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Methods for Co-production in Research and Practice

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Presentation overview

- What is co-production?
- Why is co-production important?
- Methods of co-production
- Considerations for co-production with people with learning disabilities and/or autistic people
- Examples of co-production with people with learning disabilities and/or autistic people
- Summary
- Questions, comments and ideas



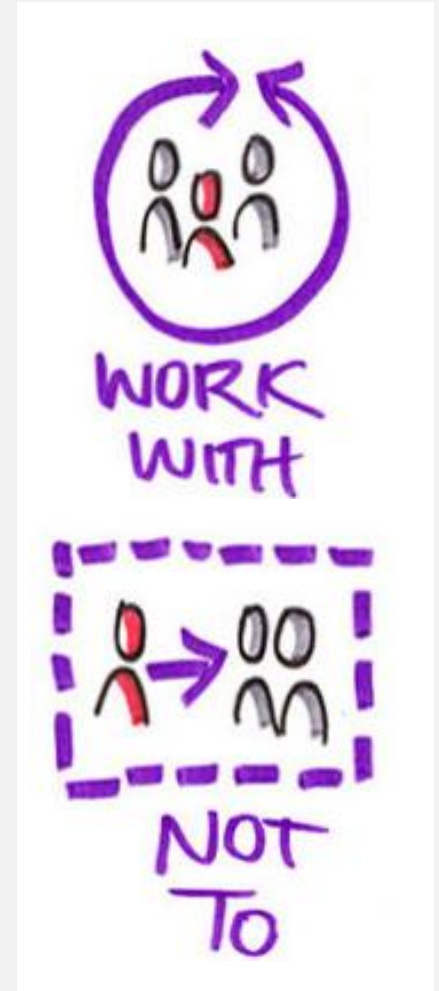
What is co-production?

- *‘Co-production is not just a word, it is not just a concept, it is **a meeting of minds coming together to find shared solutions.** In practice, co-production involves people who use services being **consulted, included and working together** from the start to the end of any project that affects them ... people who use services and carers are valued by organisations as **equal partners**, can **share power** and **have influence over decisions made**’* Think Local Act Personal National Co-production Advisory Group

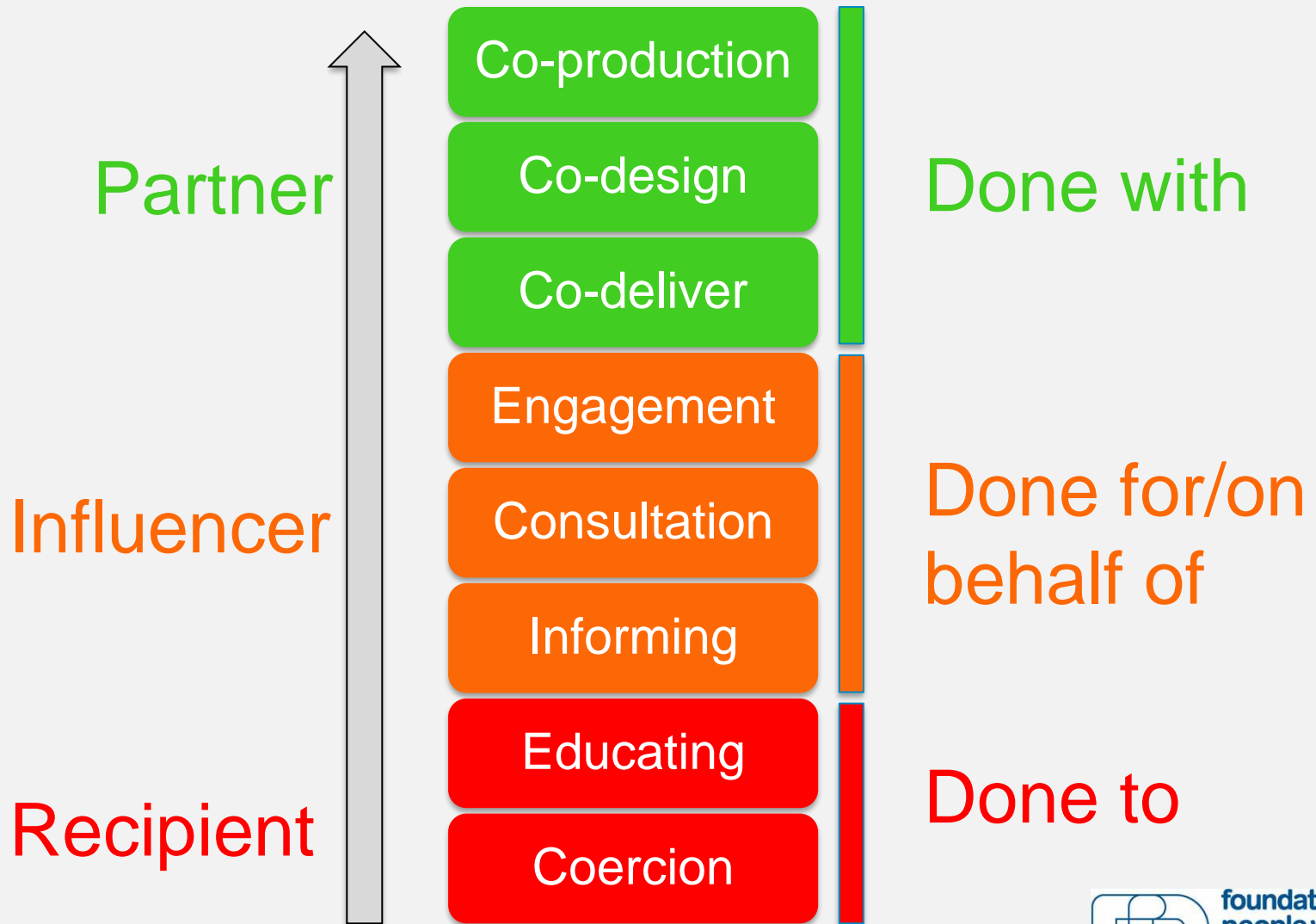


What is co-production?

- A range of approaches and methods in research or practice seeking to ***transfer power to members of the community*** the research or service seeks to help
- Recognises and supports people's contributions and ideas
- ***Doing with*** rather than ***to***, ***for***, or ***on*** – at various levels, such as to:
 - Identify research priorities
 - Design and conduct studies
 - Analyse and share findings
 - Design, commission, and deliver services
 - Evaluate services or research



Model of involvement (FPLD)



What is co-production?

- Co-production can be ***for a group or an individual***
 - Group example: Co-production of a service for autistic people
 - Individual example: Co-production of personalised support for an autistic person
- It is also sometimes described as:
 - ***Co-construction***
 - ***Co-research*** or ***peer-research***
 - ***Participatory research***
 - ***Inclusive research***
 - ***Action research***
 - ***Public involvement***
 - ***Patient and public involvement*** (PPI)
- These terms are not always interchangeable



Why is co-production important?

- ***Understanding and valuing people's views*** – communication as a human right (control, choice, and decision making)
- ***Shifting power and challenging assumptions*** – people with lived experience are equal and able to influence change
“Nothing about us without us”
- ***Enhancing the quality of services and research*** – aim to improve people's quality of life, social validity
- ***A requirement*** – policy, service standards, research funding

MY DISABILITY DOES NOT HINDER
MY ABILITY TO BE CONSIDERED EQUAL.



Methods of co-production

- ***Bringing people together to work together***
 - Groups, collectives, partnerships, networks, events
- ***Sharing perspectives in a range of ways***
that are ***accessible*** and ***supportive***
 - Standard methods – group and individual discussions, workshops, interviews, questionnaires, surveys
 - Creative methods – storytelling, art, photos, videos, comics
- ***Bringing together perspectives and group-decision making***
 - Synthesising perspectives, discussions, polls, Delphi method, data-intensive decision making, recommendation and verification
- ***Actions based on decisions***
 - Conducting research or project, developing or adapting service, creating a product, delivering training, supporting individual, etc.



Considerations for co-production with people with learning disabilities and/or autistic people

- **Planning** – accessibility, inclusion, environmental adjustments (venue, transport, safe space, sensory), overcoming barriers
- **Doing** – communication preferences and support, emotional wellbeing, choice, differing views of people involved, ensuring co-production is meaningful and not tokenistic
- **Sharing** – impact of results, effective ways to share information (visuals, symbols, language and terminology used)
- **Skills and capacity** for meaningful co-production (knowledge and understanding, values and attitudes, communication skills, time, funding)
- Multiply disadvantaged groups



Some examples of co-production and engagement (varying levels)

- Research priority setting partnerships – autism, learning difficulties, neurodevelopmental disorders
- Participatory Autism Research Collective (PARC)
- Early Positive Approaches to Support (E-PAtS)
- Covid-19 and learning disabilities study
- Digital Stories for transition
- Autscape
- PBS outcomes
- Personalised goals for PBS
- Refined definition of PBS
- Seldom Heard project
- PBS workshops



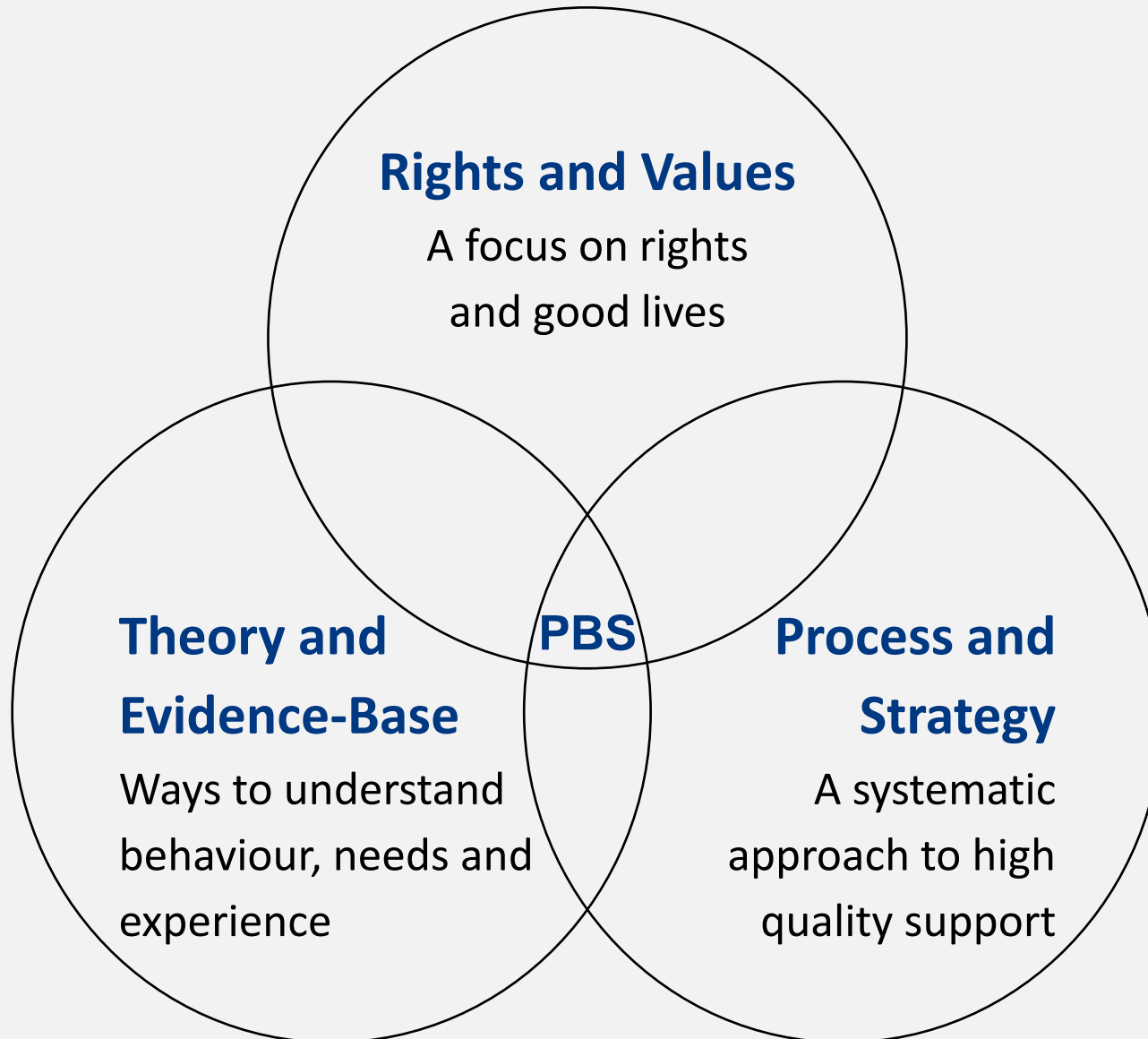
Revised definition of PBS (Gore et al., 2022)

- A team of **24 contributors** with special interests and experience in PBS, from a range of (sometimes-overlapping) groups, including:
 - ***People with lived experience, as a person***
 - with a learning disability
 - who is autistic
 - with a history of displaying behaviours that challenge
 - who is a family carer
 - ***Researchers and people from a variety of professional backgrounds who have experience of:***
 - Service delivery, commissioning, training and practice across child, adult, health, education and social care contexts
 - Working as front-line support staff, Speech and Language Therapists, Nurses, Psychiatrists, Occupational Therapists, Clinical Psychologists, Physiotherapists, and Behaviour Analysts

Revised definition of PBS

- The revised definition was **co-created** over a period of **6+ months** through a series of group workshops, individual discussions and several writing rounds, with meetings tailored to meet the individual preferences and requirements of each contributor:
 - online group workshop
 - online discussions with individual contributors
 - discussions via email
 - revisions and comments to drafts between contributors
- Key learning points and themes from discussions were **synthesised and shared** with group members for feedback and amendment, with drafts for the PBS definition and accompanying table of components shaped across a series of **iterative rounds** and **collective edits**.

Revised definition of PBS



Revised definition of PBS

<p>Rights and values: A focus on rights and good lives</p>	1. Person-centred foundation
	2. Constructional approaches and self-determination
	3. Partnership working and support for key people
	4. Elimination of aversive, restrictive and abusive practices
<p>Theory and evidence base: Ways to understand behaviour, needs, and experience</p>	5. A biopsychosocial model of behaviour that challenge
	6. Behavioural approaches to learning, experience and interaction
	7. Multi-professional and cross-disciplinary approaches
<p>Process and strategy: A systematic approach to high quality support</p>	8. Evidence informed decisions
	9. High quality care and support environments
	10. Bespoke assessment
	11. Multi-component, personalised support plans
	12. Implementation, monitoring and evaluation

Revised definition of PBS

- ***Partnership working and support for key people*** (3)
 - Centrality of working with and supporting key people (i.e., stakeholders)
 - Focal person with learning disabilities as the KEY person
 - Critical role of family caregivers
 - Consideration of how the perspectives of different people need to be synthesised
 - Honouring the expertise of lived experience
- ***Multi-professional and cross-disciplinary approaches*** (7)
 - Embraces evidence-based approaches from several disciplines, such as approaches from speech and language therapy that provide ways of supporting engagement for people with communication challenges to support the person-centred components of PBS and guide supportive interventions
 - Values expertise from people with a variety of professional backgrounds and those with lived experience – PBS is not owned by any one profession or discipline

Revised definition of PBS

Strengths

- Tailored input based on preferences and needs of each contributor
- Reflective group process
- Meaningful and balanced integration of input from group with shared definition based on consensus
- Co-production included and described within definition

Limitations

- Co-created rather than co-production – there was a starting point of the 2013 definition (*Gore et al., 2013*)
- Group of 24 but still relatively small group?
- Some but limited representation in relation to ethnicity groups and socio-cultural backgrounds

Personalised goals for PBS (Gore et al., 2021)

- Children and young people with learning disabilities and/or autistic with a range of ***behaviour that challenges*** (e.g., self injury, physical aggression, damage to property) and ***communication needs*** (e.g., verbal, signs – Makaton, symbols – PECS)
- Interviews – ***Talking Mats*** approach with verbal communication, signing and gestures, covering:
 - Preferred activities
 - Adaptive and challenging aspects of their behaviour and their caregiver’s behaviour
 - Life quality domains
- Aim – support participants to consider a range of ***possibilities for their future support*** and ***identify areas that were personally meaningful***

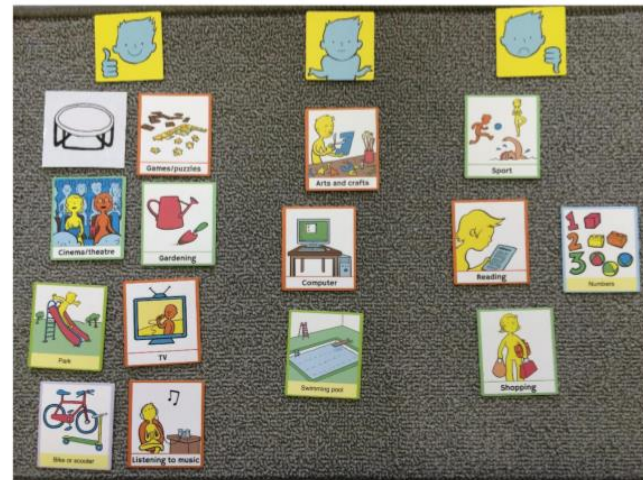


Fig. 1 TM example: "Things you like" (Laura). The Symbols are designed and © to Adam Murphy 2015 and assigned to Talking Mats Ltd. in perpetuity. They may not be reproduced without permission

Personalised goals for PBS

- ***Preparation sessions*** prior to interview and individualised plans
- Interviews completed at a time and place convenient for families, within 1-2 sessions lasting 30-60 min
- Interviews completed with 9 out of 14 children – children prioritised ***goals for future support*** and showed ***insight into behaviour, needs, and preferences***
- ***Accessible summary report*** of personalised goals and priorities generated – starting point for behaviour support planning

Personalised goals for PBS

Strengths

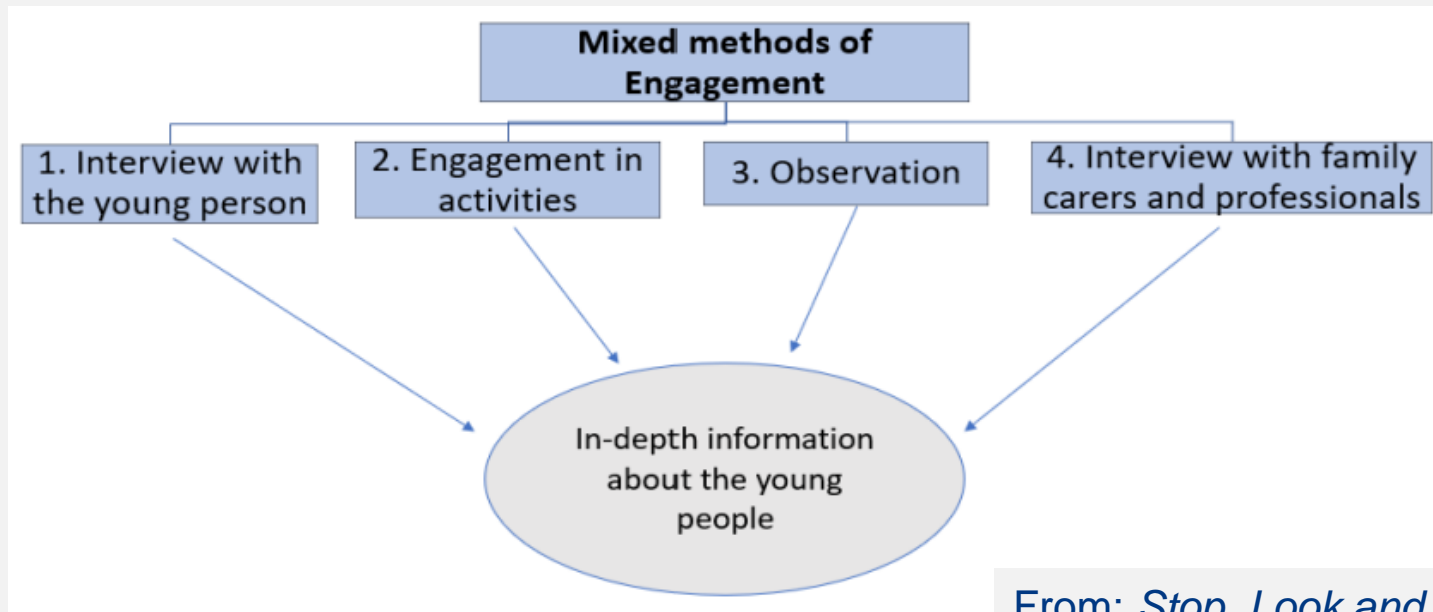
- Did not rely solely on verbal communication
- Took into account individual preferences and needs
- Multiple sessions
- No sessions prevented due to behaviours that challenge
- Lots of information about goals and areas of importance for children could be identified

Limitations

- Not able to complete interviews with all children – though this was explored in subsequent projects
 - *Stop, Look and Listen to Me* and *Seldom Heard* (CBF, Sapiets, Bradshaw & Gore)
- Did not have opportunity to assess subsequent support provision

Seldom Heard project

- Sought the ***views, perspectives and experiences of healthcare*** of people with severe or profound and multiple learning disabilities and complex communication challenges (including autistic people)
- Used ***new and creative methods*** to find out perspectives on ***how to deliver better support*** to people with learning disabilities
- Project supported by an ***advisory group***



From: *Stop, Look and Listen to me*

Seldom Heard project

- Adapted methods due to Covid-19 – **communication partners**
- **Personalised tool** – ideas on how best to gain their views and support better communication, choice and control
- Found out a lot about how people communicate in different ways – everyone able to make **choices** or **show preferences** when supported with methods best suited to their needs
- Found out a lot about what made healthcare appointments and hospital visits go well for people – e.g., listening to family carers, not assuming “*professionals know best*”, taking time to understand individual needs, using agreed communication methods, reasonable adjustments, being willing to learn and improve.
- Explored how to understand **communication in context** and how to improve **noticing skills** so we can observe what might be going on for an individual

Seldom Heard project

Key messages:

1. Seek information
2. Share information
3. Take time to prepare
4. Find out about other ways of communicating
5. Be curious about individuals
6. Make reasonable adjustments
7. Work with “communication partners”



Seldom Heard project

Strengths

- Individualised communication support – everyone able to share views and preferences
- Included advisory group
- People's views heard by NHS England – key messages, recommendations, and practical actions
- Influence how the NHS supports people with learning disabilities
- Demonstrated how everyone's views and preferences can be heard

Limitations

- Relatively small group – 9 people with learning disabilities
- Dissemination of report – not publicly shared by NHS England

PBS workshops (Challenging Behaviour Foundation)

- Workshops for family carers and professionals supporting people with severe learning disabilities on:
 - Understanding challenging behaviour
 - Supporting behaviour change
- Partnership approach core to the workshops:
 - **Co-developed** and reviewed in partnership with family carers
 - **Co-delivered** by a family carer and a PBS trainer
 - **Bring together** family carers and professionals as participants



PBS workshops

- Co-production ensures training is supported by evidence-based theory and practice in a way that is ***accessible for everyone***
- ***Facilitates partnership working*** – enables staff and families to **work together** to identify appropriate individualised behaviour support strategies that can be used consistently in all settings



PBS workshops

“

What I like best about the workshop is working alongside parents, having the time to reflect on challenging behaviour, to step back from a situation and reflect on it, and then plan together. Speech and Language Therapist

”

“

What's had the greatest impact is working as a team. We all know that we are all doing the same thing and consistency has had a huge impact.

Family carer

”

Summary

- Co-production is important and essential for research and practice
- There are challenges to co-production, both generally and specific to co-production with people with learning disabilities and/or autistic people
- However, there are several examples of how to do co-production, with varying levels of involvement, and this is a rapidly growing area
- There is no one “right way” to do co-production – get creative!

Thank you!

Thank you for listening!

Questions, comments and ideas welcome 😊

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Resources and reading

- [Revised definition of PBS](#)
- [Personalised goals for PBS](#)
- [Seldom Heard project](#)
- [Stop, Look and Listen to me](#)
- [Valuing the views of children with a learning disability](#)
- [PBS workshops](#)
- [Early Positive Approaches to Support \(E-PAtS\)](#)
- [Direct involvement of students in functional assessment](#)

Resources and reading

- [Research priority setting partnership for autism](#)
- [Research priority setting partnership for learning difficulties](#)
- [Research priority setting partnership for neurodevelopmental disorders](#)
- [Autistic perspectives on the future of clinical autism research](#)
- [Covid-19 and learning disabilities study](#)
- [Digital stories for transition](#)
- [PBS Outcomes](#)
- [Participatory Autism Research Collective](#)
- [Autescape](#)

Resources and reading

- [Review of co-research with adults with intellectual disability](#)
- [Review of participatory research for autism and neurodevelopment](#)
- [Involve Me project](#)
- [Supporting people with profound and multiple learning disabilities: Core and essential service standards](#)
- [Raising our sights: Services for adults with profound intellectual and multiple disabilities](#)
- [Communication and people with the most complex needs: What works and why this is essential](#)
- [Speaking Up – Being Heard](#)
- [Co-production in social care: What it is and how to do it](#)

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