AutismCRC

Roadmap to strengthen autistic co-production and co-leadership in autism research

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A note on terminology

We recognise that when referring to individuals on the autism spectrum, there is no one term that suits all people. In our published material and other work, we use the terms 'autistic person', 'person on the autism spectrum' or ‘person on the spectrum’. The term 'autistic person' uses identity first language, which reflects the belief that being autistic is a core part of a person's identity.

Autism Spectrum Disorder (ASD) is diagnostic terminology used by the healthcare sector and is used in the context of a person being ‘diagnosed with Autism Spectrum Disorder’.

Copyright and disclaimer

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Autism CRC

Autism CRC is the independent national source of evidence for best practice in relation to autism across the lifespan and the spectrum. Its vision is to see equity and opportunity for autistic people, guided by Autism CRC's mission to listen, learn, and lead the translation of evidence to create positive change.

We provide the national capacity to develop and deliver evidence-based outcomes through our unique collaboration with autistic people, families, professionals, services providers, researchers, and government. Together, we are addressing agreed needs and co-producing outputs with these stakeholders for the benefit of the community.

Autism CRC was established in 2013 as the world's first national, cooperative research effort focused on autism under the Australian Government's Cooperative Research Centres (CRC) Program. We receive funding from a number of sources, including the Australian Government. Autism CRC is no longer part of, or associated with, the CRC Program.

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Executive summary

Why we did this work

There is a growing commitment and intent across Australia's autism research sector to co-production and co-leadership with autistic people. However, evidence from both the literature and lived experience indicates that these commitments are not yet consistently realised in practice. Autistic people continue to report limited influence, barriers to research leadership, and experiences of tokenism; while researchers face systems, processes, and expectations that make meaningful collaboration difficult to achieve.

This work was undertaken to better understand the barriers/challenges and enablers/solutions to meaningful research collaboration, and to identify what needs to change, to enable autistic co-production and co-leadership to become standard, supported, and sustained.

What we did

We used a five-phase co-design process that involved the following activities:

- **Research**, through a literature and environmental scan to identify existing evidence, resources and initiatives relating to participatory and co-produced autism research
- **Problem definition and solution ideation**, through co-design workshops and interviews with autistic community members, researchers, and other key research stakeholders
- **Validation and testing**, through a validation survey and targeted feedback to test emerging findings and recommendations, and to ensure these reflected stakeholder experience and priorities
- **Delivery**, through the development of this roadmap, which translates the findings into priority areas and practical, system level recommendations.

Who we engaged

We engaged 33 stakeholders in co-design workshops, interviews and meetings, with a subsequent validation survey. These included autistic and non-autistic representatives from universities (n=15), autistic people representing themselves (n=10), representatives from autistic-led organisations (n=2), autism peak bodies (n=1), research organisations (n=2), and funding bodies (n=3).

What we found

We found that the challenges and solutions to autistic co-production and co-leadership in autism research sit across multiple, interconnected parts of the research system. Funding and grant administration were identified as major barriers, with current models limiting early engagement, autistic leadership, and fair remuneration. There was also strong agreement that standards, guidance, and training are lacking, leading to an inconsistent understanding of what meaningful co-production involves and how to implement it in practice.

At a systemic level, institutions, human research ethics committee (HREC) processes, and publishing were described as misaligned with co-production and co-leadership approaches, limiting opportunities for autistic people to engage as collaborators or co-leaders. In addition,

partnership-based barriers were prominent, including difficulty connecting with researchers or the autistic community, limited investment in partnership building, and challenges sustaining partnerships beyond individual projects.

Importantly, these findings point to clear and interrelated pathways for change and highlight the need for coordinated, system level action rather than isolated or project-by-project efforts. The recommendations that follow reflect this integrated approach and are organised to support change across the research system.

Priority area 1: Funding

- Recommendation 1: Reform funding systems and grant administration to enable co-production and co-leadership

Priority area 2: Knowledge, education, and information

- Recommendation 2: Establish clear, evidence-based standards, guidelines and frameworks for research co-production
- Recommendation 3: Build co-production capability through coordinated education and training
- Recommendation 4: Sustain learning, quality and consistency of co-production through a nationally coordinated community of practice

Priority area 3: Cultural and systemic change

- Recommendation 5: Revise ethics application processes and criteria to better support and enable co-production and co-leadership in research
- Recommendation 6: Establish, maintain and disseminate an evidence-base demonstrating the value, benefits and impact of research co-production
- Recommendation 7: Develop manuscript submission guidelines and requirements for documenting participatory methods, including co-production and co-leadership
- Recommendation 8: Integrate co-production as a core research practice across institutional infrastructure, policies and systems through sustained investment and governance reform
- Recommendation 9: Promote a research culture and practice that respects, recognises and values autistic people and lived experience expertise
- Recommendation 10: Establish workforce and education planning initiatives to improve retention, and support entry into and progression through research careers for autistic people

Priority area 4: Connections and partnerships

- Recommendation 11: Build and maintain meaningful connections and partnerships between researchers and the autistic community
- Recommendation 12: Establish community engagement and liaison roles to support co-produced research
- Recommendation 13: Create equitable partnerships that support meaningful and sustained engagement across the research lifecycle
- Recommendation 14: Broaden and strengthen the diversity of community members involved in co-produced research

Next steps

This report presents a roadmap of priority areas and recommendations to support meaningful autistic co-production and co-leadership in autism research. The roadmap is intended to guide coordinated, systems level action across the research ecosystem, including government, funding bodies, research institutions, ethics committees, academic publishers', researchers, and the autism and autistic communities. While grounded in autism research, literature and experiences, these recommendations reflect inclusive research principles that are transferable to other disability research contexts.

Progress depends on collaboration, ongoing commitment, and a shift from viewing co-production and co-leadership as optional to embedding them as core, supported research practices. Implementing the recommendations in this roadmap will provide a practical pathway to move from commitment to consistent, effective implementation.

1. Introduction

The National Autism Strategy (NAS) sets out a long-term vision for a safe and inclusive society in which all Autistic people are supported and empowered to thrive in all aspects of life. It embeds co-production and co-leadership as core principles, especially in research and governance. These principles reflect a growing recognition that autism research is most ethical, relevant and impactful when autistic people are meaningfully involved as partners and co-leaders throughout the research lifecycle.

Despite this growing commitment and intent across the research sector, autistic co-production and co-leadership remain inconsistently implemented in practice. Research teams continue to face significant structural, cultural, and practical challenges and opportunities for autistic leadership are often limited or constrained. Autistic people report experiences of tokenism, limited influence, and barriers to sustained engagement, while researchers describe systems that are not designed to support collaborative, partnership-based approaches to research.

Co-design work was undertaken to better understand these challenges and to identify the changes required to move from a commitment to effective implementation. The resulting roadmap responds to calls from autistic community members, researchers, and policymakers for clearer guidance, stronger systems, and coordinated action to embed co-production and co-leadership as standard, supported and sustained practices.

Although grounded in autism research and the experiences of autistic people, autism researchers and other stakeholders, the recommendations in this roadmap reflect universal principles of inclusive research design and governance that can be applied across other disability and lived experience research contexts.

1.1 Who this roadmap is for

This roadmap is intended to be used by:

- government and funding bodies to inform funding reform, grant administration, accountability mechanisms, and investment decisions
- research institutions and universities to review and strengthen policies, processes, infrastructure, and workforce development
- Human Research Ethics Committees (HRECs) and journals to improve assessment, guidance and reporting of co-produced research
- researchers and research teams to support more equitable, accessible, and collaborative research design and practice
- autistic people, families, and community organisations to inform expectations, advocacy, leadership opportunities, and engagement with the research system.

The recommendations in this roadmap are not the sole responsibility of a single stakeholder. Progress depends on coordinated and sustained action across the system.

1.2 Using this roadmap

This roadmap is designed as a practical guide to support action towards stronger autistic co-production and co-leadership in autism research. It is evidence informed, grounded in lived experience, and intended to be used flexibly by different stakeholders across the research system. It provides: a **strategic and practical guide** for embedding autistic co-production and co-leadership;

a **shared reference point** for government, institutions, funders, researchers, and the autistic community; and a tool to support **systems level change**, not a checklist for individual projects. It can be used to:

Review and assess current practice

- Reflect on how current systems, policies, or practices support, or limit, co-production and co-leadership using the priority areas.
- Identify gaps, strengths, and opportunities for improvement.

Guide planning and decision-making

- Use the recommendations to inform funding programs, institutional strategies, research planning and policy reform.
- Consider which actions can be implemented immediately and which require longer term strategic approaches and investment.

Support coordination and accountability

- Use the roadmap as a shared framework when working across teams, organisations or sectors.
- Align initiatives, investments, and responsibilities with the priority areas and recommendations.

Advocate for change

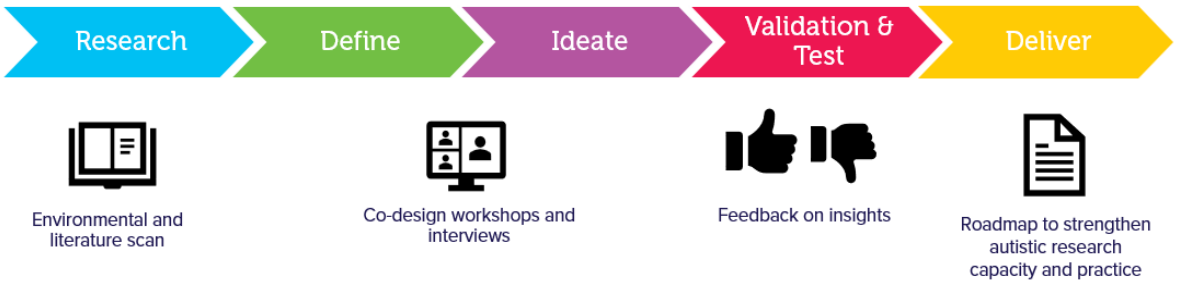
- Use the roadmap to support conversations with decision-makers about the changes needed to enable meaningful co-production and co-leadership.
- Draw on the recommendations to articulate clear, evidence-based that support effective advocacy for meaningful change.

2. The co-design process

Co-design is an investigative and creative process that brings together a diverse group of people with lived experience and the skills to explore problems and potential solutions. It aims to empower and put people with lived experience at the centre of the design process.

The co-design process for this project encompassed five phases: research, problem definition (define), solution ideation (ideate), validation and testing, and the delivery of a Roadmap to strengthen autistic research capacity and practice (deliver), as shown in Figure 1. The process for each phase is described in the subsequent sections.

Figure 1: The co-design process



2.1 Research: Literature and environmental scan

The research elements included a literature scan and an environmental scan. The literature scan focused on academic literature to identify key barriers/challenges, and enablers/solutions to autistic leadership and co-production of autism research. The environmental scan focused on identifying existing resources and initiatives to support co-production and co-leadership of autism research.

The literature and environmental scans were conducted using Google and Google Scholar. Keywords and search terms included those used to describe autism; involvement in research; and participatory research approaches, as shown in Table 1. A total of 308 academic and grey literature sources were identified and underwent screening. After screening and removing duplicates, non-English items, blogs, and non-relevant sources, 102 articles and resources underwent full review and were included in the research.

Table 1: Literature and environmental scan search terms

Autism	Involvement in research	Research approaches
• ASD • Autism • Autistic • Disabled • Disability • Neurodivergent	• Co-leadership • Co-researcher • Consumer • Leadership • Lived experience researcher • Patient • Research • Researcher	• Collaborative • Community-based participatory action research • Community engagement • Community involvement • Community-led • Co-creation • Co-design • Co-operative inquiry • Co-production • Emancipatory • Inclusive • Participatory research • Participatory action research • Public involvement

2.1.1 Analysis

Data collected from the literature, workshops, interviews (see section 3.2), and subsequent validation survey (see section 3.3) were analysed using a thematic analysis approach. Data from the three individual data sets were initially analysed separately using a deductive method to categorise into barriers/challenges and enablers/solutions. Following this, an inductive approach was used to identify common themes across the combined data sets for barriers/challenges, with enablers/solutions subsequently mapped to these themes. Data from the environmental scan were collated and are available in Appendix A.

2.2 Problem definition and solution ideation: Co-design workshops and interviews

2.2.1 Participants

A total of 33 stakeholders were engaged. This included meetings with government funding bodies (NHMRC and ARC, n=2), four co-design workshops (n=28) and three interviews (n=3). Participants included autistic and non-autistic representatives from universities (n=15), autistic people representing themselves (n=10), representatives from autistic-led organisations (n=2), autism peak bodies (n=1), research organisations (n=2) and funding bodies (n=3), as shown in Figure 2.

Participants were aged 18 years and over. The age groups in co-design workshops and interviews (N=31) were: 25–29 years (n=4), 30–39 years (n=8), 40–49 years (n=8), 50–59 years (n=7), and 60 years and over (n=4). The majority identified as female (n=24). Others identified as male (n=4), non-binary (n=2) or preferred not to say (n=1). Of the ten autistic people representing themselves: eight also identified as having co-occurring conditions; four lived in rural, regional or remote areas; three identified as LGBTQIA+; one had an intellectual disability; and one identified as Aboriginal and/or Torres Strait Islander. Of these stakeholders (N=31), eight identified as autistic, four as families/carers of autistic people, and seven as both autistic and families/carers. Most reported “a lot” of understanding of research co-production (n=22), and “a lot” of experience with research co-production (n=19), as shown in Figure 2.

Figure 2: Stakeholder representation

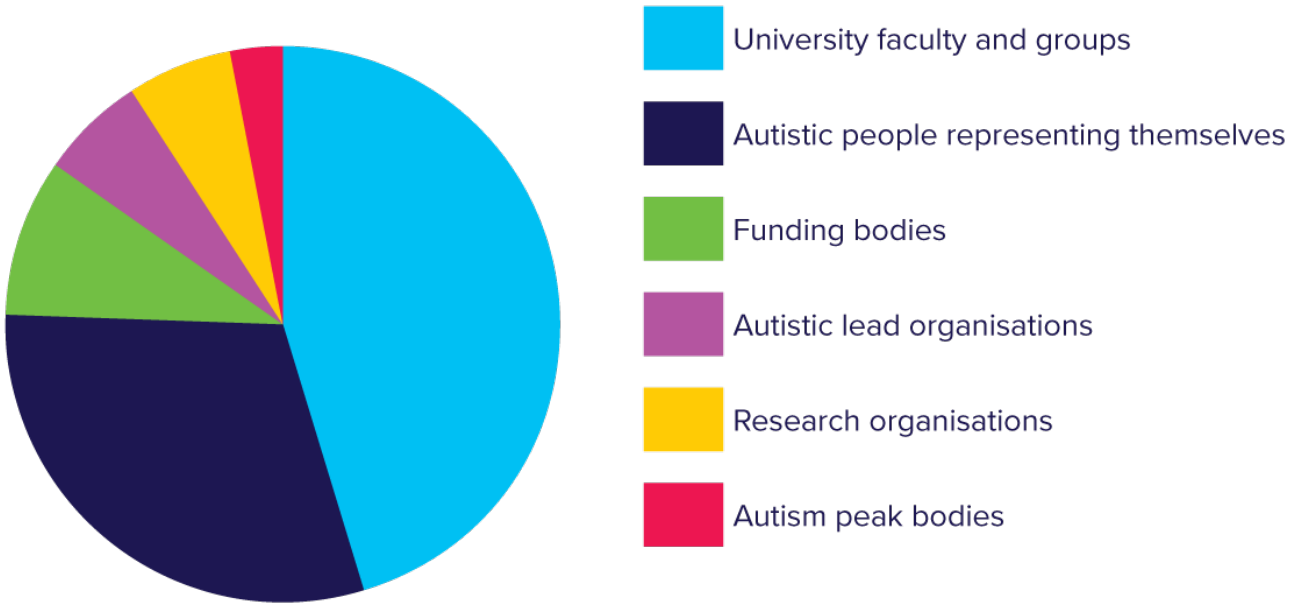
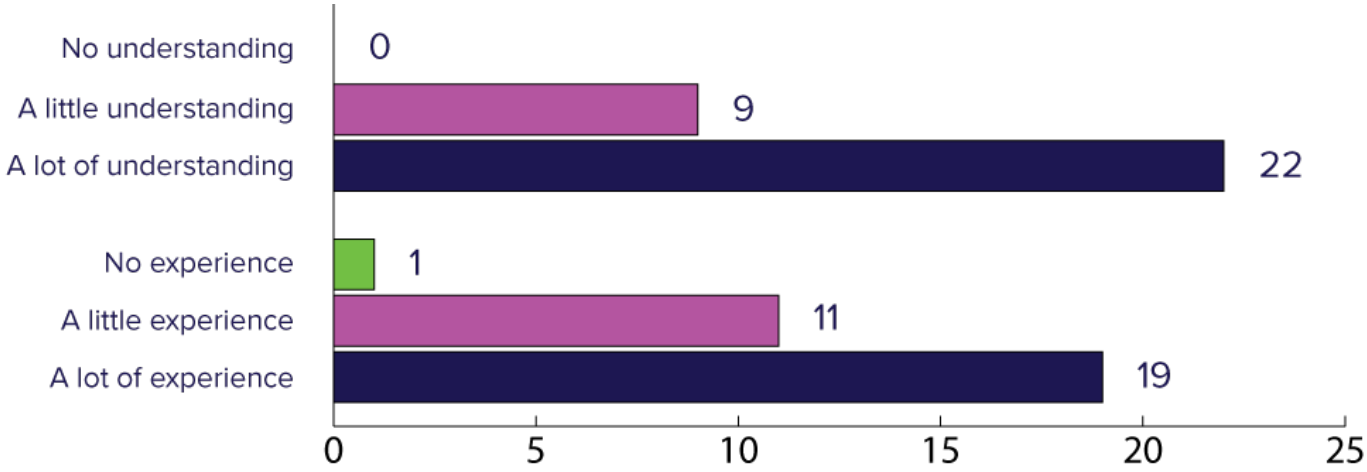


Figure 3: Participant understanding and experience of research co-production



2.2.2 Method and analysis

The workshops and interviews were co-facilitated by an autistic and a non-autistic team member using Zoom and an online whiteboard. One workshop was designated for autistic people only to create a safe and open space for discussion and experience-sharing. The workshops lasted two hours, with interviews lasting up to an hour.

Participants were asked in advance if they had any support needs or required accommodations that would facilitate their engagement and were invited to participate in the way they felt most comfortable e.g. keeping their camera off, using the chat function instead of speaking and opportunity for follow-up input. They were also provided with a workshop preparation guide that contained information including the objectives, agenda, what to expect, pre-reading, and information about the facilitators. For the purposes of data analysis, all workshops and interviews were recorded with consent, and later transcribed.

During the workshops and interviews, the facilitators guided participants through three broad stages of the research process: planning, undertaking, and dissemination. Participants were first invited to reflect on their experiences of co-production and autistic co-leadership and then to describe any barriers or challenges they had encountered, either personally or that they'd observed within the autistic and researcher communities more broadly. Subsequently, participants were guided through the research stages again to prompt discussion of potential solutions or enablers to these barriers, with the aim of supporting increased co-leadership and more meaningful and sustained co-production in autism research.

The data analysis process is described in Section 3.1.1.

2.3 Idea validation and testing: Survey

To validate and test the insights from the co-design workshops and interviews, participants were provided with a summary of the barriers and challenges, as well as the enablers and solutions. They were invited to review the summary and provide comments or examples of how the suggested ideas might be applied in practice. Participation in the validation survey was optional, with 17 participants (54.8%) completing the survey, of which 10 were autistic.

For further validation, an overview of the preliminary insights and draft recommendations was presented to the National Health and Medical Research Council (NHMRC)'s Consumer and Community Advisory Group. They were asked to provide feedback, comments or suggestions.

The data analysis process is described in section 3.1.1.

2.4 Delivery: Roadmap to strengthen autistic co-production and co-leadership in autism research

The insights derived from the literature and environment scan, co-design workshops and interviews, and validation survey have been synthesised into a series of recommendations. Together these recommendations provide a roadmap to strengthen autistic co-production and co-leadership in autism research.

3. Findings from the research phase: Literature and environmental scan

The focus of the environmental scan was to identify existing resources and initiatives to support co-production and co-leadership of autism research (available in Appendix A). The literature scan focused on the key barriers and challenges, as well as enablers and solutions for increased autistic co-leadership and co-production of autism research. Within the literature most studies referred to participatory autism research and autistic community engagement broadly, with few explicitly referencing co-production. For consistency, the term *participatory* will be used throughout this section to describe the findings.

Literature scan findings were categorised into themes (see section 3.2.3) and are detailed below.

3.1 Systemic, institutional and academic culture

Barriers and challenges

The literature indicates many **systemic challenges** associated with participatory autism research,[1] including those related to university infrastructure.[2–4] **Institutional systems**[5] and structures[6] were identified as barriers. These systems were described as inflexible,[6] challenging,[3] and often requiring advocacy[4] and negotiation from the researchers who are responsible for navigating them.[7] Institutional systems create challenges related to employment contracts for autistic community partners,[6] timely remuneration,[8] and access to funds for remuneration.[4]

The **culture of academia**[6] including academic practices, rules,[5] and restrictions[9] were reported as creating barriers to participatory autism research, alongside the unpredictable[10] and fluid[11] nature of research. Related challenges are the academic demands on researchers,[9] including schedules,[12] workloads,[10] deadlines,[13] timeframes,[14,1] time pressures and constraints.[5, 9]

Undertaking participatory research is challenging for **PhD students**,[15] with the typical challenges often being more significant .[11] As participatory approaches are not commonly used in PhDs,[4] using these approaches effectively is often reliant on having a supportive supervisor.[15] Particular participatory research challenges for PhD students include the structure and requirements of doctoral degrees, it's effect on progression and milestones, and concerns related to the originality of the work.[11,15] The time limits of **Master's**[14] and PhD degrees[11,15] can also make participatory research challenging to undertake.

Other challenges arise from the incompatibility of participatory research with research incentives,[16] alongside a lack of incentives for participatory research within institutions.[2] For early career researchers there is also insufficient support for participatory research practices from senior colleagues. [9]

Enablers and solutions

The literature indicated eleven enablers and solutions related to the theme of systemic, institutional, and academic culture. These are categorised into the sub-themes as institutional infrastructure, higher degrees by research (HDR) and supervision, and institutional funding, resources, and support shown in Table 2.

Table 2: Insights from literature scan: Enablers and solutions to systemic, institutional, and academic culture

Sub-theme	Enabler/solution
Institutional infrastructure	• Reform institutional infrastructure[3] • Embed participatory research in institutional evaluation frameworks[17] • Negotiate university requirements[6]
Higher degrees by research (HDR)s and supervision	• Adjustable and adaptive structures and requirements within HDRs[15] • HDR supervisors experienced in participatory research[4] • Support from supervisors for HDR students using participatory approaches[15] • Advocacy efforts from HDR supervisors[4]
Institutional funding, resources and support	• Institutional funding for remuneration of community members[4] • Collaboration with existing autistic university staff to ease remuneration processes[4] • Institutional recognition and support of participatory resource requirements[9] • Greater institutional capacity to accommodate and respond to participatory research[5]

3.2 Careers, employment and workplaces

Barriers and challenges

The literature scan indicated that for autistic researchers, institutions often do not meet their needs[3], stigmatise and discriminate against them,[2] and expose them to inaccessible workspaces and environments.[18] These conditions create challenges when accessing necessary supports[2] and act as barriers to disclosure and requesting support, due to insufficient policies and poor implementation, and limited staff knowledge about how to provide appropriate support.[18] Additional barriers include uncertainty regarding roles and responsibilities, challenges related to working capacity and job relocation, and unclear career pathways and expectations.[18]

Enablers and solutions

The literature indicated eight enablers and solutions related to the theme of careers, employment and workplaces and are listed below. A key source[18] references neurodivergent individuals, however, as participants in this paper encompassed autistic people it is deemed appropriate.

- Workplace training about neurodivergence for institutional staff[18]
- Workplace cultural shift[18]
- Inclusive and accessible Human Resource and recruitment policies and processes[18]
- Job relocation support for neurodivergent researchers[18]
- Reasonable adjustments and workplace accommodations for neurodivergent researchers[18]
- Career mentoring and support for neurodivergent researchers[18]
- Unions developing understanding of neurodivergent employee needs[18]
- Addressing educational barriers for autistic people.[19]

3.3 Power, tokenism and meaningful engagement

Barriers and challenges

Within participatory autism research, researchers continue to hold the majority of power and decision-making authority[5] with inequities existing between researchers and autistic community members.[11,20] This is largely driven by ingrained power imbalances[7,4] and existing power dynamics[1], that take time to address.[11] Collaboration with autistic community members in participatory autism research has been described as superficial[13] and tokenistic,[3] with the genuineness doubted.[5] It was reported that researchers have both a resistance to[21] and reservations about[5] the sharing of power within community research partnerships.

For autistic researchers, their positionality can create additional challenges within participatory autism research.[8] These include complicating their responsibilities as researchers,[15] feelings of heightened responsibility, and concerns about how their participatory approach will be regarded by their peers.[11]

Enablers and solutions

The literature scan indicated 11 enablers and solutions related to the theme of power, tokenism and meaningful engagement, as shown in Table 3.

Table 3: Insights from literature scan: Enablers and solutions related to power, tokenism and meaningful engagement

Sub-theme	Enabler/solution
Research leadership	• Autistic community partners in principal research leadership roles[20]
Acknowledgement and recognition	• Acknowledge the contributions of autistic community partners[5,15] • Provide co-authorship to autistic collaborators[22]
Authenticity	• Genuine collaboration with autistic community partners[4]
Valuing lived experience	• Listen to and value autistic people and lived experience[3,22] • Value community partners' contributions and perspectives[3,23]
Collaborative practices	• Joint establishment of processes, ways of working and planning[22] • Collaboratively identify dissemination approaches aligned with community priorities[22]
Power dynamics	• Avoid positioning autistic students, researchers, or staff as proxies for autistic lay community members[22] • Actively address power imbalances[22,24]
Capacity building	• Support research skills and career development for autistic collaborators[4,22]

3.4 Ethics committees and ethical considerations

Barriers and challenges

Ethics committees are often unfamiliar with participatory research,[10] which can create tensions between researchers and ethics committees[15] or result in additional requirements, such as informed consent from autistic collaborators.[7] In some cases, ethics committees may deem autistic people incapable of giving informed consent.[25] For PhD students, obtaining ethics approval for participatory research can be challenging[15] with the process requiring advocacy and additional work.[4]

Ethical considerations were also evident in the literature regarding participatory approaches to autism research. These include situations when professional boundaries may become less clear in researcher and community partnerships,[25] as well the potential for the creation of a void in autistic people's lives when these partnerships come to an end.[21] For autistic community members, there may also be conflicts of interest[26] and restrictions on data collection due to existing relationships with research participants.[3] For researchers, ensuring duty of care can be challenging,[10] alongside the risk of exposure to harmful research content[15] and the impact of and connectedness to the research experienced by autistic people.[2] Both researchers and autistic community members may also be personally invested in the research.[21]

Enablers and solutions

The literature scan indicated four enablers and solutions related to the theme of ethics committees and ethical considerations.

- Seek informed consent from autistic community partners[4]
- Neurodiversity-affirming approaches to biomedical research studies[16]
- Autism-affirming participatory research approaches[20]
- Work to ensure the safety of autistic partners throughout the research process.[5]

3.5 Diversity, intersectionality and representation

Barriers and challenges

Within participatory autism research, there is often limited,[27] or a lack of,[28] diversity among autistic community partners, with the same individuals frequently being recruited across studies.[13] For researchers, recruiting a diverse range of collaborators can be challenging,[29] particularly when recruiting individuals who are hard to reach[9] and/or those with higher support needs.[3] These challenges may be due to researchers limited understanding of intersectional groups,[30] and may be further limited by collaboration that is restricted to autistic community members with research experience or to smaller numbers of autistic people.[4]

Different perspectives within the autistic community can also create challenges for participatory autism research, particularly in relation to decision making[9] and research priority setting.[24]

Enablers and solutions

The literature scan indicated ten enablers and solutions related to the theme of diversity, intersectionality and representation. The have been categorised into four sub-themes, as shown in Table 4.

Table 4: Insights from literature scan: Enablers and solutions to diversity, intersectionality and representation

Sub-theme	Enabler/solution
Representation	• Diverse representation of autistic community partners[1,5,21,26] • Intersectional representation of community partners[27]
Expanded recruitment	• Broaden recruitment beyond usual or established autistic collaborators[9] • Avoid limited or biased recruitment of community partners[16] • Collaborate with different autistic people across multiple projects[26] • Collaborate with autistic lay community members[5,22] • Collaborate with under-represented autistic groups[1] • Recognise and engage with all key stakeholders[16]
Relevance	• Partner with autistic community members who have relevant expertise and lived experience[3,9,22]
Understanding and knowledge	• Build understanding of how to collaborate effectively with under-represented groups[3]

3.6 Knowledge, skills and training

Barriers and challenges

For researchers, there are knowledge[9] and understanding[1] gaps in relation to participatory research, as well as skill gaps, particularly for early-career researchers.[3] These gaps include limited understanding of meaningful engagement,[17] partnerships[31] and participatory research;[1] or unclear, vague,[32] or misaligned[17] understandings. These challenges may be attributed to a lack of consensus regarding participatory methods,[26] the unclear and vague use of terminology,[9] and method inconsistency.[17] Further, there is an absence of training in participatory autism research[2] and limited guidance,[23] including that related to remuneration.[21] This leads to researchers experiencing uncertainty,[3,10] unfamiliarity,[15] and a low level of confidence[9] in undertaking participatory autism research. For autistic community members, they may experience difficulties understanding research terminology.[22]

Enablers and solutions

The literature scan indicated fourteen enablers and solutions related to the theme of knowledge, skills and training. The have been categorised into the sub-themes of training, education and learning opportunities, and developing participatory research practice, as shown in Table 5.

Table 5: Insights from literature scan: Enablers and solutions to knowledge, skills and training

Sub-theme	Enabler/solution
Training	• Participatory research training for researchers and autistic community members[9,19] • Training focused on relationship building and communication[9] • Autism CRC's Research Program as a training and capacity building initiative[4] • Opportunities for autistic community members to develop research skills[2,4] • Research training specifically for autistic community members,[10] all stakeholders,[1] teachers and support agencies[33] • Participatory research training for researchers working in biomedical fields[16]
Education and learning opportunities	• Opportunities to build knowledge of participatory research[34] • Researcher-led masterclasses on participatory research[4] • Embed participatory research training within university degrees[19] • Ongoing professional development opportunities[19]
Developing participatory research practice	• Clear definitions of participatory research[9] • Well defined participatory research approaches[23] • Development of best-practice guidance for participatory research[21] • Development of participatory research methods in biomedical contexts.[16]

3.7 Funding and remuneration

Barriers and challenges

Funding is a significant barrier to participatory autism research.[1,16] Key challenges include funding constraints,[5] limited resources,[34] insufficient funding to support remuneration,[6] and difficulties associated with remuneration due to welfare constraints.[19]

Funding bodies lack an understanding of the requirements of participatory research, including the need for smaller grants to co-develop proposals,[34] and often do not value or prioritise community engagement in research, which without endorsement can demotivate researchers.[3] As a result, grants often have small budgets,[6] fail to include provision for participatory approaches[2,5] or are designed to be incompatible with participatory research, as is often the case in biomedical research.[16] This can lead to researchers feeling discouraged in the absence of funding body support for participatory approaches.[3]

These funding challenges can result in researchers not being paid,[6] limiting the involvement of autistic people,[4] particularly in grant development,[34] and contribute to ineffective project management.[6] In biomedical research, competitive funding environments and grant structures means that funding is often grounded in a medical model of autism and non-amenable to participatory research.[16]

Securing funding for participatory autism research is reported as challenging,[2,9] particularly for HDR students,[4] independent autistic researchers who are not institutionally affiliated,[3] and researchers seeking funding to remunerate community members.[11,20]

Enablers and solutions

The literature scan indicated 26 enablers and solutions related to the theme of funding and remuneration. These have been categorised into eight sub-themes, as shown in Table 6.

Table 6: Insights from literature scan: Enablers and solutions to funding and remuneration

Sub-theme	Enabler/solution
Timelines	• Longer project timelines to support participatory research[1,5,14,27]
Grant writing and applications	• Accessible grant application forms, including eligibility requirements, to accommodate neurodivergent researchers[18] • Budgeting for remuneration and participatory methods within grant applications[1,3,7,13] • Inclusion of participatory methods in grant applications by researchers[3]
Grant standards and requirements	• Participatory standards set by funding bodies[13] • Expanded grant eligibility to allow temporarily contracted neurodivergent researchers to act as grant leads[18] • Requirement for evidence of participatory methods in grant applications[3,32] • Embedding participatory guidelines within grant evaluation processes[17] • Clear accountability mechanisms for grant recipients[3]
Flexible budgets and funding	• Ability to use funding for collaborator accommodations[26] • Adjustable and flexible project budgets[5] • Greater flexibility in the use of student funding[4]
Remuneration	• Salaried remuneration for autistic community partners[19] • Tailored, creative, and flexible remuneration arrangements[4,19,34] • Fair and equitable remuneration practices[3,22,29] • Non-financial research career benefits and recognition[4] • Compensation for travel, meals, and accommodation for community partners[7,21]
Grants and funding opportunities	• Grants to support HDR students undertaking participatory research[4] • Increased funding dedicated to participatory research[1] • Independent grant opportunities to support participatory research[3] • Grants supporting relationship building and project planning between biomedical researchers and community partners[16]
Resources and support	• Training provided by funding bodies[31] • Funding bodies develop supportive infrastructure for participatory research[31]
Grant reviewing and awarding	• Explicit consideration of participatory methods during grant review[3] • Inclusion of lay community members in grant review processes[3] • Greater discussion around research funding decisions[24]

3.8 Establishing and maintaining connections and partnerships

Barriers and challenges

The literature indicated that initiating partnerships[4] and establishing connections with the autistic community[11] can be challenging for researchers. **Researchers** are often unsure how to engage with the autistic community or initiate contact.[2] They may lack motivation to partner with, or trust, lay community members,[5] or feel concerned about their ability to incorporate their community partners perspectives, or that their knowledge will not be respected.[3]

Building relationships requires time,[9,34] including time to get to know each individual community member involved.[29] It also requires planning,[10] resources,[5] researcher effort,[31] and managing challenges such as disclosure.[2] Developing trust can be particularly difficult,[34] including when researchers lack an understanding of autistic experiences[5] or when team members become absent.[21] Recruitment of community partners[11] and building teams[22] can also be difficult, due to factors such as employment laws.[8] **For PhD students**, establishing partnerships with community members often occurs while undertaking their doctorate rather than before commencing their PhD.[11,4] **Autistic community members** may feel distanced from research,[20] as well as sceptical about the motivations of researchers, leading to hesitancy to engage.[16]

These challenges can be further compounded by differences in research priorities,[17] the content and nature of autism research,[5] and conflicts between researchers and autistic communities expectations and needs.[15]

Enablers and solutions

The literature scan indicated 14 enablers and solutions related to the theme of establishing and maintaining connections and partnerships. The have been categorised into six sub-themes, as shown in Table 7.

Table 7: Insights from literature scan: Enablers and solutions to establishing and maintaining connections and partnerships

Sub-theme	Enabler/solution
Funding	• Funding to enable longer recruitment times[27]
Evaluation	• Ongoing evaluation of the partnership[22]
Partnership building	• Commemorate successes[22] • Maintain relationships[20] • Team bonding opportunities between autistic community partners and researchers[4,22,23]
Community-based collaboration	• Recruit autistic collaborators through organisations[9,19] • Partner with autistic-led organisations[3]
Trust	• Restore community trust and engagement[16] • Establish trust between researchers and autistic community partners[4,22] • Researchers being transparent and open about themselves[34] • Mutual effort from researchers and the autistic community[12]
Intentional engagement	• Institution-facilitated community engagement efforts[4] • Autistic people establishing connections with researchers[4] • Collaboration with autistic community members around shared goals[22]

3.9 Managing and maintaining engagement

Barriers and challenges

Participatory autism research requires significant effort,[5] additional time,[1,10,27] and planning.[28] Time is a significant challenge, with researchers often required to work beyond regular hours.[29] Participatory research processes can be lengthy[15,26] and burdensome for both researchers and autistic community members.[2] Providing sufficient time for feedback from autistic community partners[12] and aligning this to timelines or incorporating it,[23] can also be challenging for researchers.

Maintaining the involvement of autistic community partners can be difficult,[11] due to factors including fluctuating desire for engagement,[25] and the need for socialising, enjoyment, and reward from the experience.[23] Additionally, outside obligations can affect individuals' involvement[6] and availability,[29] making it difficult to schedule meetings.[23]

Communication can be challenging within teams[5,33] due to researcher perceived autistic communication challenges,[31] limited understanding and support for autistic communication needs,[20] and mutual misunderstandings between autistic and non-autistic people.[6,9] It also requires additional effort,[3] often due to the need for more frequent and detailed communication, to ensure that everyone can contribute and that equal opportunities for participation are provided.[23,28] Communicating research information to autistic community members may be challenging,[33] especially to those unfamiliar with research processes.[9]

Providing appropriate accommodations for autistic community collaborators can be challenging for researchers,[33] and this can be more difficult for autistic researchers who may have their own needs to accommodate.[8,12] Developing accessible materials also requires additional time.[28] Within teams, group meetings can be challenging,[12] particularly in reaching consensus,[3] balancing differing perspectives,[23] and fostering collaboration.[2] Remote collaboration can create additional challenges.[12] These include varying levels of digital competency[20] or technology difficulties.[26] The broad geographic spread of autistic community members can also be a challenge,[3] and create barriers related to travel.[7,26]

Autistic community members may experience challenges including sensory,[5] anxiety,[7] executive functioning,[11] and navigating social contexts.[11] They may also be unsure about their roles,[5] have difficulty finding time to review materials[28] or managing a lot of emails.[21] Autistic community members may also be expected to have access to support during their roles,[26] and challenges can arise when support people dominate interactions.[23]

Enablers and solutions

The literature scan indicated 47 enablers and solutions related to the theme of managing and maintaining engagement. The have been categorised into six sub-themes, as shown in Table 7.

Table 7: Insights from literature scan: Enablers and solutions to managing and maintaining engagement

Sub-theme	Enabler/solution
Planning	• Project planning for participatory research[6,27] • Plan accommodations for autistic community partners[23] • Plan community partner engagement[23] • Create backup plans[21] • Develop explicit project timelines[6,10] • Ensure collaborator comfort with time commitment[29] • Adopt a flexible approach[4] • Match engagement level to project needs[22]
Project coordination and facilitation	• Funding for project coordination[6] • Actively maintaining engagement of community partners[22,23] • Adjust meeting times to allow for social connection[23] • Increase meeting frequency[23] • Maintain consistent engagement from researchers[22] • Use consistent meeting rooms[26] • Identify individual needs for engagement[23] • Provide inclusive and flexible engagement[21] • Use diverse methods of engagement[22] • Use online workspaces[26] • Support participation through online conferences[7] • Allow time for processing[22] • Enable community members to contribute at their own pace[29] • Provide materials ahead of time[22] • Establish agreed systems and structures to support the project and engagement[22]
Accommodations and support	• Ongoing evaluation of accommodations[22] • Address conflicting support needs[22] • Ensure accessibility for community partners[5] • Understand communication preferences[4] • Meet individual communication needs[9] • Provide support people[23] • Consider the physical and sensory environment[26] • Engage researchers experienced in working with autistic people[7,23] • Presume competence and identify and utilise community partners' strengths[4]
Communication	• Establish and communicate expectations, responsibilities, roles, and goals[21,22] • Communicate grant limitations[19] • Communicate research processes[3,6,21] • Use structured communication[22] • Communicate in a timely and detailed manner[6] • Communicate in a consistent and clear manner[20] • Use transparent and predictable communication[4] • Provide notice of changes[10] • Provide regular updates[22]
Accessible information and communication	• Use accessible communication practices[4] • Communicate information using accessible wording and formats[22] • Communicate information using multiple accessible formats[23,35] • Use spoken communication where appropriate[21] • Send multi-format meeting reminders[23]
Capacity building	• Provide training to autistic community partners for technology use[23,26]

3.10 Attitudes, awareness and recognition

Barriers and challenges

Autistic people are often not aware that they can play a role in research[31] and are not recognised as active contributors to research.[1,] Instead, they are viewed as resources, expected to adhere to the rigidity of research,[1] and positioned solely as participants.[5] Participatory research remains the exception within autism research,[31] which may be attributable to a resistance from researchers to shifting practices.[1]

There is a lack of value placed on participatory research among both researchers and autistic community members,[2] alongside scepticism regarding the influence of participatory research.[2,31] Researchers hold perceptions including the belief that research should be left to researchers alone,[31] for reasons such as to maintain scientific rigour.[5] Participatory research is also characterised as ambitious,[1] unnecessary for all studies,[1] or only for certain communities.[9] In particular, biomedical researchers may view their work as not being of concern for the autistic community,[3] or question the need to involve autistic people in such research.[19]

Concerns exist regarding the scientific validity of participatory autism research[31,33] particularly qualitative research[33] with these concerns also extending to the involvement of autistic community members in research priority setting.[24]

For journals, it can be challenging to persuade peer reviewers of the authenticity and achievability of participatory research.[36] Further, opportunities for researchers to learn from best practice are limited by the lack of manuscript submission requirements for documenting participatory approaches.[37]

Enablers and solutions

The literature scan indicated 12 enablers and solutions related to the theme of attitudes, awareness and recognition. The have been categorised into four sub-themes, as shown in Table 8.

Table 8: Insights from literature scan: Enablers and solutions to attitudes, awareness and recognition

Sub-theme	Enabler/solution
Publications	• Mandated journal reporting requirements for participatory research[32,37] • Documentation of participatory research approaches in manuscripts[23] • Include autistic people at all levels of the publishing process, including peer review[36]
Recognition	• Better recognition of autistic people's strengths[16] • Better recognition of the value of participatory research[5,15]
Mindset shift	• Broaden perspectives and challenge assumptions[3] • Attitudinal change[1,17] • Cultural change[5,17] • Acceptance and inclusivity within academia towards autistic students and researchers[36]
Awareness and promotion	• Build awareness of participatory research[15] • Greater promotion of co-production[27] • Support and inclusion of researchers whose work is not aligned with participatory research[3]

4. Findings from the define and ideate phases: Co-design workshops and interviews

The focus of the co-design workshops and interviews was to gain stakeholder understanding of the barriers and challenges as well as enablers and solutions to increased co-production and autistic co-leadership of autism research. The findings were categorised into themes (see section 3.2.3) and are detailed sequentially below.

4.1 Systemic, institutional and academic culture

> *"...the research systems are set up in ways that make it really, really difficult to do good co-production."*

Barriers and challenges

During the workshops and interviews, we heard that researchers experience pressure to undertake co-production; however, there is currently no infrastructure in place to support this. University systems and processes were described as slow moving and changing, complicated, hierarchical, and not designed to support co-production, cross-institutional collaboration, or partnering with external organisations or individuals.

Participants shared that human resources, finance, and payroll systems create difficulties with hiring and remunerating autistic community members, whilst data management systems and processes, make it challenging for community members to access data. They also indicated that universities often hold concerns regarding intellectual property in co-production.

Furthermore, we heard that prevailing academic culture, including pressure to publish, timelines, milestones and deadlines can create additional pressure for researchers and make it difficult to prioritise co-production. Researchers reported increasingly limited capacity for co-production, often juggling multiple projects and competing deadlines, which can result in a reliance on familiar and less time-intensive approaches, such as advisory groups. For PhD students particularly, the constrained timelines of doctoral degrees can make the additional planning required for co-production difficult.

Enablers and solutions

The workshop and interview data indicated 16 enablers and solutions related to the theme of systemic, institutional and academic culture. The have been categorised into four sub-themes, as shown in Table 9.

Table 9: Insights from co-design workshops and interviews: Enablers and solutions to systemic, institutional and academic culture

Sub-theme	Enabler/solution
Institutional policies and processes	• Change institutional grant policies to include co-production and remuneration budgeting • Change intellectual property policies • Expand Key Performance Indicators (KPIs) and funding decisions to include event attendance and alternative dissemination and knowledge translation • Change payment processes to enable invoicing remuneration • Employment and payment processes that enable co-production • Non-employment collaboration pathways for autistic community partners
Change	• Advocate for institutional and policy changes • Systemic change in research and institutions • Systemic change in research to support maintaining relationships
Institutional support and funding	• Institutional support for researchers and autistic community partners • Institutional infrastructure, funding and support for co-production • Institutional recognition of co-production as research infrastructure
Education and training	• Provide education and training to institutions on co-production barriers • Autistic-led organisational training to institutions on co-production barriers and enablers • Cross institutional education on co-production practices • Cross institutional replication of co-production practices

4.2 Careers, employment and workplaces

> *"I was never approached to do any post-doc work and had no idea how I should have progressed..."*

Barriers and challenges

We heard that career pathways and information about postdoctoral careers are often unclear, leaving autistic PhD candidates unsure about the processes or how to effectively demonstrate their skills when applying for postdoctoral roles. Autistic people also reported health and mental health concerns as barriers to applying for PhD programs, alongside experiences of universities as alienating environments. Participants shared that opportunities for autistic community partners are often unstable, and only casual or short-term contracts.

We heard that a barrier to co-production of autism research is the insufficient number of researchers, including First Nations disability researchers. It was suggested that this shortage may be attributed to difficulties securing funded postdoctoral positions or funding for ongoing roles, resulting in researchers returning to teaching or, for many autistic people, being without employment following PhD completion.

Enablers and solutions

Twenty-five enablers and solutions were generated through the workshops and interviews, and categorised into five sub-themes, as shown in Table 10 below.

Table 10: Insights from co-design workshops and interviews: Enablers and solutions to careers, employment and workplaces

Sub-theme	Enabler/solution
Career development	• Education, events, and information to support autistic students and researchers in navigating academia, applying for and completing HDR study, and exploring postdoctoral career pathways and transitions • Post-doctoral mentoring for autistic researchers • Mentoring for autistic students and early career researchers • PhD positions for autistic people
Employment	• Training course for non-academic autistic people to gain employment in research • Clear and funded employment pathways • Meaningful employment opportunities for autistic people
Support	• Support for autistic researchers, such as navigators • Staff advisors for autistic staff • Social and peer support and networks • Hubs and safe spaces for autistic researchers • Institutional and cross-institutional peer networks for students and researchers • Institutions to develop more inclusive working environments, including for autistic PhD students
HDR and students	• Support for autistic Higher Degrees by Research (HDR) students, including peer support • Positive relationships between PhD candidates and supervisors • Training and support for PhD supervisors in co-production • Evaluation of student support services • Participatory research experience as recognition of prior learning for community partners • Requirements in PhD applications to develop participatory research skills • Part time scholarships for autistic people
Workforce	• Autistic people employed at universities • Invest in disability researchers, including younger and early career researchers • Increase the number of disability researchers • Clear and funded research career pathways • Research career pathways for autistic people

4.3 Power, tokenism and meaningful engagement

> *"Involvement without the ability to make or influence decisions can be tokenistic and erode trust and relationships."*

Barriers and challenges

In the workshops, participants shared that autistic people are often not meaningfully included as members of research teams. Instead, involvement was frequently characterised as superficial or tokenistic, with autistic people positioned as research participants or advisors rather than genuine research partners. It was suggested that this leads to community members feeling unheard, dismissed, or as though they did not belong.

We also heard about perceived hierarchies within research settings that privilege academic credentials, and assumptions that autistic people without university degrees have little to offer. These experiences were described as contributing to autistic individuals' feelings of being undervalued, not seen as accomplished or not experienced enough. Participants described researchers as holding most of the power within teams, with autistic community members having

limited influence over decisions, which often resulted in researchers defaulting to established or familiar research practices, pre-determined methods, and fixed levels of engagement.

Participants further reported significant power imbalances within teams, sometimes described as creating an “us versus them” dynamic between researchers and autistic community members. While autistic researchers were perceived as holding more power than non-academic community members, it was noted that the autistic researchers could still be sidelined by non-autistic researchers. Difficulties with communication were also raised, with academic language and content described as inaccessible or intimidating for some community members. Autistic participants also shared experiences of their ideas and positions being dismissed when they did not align with dominant narratives.

Addressing these power dynamics was described as challenging. Participants suggested that some researchers may be reluctant to have their authority questioned or to relinquish control. We also heard that autistic community members may find it difficult to take on power and may expect researchers to lead. Co-production itself was described as an approach that challenged established academic norms for planning, communicating, and conducting research, which participants felt compounded these difficulties.

Participants also reported that research was frequently pre-planned without community engagement, and that autistic people were rarely listed as investigators on grants. Involvement was often described as occurring after funding had been awarded, typically to review already designed projects rather than to shape project inception or planning. When autistic people were involved, participants reported that this involvement was often limited, inconsistent across the research lifecycle, or lacking clarity about how contributions were incorporated or followed through.

Autistic participants noted that their contributions were often unacknowledged, reflected in limited co-authorship, lack of shared recognition or awards, and inadequate remuneration. Experiences of exclusion among community members were also described, including being excluded from meetings, specific stages of research, or being confined to narrow roles that did not reflect their skills and strengths. Further, research conferences were indicated by autistic community members as largely inaccessible, citing barriers such as inaccessible registration and information, poor sensory accommodations, unsuitable food options, limited support, alongside challenges related to travel, location, and formats. Low autistic representation and harmful or poorly informed discourse at conferences contributed to feelings of exclusion, while presenting at conferences was described as particularly challenging due to anxiety, lack of confidence, short formats, audience interaction, and the emotional impact of presenting.

Overall, we heard that these practices as contributing to research that did not adequately reflect lived experience, were perceived as less impactful and reduced the likelihood of autistic community members would choose to participate or engage in future research.

Enablers and solutions

The workshop and interview data indicated 31 enablers and solutions related to the theme of power-tokenism and meaningful engagement. The have been categorised into five sub-themes, as shown in Table 11.

Table 11: Insights from co-design workshops and interviews: Enablers and solutions related to power, tokenism and meaningful engagement

Sub-theme	Enabler/solution
Autistic leadership and empowerment	• Autistic people to have project governance and research leadership roles • At least two autistic community partners within research teams • Empower and develop confidence in autistic partners
Shared power and decision making	• Identifying the power dynamics and address power imbalances • Inclusion in the research team • Share roles, decision making, problem solving and responsibilities • Involvement in all activities • Autistic community-led dissemination
Recognition and acknowledgment	• Acknowledge and value community partner contributions, including co-authorship on publications and on awards • Standards for acknowledgment and recognition • Recognise and utilise the skills and strengths of autistic people in data collection, analysis and dissemination • Elevate the status of autistic community partners, including through appropriate role titles
Respect	• Listen and respect autistic community partners • Use respectful language guidelines • Value autistic people as people
Transparency, communication and accountability	• Accountability processes for feedback and input • Provide clear and transparent information about expectations, roles, titles, payment, meetings, responsibilities, feedback, processes • Ongoing communication about project progress and updates • Defined roles • Conflict resolution processes • Autistic community partners need to understand roles and the research
Conferences and events	• Support for conference participation including venue walk-throughs, designated support staff • Quiet and autistic-only spaces • Training for event staff • Online conferences • Option to present live or pre-recorded • Accessible information • Plain language presentations • Slower paced conferences • Autistic-led or co-led conferences • Presentations co-presented with autistic community members

4.4 Ethics committees and ethical considerations

> *"...ethics committees putting up great obstacles re: inclusion that prevent it happening"*

Barriers and challenges

Participants shared that research co-production necessitates the submission of ethics applications, which are often difficult to secure approval for. We heard that ethics committees: have a limited understanding of co-production, its value and necessity, often misinterpreting it as data collection; view co-production as a risk; and, hold perceptions of autistic people as "vulnerable." This results in the imposition of additional requirements, or rejection of applications. Participants also reported additional ethics committee challenges when collaborating with children, individuals with

co-occurring conditions, or in countries where formal diagnoses and guardian consent are required for autistic community partners.

Participants also raised concerns about relational ethics of care, particularly where community engagement was perceived as tokenistic rather than meaningful, and the grief experienced by community members when research projects conclude. In addition, we heard that for researchers, hearing community partners' experiences of trauma can have emotional impacts, highlighting a need for appropriate support.

For autistic individuals, being in a research space which is often ableist, or exposed to research that is not neurodiversity-affirming, was reported as confronting and exhausting. They also shared concerns about confidentiality, disclosure, the sharing of personal experiences or information, and the risks of being publicly identified as an autistic health professional or researcher.

Enablers and solutions

Twenty-nine enablers and solutions were generated through the workshops and interviews, and categorised into four sub-themes, as shown in Table 12 below.

Table 12: Insights from co-design workshops and interviews: Enablers and solutions to ethics committees and ethical considerations

Sub-theme	Enabler/solution
Ethics and HRECs	• "Minimum standards" for HRECs • HREC reviews to assess approaches, accessibility, team supports, and remuneration for autistic collaborators • HREC approach for marginalised groups like ATSI research • Embed questions in ethics applications about community involvement • Requirements for HREC's to read autism language guidelines • Ethics application requirements for researchers to read and agree to respectful language guidelines and undertake co-production training, and include roles and titles • Researchers could use appropriate co-production language in ethics applications • Diversity in HREC membership, including autistic members and a recruitment platform • Autistic HREC committee
Education, support and resources	• Co-production education, training and resources for HRECs • HREC recognition of autistic people as valued team members • HREC understanding of participants vs. collaborators • Meetings with HRECs to educate about co-production and benefits • Neurodiversity-affirming practice training for HRECs • Educate and train community partners on ethics processes • Admin training and support for researchers for HREC processes
Mental health and wellbeing	• Access to university counselling services for autistic community partners • Wellbeing and mental health planning and support for all team members, including consideration of the emotional labour for community members • A dedicated person for autistic collaborators to talk to for support • Offering debriefs and check-ins for support • Ability to leave the project if needed • Risk mitigation for potential grief and impact when the project ends • Team member skilled in mental health first aid
Ethical practice	• Neurodiversity-affirming research • Researcher training for ethical approaches • "Safe spaces" for autistic collaborators • Mitigation of the risk and impact of collaborator grief when the project ends • Trauma-informed approaches • Option for autistic community partners to be anonymous

4.5 Diversity, intersectionality and representation

> *"...you get the privileged voices speak and the disadvantaged and more vulnerable voices are not heard"*

Barriers and challenges

Participants reported concerns about limited diversity and representation among autistic community partners in co-produced autism research. They noted that many perspectives are missing or rarely invited, including those of children, ageing autistic people, individuals with high and complex support needs and/or intellectual disability. We heard that intersectionality is often overlooked, and was itself a barrier to engagement, particularly for non-speaking autistic people, First Nations autistic people, and culturally and linguistically diverse (CALD) autistic people.

It was reported that researchers are more inclined to collaborate with autistic people with lower support needs, and often rely on the same individuals for co-production, with limited efforts to seek out new or more diverse perspectives. Further, autistic community members who reflected the populations being studied were not consistently engaged, collaborators were sometimes selected without lived expertise aligned to the research focus, and those without professional expertise were chosen over those who do. In addition, concerns were also raised about the implications for autistic community members who do not identify with the leading autistic voices within the community, and that there is limited autistic representation at conferences.

We heard however, that there is a lack of understanding and training for researchers working with specific communities, including people with intellectual disability. Further, there is a limited pool of autistic community members with specific areas of expertise, which was linked to existing barriers to higher education for autistic people.

Enablers and solutions

Through the workshops and interviews, 16 enablers and solutions were generated related to the theme of diversity, intersectionality and representation. They have been categorised into four sub-themes, as shown in Table 12.

Table 12: Insights from co-design workshops and interviews: Enablers and solutions to diversity, intersectionality and representation

Sub-theme	Enabler/solution
Deliberate and targeted recruitment	• Specifying diversity markers, asking questions and using demographic matrices in recruitment • Targeted recruitment for diverse representation • Community partners representative of the research topic • Partnerships with lay community members
Partnerships with unrepresented groups	• Support underrepresented groups to lead or co-lead research (e.g. people with intellectual disability, non-speaking autistic people, Aboriginal and Torres Strait Islander) • Prioritise partnerships with underrepresented groups
Capacity building and supports for engagement	• Increase understanding of reaching and engaging underrepresented groups • Collaborate with peak bodies to understand the reasons for underrepresentation • Seek engagement guidance from diverse groups • Researcher training for working with people with high support needs people, including AAC users • Provide supports and accommodations for diverse groups • Longer project timelines and increased to enable engagement with diverse groups
Diversified engagement	• Collaborate with more community partners • Prioritise diverse representation and diverse groups of collaborators • Diversity of lived experiences and intersectionality amongst community partners • Expand engagement through time-limited opportunities and/or groups of advisors

4.6 Knowledge, skills and training

> *"...it was nowhere in the sort of formal structured training that I received as part of a PhD program..."*

Barriers and challenges

We heard that there is a lack of understanding, knowledge, skills, and confidence related to research co-production. This includes limited understanding of partnerships, how to undertake co-production, and recognition that co-production is an ongoing process. Formal training opportunities are scarce or inadequate, and co-production is largely absent from higher education curricula, particularly post-doctoral training. Participants shared that resources and information on co-production are limited, and of varied quality and content. There is a lack of clear guidance, definitions, and standard protocols, particularly in the basic sciences, as well as the presence of ill-defined or misunderstood terms.

Researchers noted that it is difficult to know what resources exist or how to assess their quality, with concerns raised about relying on documented experiences in journal articles. This was considered to contribute to poor implementation and an over-reliance on familiar approaches. Researchers were described as having limited experiences or interactions with autistic people, as well as a lack of understanding of autism, and lacking interpersonal and general skills required to work with autistic people. Participants reported that outside of Autism CRC's Sylvia Rodger Academy's Research Program, there is a lack of training opportunities specifically for autistic people. Autistic people described the research knowledge they do have as being limited and obtained through self-directed learning. For researchers, finding the time and capacity to reflect, learn, and upskill can be challenging.

Enablers and solutions

The workshop and interview data indicated 23 enablers and solutions related to the theme of knowledge, skills and training. They have been categorised into four sub-themes, as shown in Table 13.

Table 13: Insights from co-design workshops and interviews: Enablers and solutions to knowledge, skills and training

Sub-theme	Enabler/solution
Evidence-base	• Case studies of co-production available outside of journals • Research on the benefits and value of co-production to build an evidence-base, including for use with ethics committees
Education, training and upskilling	• HREC and funding requirements training to include co-production • Co-production education and training for researchers, community members, university administration staff and students, including: – online workshops and courses – community workshops – conference-based masterclasses. • Research skills training for community members, including presenting, grant writing, data analysis and collection • Upskill researchers in autism, plain language, collaborations, co-occurring conditions, and co-leadership • Education, capacity building, training, upskilling and professional learning opportunities are offered in different formats and settings • Embed co-production education in curricula • Institutional academic-led training for students and early career researchers • Upscale Autism CRC's Sylvia Rodger Academy Research Program, including an online-only offering • Cross-institutional education • Scholarships and grants for upskilling • Shared responsibility across teams for upskilling
Peer learning and support	• Mentoring and peer support for community members and researchers, including PhD students • Opportunities for peer learning, connection, reflection and knowledge and experience sharing • Sharing of case studies outside of journals • Support for researchers
Resources	• Ethical framework for co-production • NHMRC guidelines for co-production • Co-produced resources, guidelines, checklists and definitions, including 'gold standards' and 'how to' guides • Communities of practice and resource hub for co-production • Customisable recommendations and options for co-production • Autism CRC hosted resources

4.7 Funding and remuneration

> *"..autistic people not being named chief/associate investigators on grants, and are engaged only after funding is awarded/project starts"*

Barriers and challenges

In the co-design workshops and interviews, funding was identified as a significant barrier to co-production. We heard that funding bodies are largely indifferent to co-production, fail to recognise its true costs and are often unwilling to fund it. When co-production is included, it is designed to support "tick box" engagement. Participants raised concerns that funding bodies may prioritise cost savings and view co-production as a reputational risk. Access to funding was described as challenging, with limited funding and information about grant opportunities, the need for larger grants to fund co-production activities, alongside lack of funding body interest in dissemination, knowledge translation, autism research, or fields outside of medical research. Difficulties in securing grants were also described, including challenges obtaining ongoing funding, repeated unsuccessful applications leading to exhaustion, and limited grants supporting co-production. Researchers noted that funding is often awarded to the same teams or well-established researchers.

When applying for grants, researchers reported that they included co-production activities in application frameworks that did not explicitly allow or support them. Other additional challenges identified included: engaging autistic people in planning and grant writing without funding in place to remunerate them; inability to list autistic community members as investigators; and a lack of governance and leadership to support co-production.

We heard that when research is funded, budgets are constrained with limited or no funding for co-production, dissemination, or the remuneration or upskilling of autistic community partners. This includes funding for autistic community members to attend and co-present at conferences. A lack of understanding about fair remuneration for community members was reported, with remuneration often being delayed, or unpaid. In the absence of funding, we heard people don't get paid, that autistic researchers self-fund their projects, and that researchers lack creativity and flexibility in ensuring that autistic community members are appropriately compensated. Outside of funding bodies, we heard there is a lack of long-term or ongoing funding, and limited in-kind support from universities.

Enablers and solutions

The workshop and interview data indicated 27 enablers and solutions related to the theme of funding and remuneration. They have been categorised into four sub-themes, as shown in Table 13.

Table 13: Insights from co-design workshops and interviews: Enablers and solutions to funding and remuneration

Sub-theme	Enabler/solution
Advocacy	• Advocate to government ministers and funding bodies • Media advocacy to highlight the lack of co-production in grants • Advocate to funding bodies for co-production and dissemination requirements
Remuneration	• Adequate and fair remuneration for community members • Community members are paid at the same rate as researchers • Remuneration to include grant writing, conference attendance and presentations • Alternative and creative methods of remuneration, including waged salaries, gift cards and honorariums • Duty of care by funding bodies to prevent unremunerated or undisclosed unpaid work • Remuneration standards, including for lived experience expertise • Transparency in publications about payments and funding • Transparency in funding allocation • Co-production with a single autistic community member
Grant requirements	• Government funded research requirements for co-production and remuneration • Grant requirements for reporting, co-production, payments and remuneration • Co-production guidelines, standards and criteria for grants • Embed co-production questions into grants • Realistic and flexible budget allocation for co-production in grant submissions • Extended time between funding announcement and proposal deadline, and project timelines to enable co-production • Autistic grant reviewers
Funding	• Independent co-production funding body • Seed funding for ECR's and PhDs for co-production • Seed funding for planning co-production • Grants for relationship building and community partnerships • Dedicated funding and funding streams for co-production • Scholarships tied to co-production • EOI-based grants with seed funding for shortlisted applicants • Increased funding and improved funding systems

4.8 Establishing and maintaining connections and partnerships

> *"...I never know how to get involved in research teams and I never know what research is going to be done or is being done."*

Barriers and challenges

Despite a desire to connect with the autistic community, **researchers** reported that initiating engagement can be challenging due to a lack of existing community connections, limited awareness of interested parties, and an absence of networks. Researchers also described hesitation to engage with the autistic community if funding has not been secured, as well as concerns about consultation fatigue and not wanting to overburden community members.

We heard that for **autistic community members**, connecting with researchers can be difficult due to the exclusivity of research and a lack of engagement pathways for those not affiliated with universities, or those not already known to researchers. Finding opportunities was considered challenging due to a lack of awareness, researchers' reliance on social media recruitment, and unclear recruitment information, including uncertainty about eligibility for those who self-identify.

Autistic community members also reported being excluded from opportunities due to not having enough research experience and knowledge.

It was also suggested that, for autistic community members, there were limited opportunities to connect with one another within research contexts. This was also a consideration for early-career researchers due to researchers often working in silos or smaller teams, as well as to a lack of awareness of connections for dissemination or knowledge translation. We heard that for **autistic researchers**, building relationships with other researchers can also be difficult, particularly following periods of absence from research.

Participants described a lack of community trust towards researchers, due to historical and ongoing harm, as well as the sharing of negative research co-production experiences amongst the autistic community. Additional barriers to building connections included misalignment between research agendas and community priorities, with autistic people reporting that research often feels focused on academic outcomes rather than community benefit. Participants reported a lack of mechanisms to facilitate relationship building between researchers and the autistic community. Developing relationships was described as taking time, particularly longer for individuals with higher support needs. Additional challenges to building relationships include lack of funding, time, and opportunity.

The absence of established relationships was reported as making it more difficult for researchers to respond to funding opportunities. Once relationships were established, we heard that they can be difficult to maintain due to time, limited funding, and the cyclical nature of research projects. When relationships are not sustained, this can be interpreted by autistic community members as a loss of interest, leaving individuals feeling they have been “left hanging.”

Enablers and solutions

The workshop and interview data indicated 27 enablers and solutions related to the theme of establishing and maintaining connections and partnerships. They have been categorised into five sub-themes, as shown in Table 14.

Table 14: Insights from co-design workshops and interviews: Enablers and solutions to establishing and maintaining connections and partnerships

Sub-theme	Enabler/solution
Relationship building and maintaining	• Dedicated funding or utilise funding to build relationships • Dedicate time and establish opportunities and mechanisms to build and maintain relationships, and embed this in projects • Support team building through celebrating project milestones and connecting post project • Create neurodiverse teams to support relationship building and maintaining • Evaluate partnerships and engage in reflective and reflexive practices • Establish relationships before planning and grants • Smaller teams to support relationship building and maintaining
Trust and reputation	• Trust, effort respect and mutuality • Opportunities shared by trusted person • Safe organisation as the 'home of the project' • Having a positive reputation as a researcher
Infrastructure and mechanisms	• Matching services, networks and databases and/or platform for those wanting to engage in co-production • Capitalise on ECR and HDR drive • Have a neutral 'go to person' • Dedicated recruitment body or community partnership to connect and facilitate partnerships • Establish connections and networks • Recruit through Autistic team members, colleagues and/or consumer and community groups and organisations • Autism CRC funded to provide community partners • EOI processes for co-production opportunities • Support and guidance for researchers and community members on building and maintaining relationships • Universities to directly advertise • Educate university career services about opportunities
Pathways to Engagement	• Broad advertisement of opportunity inside and outside of academic settings, including autistic spaces • Diverse reach including local disability organisations • Invite for opportunities • Opportunities for Autistic community member input into research topics • Pathways for research topic consideration and to apply for grants • Diversify research topics • Networking events for researchers and autistic community members • Present autism research at non-autism conferences • Pool of ready autistic community members e.g. 'Research buddies' CCI Program • Network of autistic researchers to collaborate with • Autistic community members being known to researchers
Capacity building	• Education and educational events about partnerships and relationship building • Build capacity and support research teams • Researchers to build relationships and networks with other researchers

4.9 Managing and maintaining engagement

> *"Researchers engage and commit to co-design work because they are committed, but unfortunately their workloads become unmanageable..."*

Barriers and challenges

Participants consistently described time as a significant barrier to, and ongoing challenge in, co-production, with co-produced research taking longer overall. This barrier was reported to impact the time available for project delivery, and specifically, for reviewing materials, meaningful community engagement, and creating pressure for teams. Managing community engagement and input in group settings was reported as challenging, including organising meetings, or navigating dominant voices.

Autistic community members reported that ongoing involvement can be affected by fluctuating capacity, limited time, work and caring responsibilities, and consultation fatigue. Engagement is further impacted by funding constraints and the lengthy nature of research cycles, particularly during dissemination and publication processes. Participants noted that autistic community members bring diverse needs, preferences, life experiences, and levels of research familiarity. Researchers reported difficulty meeting these varied needs, sometimes resulting in unsuitable forms of engagement or exclusion. They described that adapting, communicating, or translating research materials—particularly for individuals with intellectual disability or higher support needs—into accessible formats such as Easy Read or visuals requires time, skills, and funding that are often unavailable. Additional challenges were reported when collaborating with individuals with higher support needs, including navigating the involvement of parents and carers, and a lack of recognition of the additional time required. Autistic participants described information as being inaccessible, confusing or difficult to understand, reported inadequate support, and expressed uncertainty about their roles, expectations, and contributions.

Autistic participants also reported feeling overwhelmed during certain activities, such as data analysis or dissemination. They also described their lack of confidence and challenges giving input, often holding back ideas or suggestions due to concerns or uncertainty about how their input would be received or understood. Further, they reported challenges related to being authentic, anxiety, and rejection sensitivity. Researchers reported difficulties working with community partners who are unfamiliar with research processes, with autistic collaborators often lacking confidence due to not being "researchers". For autistic researchers, it can be challenging to refamiliarise themselves with research language after a period of absence.

We also heard that researchers may underestimate the importance of communication, or perceive it as burdensome, resulting in a lack of communication with community partners about key information, including updates, progress, decisions, and role clarity. This could be attributed to time pressures and assumptions that community members were already aware of such information. Autistic participants noted that if engagement was not done well, they would be reluctant to engage in future projects.

Enablers and solutions

Thirty-six enablers and solutions were generated through the workshops and interviews, and categorised into four sub-themes, as shown in Table 15 below.

Table 15: Insights from co-design workshops and interviews: Enablers and solutions to managing and maintaining engagement

Sub-theme	Enabler/solution
Planning and time	• Plan for co-production from the start and embed it in project design • Plan for and prioritise dissemination and knowledge translation • Ensure appropriate methodology • Build in more time and longer timelines • Apply for grants with longer timelines • Allow more time for planning, co-planning and engagement • Collaboratively define success for the team • Build flexibility into timelines and adapt as needed • Understand and plan for co-occurring conditions, individual needs and preferences • Additional funding to support time and engagement • Mentoring, training, and resources for teams to undertake planning • Funding and resources for accessibility
Project management	• Employ and assign people to specific tasks (e.g. dissemination roles) • Communications officer for dissemination • Maintain communication with community members • Confirm engagement commitments • Communication bridge/translator/go between/neutral 'go to' person between community members and researchers • Engagement officer to liaise with the research team • Key contact for the project • Understand the strengths of autistic community partners
Supports and accommodations	• Individualised and appropriate supports • Allow support people and appropriate breaks in meetings • Use of technology to support accessibility • Improved accessibility and inclusion • Autism-knowledgeable researcher or autistic person to guide supports • Check-ins with autistic collaborators • Person-centred approach
Engagement and communication	• Diverse, accessible, flexible, appropriate, creative and preference-based ways of working and engagement • Small group or one-on-one engagement to provide information and talk through processes • Accessible information and communication (e.g. Easy Read, videos, visual formats, descriptions, subtitles, screen reader compatible) • Adequate processing, response and preparation time • Information and agendas provided in advance • Transparent and explicit communication about expectations, remuneration and processes • Opportunities for autistic community partners to ask questions • Build rapport • User testing of communications with autistic community partners

4.10 Attitudes, awareness and recognition

> *"...the biggest issue is the university's mindset around to be honest, the value of autistic researchers."*

Barriers and challenges

We heard that the attitudes and mindsets of some researchers can act as a barrier to co-production, particularly where there is resistance to different ways of working and a preference for familiar or more comfortable forms of community engagement and research methods. It was noted that internal reflection is needed for researchers and that negative experiences with participatory approaches can dissuade them for further attempting such approaches. Some researchers were described as holding assumptions about which topics are important, that co-production must involve autistic researchers rather than lay community members, and that it was the responsibility of autistic researchers.

For researchers working in basic or foundational science, co-production was described as particularly challenging, as research methods were perceived to be less accessible to community members. However, it was also indicated that there is a belief that co-production, particularly in fields such as neuroscience is too difficult to undertake, or that autistic collaborator expertise in these areas is a required. Participants described a lack of evidence of the value and impact of co-production and a lack of public awareness of co-produced research.

It was suggested that there are assumptions that autistic community partners want to be publicly identified and acknowledged as autistic. Participants also reported that some researchers hold stigmatising views of autistic people, including assuming they are not autistic, or believing they have high levels of knowledge and understanding of autism and how to work with autistic people. In autism research, autistic people reported feeling that their voices are often drowned out by non-autistic perspectives, with their experiences filtered, reframed, or assumptions made. We heard that there is a disregard, lack of recognition and valuing of autistic lived experience and expertise, with autistic community partners employed on hourly contracts feeling that they are often perceived as less valuable and not worthy of investment or training. Researchers may also hold patronising assumptions, such as the belief that autistic people need to be handled "gently" or are not able to understand or contribute meaningfully.

We heard that although dissemination is considered the "best" aspect of co-production, journals often lack an understanding of co-production, and there are limited requirements for transparent reporting of participatory methods. Where reporting requirements do exist, participants shared that this can sometimes result in the reporting of non-genuine co-production.

Enablers and solutions

Through the workshops and interviews, 26 enablers and solutions were generated related to the theme of attitudes, awareness and recognition. They have been categorised into five sub-themes, as shown in Table 16.

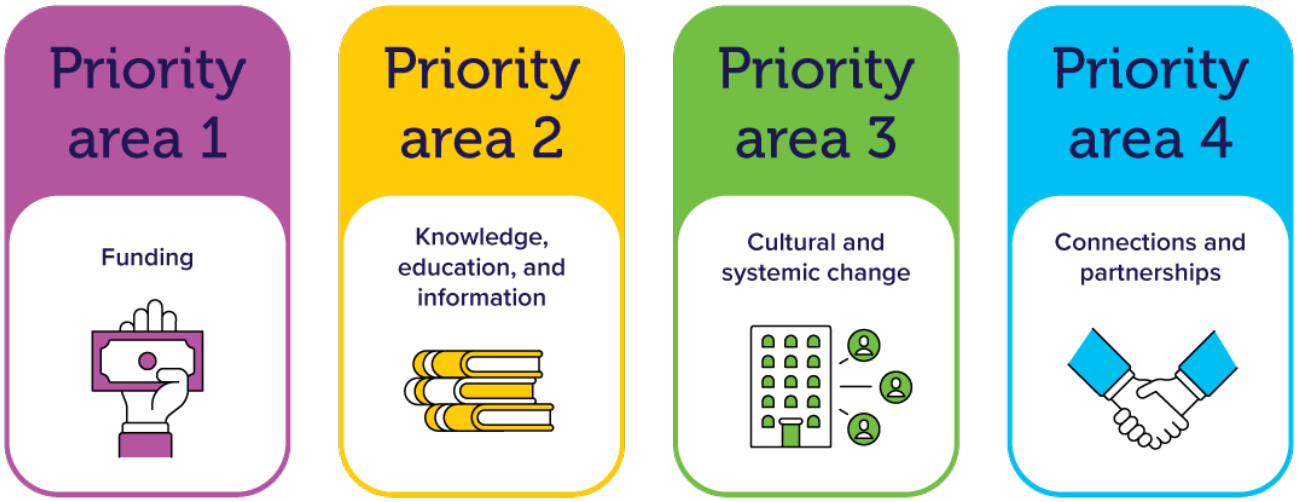
Table 16: Insights from co-design workshops and interviews: enablers and solutions to attitudes, awareness and recognition

Sub-theme	Enabler/solution
Valuing co-production	• Awareness and recognition of co-production by funding bodies and universities • Educate researchers on the value of co-production • Demonstrate to universities the benefits and importance of co-production • More awareness about benefits of co-production • Promote the benefits of co-production, including in conference presentations • Include co-production in research strategies
Value of lived experience	• Events that centre lived experience • Universities to value autistic researchers • Destigmatise autism and autistic people in autism research and research spaces • Value experiential expertise
Representation and visibility	• Increased autistic representation at conferences • Increase visibility and respect towards autistic people • Autistic representation in research spaces • Autistic community focused and centred conferences and events
Mindset shift	• Shift researcher attitudes • Research leadership narratives • Use documented co-production in publications to counterargument against ethics committees • Shift in academia to ensure co-production as the norm rather than an exception • Accept that not all researchers will do co-production
Recognition	• Co-production awards that recognise researcher and community partners • Celebrate cross institutional collaboration • Celebrate autistic researchers
Publications	• Mandate reporting of co-production in journals • Peer reviewers to encourage reporting of co-production • Outcome measures of co-production in journals • Document participatory research experiences in papers

5. Recommendations

The findings outlined in Sections 4 and 5 demonstrate that the barriers as well as the potential enablers and solutions to support autistic co-production and co-leadership operate across funding systems, institutional structures, research culture, and everyday research practice. No single action or stakeholder can address these challenges in isolation. The recommendations that follow identify coordinated, systems level actions across four priority areas to support more consistent, ethical and impactful autistic co-produced and co-led autism research.

Figure 4: Priority areas for increased co-production and co-leadership of autism research



5.1 Priority area 1: Funding

Why it matters and what needs to change

Findings from the co-design workshops, interviews and literature indicate that current funding systems and grant administration processes represent some of the most significant structural barriers to meaningful autistic co-production and co-leadership in autism research. Across sources, funding models were found to exclude or constrain autistic involvement in grant development and project leadership roles, impose restrictive timelines, and inadequately resource projects including for accessibility, relationship building and fair remuneration. Competitive funding environments, limited opportunities, and limited funder understanding and recognition of participatory research approaches further entrench tokenistic involvement, limit engagement and constrain genuine collaboration. These insights point to a clear need for coordinated reform of funding systems and grant administration to enable co-produced research to be planned, resourced and governed in ways that are responsive to lived experience expertise and supportive of autistic co-leadership.

Recommendation 1: Reform funding systems and grant administration to enable co-production and co-leadership

Who needs to act

Responsible stakeholder

Government and **funding bodies** - to reform funding mechanisms and grant structures, grant administration and governance arrangements to require and resource co-production and co-leadership of research.

Enabling stakeholders

- **Universities and research institutions** – to align internal grant support, opportunities, finance and governance systems.
- **Researchers and research teams** – to design and deliver co-produced research within reformed funding frameworks.
- **Community members, families and community organisations** – to inform research and funding priorities, co-lead projects, contribute to grant development and advocate for reform.

What this might look like in practice

Funding mechanisms and structures

- Proactively promote grants via accessible and diverse channels, targeted outreach and clear guidance on eligibility and application processes.
- Introduce dedicated seed and early-stage funding streams that provide resourced time, remuneration, and accessibility supports for community members to engage meaningfully in grant development. These programs could build upon existing co-production seed funding initiatives such as those administered by the National Disability Research Partnership (NDRP), the National Centre of Excellence in Intellectual Disability Health, and the University of New South Wales (UNSW) Disability Innovation Institute.
- Establish and expand funding schemes and grant programs that explicitly support co-produced research and co-leadership, with guidelines that explicitly encourage and provide for activities related to: accessibility, relationship building and community engagement; community member conference attendance and participation; and upskilling for both researchers and community members. This action may be informed by existing initiatives, such as the National Disability Conference Initiative, conference grants and scholarships offered by the International Society for Autism Research (INSAR), the Australian and New Zealand Mental Health Association and the Disability Research Leadership Program by National Disability Research Partnership (NDRP).

Grant administration and governance

- Develop and mandate a grant administration framework for research that embeds the principles of co-production and co-leadership across funding design, assessment and reporting processes. This framework may build upon existing models, such as those

developed by Autism CRC, the National Disability Research Partnership (NDRP) and the NHMRC Policy on Consumer and Community Participation in Peer Review.

- Implement flexible budget and timeline requirements that reflect the realities of co-produced research, recognise its iterative nature and allow projects to evolve in response to lived experience input.
- Revise grant eligibility criteria to enable and support community members to be named as chief or associate investigators and research leaders.
- Mandate clear standards and minimum requirements for co-production, including accessibility, remuneration and diversity, within grant guidelines and assessment criteria. This should align with the Medical Research Future Fund's (MRFF) Principles for Consumer Involvement in Research and build on existing MRFF requirements for Consumer Involvement Statements.
- Introduce accountability mechanisms, requiring funded projects to report on co-production commitments, diversity objectives and intended impacts that are implemented in practice, including clear indicators and examples.
- Embed community member involvement in review and funding decision-making processes, ensuring appropriate support and remuneration. This might leverage Autism CRC's long-standing model of autistic participation in research funding governance, mirrored in the more recently established National Disability Research Partnership (NDRP), as well as the Medical Research Future Fund's (MRFF) Grant Assessment Committees.

5.2 Priority area 2: Knowledge, education and information

Why it matters and what needs to change

Findings from the co-design workshops, interviews and literature consistently highlight interconnected and widespread gaps across the research system in knowledge, skills, confidence, and shared understanding of co-production, including ethical co-produced research. These gaps are compounded by limited consensus on what meaningful co-production entails and how to implement it, inconsistent terminology, and scarce access to resources, guidance, training, education and few opportunities to upskill.

Importantly, findings indicate that training and guidance alone are insufficient for sustained change, with researchers and autistic community members experiencing isolation and limited opportunities for peer learning, reflection and practice-based knowledge sharing. Combined with limited experience, these conditions contribute to uncertainty, misunderstandings, poor implementation, variable quality, the persistence of tokenistic approaches, and an over-reliance on familiar forms of community engagement. These findings call for coordinated action that combines clear, evidence-based standards, practical guidance, comprehensive education and training, and ongoing opportunities for shared learning. This approach would provide a shared foundation for consistent co-production practice across the research system, while building capability across stakeholders and career stages.

Recommendation 2: Establish clear, evidence-based standards, guidelines and frameworks for research co-production

Who needs to act

Responsible stakeholder

Government - to commission and fund the development of standards, and officially endorse and mandate the adoption of nationally consistent guidance for all relevant research activities.

Enabling stakeholders

- **Funding bodies** – to embed standards within grant requirements, guidelines, eligibility requirements, assessment criteria and reporting.
- **Universities and research institutions** – to align internal policies, strategies, infrastructure and training with co-production standards.
- **HRECs (Human Research Ethics Committees)** – to integrate standards into ethics review processes and guidance.
- **Researchers and research teams** – to apply standards in research design and delivery.
- **Journals** – to strengthen transparency and reporting for co-production.
- **Community members, families, and community organisations** – to inform expectations for engagement, advocate for co-production and support accountability.

What this might look like in practice

- Develop and publish clear principles and shared definitions of meaningful co-production and co-leadership, to be adopted within funding guidelines, institutional and journal policies and research governance processes. This should be consistent with the NHMRC's Statement on Consumer and Community Involvement in Health and Medical Research (currently in review).
- Produce practical "how-to" guidance outlining approaches for embedding co-production across research settings, stages of the research lifecycle and disciplines, including biomedical and foundational sciences. This may build upon existing guidance, such as Autism CRC's Participatory and inclusive Autism Research Practice Guides and implementation resources, and the UNSW Disability Innovation Institute's co-production guidelines.
- Establish fair remuneration frameworks for community members, that recognise lived experience expertise.
- Produce and implement standards for accessible participatory research practice, including clear expectations and processes for communication, engagement methods, reasonable adjustments and ongoing accessibility planning.
- Develop guidance to support consistent recognition of community members, including appropriate roles, titles, and authorship arrangements.
- Issue guidance and standards for accessible and inclusive research conferences and events, covering both attendance and presentation. This could extend existing guidance, including the Australian Psychological Society's Neurodivergent-inclusive Event Guidelines, the Department of Health, Disability and Ageing's Good Practice Guidelines for Engaging with

People with Disability and Autism CRC's Guidelines for Creating Autistic Inclusive Environments.

- Develop guidance for ethical research co-production, addressing vulnerability, confidentiality, duty of care, potential impacts on community members, and the use of trauma-informed and neurodiversity-affirming practices. Autism CRC's project report, Participatory Approaches in HREC processes, recommends co-produced published guidance on ethical autism research for autism researchers, autistic individuals, HRECs, universities and institutions. This may draw on UNSW's Disability Innovation Institute's Guidance on Ethical Issues in Co-production and should be consistent with NHMRC's 2025 National Statement on Ethical Conduct in Human Research.

Recommendation 3: Build co-production capability through coordinated education and training

Who needs to act

Responsible stakeholder

Universities and research institutions, with support from **government and funding bodies**, to embed education and training within research systems and career pathways.

Enabling stakeholders

- **Researchers and research teams** – to develop skills and apply co-production in practice, including in student research supervision.
- **Funding bodies** – to resource, require and incentivise participation in co-production education and training.
- **HRECs** – to strengthen committee members' understanding of co-produced research.
- **Autistic people, families, and community organisations** – to develop co-production and research skills and apply in practice as community partners and co-leaders.

What this looks like in practice

- Design and deliver targeted co-production training programs for researchers, supervisors, students, community members, universities, funding bodies and ethics committees. This could build upon and extend existing training initiatives, such as Autism CRC's Sylvia Rodger Academy Research Program and the Western Australian Health Translation Network's (WAHTN) Consumer and Community Involvement (CCI) Program.
- Embed co-production education across different career stages and research disciplines, including discipline specific modules for biomedical and foundational sciences, to ensure relevance and uptake across the research system.
- Create structured opportunities for community members to develop research skills and leadership capacity, including training pathways, mentoring and paid development roles within research projects.
- Deliver training through multiple formats and settings, including online, in person, synchronous and asynchronous options, to maximise engagement, reach, and inclusion. Existing research education models may provide useful examples to explore, including the International Society for Autism Research's (INSAR) approach to pre-conference and

membership-based research masterclasses and workshops, as well as similar offerings by the Australasian Society for Autism Research (ASfAR).
- Expand and strengthen existing research and co-production capacity-building initiatives, such as Autism CRC's Sylvia Rodger Academy Research Program by increasing resourcing, reach and integration with broader research training systems.

Recommendation 4: Sustain learning, quality and consistency of co-production through a nationally coordinated community of practice

Who needs to act

Responsible stakeholder

Government - to commission and fund a national community of practice for co-production.

Enabling stakeholders

Universities and research institutions – to amplify the community of practice.

- **Researchers and research teams** – to engage in reflective practice and shared learning through the community of practice.
- **Community members, families and community organisations** – to contribute lived experience and leadership.
- **HRECs** – to engage with evolving practice.
- **Funding bodies** – to support coordination and sustainability through alignment of funding, expectations and incentives.

What this looks like in practice

- Establish a national coordinated community of practice that enables researchers and community members to access information, resources and upskilling opportunities. This could be facilitated through Autism CRC's Autism CoLab: A Community of Practice for Participatory Autism Research and Translation.
- Embed reflective practice mechanisms to support ongoing learning and continuous improvement in a community of practice, Autism CRC's CoLab being an existing model. This should align with and/or support informal communities of practice within universities and institutions.
- Create formal connection and networking mechanisms by linking individuals, including autistic community members, and research teams across institutions, disciplines and research career stages supporting collaboration, mentoring and dissemination of good practice. Examples of this include Autism CRC's Autism CoLab and within the health sector, a feature of the (WAHTN) Consumer and Community Involvement (CCI) Program.

5.3 Priority area 3: Cultural and systemic change

Why it matters and what needs to change

Findings from the co-design workshops, interviews and literature demonstrate that attitudes, awareness and systemic recognition play a central role in enabling or constraining autistic co-production and co-leadership of autism research. Across sources, autistic lived experience expertise was frequently described as undervalued, with persistent power imbalances and research cultures that prioritise traditional academic authority while marginalising autistic perspectives. Autistic people were often positioned as research participants rather than collaborators or leaders, a position reinforced by scepticism about the value and rigour of participatory approaches. A lack of visible, accessible evidence demonstrating the value and impact of co-produced research contributes to ongoing scepticism and limits uptake across the system. This results in dynamics where co-production is often treated as optional and dependent on individual goodwill, rather than supported through sustainable systems. These insights point to the need for deliberate cultural and systemic change to ensure autistic people, and lived experience expertise, are respected and valued; and co-production is meaningfully embedded and recognised across research systems.

Recommendation 5: Revise ethics application processes and criteria to better support and enable co-production and co-leadership in research

Who needs to act

Responsible stakeholder

Human Research Ethics Committees (HRECs), supported by universities and research institutions, to revise ethics processes and assessment criteria.

Enabling stakeholders

- **Universities and research institutions** – to support ethics reform including consideration of governance arrangements and training.
- **Researchers and research teams** – to clearly articulate co-production in ethics applications.
- **Community members, families and community organisations** – to inform ethics guidance and committee representation.

What this looks like in practice

- Support streamlined and informed HREC review by encouraging clear and transparent documentation of co-production, including ethical considerations and remuneration for community members, within ethics applications. This should align with the NHMRC National Statement on Ethical Conduct in Human Research principles.
- Develop and deliver targeted education and training for HRECs on co-production and ethical co-produced research. Autism CRC's project report, Participatory Approaches in HREC Processes, recommends this be fulfilled by a co-produced, publicly available short e-learning program on autism and participatory research for HRECs and other stakeholders, commissioned and funded by the Commonwealth Government.
- Increase diversity in ethics committee membership by actively including community members, with appropriate support and training. This should align with the governance

responsibilities set out in the NHMRC's National Statement on Ethical Conduct in Human Research guidelines. Autism CRC's project report, Participatory Approaches in HREC Processes, recommends a capacity-building program for autistic adults in Australia and the establishment of a pool of autistic consultants / expert reviewers / potential committee members, commissioned and funded by the Commonwealth Government.

Recommendation 6: Establish, maintain and disseminate an evidence-base demonstrating the value, benefits and impact of research co-production

Who needs to act

Responsible stakeholder

Universities and research institutions, supported by government and funding bodies, to build and maintain the evidence-base.

Enabling stakeholders

- **HRECs** – to support ethical review.
- **Journals** – to publish and promote evidence.
- **Researchers and research teams** – to evaluate and document practice.
- **Community members, families and community organisations** – to support advocacy and accountability.

What this looks like in practice

- Implement systematic evaluation of co-produced research that assesses co-production processes, research outcomes and broader impacts, and involves community members in evaluation design and interpretation.
- Actively disseminate evaluation findings and evidence through public reports, academic and community channels to strengthen awareness of and confidence in the value, quality and legitimacy of co-produced research.

Recommendation 7: Develop manuscript submission guidelines and requirements for documenting participatory methods, including co-production and co-leadership

Who needs to act

Responsible stakeholder

Journals to establish and enforce reporting requirements.

Enabling stakeholders

- **Researchers and research teams** – to document co-production practices.
- **Universities and research institutions** – to recognise co-produced outputs.
- **Autistic people, families and community organisations** – to support advocacy.

What this looks like in practice

- Introduce clear journal reporting requirements requiring authors to describe community members' involvement across all stages of the research lifecycle. Existing initiatives such as the Journal *Autism's* requirements for community involvement statements provide an example.
- Provide structured guidance for authors on documenting co-production practices, including roles and responsibilities, decision-making processes, accessibility measures, remuneration and authorship or acknowledgement of community partners. This should be consistent with the NHMRC's Authorship: A guide to supporting the Australian Code for Responsible Conduct of Research publication.
- Develop guidance and resources for peer reviewers to build understanding of participatory approaches, including co-production.

Recommendation 8: Integrate co-production as a core research practice across institutional infrastructure, policies and systems through sustained investment and governance reform

Who needs to act

Responsible stakeholder

Primary responsibility sits with **universities and research institutions** - to embed co-production within infrastructure, policies and governance.

Enabling stakeholders

- **Researchers and research teams** – to undertake co-production within supported systems.
- **Funding bodies** – to align processes with reformed institutional systems and support consistency in the application of co-production principles.
- **HRECs** – to ensure consistency across systems.
- **Community members, families, and community organisations** – to engage in and/or support opportunities in co-production and participate in governance and advisory roles.

What this looks like in practice

- Streamline institutional processes for hiring and remunerating community members, including simplified payment workflows, clear guidance and timely access to funds to support engagement in co-production activities.
- Establish dedicated internal funding mechanisms, including grants and scholarships specifically to support co-production and related activities, such as upskilling and community engagement.
- Review and update Higher Degree by Research (HDR) structures and requirements to accommodate co-produced research, and provide targeted supervisory guidance, administrative flexibility and institutional support for HDR candidates undertaking co-production. This should be consistent with the NHMRC's Supervision: A guide to supporting the Australian Code for Responsible Conduct of Research publication.
- Embed recognition of co-production within institutional performance frameworks, including promotion criteria, grant assessment criteria and key performance indicators.

- Integrate co-production into higher education curricula and professional development programs, ensuring researchers and students develop the knowledge and skills required for meaningful co-production. Autism CRC's project report, Participatory Approaches in HREC Processes, recommends that this be fulfilled by a co-produced, publicly available short e-learning program on autism and participatory research for autism researchers, autistic individuals, HRECs, universities and institutions.
- Establish an institutionally supported pool of community members to enable timely engagement of community partners. This could be modelled on Western Australian Health Translation Network's (WAHTN) Consumer and Community Involvement (CCI) Program.
- Implement mentoring and peer support initiatives for researchers, HDR supervisors and students engaged in co-production.
- Develop and resource cross-institutional education and training initiatives to build co-production capability, support collaboration and enable the sharing and replication of effective co-production practices. This might be in the form of a community of practice (see recommendation 4), however, requires supportive university and institutional infrastructure and promotion.
- Recognise and reward exemplary co-production practices and partnerships through institutional initiatives, including awards, media profiling, presentation opportunities and formal recognition programs.

Recommendation 9: Promote a research culture and practice that respects, recognises and values autistic people and lived experience expertise

Who needs to act

Responsible stakeholder

Primary responsibility sits with **universities and research institutions** - to lead cultural change, reinforced by funding bodies and journals.

Enabling stakeholders

- **Researchers and research teams** – to shape everyday practice.
- **HRECs** – to uphold inclusive and respectful approaches.
- **Community members, families, and community organisations** – to advocate for recognition and equity.

What this looks like in practice

- Formalise institutional and best practice expectations and practices that recognise lived experience, including the use of appropriate role titles, co-authorship, fair remuneration, and visible contribution statements within research projects and outputs.
- Create formal mechanisms for community member representation in research leadership, and governance structures with clear roles, decision making authority and appropriate support.
- Establish formal pathways for the inclusion of community members in journal editorial and peer review processes, and where appropriate, with clear guidance and support to enable meaningful participation. The *Autism in Adulthood's* journal peer review policy, which includes autistic reviewers, may serve as a model for other journals to build upon.

- Increase the visibility and profile of lived experience researchers and community members by establishing showcases, awards, and leadership opportunities that recognise expertise, contribution and impact. Existing research recognition initiatives include Autism CRC's annual Inclusive Research Practice and Translation of Autism Research Awards; the International Society for Autism Research's (INSAR) approach to autistic conference keynote speakers and their award for autistic researchers; and the Australasian Society for Autism Research's (ASfAR) annual Margot Prior Award for autistic researchers.
- Establish accessibility standards for research environments and activities, including physical and virtual spaces, conferences, meetings, engagement processes and communication formats. This should be supported by clear expectations, resourcing and accountability for compliance.

Recommendation 10: Establish workforce and education planning initiatives to improve retention, and support entry into and progression through research careers for autistic people

Who needs to act

Responsible stakeholder

Universities and research institutions, and the **government** - to design, resource, implement and sustain workforce, education and employment systems that enable autistic participation, progression and leadership in autism research.

Enabling stakeholders

- **Funding bodies** – to shape incentives, expectations and standards through funding, and scholarships and fellowships.
- **Researchers and research teams** – to provide inclusive mentoring and supervision.
- **Community members, families and community organisations** – to inform expectations for inclusion and advocacy efforts.

What this looks like in practice

- Create and support research career pathways for community members across academic and non-academic roles within universities and research institutions.
- Offer higher degree by research scholarships and post-doctoral positions for autistic community members. Examples of non-institutionally affiliated scholarships include Autism CRC's Scholars Program and the National Disability Research Partnership's (NDRP) Disability Research Leadership Program.
- Provide structured education, information, mentoring and career support for lived experience students and researchers to navigate research careers, academia, and post-PhD career transitions.
- Develop or revise organisational policies to support inclusive recruitment practices, reasonable adjustments, and disability workplace inclusion, across research roles. These may be incorporated as an action into university and research institutions' Disability Inclusion Action Plans (DIAP).
- Design and deliver workplace training or resources for staff, including supervisors, human resources, researchers, to improve understanding of autism, and support inclusive

environments for lived experience researchers, staff and students. This may be incorporated into university and research institutions Disability Inclusion Action Plans (DIAP).
- Establish a dedicated peer network for autistic researchers, staff, and students that provides peer support, safe spaces for connection, shared learning, and opportunities to discuss and navigate academic experiences.

5.4 Priority area 4: Connections and partnerships

Why it matters and what needs to change

Findings from the co-design workshops, interviews and literature indicate that effective co-production depends on strong, trusted, equitable, and sustained partnerships between researchers and the autistic community. Across sources, challenges were identified, including experiences of research/er mistrust, power imbalances and tokenistic engagement, identifying opportunities for engagement, lack of clear pathways for connection, lack of understanding of research partnerships and insufficient time and resources to build and maintain relationships. It was emphasised that developing and sustaining research partnerships requires time, funding, reciprocity, transparency, effort, and that failure to invest in relationships contributes to reduced community engagement and underrepresentation of community perspectives in research. These findings highlight the need for supportive infrastructure and sustained individual investment to establish connections, and build and maintain partnerships between researchers and autistic community members.

Recommendation 11: Build and maintain meaningful connections and partnerships between researchers and the autistic community

Who needs to act

Responsible stakeholder

Universities and **research institutions** - to enable and resource partnership-building and maintenance.

Enabling stakeholders

- **Researchers and research teams** – to establish and sustain research partnerships.
- **Community members, families and community organisations** – to establish and sustain research partnerships, and co-lead projects.

What this looks like in practice

- Facilitating structured opportunities to bring researchers and community members together, such as community conversations, networking events, and conferences. This could include embedding a nationally coordinated community of practice (see recommendation 4).
- Actively working to build and restore community trust, including acknowledging and addressing historical and ongoing harms associated with research.
- Recruiting community members through partnerships with trusted organisations, networks, and community groups. An example of this is Autism CRC's Sylvia Rodger Academy which provides opportunities for community members to engage in research and facilitates promotion of external research opportunities.

- Establishing databases, matching services, or linkage mechanisms to promote collaboration and share opportunities. Existing initiatives- such as Autism CRC's Autism CoLab, the International Society for Autism Research's (INSAR) Community Collaborator Request platform and the Consumer and Community Involvement (CCI) Program- may be useful for organisational embedding, promotion and support.
- Actively maintain relationships beyond individual projects, by planning and resourcing team-bonding activities, scheduling regular check-ins, embedding reflective and evaluative practices, and create opportunities for connection throughout and beyond the life of research projects.

Recommendation 12: Establish community engagement and liaison roles to support co-produced research

Who needs to act

Responsible stakeholder

Universities and research institutions - to establish and resource community engagement and liaison roles.

Enabling stakeholders

- **Researchers and research teams** – to work with community engagement and liaison roles to support accessible, ethical, and effective co-produced research.
- **Community members, families, and community organisations** – to engage with community engagement and liaison roles, inform their design and operation, and participate in research partnerships.

What this looks like in practice

- Provide centralised support and practical guidance on accessibility and co-production practices, including advisory services and consultation to research teams.
- Establish dedicated coordination and facilitation roles that act as intermediaries between research and community members, supporting clear, accessible and ongoing communication throughout the research lifecycle.
- Offer hands-on assistance to support researchers and community members navigate institutional processes, including payments, ethics approvals, contracts, accessibility arrangements and reporting requirements.
- Create and maintain structured engagement mechanisms (such as partnership registries, brokerage services or facilitated networks) to enable initial connections and sustain relationships with stakeholders over time.

Recommendation 13: Create equitable partnerships that support meaningful and sustained engagement across the research lifecycle

Who needs to act

Responsible stakeholder

Researchers and research teams, supported by university and research institution systems, to create and sustain community partnerships.

Enabling stakeholders

- **Community members, families, and community organisations** – to inform partnership expectations.
- **Funding bodies** – to reinforce requirements.

What this looks like in practice

- Reduce power imbalances by embedding shared roles, responsibilities, and decision-making structures within research teams, including formal agreements outlining how researchers and community members share authority.
- Project planning that embeds co-production.
- Adopt measures to ensure accessibility and inclusion at every research stage by providing clear information, flexible engagement options, adequate preparation time and individualised supports.
- Establish and document clear, shared expectations for communication, roles, responsibilities, remuneration, decision-making, conflict resolution and implementation of input at the start of each project.

Recommendation 14: Broaden and strengthen the diversity of community members involved in co-produced research

Who needs to act

Responsible stakeholder

Universities and research institutions and **funding bodies** - to enable inclusive engagement through policy, resourcing and expectations.

Enabling stakeholders

- **Researchers and research teams** – to broaden recruitment and engagement and adapt practice.
- **Community members, families and community organisations** – to guide inclusive practice, inform engagement approaches, and partner in decision-making.

What this looks like in practice

- Implement targeted recruitment strategies to engage community members with diverse, relevant lived experience, including tailored outreach, and accessible and culturally appropriate recruitment materials.
- Prioritise partnership and co-leadership with underrepresented groups by actively including community members with higher support needs, intersecting identities, and limited prior research involvement.
- Build researcher capability through structured learning to improve understanding of the needs, experiences, and barriers faced by different community groups in research co-production.
- Adapt engagement approaches to support inclusive and culturally safe participation, including flexible methods, and culturally responsive practices and appropriate supports.

6. Conclusion

This roadmap brings together evidence from the literature, and co-design workshops and interviews, to outline the actions needed to strengthen autistic co-production and co-leadership in autism research. While there is growing commitment to co-production and co-leadership, systemic, cultural, and practical barriers continue to limit meaningful and sustained collaboration. These barriers are not the responsibility of any single group, but are embedded across funding systems, institutional structures, research practices, and broader research culture.

The recommendations presented in this report move beyond principles and intent to identify practical, system level actions that can enable lasting change. Collectively, they emphasise that meaningful co-production and co-leadership requires early and ongoing involvement, sufficient resourcing, shared power, clear standards, accessible processes, and long-term investment in partnerships and capacity-building. Importantly, the roadmap recognises that co-production is not confined to a single activity or stage of research but is an embedded way of working that occurs across and alongside the entire research lifecycle.

No single recommendation alone will achieve the shift required. Progress relies on coordinated action across stakeholders, sustained commitment, and a willingness to rethink established ways of working. Implementing this roadmap requires recognising autistic people not only as contributors to research, but as leaders, partners, and decision-makers whose lived experience is essential to producing research that is ethical, relevant, and impactful.

By acting on these recommendations, stakeholders can shift from good intentions to a research system in which autistic co-production and co-leadership are core, valued, and expected practices, ultimately strengthening the quality, relevance, and impact of autism research.

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Appendix A: Co-production resources and initiatives

Resource Name	Type	Organisation	National/ International	Purpose	Reference
Lancaster Disability Studies Conference 2018: Critical dialogues on neurodiversity	website	Lancaster University	International	initiative	Lancaster University. (2018). Critical dialogues on neurodiversity. Lancaster Disability Studies Conference. http://wp.lancs.ac.uk/disabilityconference2018/call-for-papers/critical-dialogues-on-neurodiversity/
AASPIRE Inclusion Toolkit	website	AASPIRE	International	resource	Academic Autism Spectrum Partnership in Research and Education. (n.d.). Participatory research. AASPIRE Inclusion Toolkit. https://aaspire.org/inclusion-toolkit/participatory-research/
Autistic Researcher Review Board	website	Autism Intervention Network on Physical Health	International	initiative	AIR-P Network. (n.d.). Autistic Researcher Review Board. https://airpnetwork.ucla.edu/autistic-researcher-review-board/
Conducting Inclusive Research	website	Autism Intervention Network on Physical Health	International	resource	AIR-P Network. (n.d.). Conducting inclusive research. https://airpnetwork.ucla.edu/icr/conducting-inclusive-research
Autistic and Neurodivergent Scholars Working for Equity in Research (ANSWER)	website	Autism Intervention Network on Physical Health	International	initiative	AIR-P Network. (n.d.). ANSWER research partners. https://airpnetwork.ucla.edu/research-partners/answer
Research Basics Training	website	Autism Intervention Network on Physical Health	International	initiative	AIR-P Network. (n.d.). Community-based training. https://airpnetwork.ucla.edu/resources-publications/community-based-training
2024 ASfAR Autistic Researchers' Webinar Series	website	Australasian Society for Autism Research	National	initiative	Australian Society for Autism Research. (2024). 2024 ASFAR autistic researchers' webinar series. https://asfar.org.au/2024-asfar-autistic-researchers-webinar-series/
Autism Research: Nothing About Me Without Me	video	Autism Research Institute	International	resource	Lawson, W. (n.d.). Autism research: Nothing about me without me [Presentation]. World Autism Organisation & Autism Research Institute. https://autism.org/autism-research-nothing-about-me-without-me/

Resource Name	Type	Organisation	National/ International	Purpose	Reference
CAN-DO: Collaboratively Advancing the Network: Designing Opportunities	website	Autism Intervention Research Network on Behavioral Health	National	initiative	AIR-B Network. (n.d.). CAN-DO: Collaboratively advancing the network: Designing opportunities. https://www.airbnetwork.org/community-outreach/can-do-collaboratively-advancing-the-network-designing-opportunities
Strategies for Community Engagement with Autistic Adults and Caregivers in Early Intervention Autism Research	document	Early Intervention Research Group - Northwestern University	International	resource	Roberts, M. Y., Giwa Onaiwu, M., & Lee, J. (2024, August 30). Engagement strategies for researchers: Community engagement in early childhood autism research [PDF]. Northwestern University, Center for Community Engagement. https://www.eicollab.northwestern.edu/files/2025/06/EngagementStrategieswithAppendices.pdf
Co-production Best Practice Using Digital Tech and Innovation in Health and Social Care	document	Brain in Hand	International	resource	Brain in Hand. (n.d.). Co-production best practice [PDF]. https://braininhand.co.uk/media/41aj0cpd/co-production-best-practice.pdf
UVM Autism Collaborative	website	Center on Disability and Community Inclusion - University of Vermont	International	Initiative	University of Vermont, Center on Disability & Community Inclusion. (n.d.). UVM Autism Collaborative [blog]. https://cdci.w3.uvm.edu/blog/autism/
Community Partnerships in Autism Research (CPAR2) Training	website	Center on Disability and Community Inclusion - University of Vermont	International	initiative	The University of Vermont, Center on Disability & Community Inclusion. (n.d.). Community Partnerships in Autism Research. Training. https://cdci.w3.uvm.edu/cpar2/wordpress/training/
Neurodiversity: Participatory Action in Research and Education	website	University of Amsterdam	International	initiative	University of Amsterdam. (n.d.). Course Catalogue 2024-2025. Neurodiversity: Participatory Action in Research and Education. https://coursecatalogue.uva.nl/xmlpages/page/2024-2025-en/search-course/course/116890
Community-led Autism Research, Engagement, and Service (CARES)	website	CARES (Community-led Autism Research, Engagement, and Service)	International	initiative	Bates, J. (n.d.). Community-led Autism Research, Engagement, and Service. https://www.caresinitiative.com/

Resource Name	Type	Organisation	National/ International	Purpose	Reference
Community Partner Recruitment Pack	Google Drive Folder	n.a.	International	resource	Fletcher Watson, S. (2022, April 15). Community partner recruitment pack [Google Drive folder]. https://drive.google.com/drive/folders/1EVeUTF01szrbgmtQ6PpsoWEbu2dy58Sn
Co-production in a neurodiversity context	website	EDI Caucus	International	initiative	EDICa. (n.d.). Research methods: Co-production in a neurodiversity context. https://edicaucus.ac.uk/research-methods-co-production-in-a-neurodiversity-context/
Inclusive Participatory Research in Autism Research: Methods and Practice	website	University of Warwick	International	initiative	University of Warwick. (2025, July 21). Webinar – Inclusive participatory research in autism research: Methods and practice [Webinar]. https://events.teams.microsoft.com/event/a8e4f5dd-3c3e-479e-9c65-3d37c24e772c@09bacfbd-47ef-4465-9265-3546f2eaf6bc
Global Autistic Task Force on Autism Research	website	Global Autistic Task Force on Autism Research	International	initiative	GATFAR. (n.d.). Global Autistic Task Force on Autism Research. https://gatfar.org/
Community Involvement Reporting: Frequently Asked Questions	paper	Sage Publications		initiative	Sage Publications. (n.d.). Community involvement reporting: Frequently asked questions [PDF]. https://journals.sagepub.com/pb-assets/cmscontent/AUT/Community-Involvement-Reporting-FAQ-1626698718.pdf
A Workbook to Support Community-Engaged Autism Research: Lessons from Project STEER	document	The Ohio State University Nisonger Center	International	resource	Wainer, A. L. & Walton, K. M. (2023, April). A workbook to support community-engaged autism research [PDF]. The Ohio State University Nisonger Center and AARTS Center at Rush. https://nisonger.osu.edu/wp-content/uploads/2023/04/A-Workbook-to-Support-Community-Engaged-Autism-Research_Fillable.pdf
New methods for research on/with neuro-medical subjectivities	website	2024 quadrennial joint meeting of the European Association for the Study of Science and Technology (EASST) and the Society for Social Studies of Science (4S)	International	initiative	Nomadit. (2024, July 19). New methods for research on/with neuro-medical subjectivities [Conference panel]. EASST-4S 2024: Making and Doing Transformations, Amsterdam, The Netherlands. Retrieved July 8, 2025, from https://nomadit.co.uk/conference/easst-4s2024/p/15013

Resource Name	Type	Organisation	National/ International	Purpose	Reference
The Participatory Autism Research Collective	website	The Participatory Autism Research Collective	International	initiative	The Participatory Autism Research Collective. (n.d.). The participatory autism research collective. https://participatoryautismresearch.wordpress.com/
I Am a Researcher	website	Reframing Autism	National	resource	Reframing Autism. (n.d.). I am a researcher. https://reframingautism.org.au/service/i-am-a-researcher/
Autistic Adults and other Stakeholders Engage Together (AASET), Engagement & Compensation Guide	document	Patient-Centered Outcomes Research Institute (PCORI)	International	resource	Patient-Centered Outcomes Research Institute. (2018, December). Autistic adults and other stakeholders engage together (AASET), engagement & compensation guide [PDF]. https://www.pcori.org/sites/default/files/Engagement-Guide-as-of-122018-2.1.pdf
Neurodiversity and Participatory Research Advisory Board	website	RESPECT 4 Neurodevelopment (Responsible, Reliable, Scalable and Personalised Neurotechnologies for Infants and Children with Neurodevelopmental Conditions)	International	initiative	Respect 4 Neurodevelopment. (n.d.). Neurodiversity and participatory research advisory board. https://respect4neurodevelopment.com/neurodiversity-and-participatory-research-advisory-board/
Research 101: Collaborating in Participatory Autism Research	website	The University of Edinburgh	International	initiative	The University of Edinburgh Salvesen Mindroom Research Centre. (n.d.). Research 101: Collaborating in participatory autism research. https://salvesen-research.ed.ac.uk/our-projects/research-101-collaborating-participatory-autism-research
Shaping Autism Research UK	website	Shaping Autism Research UK	International	initiative/ resource	Shaping Autism Research in the UK. (n.d.). Shaping autism research UK. https://shapingautismresearchuk.tumblr.com/
Strategies for Effective Supervision, Career Advancement, and Job Supports of Individuals with I/DD	website	American Association on Intellectual and Developmental Disabilities (AAIDD)	International	initiative	Kramer, J., Winsor, J., Kramer, J., & Wolfe, A. (2014, November 6). Strategies for effective supervision, career advancement, and job supports of individuals with I/DD [Webinar]. American Association on Intellectual and Developmental Disabilities. https://aaidd.org/education/event-details/2014/11/06/default-calendar/strategies-for-effective-supervision-career-advancement-and-job-supports-of-individuals-with-i-dd#.WTXPpnrGq_F

Resource Name	Type	Organisation	National/ International	Purpose	Reference
Accessible and Collaborative Research Network		Dublin City University - School of Inclusive & Special Education	International	initiative	Dublin City University School of Inclusive & Special Education (n.d.). Accessible and collaborative research network. Inclusive autism and participatory research @DCU. https://sites.google.com/view/acorn-network/home
SPARK Outreach & Engagement Advisory Board	website	Simons Powering Autism Research for Knowledge (SPARK)	International	initiative	SPARK. (2026, March 3). Outreach & engagement advisory board. https://sparkforautism.org/portal/page/outreach-engagement-board/
SPARK Scientific Advisory Board	website	Simons Powering Autism Research for Knowledge (SPARK)	International	initiative	SPARK. (2026, February 17). Meet our scientific advisory board. https://sparkforautism.org/portal/page/meet-our-advisory-board/
SPARK Community Advisory Council	website	Simons Powering Autism Research for Knowledge (SPARK)	International	initiative	SPARK. (2025, April 2). SPARK community advisory council. https://sparkforautism.org/portal/page/spark-community-advisory-council/
Neurodiversity and Autism Research in Education Committee (NAREC)	website	American Educational Research Association	International	initiative	American Educational Research Association. (n.d.). Neurodiversity and Autism Research in Education Committee (NAREC). https://www.aera.net/SIG113/Neurodiversity-and-Autism-Research-in-Education-Committee-NAREC
Café Autistíque	website	The University of Manchester Autism@Manchester	International	initiative	The University of Manchester Autism@Manchester. (n.d.). Café Autistíque. https://www.autism.manchester.ac.uk/connect/events/cafe-autistique/
Expert by Experience Advisory Group	website	The University of Manchester Autism@Manchester	International	initiative	The University of Manchester Autism@Manchester. (n.d.). Expert by experience advisory group. https://www.autism.manchester.ac.uk/connect/expert-by-experience/
Autistic involvement in research: Online Learning Activity	website	The University of Manchester Autism@Manchester	International	resource	The University of Manchester Autism@Manchester. (n.d.). Autistic involvement in research: Online learning activity. https://www.autism.manchester.ac.uk/research/projects/ola/
Guidelines for conducting research with the autistic community	document	The University of Manchester Autism@Manchester	International	resource	Gowen. E, Taylor. R, Bleazard. T, Greenstein. A, Baimbridge. P & Poole.D (2019). Guidelines for conducting research with the autistic community. Autism policy and practice. Vol 2 No 1. The University of Manchester Autism@Manchester. https://www.autism.manchester.ac.uk/research/projects/research-guidelines/

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Autism Action Community Network	website	Autism Centre of Excellence at Cambridge	International	initiative	Autism Action. (n.d.). Autism Action Community Network. https://autismaction.org.uk/get-involved/community/
Research Program	website	Autism CRC	National	initiative	Autism CRC. (n.d.). Sylvia Rodger Academy research program. https://www.autismcrc.com.au/sylvia-rodger-academy/research-program
INSAR Community Collaborator Request (ICCR)	website	International Society for Autism Research (INSAR)	International	initiative	International Society for Autism Research. (n.d.). International collaborative community research (ICCR). https://www.autism-insar.org/general/custom.asp?page=iccr
Equitable Inclusion of Autistic Adults as Co-Researchers	website	International Society for Autism Research (INSAR)	International	resource	International Society for Autism Research. (2018, June 29). Equitable inclusion of autistic adults as co-researchers, Summer Institute Christina Nicolaidis & Dora Raymaker Session. https://www.autism-insar.org/general/custom.asp?page=session3_2018
Autistic Researchers Committee	website	International Society for Autism Research (INSAR)	International	initiative	International Society for Autism Research. (n.d.). Autistic Researchers Committee. https://www.autism-insar.org/page/InsarARC
Community engagement	website	University of Cambridge Autism Research Centre	International	initiative	Autism Research Centre. (n.d.). Community engagement. https://www.autismresearchcentre.com/volunteer/community-engagement-commitment/
Autistica Insight Group	website	Autistica	International	initiative	Autistica. (n.d.). Autistica Insight group. https://www.autistica.org.uk/get-involved/insight-group
Autistica Network	website	Autistica	International	initiative	Autistica. (n.d.). The Autistica Network. Take part in autism research. https://www.autistica.org.uk/our-research/network-researchers
Blueprint for Autism Community Involvement in Research	document	Centre for applied autism research (CAAR) - University of Bath	International	resource	Centre for Applied Autism Research. (n.d.). Blueprint for autism community involvement in research [PDF]. https://www.bath.ac.uk/publications/resources-for-researchers-and-the-autism-community/attachments/caar_blueprint_for_autism_community_involvement_in_research.pdf
Neurodivergent Researchers Network	website	British Educational Research Association (BERA)	International	initiative	British Educational Research Association. (n.d.). Neurodivergent Researchers Network. https://www.bera.ac.uk/community/neurodivergent-researchers-network

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Healthy Engagement in Autism Research Dialogue (HEARD)	website	Broad Institute	International	initiative	Broad Institute. (n.d.). Healthy engagement in autism research dialogue (HEARD). https://www.broadinstitute.org/neurodevelopmental-variability-initiative/healthy-engagement-autism-research-dialogue-heard
CAN Community	website	CAN Research	National	initiative	CAN Research. (n.d.). CAN community. https://www.canresearch.com.au/can-community
Autistic Partnership Aotearoa New Zealand (AP-NZ)	website	University of Canterbury Autism Research Centre	International	initiative	University of Canterbury. (n.d.). Autistic partnership Aotearoa New Zealand (AP-NZ). https://www.canterbury.ac.nz/research/about-uc-research/research-groups-and-centres/child-wellbeing-research-institute/cwri-research/autism-research-centre-aotearoa-new-zealand/autistic-partnership-aotearoa-new-zealand--ap-nz-
Best Practice Guidelines	document	Eating Disorders and Autism Collaborative (EDAC)	International	resource	EDAC Research. (n.d.). Best practice guidelines [PDF]. https://www.edacresearch.co.uk/img/news/Download%20Handouts%20Complete%20Best%20Practice%20Guidelines_1709035188.pdf
Interagency Autism Coordinating Committee (IACC)	website	U.S. Department of Health & Human Services	International	initiative	Interagency Autism Coordinating Committee. (n.d.). About IACC. https://iacc.hhs.gov/about-iacc/
Statement on Language and Participatory Research	website	La Trobe University, Olga Tennison Research Centre (OTARC)	National	initiative	La Trobe University, Olga Tennison Autism Research Centre. (2025, July 29). Statement on language and participatory research. Retrieved July 8, 2025, from https://www.latrobe.edu.au/otarc/statements/statement-on-language-and-participatory-research
Autism Research Innovation Centre	website	University of Lincoln	International	initiative	University of Lincoln. (n.d.). ARIC: Autism research innovation centre. https://www.lincoln.ac.uk/psyspw/psychologyresearch/aric/
Critical Autism and Disabilities Studies	website	London South Bank University	International	initiative	London South Bank University. (n.d.). Critical autism and disabilities studies (CADS). https://www.lsbu.ac.uk/our-colleges/law-and-education/research/cads#content1-325316
Register your interest in upcoming Co-production and engagement opportunities	website	Norfolk Autism Partnership	International	initiative	Norfolk Autism Partnership. (n.d.). Interest register. https://www.norfolkautismpartnership.org.uk/interest-register/

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Pittsburgh Adult Autism Research Community Collaborative	website	University of Pittsburgh Autism Center of Excellence	International	initiative	University of Pittsburgh. (n.d.). PAARCC. https://www.reaact.pitt.edu/PAARCC
Co-Production Guidance	document	Black Country Healthcare NHS Foundation Trust	International	resource	The Recovery College. (n.d.). Co-production guidance [PDF]. https://www.therecoverycollege.co.uk/images/easyblog_articles/624/Co-Production-Guidance-DIGITAL.pdf
NAIT Guide to Co-Production with Neurodivergent Communities (2024)	document	National Autism Implementation Team (NAIT)	International	resource	National Autism Implementation Team. (2024). NAIT guide to co-production with neurodivergent communities [PDF]. https://nait.scot/document/nait-guide-to-co-production-with-neurodivergent-communities-2024/
Academic Collaborative Centre for Autism	website	Academic Collaborative Centre for Autism	International	initiative	Academic Collaborative Centre for Autism. (n.d.). https://academiccollaborativecentreforautism.be/
Peer Research and Participation Involving Autistic Young People	document	Youth Futures Foundation	International	resource	Youth Futures Foundation. (2023, August). Peer research and participation involving autistic young people [PDF]. https://youthfuturesfoundation.org/wp-content/uploads/2023/08/Peer-Research-and-Participation-Involving-Autistic-Young-People.pdf
National Autism Lived Experience Advisory Group	website	Autism Alliance of Canada	International	initiative	Autism Alliance of Canada. (n.d.). National autism lived experience advisory group. https://autismalliance.ca/initiative/autism-data-collaborative/national-autism-lived-experience-advisory-group/
Five-year NHS autism research strategy for England	document	NHS	International	initiative	NHS England. (2022, March 28). Five-year NHS autism research strategy for England version 1 [PDF]. https://www.england.nhs.uk/wp-content/uploads/2022/03/B1004-five-year-NHS-autism-research-strategy-for-england-march-2022.pdf
Research Fundamentals: Early Childhood Autism Therapy Research	website	Northwestern University Early Intervention Research Group	International	resource	EI-Collab. (n.d.). Research fundamentals tool. https://www.eicollab.northwestern.edu/research-fundamentals-tool/

Our values

Inclusion
Valuing lived experience

Innovation
Solutions for long term challenges

Evidence
Truth in practice

Independence
Integrity through autonomy

Cooperation
Capturing opportunities together

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Independent national source of evidence for best practice