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Article:
Powell, L. (2025) We're not your empathy exercise: reclaiming co-production in neurodivergent research and practice. Neurodiversity, 3. ISSN: 2754-6330

https://doi.org/10.1177/27546330251363393

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Commentary

We're Not Your Empathy Exercise: Reclaiming Co-Production in Neurodivergent Research and Practice

Neurodiversity
Volume 3: 1–7
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DOI: 10.1177/27546330251363393
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Abstract

Co-production, a collaborative approach to research and practice, has gained traction in neurodiversity studies as a means to include autistic and otherwise neurodivergent individuals. However, superficial or under-supported co-production risks losing its transformative potential, leaving contributors feeling exploited or excluded. This commentary draws on personal experience as a late-diagnosed autistic and attention deficit hyperactivity disorder (ADHD) academic woman to examine the risks of tokenistic or extractive co-production and proposes a justice-oriented vision rooted in equity, accountability, and solidarity. Key terms are defined, the distinction between inclusion and equity is explored, and practical principles for ethical co-production are outlined. Emphasising ethical listening, intersectionality, and clear feedback loops, this paper offers a constructive path towards relational justice and neurodivergent leadership.

Lay Abstract

Co-production in neurodivergence research aims to involve autistic and neurodivergent people as equal partners, but shallow efforts can leave contributors feeling used or ignored. As a late-diagnosed autistic and ADHD academic woman, I explore these challenges and propose a better way forward. Too often, neurodivergent voices are heard but not acted upon, turning co-production into storytelling without power-sharing. This commentary outlines six principles for ethical co-production, focusing on equity, transparency, and diverse inclusion, especially for marginalised groups like non-speaking individuals or those with intellectual disabilities. By valuing lived experience as expertise, ensuring clear feedback, and supporting neurodivergent leadership, research can truly empower communities. Funders and researchers must provide accessible tools, fair pay, and shared decision-making to make co-production meaningful. This approach not only improves research but also drives real-world change in policy and practice, respecting neurodivergent identities. Written for researchers, funders, and advocates, this commentary offers a practical roadmap to transform co-production into a tool for justice and collaboration, ensuring neurodivergent people are partners, not just participants.

Keywords

Neurodiversity, equity, co-production, participatory research, intersectionality

Received: May 30, 2025; accepted: July 14, 2025

Introduction

Thank you for sharing. That was powerful.

A familiar phrase in lived experience events. But also, a warning sign.

It may signal a moment when co-production slips into unreciprocated storytelling: when neurodivergent people's experiences are valued emotionally but not acted upon strategically. When stories are welcomed for emotional resonance but overlooked for their intellectual or strategic value. When institutions benefit from neurodivergent insights without sharing power. This is not authentic co-production; it is participation without partnership. Such

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practices risk perpetuating epistemic injustice, where neurodivergent knowledge is marginalised as less credible than academic expertise (Kusch, 2009), and reinforce normalising structures that privilege neurotypical frameworks (Foucault, 1977).

Rooted in disability justice and grassroots activism, co-production has become increasingly integrated into research frameworks, funding calls, and policy strategies. Within neurodiversity research, it is viewed as a way to correct histories of exclusion and pathologisation (Pettican et al., 2023). Yet, inviting participation does not ensure equity. Co-production, when done ethically, challenges traditional epistemological hierarchies by valuing lived experience as a legitimate form of knowledge, disrupting biomedical models that prioritise symptom reduction over acceptance. As a late-diagnosed autistic and attention deficit hyperactivity disorder (ADHD) cis-female academic who co-produces research and resources with neurodivergent communities, I have witnessed co-production's potential to build trust, challenge norms, and redefine practices. Yet, challenges such as tokenism, uncredited labour, emotional fatigue, and unmet expectations. These underscore the need to approach co-production as a practice of shared power and responsibility, not as a passive inclusion gesture.

This commentary invites a reframing of co-production as an ethical, structured, and community-rooted practice. Drawing on concepts of epistemic justice and power dynamics, alongside my lived and professional experiences, I offer six principles for ethical co-production, emphasising equity, transparency, and structural support to mitigate systemic barriers. I focus on autism and ADHD, but note relevance to broader neurodivergent communities. Ethical listening, respecting diverse communication methods, such as augmentative and alternative communication (AAC), is respected and integrated.

Defining Key Terms

To ground this commentary, three key terms are defined:

Neurodiversity, emerged from 1990s autistic self-advocacy, notably through communities such as Independent Living on the autistic spectrum (InLv) (Dekker, 2020), and was formally named by Judy Singer in 1998 (Singer, 2017). It challenges deficit-based frameworks, viewing neurological differences (e.g., autism, ADHD, and dyslexia) as part of human diversity. This paradigm encourages research that integrates neurodivergent perspectives to address structural barriers and promote inclusion (Shah & Holmes, 2023).

Co-production refers to collaborative processes in which individuals with lived experience work alongside researchers to shape studies from design, conduct, and dissemination (Langley et al., 2022; Nimbley et al., 2024; Sonuga-Barke et al., 2024). Unlike traditional Patient and Public Involvement and Engagement (PPIE), co-production implies mutual respect, shared decision-making, and equitable contribution (Langley et al., 2018; Smith et al., 2023). In neurodivergence research, ethical co-production should integrate diverse communication needs (e.g., AAC tools for non-speaking individuals), ensuring all contributors are supported to participate fully (Aidonopoulou-Read, 2025).

PPIE involves consulting or engaging individuals with lived experience in research, often through advisory roles or feedback sessions, but typically with less decision-making power than co-production (Langley et al., 2018; Smith et al., 2023). PPIE aims to enhance research relevance but can risk tokenism if input lacks influence. Co-production, by contrast, positions contributors as equal partners across all research stages. This commentary focuses on co-production, but its principles: equity, transparency, and accessibility, often apply to PPIE, encouraging empowering practices in any participatory framework (Langley et al., 2018).

The Rise and Risks of Co-Production

The increasing use of co-production reflects a valuable shift towards participatory justice-oriented research. In neurodiversity contexts, meaningful involvement of neurodivergent individuals is increasingly recognised as enhancing research relevance, rigour, and trust (Amann & Sleigh, 2021; Coldham, 2018; National Institute for Health and Care Research (NIHR), 2024; UK Research and Innovation (UKRI), 2025). Funders now often encourage, or mandate, lived experience input, participatory design, and public engagement, acknowledging the value of lived expertise. Yet, institutional and funding constraints frequently limit the depth of these efforts (Amann & Sleigh, 2021; Dembele et al., 2024).

Superficial engagements, such as inviting input on predetermined research questions without allowing genuine influence, can reduce co-production to a tick-box exercise (Arnstein, 1969; Den Houting et al., 2021). Contributors may be excluded from shaping data analysis, authoring outputs, or receiving fair credit, leaving them feeling undervalued (Bertilsdotter Rosqvist et al., 2025; Putnam et al., 2025).

However, barriers to inclusive practices often arise from limited funding or institutional constraints (Amann & Sleigh, 2021; Dembele et al., 2024). To address this, funders should provide ring-fenced resources for accessibility, including AAC tools, sensory-friendly environments, and fair contributor compensation (Aidonopoulou-Read, 2025; Nimbley et al., 2024). Ensuring researchers aren't forced to prioritise feasibility over inclusion. These resources ensure researchers can prioritise inclusion without compromising feasibility.

Moreover, funding processes themselves can be exclusionary. Dense, jargon-heavy, and fragmented application guidelines often hinder access for neurodivergent individuals (Gratton et al., 2023; Sonuga-Barke et al., 2024). Funders could address this by consolidating guidance into a single, accessible document with clear bullet points, bolded key details, and plain language to accommodate diverse cognitive needs.

Additionally, the lack of accessible tools and practices such as AAC for non-speaking individuals perpetuates marginalisation under the guise of "engagement" (Aidonopoulou-Read, 2025). True co-production requires tangible material support, rather than symbolic gestures, to foster collaboration and trust (Dembele et al., 2024).

Inclusion is not Equity.

A fundamental distinction in co-production lies between inclusion and equity (Arnstein, 1969; Bertilsdotter Rosqvist et al., 2025; Dembele et al., 2024). Inclusion invites neurodivergent individuals into research spaces but does not guarantee meaningful influence (Arnstein, 1969; Den Houting et al., 2021). Equity, by contrast, redistributes power, positioning contributors as co-leaders with agency over design, execution, and dissemination (Arnstein, 1969). Too often, co-production stops at inclusion, where contributors are asked to validate pre-determined research ideas or share experiences without receiving fair credit, compensation or decision-making authority (Arnstein, 1969; Bertilsdotter Rosqvist et al., 2025; Putnam et al., 2025). This reinforces a hierarchy that privileges academic knowledge over lived expertise (Den Houting et al., 2021).

Equity recognises neurodivergent contributors as legitimate knowledge-holders, deserving fair compensation, credit, and decision-making authority (Coldham, 2018; Dembele et al., 2024; Shaw et al., 2025). This aligns with the concept of epistemic justice, which challenges the marginalisation of neurodivergent voices as less credible than academic expertise (Kusch, 2009). While inclusion offers visibility, equity ensures influence. Without this, co-production risks reinforcing stigma by prioritising symptom reduction over acceptance, perpetuating normalising practices that privilege neurotypical frameworks (Foucault, 1977; Shaw et al., 2025). Researchers should transparently document their inclusive practices, detailing who was involved, their roles (e.g., advisory, co-design, and co-authorship), when contributions occurred, and their impact (Coldham, 2018; Nimbley et al., 2024). Rigorous record-keeping is critical to demonstrate equitable collaboration and prevent overstated claims of involvement (Coldham, 2018; Nimbley et al., 2024).

Burrell et al. (2025) argue that without structural redesign, co-production perpetuates inequalities, particularly for those with invisible disabilities (Burrell et al., 2025). Researchers with lived experience bring authenticity but should not face pressure to disclose. Voluntary disclosure, supported by safe environments and clear boundaries, can foster collaboration (Bertilsdotter Rosqvist et al., 2025; Dembele et al., 2024).

Lived Experience or Lived Extraction?

The absence of AAC tools or trained facilitators for non-speaking individuals further marginalises their perspectives (Langley et al., 2018; National Institute for Health and Care Research (NIHR), 2024). This dynamic, where lived experiences are consumed but not acted upon, reinforces inequity. Such practices reflect epistemic injustice, where neurodivergent knowledge is extracted without recognition or influence, and normalisation, where institutional structures uphold neurotypical standards under the guise of inclusion (Foucault, 1977; Kusch, 2009). True co-production requires co-creation, not mere consultation.

Lived experience is increasingly recognised as valuable, yet is sometimes used in ways that feel extractive. Contributors may be asked to share personal experiences, join focus groups, or speak on panels without clear outcomes, fair compensation or influence over the project, leaving them feeling exploited and intellectually undervalued (Burrell et al., 2025). For non-speaking contributors, the absence of AAC tools or trained facilitators in research silences their voices, reinforcing hierarchies between verbal and non-verbal knowledge (Aidonopoulou-Read, 2025; Coldham, 2018).

Community discussions and emerging literature highlight a recurring issue: neurodivergent contributors are often sidelined after providing input, excluded from shaping research questions, interpreting findings, or co-authoring publications (Den Houting et al., 2021; Lovelace et al., 2022). They may receive only a footnote acknowledgement rather than co-authorship or equitable compensation. This is not co-production. It is *lived extraction*: taking without giving, listening without acting, and thanking without changing.

Intersectionality and Transparency

Ethical co-production requires intersectionality to amplify voices from marginalised neurodivergent communities, including those who are queer, gender-diverse, or multiply disabled (Gratton et al., 2023; Lovelace et al., 2022; Putnam et al., 2025). These groups face compounded systemic barriers, such as inaccessible research processes or cultural stigmas, which require intentional, tailored efforts to ensure meaningful inclusion (Amann & Sleigh, 2021; Giwa Onaiwu, 2020). For example, in non-Western contexts such as East Asia, cultural values such as collectivism and stigma around neurodivergence shape experiences, requiring culturally sensitive co-production that engages community leaders to align research with local priorities (Hirota et al., 2024).

Transparency is equally essential to build trust and accountability. While existing guidance highlights the importance of documenting contributor involvement (Amann & Sleigh, 2021), I argue that co-production processes should go further by explicitly reporting:

- Demographic diversity of contributors (e.g., race, gender, and disability status).
- Contributor roles (e.g., advisory, co-design, and co-authorship).

- Accessibility measures (e.g., sensory-friendly environments, flexible timelines, and AAC tools for non-speaking contributors).
- Compensation structures ensure fair pay for time and expertise.

These recommendations are intended to support transparency, accountability, and trust in co-production. However, any collection of demographic or personal information must comply with relevant data protection legislation, such as the UK General Data Protection Regulations (Regulation, Protection, 2018), ensuring informed consent, secure data storage, and clarity on how data will be used and reported. Researchers must balance transparency with ethical responsibilities to protect contributor privacy, particularly where identities may be inferred from detailed demographic information. If marginalised groups are underrepresented, researchers should acknowledge this, explain barriers and outline future inclusion plans.

Closing the Loop: Building Community Resonance

"Closing the loop" refers to providing clear, accessible feedback on how contributions shape research, which is essential but is often overlooked (Amann & Sleigh, 2021; Hickey et al., 2018). Neurodivergent contributors deserve to know: What were the findings? How was their input used? Did it lead to change? Without this feedback, contributors may feel their efforts were undervalued, which can erode trust.

Closing the loop is a vital practice that demonstrates respect and helps communities see that their contributions are valued and meaningful. In neurodiversity studies, where shared experiences often spark powerful "me too" connections, accessible feedback validates contributors' roles as co-creators. Based on my experience, I suggest the following practical steps to support ethical feedback practices:

- Setting clear feedback expectations at the outset.
- Sharing timely, accessible updates (e.g., plain-language summaries, visual reports, or AAC-compatible formats).
- Offering opt-in communication channels to respect individual preferences.
- Integrate feedback plans into funding applications and ethics documentation.

These suggestions are grounded in co-production principles and my own practice, and are intended to promote inclusion, recognition, and accountability. In my experience, contributors' value updates reflect a shared desire to know their impact. Funders can support this by requiring documented feedback plans to ensure accountability and build trust.

Addressing Power Imbalances in Co-Production

Power imbalances stem from well-recognised barriers such as academic authority, resource access and control over outputs, which undermine equitable co-production. To further strengthen ethical co-production, addressing power imbalances is essential. Therefore, I propose the following strategies, based on my practice and aligned with emerging literature, to support more equitable research (Oliver et al., 2019):

- Establish steering groups led by neurodivergent individuals, giving them genuine influence over decision-making and direction.
- Provide accessible training for researchers on neurodiversity, intersectionality, and anti-ableist research practices.
- Offer mentorship programs to support contributors' research skills and leadership development (Sonuga-Barke et al., 2024).
- Use participatory budgeting, enabling communities to shape how resources are allocated to reflect their priorities.

These proposed actions are intended to shift power away from academic gatekeeping and toward community-led research, aligning with disability justice principles. Addressing power imbalances drives systemic change and helps prevent the replication of exclusion within supposedly inclusive frameworks.

Institutional and Funding Responsibilities

Funding structures often fail to be neurodiversity-affirmative, despite calls for inclusion and equity. Complex, jargon-heavy guidelines and scattered resources create barriers for neurodivergent researchers, contradicting the principles funders aim to support. Based on practice-informed insights and in alignment with wider inclusion frameworks, I propose the following strategies to enhance accessibility in funding processes (Hickey et al., 2018; Oliver et al., 2019):

- Provide a single, accessible guidance document with clear bullet points, bolded key points, and plain language.
- Offer templates or examples of successful applications to clarify expectations and reduce ambiguity.
- Create neuroinclusive processes, such as optional video submissions or extended deadlines to accommodate diverse communication and processing needs.

To reinforce inclusion, I recommend that funders should also enforce accountability through evidence-informed practices, including:

- Require co-authorship and shared credit for neurodivergent contributors, where appropriate.
- Audit compensation practices to ensure equity and fairness.
- Support neurodivergent leadership roles across the research cycle.
- Mandate transparent reporting on inclusion and equity, including contributor demographics, roles and accessibility measures (Coldham, 2018).

Additionally, funders should allocate specific resources to support accessibility, such as AAC tools, sensory-friendly environments, and translation services for non-Western contexts, to ensure diverse neurodivergent voices are meaningfully included. These combined measures reflect a shift from symbolic inclusion to systemic support, making co-production more practical, ethical, and sustainable.

Principles for Ethical Co-Production

I propose the following principles, synthesised from my practice and the literature, to advance ethical co-production by redefining knowledge production to centre neurodivergent expertise and challenge epistemological hierarchies that privilege academic over lived experience:

1. *Centre Neurodivergent Leadership:* Ensure neurodivergent individuals are co-leaders, with decision-making authority, respecting community-preferred terminology, such as "autistic person" over "person with autism," to honour self-identification and build trust, as emphasised by autistic advocates (Dwyer et al., 2025).
2. *Prioritise Equity Over Inclusion:* Redistribute power through co-authorship, equitable compensation, and shared ownership (Amann & Sleigh, 2021; Arnstein, 1969; Den Houting et al., 2021). Equity should be evident in budgets, outputs, and decision-making.
3. *Embrace Intersectionality:* Amplify marginalised neurodivergent voices, use AAC tools, and foster safe, voluntary disclosure (Aidonopoulou-Read, 2025; Bertilsdotter Rosqvist et al., 2025; Dembele et al., 2024).
4. *Commit to Transparency:* Clearly document who was involved, how contributions shaped outcomes, and steps that ensured diverse representation (Amann & Sleigh, 2021; Coldham, 2018).
5. *Close the Loop:* Provide accessible, timely feedback to validate contributors' roles (Amann & Sleigh, 2021).
6. *Value Relational Ethics:* Build reciprocal, respectful relationships that prioritise contributors' well-being (Amann & Sleigh, 2021; Heyworth, 2024; Noddings, 2017).

These principles, grounded in disability justice and neurodiversity paradigms, offer a practical roadmap for researchers, funders, and institutions to move beyond tokenism towards genuine partnership.

Practical Applications of Intersectional Co-Production

To realise inclusive, intersectional co-production, researchers should:

- Provide AAC tools for non-speaking participants to ensure their voices are included (Aidonopoulou-Read, 2025).
- Co-design gender-inclusive studies with autistic women and non-binary individuals to reflect their unique experiences (Putnam et al., 2025).
- Partner with Black autistic communities to address their historic underrepresentation and systemic inequities (Lovelace et al., 2022).
- Respect transgender and non-binary contributors' identities with gender-affirming accommodations to create inclusive research environments (Gratton et al., 2023).
- Collaborate with neurodivergent youth to shape research that reflects their priorities and needs (Sonuga-Barke et al., 2024).
- Engage neurodivergent individuals with intellectual disabilities using accessible methods (e.g., simplified materials and supported decision-making) to include their perspectives (Aidonopoulou-Read, 2025).

These actions ensure co-production is responsive to diverse identities and promotes equity across neurodivergent communities.

Conclusion

Co-production has immense promise, but only when it embraces equity and accountability. Lived experience is a vital form of expertise, not a resource to be mined, nor is co-production an empathy exercise. It is a shared commitment to co-create knowledge that respects and empowers communities. By addressing epistemic injustice and challenging normalising practices, co-production can disrupt systemic inequities and centre neurodivergent expertise (Foucault, 1977; Kusch, 2009).

I argue that by centring neurodivergent leadership, embracing intersectionality, ensuring transparency, and closing the loop, we can transform co-production into a tool for meaningful change in research, policy, and practice. This commentary advances understanding by offering a novel framework that contrasts with biomedical epistemologies, which often marginalise lived experience, and instead promotes a collaborative, justice-oriented model of knowledge co-creation. This requires researchers to adopt ethical

listening practices, particularly for non-speaking contributors, and to value lived experience without mandating disclosure. Funders and institutions should support this shift through accessible processes and robust accountability measures. Together, these efforts can build a neurodiversity research paradigm rooted in justice and collaboration.

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Ethical Approval and Informed Consent Statements

Not applicable.

Funding

The author received no financial support for the research, authorship, and/or publication of this article.

Declaration of Conflicting Interests

The author declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data Availability Statement

Not applicable.

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