C., Ferdinand, M., Buescher, A. and Trachtenberg, M. (2016),
53 "Positive behavioural support for children and adolescents with learning disabilities and behaviour
54 that challenges: an initial exploration of service use and costs", *Tizard Learning Disability Review*,
55 Vol. 21 No. 4, pp. 169-180. <https://doi.org/10.1108/TLDR-03-2015-0013>
56
57
58
59
60

1
2
3 Jones, V. R., Waring, J., Wright, N. and Fenton, S-F. (2024), "A rapid realist review of literature
4 examining Co-production in mental health services for youth", *JCPP Advances*, Vol. 4 No. 4, e12272.
5 <https://doi.org/10.1002/jcv2.12272>
6
7

8
9
10 Kohler, G., Sampalli, T., Ryer, A., Porter, J., Wood, L., Bedford, L., Higgins-Bowser, I., Edwards, L.,
11 Christian, E., Dunn, S., Gibson, R., Ryan Carson, S., Vallis, M., Zed, J., Tugwell, B., Van Zoost, C.,
12 Canfield, C. and Rivoire, E. (2017), "Bringing value-based perspectives to care: Including patient and
13 family members in decision-making processes", *International Journal of Health Policy and*
14 *Management*, Vol. 6 No. 11, pp.661–668. <https://doi.org/10.15171/ijhpm.2017.27>
15
16
17

18
19
20 Landis, J.R. and Koch, G.G. (1977), "The measurement of observer agreement for categorical data",
21 *Biometrics*, Vol. 33 No. 1, pp.159-174. <https://doi.org/10.2307/2529310>
22
23

24
25 Mockford, C., Stanisiewska, S., Griffiths, F. and Herron-Marx, S. (2012), "The impact of patient and
26 public involvement on UK NHS health care: A systematic review", *International Journal for Quality in*
27 *Health Care*, Vol. 24 No. 1, pp.28–38. <https://doi.org/10.1093/intqhc/mzr066>
28
29

30
31 National Institute for Health and Care Excellence (2018). *Learning disabilities and behaviour that*
32 *challenges: Service design and delivery NG93*. Available at: <https://www.nice.org.uk/guidance/ng93>
33 (Accessed: 29 June 2025).
34
35
36

37
38 NHS England (2015). *Supporting people with a learning disability and/or autism who display*
39 *behaviour that challenges, including those with a mental health condition: Service model for*
40 *commissioners of health and social care services*. Available at: [https://www.england.nhs.uk/wp-](https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf)
41 [content/uploads/2015/10/service-model-291015.pdf](https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf) (Accessed: 29 June 2025).
42
43
44

45
46 NHS England (2022). *Working in partnership with people and communities: Statutory guidance*.
47 Available at: [https://www.england.nhs.uk/long-read/working-in-partnership-with-people-and-](https://www.england.nhs.uk/long-read/working-in-partnership-with-people-and-communities-statutory-guidance/)
48 [communities-statutory-guidance/](https://www.england.nhs.uk/long-read/working-in-partnership-with-people-and-communities-statutory-guidance/) (Accessed: 29 June 2025).
49
50
51

52
53 Nordin, A., Kjellstrom, S., Robert, G., Masterson, D. and Josefsson, K.A. (2023), "Measurement and
54 outcomes of co-production in health and social care: A systematic review of empirical studies", *BMJ*
55 *Open*, Vol.13 No. 9, e073808. <https://doi.org/10.1136/bmjopen-2023-073808>
56
57
58
59
60

1
2
3 Palumbo, R. (2016), "Contextualizing co-production of health care: a systematic literature review",
4 *International Journal of Public Sector Management*, Vol. 29 No. 1, pp.72-90.

5
6 <https://doi.org/10.1108/IJPSM-07-2015-0125>
7

8
9
10 Peat, M., Entwistle, V., Hall, J., Birks, Y. and Golder, S. (2010), "Scoping review and approach to
11 appraisal of interventions intended to involve patients in patient safety", *Journal of Health Services*
12 *Research & Policy*, Vol. 15 No. 1, pp.17-25. <https://doi.org/10.1258/jhsrp.2009.009040>
13
14

15
16 Prior, L. (2014), "Content analysis", Leavy, P. (Ed.), *The Oxford Handbook of Qualitative Research*,
17 Oxford University Press, Oxford, UK, pp.359–379.
18
19

20
21 Social Care Institute for Excellence (2022). *Co-production: What is it and how to do it*. Available at:
22 <https://www.scie.org.uk/download/22652/?tmstv=1699958786> (Accessed: 29 June 2025).
23
24

25
26 Sutherland, D., Griffin, J., Austin, D., Bjornstad, G., Bradshaw, J., Charles, M., Cooper, V., Divers, J.,
27 Evan-Jones, K., Foxwell, S., Gore, N., Minhas, S., Penfold, I., Singh, G. and Hastings, R. (2025),
28 "Developing guidance on co-producing research with family carers of people with learning
29 disabilities", *Tizard Learning Disability Review*, Vol. 30 No. 3, pp.143-153.
30
31

32
33 <https://doi.org/10.1108/TLDR-12-2024-0040>
34
35

36
37 REDACTED FOR REVIEW
38
39

40 The Child Safeguarding Practice Review Panel (2022). *Safeguarding children with disabilities and*
41 *complex health needs in residential settings: Phase 1 report*. Available at:
42 [https://assets.publishing.service.gov.uk/media/635914568fa8f557d066c1ad/safeguarding_children](https://assets.publishing.service.gov.uk/media/635914568fa8f557d066c1ad/safeguarding_children_with_disabilities_in_residential_care_homes_phase_1_report.pdf)
43 [with_disabilities_in_residential_care_homes_phase_1_report.pdf](https://assets.publishing.service.gov.uk/media/635914568fa8f557d066c1ad/safeguarding_children_with_disabilities_in_residential_care_homes_phase_1_report.pdf) (Accessed 29 June 2025).
44
45
46

47
48 The Child Safeguarding Practice Review Panel (2023). *Safeguarding children with disabilities and*
49 *complex health needs in residential settings: Phase 2 report*. Available at:
50 [https://assets.publishing.service.gov.uk/media/643e82136dda69000c11df6a/Safeguarding_children](https://assets.publishing.service.gov.uk/media/643e82136dda69000c11df6a/Safeguarding_children_with_disabilities_in_residential_care_homes_phase_2_report.pdf)
51 [with_disabilities_in_residential_care_homes_phase_2_report.pdf](https://assets.publishing.service.gov.uk/media/643e82136dda69000c11df6a/Safeguarding_children_with_disabilities_in_residential_care_homes_phase_2_report.pdf) (Accessed 29 June 2025).
52
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55
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59
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1
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3 Titheradge, N. and Deas, A. (2024). 'Special school pupils 'tortured' in calming rooms, BBC
4 investigation finds', *BBC News*, 30 April. Available at: <https://www.bbc.co.uk/news/uk-68897335>
5 (Accessed: 29 June 2025).
6
7
8

9
10 Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C. and Wiseman, T. (2012),
11 "Implementing patient-centred cancer care: Using experience-based co-design to improve patient
12 experience in breast and lung cancer services", *Supportive Care in Cancer*, Vol. 20, pp.2639–2647.
13
14 <https://doi.org/10.1007/s00520-012-1470-3>
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Table 1

Examples from interviewer notes for each type of self-reported co-production activity.

Code/sub-codes	Example (interviewer notes – not verbatim quotes)
Service planning/evaluating and modifying the existing service/consultation with groups	<p>“We've worked with some of our local parent support groups historically to kind of test out those training materials and gather feedback from them about how accessible they found the training, how useful... anything that needed to be changed to make it easier for families to access.”</p> <p>(Participant 29)</p>
Service planning/evaluating and modifying the existing service/feedback processes	<p>“If there is feedback in a parental feedback form they [<i>the service</i>] take that into consideration”</p> <p>(Participant 30)</p>
Service planning/evaluating and modifying the existing service/specific staffing	<p>“We have positions available called Experts by Experience who are paid to be involved in service design and delivery. In our service, this is a parent of a child with a learning disability. I think her support to us as a team is invaluable...there is nothing that I can think of that we've adapted or that we've done within the team that hasn't had that input’</p> <p>(Participant 51)</p>
Service planning/setting up the initial service model/consultation with groups/groups brought together specifically for this purpose	<p>“Had a group of parents and young people who told what they wanted out of services. This involved children drawing pictures to communicate their desires.”</p> <p>(Participant 39)</p>
Service planning/setting up the initial service model/consultation with groups/consulting pre-existing parents groups or fora	<p>“We have close links with the parent-carer forums, they are our main link when we're developing new services. We seek consultation from them and work in partnership to co-produce the services.”</p> <p>(Participant 50)</p>

<p>Service planning/setting up the initial service model/children and parent groups identifying the need for a new service</p>	<p>“Met with group of children and parents who said they go to an out of county school for sensory impairment, found difficult due to distance e.g., around forming friendship groups. Worked together with [organisation name] to design a new service.” (Participant 39)</p>
<p>Recruitment processes and decisions</p>	<p>“They [the service] have a young person's panel when recruiting” (Participant 14)</p>
<p>Individual case work</p>	<p>“It is a shared care plan...work together to look at what actually the goals are for that child” (Participant 4)</p>
<p>Resources used within the service</p>	<p>“Produced a video involving staff, children/young people, and parents explaining service and their experience of it” (Participant 38)</p>
<p>Running training, workshops and groups</p>	<p>“Having parents join our positive behaviour support parent groups, so they've been through the group themselves, so they're invited to support us in the next groups” (Participant 52)</p>
<p>The service's physical environment</p>	<p>“When we had changes in the buildings...children got involved in terms of naming the rooms, doing artwork for the rooms” (Participant 37)</p>

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Table II

Number of self-reported co-production activity classified within each co-production definition

Co-production activity	Co-production classification definition											
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	Descriptive	Intermediate	Transformative	Participation	Co-production	Co-creation	Co-pro\duction	No fit	Co-design	Co-decision making	Co-delivery	Co-evaluation
Service planning – evaluating and modifying existing service (31 services)	0	28	3	28	3	28	3	0	0	0	0	31
Service planning - setting up initial service model (8 services)	0	7	1	7	1	7	1	0	8	0	0	0
Recruitment processes and decisions (25 services)	0	25	0	25	0	25	0	0	0	25	0	0
Individual case work (23 services)	23	0	0	23	0	23	0	23	0	0	0	0
Resources used within the service (19 services)	0	19	0	19	0	19	0	19	0	0	0	0
Running training, workshops and groups (5 services)	0	2	3	2	3	2	3	0	0	0	5	0
The service’s physical environment (5 services)	0	5	0	5	0	5	0	5	0	0	0	0