

# DOING RESEARCH INCLUSIVELY:

Guidance on Ethical Issues in Co-Production



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# Summary

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People with disability are experts in their own lives through experience. Co-production is an approach that enables people with disability to work collaboratively with researchers to conceptualise, structure, design and implement research that addresses issues of importance to people with disability. As a research approach, co-production is built on respect and acknowledgement of the life experience of the person with disability. Consequently, it is flexible, responsive and open, and how it is done will vary between different projects. The National Statement on Ethical Conduct in Human Research 2007 (updated 2018), which guides all human research conducted in Australia, recognises the importance of people with disability participating in research but does not explicitly address co-production. This means that researchers are currently without clear guidance on how to articulate co-production in their research ethics applications, and ethics committees are similarly unsupported in how to assess the ethical implications of proposed co-production. This document has been developed to address these two issues. Firstly, the content supports researchers in submitting applications for ethics approval for projects involving co-production. Secondly, it guides ethics committees in assessing the ethical implications of co-production in applications for ethics approval.

## Purpose

This document focuses on co-production which is university-led, where academic researchers work in collaboration with co-researchers with disability who may represent community disability organisations or work as individual lived experience experts. It addresses ethical issues in co-production research with people with disability in the university context in Australia. It focuses on issues for academic researchers in the preparation of applications for ethics approval for proposed co-produced research, and for ethics committees in the review, approval and monitoring of those projects. The document provides an opportunity for stakeholders to develop a shared understanding of the ethical considerations in co-production with people with disability. Researchers and ethics committees are encouraged to read it in its entirety.

## Approach

The issues and strategies outlined in the document are informed by:

- a review of existing international and national literature
- scoping of relevant guidance in other jurisdictions
- interviews with Australian academic researchers with and without disability, and co-researchers with disability, who conduct co-produced research
- interviews with Chairs of Australian university ethics committees.

See *Ethical issues in co-production research with people with disability: Background paper* for details of the approach used to develop this guidance.

## Terminology

Currently, a wide range of terms and models are used to describe co-production processes and the various stakeholders involved in disability research. We acknowledge that approaches and terminology reflect local practice and individual preference, and that usage is evolving.

Additionally, we recognise that people with disability can have multiple roles in research; as university-based academics, as members of disability organisations representing the interests of people with disability in research, and/or as individual co-researchers working within research teams.

Co-production has a long history in diverse areas of research. Accordingly, it can take many forms including university-led, community-led, or as a partnership between organisations and research institutions. This document focuses on co-production which is university-led. This typically involves academic researchers in the university context working with co-researchers with disability who may work independently or act on behalf of community disability organisations.

Some key terms are used for consistency in this document. Detailed definitions of these and other terms related to the ethical review process and disability research are provided in the Glossary.

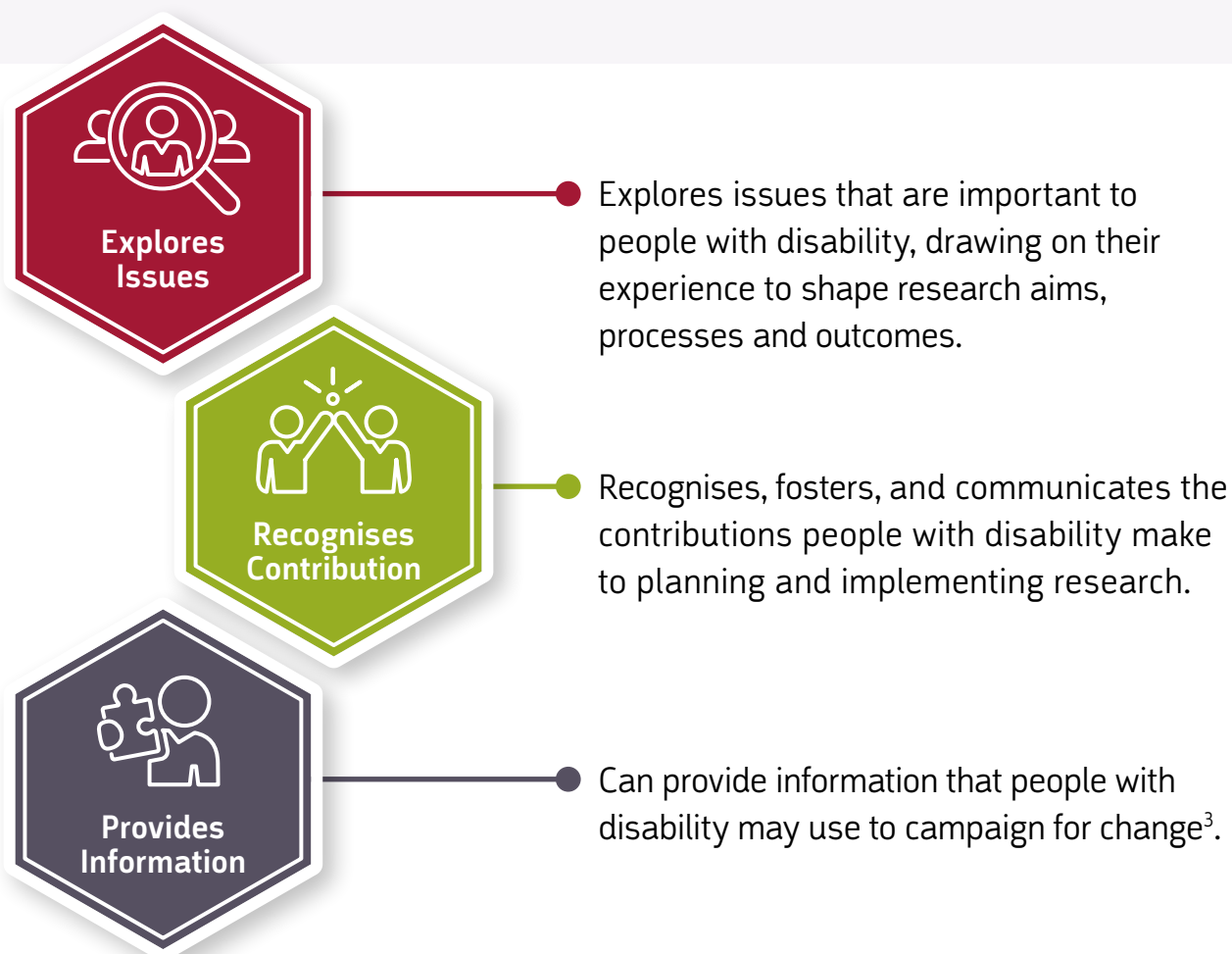
- **Co-production:** knowledge creation that involves authentic collaboration, collective decision making, and power-sharing between people with disability and researchers<sup>12</sup>.
- **Academic researchers:** people who are employed by universities and/or research institutes, with formal academic training and/or qualifications. They may or may not have a disability.
- **Co-researchers:** people involved in co-production research who have lived experience of disability as well as expertise in the research topic. They may represent community disability organisations or be individually employed in research teams. ‘Co’ suggests an equal but different contribution and has the implication of ‘collaborative’. Other terms are used in Australia and internationally, such as ‘community researchers’, ‘participatory researchers’, and ‘lived experience researchers’.
- **Research participants:** people whose data is collected for the purpose of a research project which is about them as opposed to with them or by them.
- **Ethics review:** the process of assessing and evaluating the ethical implications of research involving human participants.

## Limitations and Next Steps

This guidance is a first step in building better practice in ethics applications and review of co-produced disability research in Australia. It focuses only on university-led research ethics processes. As a result, the content does not engage with community-led co-production research or co-researcher models in non-university settings. Future guidance for community-led co-production and for non-university ethics approval bodies would be a valuable next step.

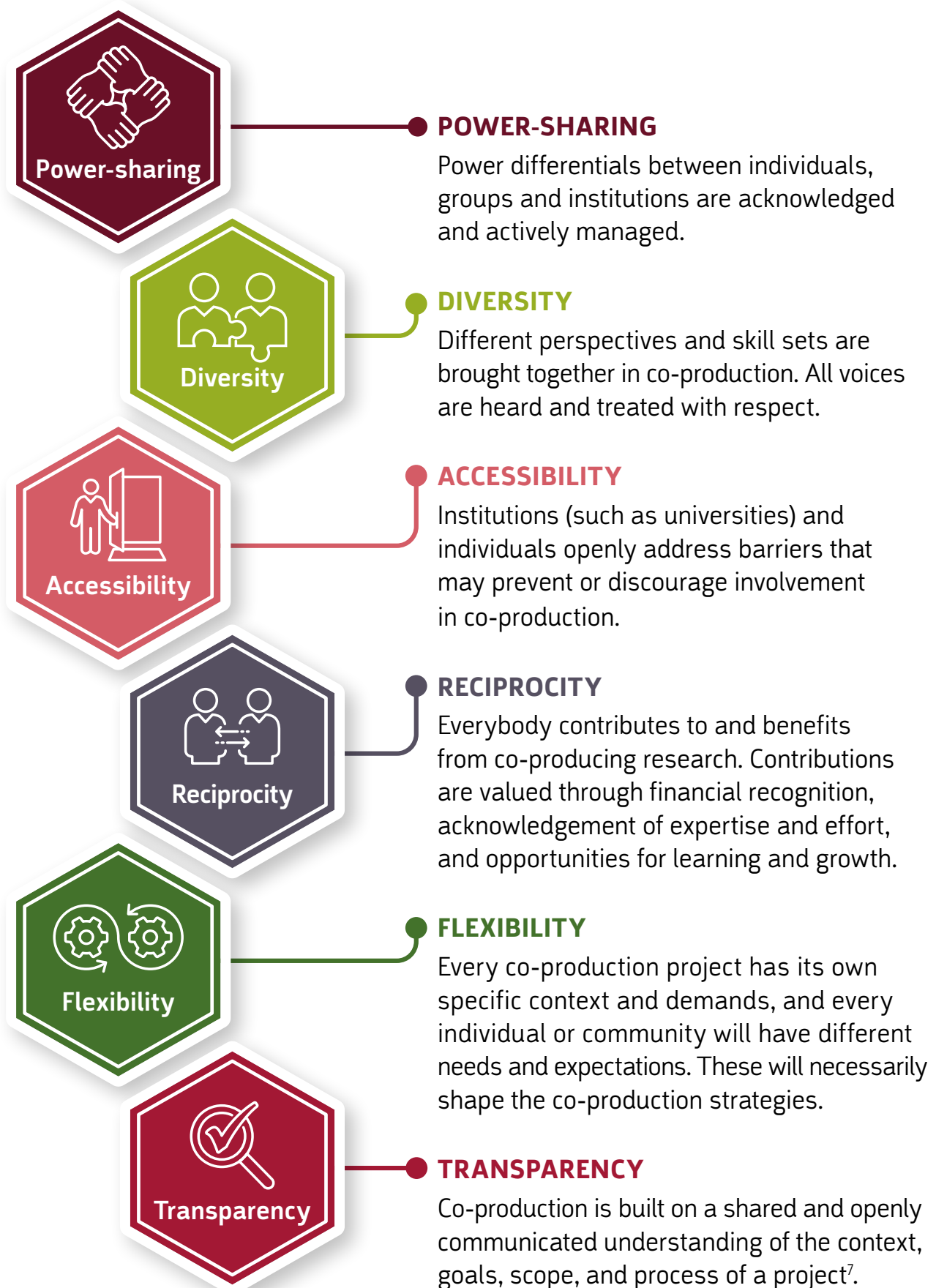
# Inclusive Research and Co-Production

In inclusive research, people with disability are involved not only as participants, but as co-researchers. Broadly, inclusive research:



Co-production is recognised as a key way to operationalise inclusive research in the disability context. Co-production is a process of collaboration and collective decision-making between people with disability and researchers, which involves challenging the traditional separation of the producers and users of research<sup>4</sup>. A co-production approach creates a shared community of practice in which everyone has a role in knowledge creation<sup>5</sup>. The values of co-production emphasise genuine power-sharing and a democratisation of relationships between the individuals, organisations and institutions (such as universities) involved<sup>6</sup>.

# Principles of Co-Production







# Ethical Review Processes in Australia

- In Australia, ethics review is a requirement for all human research. The National Statement on Ethical Conduct in Human Research 2007 (updated 2018) (National Statement) provides guidance for researchers, ethical review bodies, those involved in research governance and potential research participants. The National Statement is underpinned by four core principles: (i) merit and integrity, (ii) beneficence, (iii) justice, and (iv) respect. It provides advice on benefits and risks, informed consent, privacy, and methodologies of research<sup>8</sup>.

The ethics review process is undertaken by ethics review bodies based at universities, research institutes, and other organisations. The National Statement sets out the responsibilities, processes and procedures of review bodies, and the level of review required for different types of research according to their level of risk (see Section 5.1). A judgement that a human research application meets the requirements of the National Statement and is ethically acceptable must be made before research can begin. The process of ethical review may vary between institutions but usually requires research teams to compile formal documentation and address key questions, such as participant safeguards and research methodology.

## Disability in the National Statement

People with disability are not addressed as a group within the National Statement, but some people with disability are noted as one of the participant groups for whom there may be specific ethical considerations (see Sections 4.3 & 4.5). Research involving the following sub-groups requires review by a Human Research Ethics Committee (see Section 5.1.6):

- Those who may be in an unequal or dependent relationship such as a relationship between carers and people with disability.
- People with a cognitive impairment, an intellectual disability, or a mental illness.

Ethical issues considered in relation to these groups generally refer to their role as research participants. These ethical issues include capacity to consent and how that is assessed, consent being granted by another person authorised by law (such as a guardian), power imbalances, recruitment, minimising discomfort and distress during the research process, harm to non-participants such as family members and the wider community, inconvenience of participation, the benefits of participation in research, and how participants are compensated for their participation in research projects.

The National Statement also refers to the importance of research being accessible to participants. Ensuring research is accessible for people with disability can include providing specific adjustments and accommodations, such as ensuring accessibility of environment (for example, wheelchair access and accessible bathrooms), accessibility of documentation (for example, consent forms being presented in Easy Read format), or providing Auslan interpreters or documents in alternative formats.

## Co-Production and the National Statement

The National Statement does not make specific mention of co-production in research, or of other types of inclusive research where co-researchers are part of a research team.

The National Statement, by its own admission, “does not exhaust the ethical discussion of human research” and recognises that “even a single research field covers a multitude of different situations about which the National Statement will not always offer specific guidance, or to which its application may be uncertain”<sup>9</sup>. Co-production in disability research is one such example.



# Ethical Issues in Co-Production in Disability Research

This section highlights some core factors that underpin current co-production approaches for researchers and ethics committees. The section also identifies six key issues requiring consideration in the articulation and ethical review of co-produced disability research.

## Core Factors

The following core factors are identified as key to understanding and articulating (for researchers) and assessing (for university ethics committees) co-production in disability research.



### CO-PRODUCTION ENHANCES INTEGRITY

Co-production, when appropriate and done well, enhances the integrity and quality of a project and may contribute to better research outcomes. Co-production can highlight aspects of lived experience that may otherwise be missed or undervalued<sup>10</sup>. Most importantly, co-production advances recognition of the roles that previously marginalised people can play in research. It can also serve as an ethical assurance to participants to know that co-researchers have been involved in the research process.



### INACCESSIBLE APPLICATION PROCESSES

The ethics application process can exclude co-researchers. The complex format and language of the application process may be inaccessible and can marginalise those not familiar with academic research contexts. As a result, co-researchers may be left out of decision-making related to the research<sup>11</sup>.



### **HARM IN THE APPLICATION PROCESS**

A lack of understanding may mean ethics committees apply a ‘medical model’ which perceives disability as a deficit when considering co-production research, resulting in a more ‘protectionist’ approach to assessment<sup>12</sup>. Co-researchers can experience harm and insult because of the requirement in the application process to identify certain people with disability (such as those groups identified in the National Statement as raising specific ethical considerations as participants in the research) as potentially lacking capacity or being vulnerable, by virtue of their diagnostic label. This reinforces the belief that people with disability do not have the potential or ability to be research partners<sup>13</sup>. This also presents a professional and ethical dilemma for researchers.



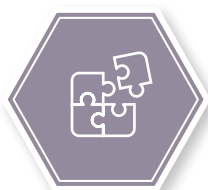
### **COUNTERPRODUCTIVE ASSUMPTIONS**

Researchers and ethics committees may make assumptions that can undermine the effectiveness of the ethics review process. Researchers may incorrectly assume committee members understand the rationale for co-production and fail to explain this in their applications. On the other hand, researchers may assume that co-production is a red flag for ethics committees, attracting a level of scrutiny that makes co-production ‘too much trouble’. Relatedly, ethics committees may assume that co-production adds ethical complexity rather than ethical rigour to an application.



### **CONFLICTING ETHICAL PRINCIPLES**

Limited ethical guidance on co-produced research may mean that researchers and members of ethics committees make personal judgments where decisions are influenced by their personal experiences with, and attitudes toward disability<sup>14</sup>.



### UNFAMILIARITY WITH THE PROCESS

Researchers may be unfamiliar with ethics processes and the terminology and information required. A sound understanding of the National Statement will ensure a well explained co-produced project in ethics applications. Ethics committees may be unfamiliar with the principles, processes, and practices of co-production, and have limited experience in reviewing co-produced research applications.



### VARIABILITY IN EXPERIENCE AND MOTIVATION

Researchers come to co-production in different ways and from different disciplines which will mean varying levels of research experience and confidence in design and implementation. The motivations for adopting a co-production approach can range from a professional and political commitment to inclusion, to the growing demand by funders for inclusive and co-produced knowledge generation.



### EDUCATION RATHER THAN CONFRONTATION

How ethics committees and researchers engage with each other can impact the experience of the application and approval process. Concerns about litigation and risk exposure can override issues of inclusion and collaboration in co-produced research. Direct relationships and open lines of communication between researchers and ethics committees can enable all parties to learn from each other and support the development of co-produced research with people with disability<sup>15</sup>.

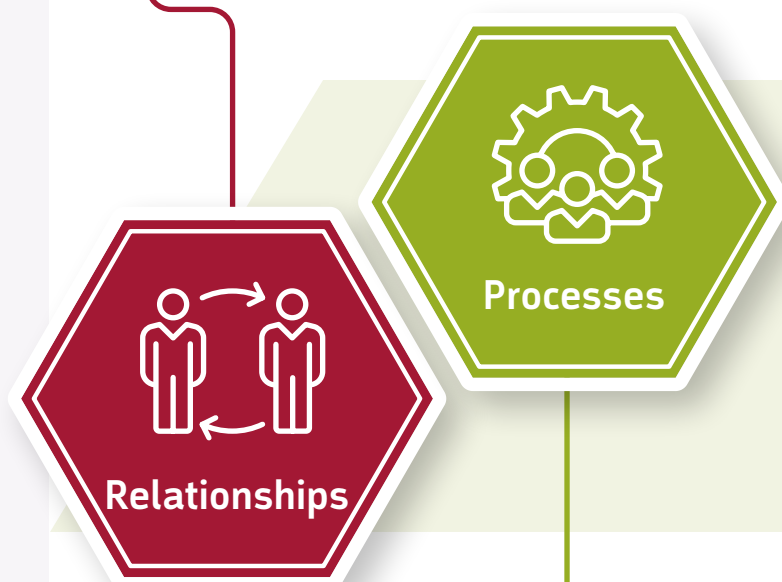
# Ethical Issues

All research raises ethical issues, and there are particular ethical issues specific to contemporary co-production practice in disability research. How these are best managed, and measures operationalised, will vary between inclusive teams and ethics committees. For clarity, each ethical issue described below is defined and considerations relevant to it are used to expand understanding. Strategies for both researchers and ethics committees are then drawn out.

Co-production enhances the integrity of disability research, but the ethics application and review process can be challenging for both researchers and ethics committees.

## RELATIONSHIPS IN CO-PRODUCTION

Relationships grounded in collaboration, mutual respect, and shared decision-making are key to ethical co-production. This requires a person-centred approach addressing power dynamics and accessibility so that the perspectives of co-researchers are valued and included. Ethics committees should be made aware of these issues and researchers should be clear how they are addressed in their applications.



## PROCESSES IN CO-PRODUCTION

Processes develop as co-production progresses, and detailed co-production methodologies may be difficult to clarify in ethics applications. For transparency, researchers should describe the co-production process across the life of a project and/or prepare ethics applications in stages as the project progresses.

## ROLES IN CO-PRODUCTION

Roles in a co-production team can change as co-production progresses. Role titles and duties can be inconsistent between projects, with different terms being used to describe the same thing or the same term used to describe different things. Thus a clear definition of all roles is needed in an ethics application, including a differentiation between co-researchers and research participants.

## VULNERABILITY AND CAPACITY IN CO-PRODUCTION

Assuming vulnerability and requiring demonstration of the capacity to consent by people with disability involved in research can be disempowering and oppressive. It can also pose ethical difficulty for research teams working in co-production. As university ethical review tends to focus on vulnerability and informed consent, a more nuanced approach that considers vulnerability as contextual, intersectional, and dynamic is needed.



### Roles

### Benefit and risk

### Vulnerability and capacity

### Quality

## BENEFIT AND RISK IN CO-PRODUCTION

Co-production has a range of benefits for all research stakeholders, including personal growth, skills development, and the production of knowledge relevant to the lives of people with disability which can have a positive impact on those involved. Identifying and managing risks should be balanced against these benefits.

## QUALITY IN CO-PRODUCTION

There are no existing measures of quality in co-production and so research teams need to reflect on their own practice to identify and demonstrate quality in their co-production applications. Ethics committees should also build their capacity for effective evaluation of quality in co-production projects.



## Relationships in Co-Production

### ● The Issue

Co-production is understood as a relationship between researchers, co-researchers and other stakeholders. This relationship is characterised by collaboration, mutual respect, and shared decision-making throughout the research process. In line with the co-production principle of power-sharing, relationality considers power dynamics and the ways to value and integrate the voices and perspectives of co-researchers. Another key characteristic of the co-production relationship is the active promotion of inclusion, which involves removing barriers to allow all team members to participate fully in the research process. A person-centred approach to collaboration is also key. This means placing the individual characteristics, needs, and preferences of the person at the centre of considerations<sup>16 17</sup>. Evidence of the research team's planning for supports, and justification of reasonable adjustments or accommodations, demonstrate that the principle of accessibility has been properly considered. Evidence of power-sharing, inclusion, and accessibility can make an ethical assessment of co-production easier<sup>18</sup>.

### Researcher Insight

*“Relationality is central to articulating the who, what, where, and how of ethical co-production – it’s the credibility, it’s the relationships, the depth of relationships and the respect for those relationships.”*





## ● Considerations

- Co-production can challenge conventional ideas of research partnerships, relationships, and participation. Differentiation between co-researchers and research participants is needed, as is clarity about the nature of the relationships in the research team and how these differ from traditional research approaches<sup>19</sup>.
- Establishing trust in co-production relationships takes time and effort<sup>20</sup>. Providing information in the ethics application about the past, present, and future of the relationships in the research team can provide evidence of this, and also mitigate concerns about the risks of coercion<sup>21</sup>.

The National Statement requires that research teams uphold four core principles. When applied to the research relationship in co-production these can be understood as:

- **Merit and integrity:** demonstrated through clear shared goals in the team, areas of investigation that are jointly identified, and outcomes that focus on improving the lives of people with disability<sup>22</sup>.
- **Beneficence:** co-production can be a safeguard that the research will not be harmful to participants. The contribution of co-researchers also benefits the way research is conducted and findings interpreted. Co-production requires wider consideration of potential harms and necessary protections, e.g., harm to participant, harm to researchers, and harm to the disability community.
- **Justice:** people with disability are entitled to participate in research, not only as subjects of the research but also as co-researchers in the co-production process.
- **Respect:** co-researchers can experience disrespect when a diagnostic label associated with disability is assumed to imply a lack of capacity or vulnerability.



## ● Strategies for Research Teams

### **Model of co-production**

- Draw attention to the relational quality of a project by communicating the specific ways in which co-production is implemented within the project, referencing this as appropriate.
- Describe the relationships within the team (past, present, and future) rather than the individual vulnerabilities or capacities of any one team member.

### **Safety**

- Recognise that all members of the research team may need support at some point.
- Demonstrate how support needs will be continuously assessed.
- Provide support when needed, both in general and in the context of the specific nature and topic of the research.

### **Person-centred approach**

- Show how respect for and collaboration with co-researchers are demonstrated through all stages of the project.
- Specify how accommodations and accessibility are used throughout the phases of research, and how this may look different from traditional research projects<sup>23</sup>.

### **Differentiation**

- Clearly distinguish between co-researchers and research participants through explicit definitions.
- Clarify the difference between co-researchers and research participants in practice and how they operate in the specific context of the project.



## ● Strategies for Ethics Committees

### Nature of research relationships

- Ethical co-production should be assessed by examining the nature of the relationships within a research team rather than focusing on an individual co-researcher and their capacity.

### Support

- Consider the potential impact of the research on the well-being of researchers and co-researchers.
- Evaluate the stated measures in place to mitigate or minimise potential harm.
- Assess whether supports have been adequately considered and how they will be implemented, including debriefing, communication support, accessible formats, appropriate training and/or mentoring.

### Specificity

- Provide a section within ethics application documentation to prompt research teams to detail how the project operationalises a co-production relationship.



### Ethics Committee Chair Insight

*“Co-production, for me, has to come out of relationships, and those relationships take an investment of time and energy. It’s got to be based in a relational encounter. Not transactional, but having more invested in it, that you have to give something.”*



## Processes of Co-Production

### ● The Issue

Co-production is about putting inclusive research into practice. The flexibility needed in a co-production research design may be unlike mainstream research approaches and can therefore appear incompatible with traditional ethics application. Specifically, it may not be possible to provide details of certain aspects of the research until they have been developed collaboratively in the co-production process. For example, research questions or approaches to data collection may only be formulated when researchers and co-researchers have consulted with the disability community. This means that methodologies using co-production can sometimes appear vague or unspecific at the point of ethics application submission. To address the co-production principle of transparency, a clear description of the co-production process itself across the life of a research project is needed. Co-production is built on a shared understanding of the context, goals, scope, and outcomes of a project, as well as each person's role in it. Open communication, trusting relationships, and research team reflexivity help to maintain transparency.



### Ethics Committee Chair Insight

*"The ethics process is not simply filling in a form. Instead, it's about setting up a whole story around how the research came to be."*



## ● Considerations

- The capacity of a committee to assess the co-production research application for ethics approval will depend on what is presented to them, as well as their own knowledge about co-production.
- Researchers may experience ethical dilemmas if applying for approval of co-produced projects requires them to identify co-researchers as vulnerable or potentially lacking capacity. Researchers may challenge and reinterpret ideas of capacity and vulnerability in their applications.
- It is important that researchers clearly articulate why a project has chosen to use co-production. This includes explaining why the project is improved by using co-production, involving people with disability as experts, and describing how their expertise contributes to addressing the research goals.
- Researchers may find the UNSW DIU *Co-production in action* guidelines useful in articulating co-production according to the phases of research: Initiating, Planning, Doing, Sense making, Sharing, and Reflecting. Similarly, ethics committees may find these guidelines useful in developing their understanding of co-production in disability research, and when assessing the processes of co-production in applications.



## Researcher Insight

*“There is a certain degree of confidence you need in writing an ethics application for an inclusive project, and so, explaining decisions.”*



## ● Strategies for Research Teams

### Strengthen

- Use the ethics application process to clarify and strengthen the co-production design.
- Articulate the nature of the co-production process itself and decision-making processes.

### Explain

- Describe the iterative nature of co-production and the likely challenges.
- Justify how the proposed approach is the most ethically appropriate for the project.

### Clarify

- Detail and rationalise what is going to happen in the co-production process.
- Make explicit where and how co-production will inform the research phases.
- Identify decisions that may be resolved in the future and be comfortable that these will need to be reviewed by the ethics committee at a later date.

### Evidence

- Draw on available evidence and literature to explain and justify your approach.
- This may be particularly relevant for making arguments to challenge concepts of vulnerability and capacity.

### Time

- Allow enough time for all members of the research team to review the application and formulate their opinions, including for developing appropriate and accessible information.
- Experienced inclusive researchers suggest allowing “double the time you think you need”.



## ● Strategies for Ethics Committees

### Guidance

- Provide explicit guidance for researchers about expected content and rationale to be included in applications for ethics approval for co-produced projects.

### Iterative

- Adopt iterative approval as a standard approach for assessing co-production.
- Be aware of the potential limits to a committee's capacity to assess co-production and use outside expertise when necessary.

### Justification

- Provide justifications and clear directions to researchers if aspects of an application need further development.
- Explain to researchers what cannot be assessed and why.
- Identify the relevant ethical issue, rather than a methodological or social issue, to highlight the central ethical concerns which should be addressed in co-production.

### Learning

- Reflect on the gaps in committee members' knowledge about co-production.
- Educate committee members, drawing on the expertise and experience of inclusive researchers within your own institution.

### Representation

- Recognise that the composition of a committee has significant implications for the decision-making process about ethical issues in co-production.
- Where possible, membership should include a person with disability.
- All members should have an up-to-date understanding of models of disability, to avoid a deficit-focused approach to assessment of ethics applications.



## Roles in Co-Production

### ● The Issue

The titles and descriptions of the different roles that research team members undertake in co-produced research vary. In line with the co-production principles of diversity and flexibility, decisions about roles and role designations are often made collaboratively within a research team. The types and involvement of different roles may also be project-dependent or person-dependent, and agreed on in the co-production process itself. Research teams may choose not to explicitly acknowledge disability in titles or descriptions of roles as all members are integral and equal members of a team. Where roles are given a name, different researchers may use different terms to describe the same thing or use the same term to describe different things. This inconsistency can be confusing for ethics committees making assessments of applications using co-production.

### ● Considerations

- Ethics application documentation usually requires that individual research team members are named and assigned a role. Role designations such as chief investigator, co-investigator, student investigator, research assistant or project manager reflect responsibilities and/or duties. These may differ from the role designations used in co-production research.
- In naming and describing roles in co-production, a wide range of terms are found in the literature and in practice including: 'advisor', 'consultant', 'co-researcher', 'lived-experience researcher', 'subject matter expert', 'expert by experience', 'peer researcher', and 'community researcher'. The choice of term may be determined by the type of expertise a team member brings, or the specific purpose of their role in the project. An inclusive approach suggests that members of the research team should have the choice of how they want to be identified or recognised for their contribution.



- The difference between the terms required in an ethics application and those used for roles within a co-production team mean that ethics committees can find it difficult to understand the roles of people with disability in co-production research.
- Generally, there should be a clear distinction between co-researchers and research participants in a co-production project. It would be expected that co-researchers, as members of a research team, are in paid roles and their appointment is a contractual and human resources matter for the employing institution. Research participants, on the other hand, may be compensated for their time to participate in the research. Their form of payment is usually specified in an ethics application. Co-researcher and participant roles can sometimes overlap, such as where a research team reflects on the co-production process and uses these reflections as data for a publication, or in certain methodologies such as auto-ethnography or participatory action research. Establishing clarity between these roles is crucial for the purposes of ethics approval<sup>24</sup>.
- Developing co-researchers' research skills, knowledge and confidence is a key part of the co-production process<sup>25</sup>. Evidence of reflection on co-researchers' strengths and shared responsibility for co-researchers' skill development can further demonstrate ethical processes of engagement with people with disability in co-researcher roles<sup>26</sup>.



### Researcher Insight

*“Committees could be asking more and expecting more of research teams who have community researchers [co-researchers], to make sure that they are being used well and being supported well.”*



## ● Strategies for Research Teams

### Choice

- Explain in ethics applications that co-production may mean that team members have a choice in how their roles are named and described.

### Clarity

- Clearly define and provide a rationale for any role title used in an ethics application<sup>27</sup>.
- Provide a rationale for the approach to naming and role definition used by the research team.

### Consistency

- Ensure that role titles and responsibilities are consistently expressed in all parts of an ethics application, within the research team and its communications, and in the dissemination of research findings including publications.

### Explicit

- Demonstrate how co-researcher roles are valued and supported within a co-production project.
- Be explicit about the ways the research team undertakes collective exploration and evaluation of support strategies for co-researcher roles.



## ● Strategies for Ethics Committees

### Accommodate

- Accommodate the collaborative nature of role designation in co-production research.

### Logic

- Assess the logic and coherence of descriptions of research team roles to ensure that the roles and duties of co-researchers have been properly considered.
- Ensure role descriptions align with the principles of Integrity, Beneficence, Justice, and Respect.

### Limits

- Check that research teams, including co-researchers, have assessed the actual or potential limits of a co-researcher role (i.e., what it is they will not be doing and engaging in).
- Recognise the ethical and safety issues associated with research of a sensitive nature and the need for accessible and tailored supports for co-researchers undertaking this type of research.



### Ethics Committee Chair Insight

*“The harder it is to understand the nature of the roles, the more there are going to be questions and concerns.”*



## Benefit and Risk in Co-Production

### ● The Issue

Co-production has been shown to have a range of benefits for all research stakeholders<sup>28 29</sup>. It offers all researchers an opportunity for personal growth and skills development. Additionally, it has the potential to empower co-researchers with disability, give them a voice, and provide them with training, skills, and job opportunities<sup>30 31</sup>. Co-production has been shown to improve knowledge, helping to ensure that the concerns and interests of people with disability and their communities are at the heart of research and enhancing opportunities for real-world impact. While ethics committees have historically assumed that the research experience is detrimental or negative for people with disability, experience suggests the opposite is usually the case. People with disability value the opportunity to contribute to research, and this should be perceived as a benefit<sup>32</sup>.

The National Statement provides detailed guidance on identifying, assessing, minimising, and managing risks in human research. It also notes that “the benefits of research may include, for example, gains in knowledge, insight and understanding, improved social welfare and individual wellbeing, and gains in skill or expertise for individual researchers, teams or institutions”<sup>33</sup>. In assessing applications, ethics committees are asked to decide “whether the risks are justified by the benefits” but are not given guidance on how to assess this balance. This means that if ethical principles come into conflict, members of ethics committees may be left to make individual judgments that are influenced by their personal experiences of or attitudes toward disability<sup>34</sup>.

### Researcher Insight

*“Co-production is an important strength to the research design of projects, and rather than seeing this as a risk, see it as something that actually bolsters the research design rather than presents risk to the research design.”*



## ● Considerations

- When assessing ethics applications, committees should take into account the context of the project and its goals as well as the history of collaboration in the research team<sup>35</sup>.
- Long-standing engagement with co-researchers in a research team can reduce the risk of coercion. Pre-existing relationships between research team members and co-researchers can be evidence of this history, and can enhance benefits and mitigate risks<sup>36</sup>.
- Literature suggests that the risks and benefits to co-researchers with disability should be contextually assessed<sup>37 38</sup>.
- Researchers may consider their application to be overall low risk yet find that the inclusion of a person with intellectual disability on the team automatically escalates an application to more than low risk. This may reduce the motivation to undertake co-production.
- Paradoxically, the ethical review process itself can introduce risk into the co-production process. The inaccessibility of the format and content of ethics documentation can be a barrier to the involvement of people with disability in the ethics approval process<sup>39</sup>. This can result in co-researchers being left out of the ethics process and therefore out of decision-making related to the research<sup>40</sup>.
- The sensitive nature of a research topic may be a concern for ethics committees when assessing applications. This can be mitigated by the research team collaborating and deciding on an approach that safeguards all members.



## Ethics Committee Chair Insight

*“The nature and culture of ethics committees is that they tend to incline towards attention to risk over benefit. I think concerns around vulnerability and harm often carry more weight than benefits around inclusion, broadly speaking.”*



## ● Strategies for Research Teams

### Articulate

- Use the ethics application process to clearly identify and articulate the benefits of co-production.
- Include potential beneficiaries beyond the individual participants.

### Acknowledge

- Recognise the importance of the collective knowledge and experience of the team in co-production.
- Detail any previous experiences of the team working together.

### Transparency

- Openly discuss any risks that may arise in the co-production process.
- Include a plan that describes how the team will respond to and manage any risks, such as conflict of interest or emotional distress of team members.



## ● Strategies for Ethics Committees

### Perspective

- Ensure that committee members have the information and knowledge needed to assess benefits against risks, beyond risk to individual participants.

### Experience

- Consider the experience of the research team in working with co-researchers and people with disability in general.
- Long-standing professional or personal experience in the field and sustained relationships with co-researchers are key markers of reduced risk.

### Safeguarding

- Recognise that in co-production, there may be protocols for safety, processes of de-briefing, and support practices that are unique to the team and that may differ from practices traditionally used with research participants.



## Vulnerability and Capacity in Co-Production

### ● Vulnerability: The Issue

Ensuring that no harm is caused is an important consideration in all forms of research, and co-production is no exception. Research involving people with disability has historically been experienced as abusive and harmful<sup>41</sup>. Ethical review that carefully examines research practices, and the adoption of co-production in disability research, both aim to prevent harm. One aspect of this scrutiny is the identification of particular groups, including people with a cognitive impairment, an intellectual disability, or a mental illness, as “vulnerable”. While the National Statement expresses general support for principles of inclusion it is much less specific about the nature of vulnerability. Instead, these groups are identified in general terms as having “distinctive vulnerabilities as research participants which should be taken into account” and that they “may be more-than-usually vulnerable to various forms of discomfort and stress”<sup>42</sup>. However, while the concept of vulnerability is generally understood in the ethical review process as offering protection to these groups, in practice it can be disempowering and experienced as oppressive<sup>43</sup>. This paradox can be difficult for ethics committees and research teams to manage.

### Researcher Insight

*“Peer researchers... I think they were the ones that first alerted me to the fact that that’s not a great term (vulnerable), and the reasons why, and I read up on it, and I was like, yeah, that makes sense.”*





### Disability Scholar Reflection

*“Vulnerability is strongly associated with qualities such as immaturity, weakness, helplessness, passivity, victimhood, and humiliation; moreover, it can specifically entail being unusually open to manipulation and exploitation by other more powerful, knowledgeable, or unscrupulous people. Against a background of such strong negative associations, the more vulnerable a disabled person is believed to be, the less likely it is that others will treat the choices she makes or opinions she holds as worthy of respect<sup>44</sup>.”*

Within disability studies and in the disability community more generally, vulnerability is a highly contested concept. The co-production principle of diversity recognises that people with disability are a heterogeneous group and that being labelled with a particular diagnosis, such as intellectual disability, is not inherently linked to vulnerability. Instead, vulnerability should be understood as contextual, intersectional, and dynamic. The lack of a nuanced understanding of vulnerability and the absence of specific guidance in making assessments of vulnerability in research, including co-production, make this aspect of ethical review one of the most challenging for researchers and ethics committees alike.



## ● Capacity: The Issue

Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) recognises that persons with disability have legal capacity on an equal basis with others<sup>45</sup>. In other words, an individual cannot lose his/her legal capacity simply because of a disability. The National Statement similarly asserts that “respect for human beings involves giving due scope to people’s capacity to make their own decisions” and in relation to participation in research requires that “consent should be a voluntary choice and should be based on sufficient information and adequate understanding of both the proposed research and the implications of participation in it”<sup>46</sup>. When a person with a disability acts in the role of co-researcher, inclusive teams follow these principles of recognition and assume capacity on the part of a co-researcher to choose to be a co-researcher, in the same way as other members of the research team. The need for a formal demonstration of capacity to consent and the associated signing of consent forms, which is ordinarily expected of research participants, is considered unnecessary because co-researchers are acting as employees rather than as research participants. However, this has been noted as a grey area in contemporary inclusive research practice and in ethical review.

This may be further complicated in instances where the co-researcher is also a research participant. For example, a research team may be invited to participate in another project about their co-production approach and experience, where data is collected, analysed and prepared for publication. In this case, it is likely that consent would be required from all research team members involved and it is expected that a range of accessible methods of giving consent (e.g., Easy Read, verbal consent) would be provided.



## ● Considerations

- Societal presumptions about all marginalised groups, for example that people with disability are a homogeneous group with the same characteristics, or that all people with intellectual and cognitive disability are automatically vulnerable, can influence the thinking of ethics committee members.
- Researchers may experience ethical difficulty if the process of applying for ethics approval requires them to identify co-researchers as vulnerable or potentially lacking capacity by virtue of their disability. The automatic attribution of vulnerability in the ethical review process is often perceived by co-researchers as insulting, and the continued requirement to use this terminology poses an ethical difficulty for research teams. Teams may need to challenge and reinterpret these ideas in their applications.
- Where people with disability are hired as co-researchers, their recruitment, contracted duties and responsibilities and rates of pay are generally regarded as a Human Resources process. By contrast, processes associated with people with disability who are recruited as research participants are matters for ethical review.



### Ethics Committee Chair Insight

*“There are instances where aspects of disability can produce vulnerability to which people need to be particularly attentive. I think that’s very different to saying disability in and of itself makes a person or a group vulnerable.”*



## ● Strategies for Research Teams

### **Articulate**

- Use the ethics application process to clarify the research team's approach to conceptualising, identifying, and assessing vulnerability.

### **Acknowledge**

- Acknowledge that all researchers, not just co-researchers, are vulnerable to experiencing distress and trauma when researching sensitive topics.
- Ensure ethics committees are aware of any potential for distress or trauma.
- Clearly describe measures to mitigate potential risks.

### **Explain**

- Be explicit about the differences between co-researchers as employees of the institution, and people with disability who are recruited as research participants.
- Detail the relevant responsibilities for institutions.



## ● Strategies for Ethics Committees

### Perspective

- Adopt a strengths-based perspective which looks at people's capabilities rather than deficiencies.
- Be critical of assumptions about vulnerability and capacity.

### Relevance

- Build an understanding of the nature of potential or actual concerns regarding vulnerability and capacity.
- In feedback to researchers, explicitly identify the relevant ethical issue of concern as an educative measure for research teams.

### Reflect

- Disability awareness training is useful to understand the diversity of people with disability and the issues related to vulnerability and capacity.
- Encourage committee members to reflect on their own presumptions about marginalised groups' capacities and how these presumptions may affect their assessment of ethics applications.



## Quality in Co-Production

### ● The Issue

While there is broad agreement that co-production has the potential to enhance the quality of research processes and outcomes, there is a general lack of clarity about what constitutes quality in co-production. Co-production done poorly can risk individual harm to co-researchers as well as reputational harm to researchers and their institutions. There is currently no evidence-informed indicators of quality or evaluation frameworks for co-produced research. As the field matures and diversifies, research teams need to reflect on and interrogate their own practice in order to articulate quality in their co-production applications. Ethics committees also have a duty to build their capacity to engage with the unique characteristics of co-production. This will enable effective consensual decision-making about quality, and avoid protracted or ill-informed ethical review processes acting as a disincentive to researchers using co-production methods. Together these will contribute to building a better understanding of the key components of quality in co-production.

### Researcher Insight

*“You can’t do this poorly; you have to do it well. And I think doing it poorly is worse than not doing it.”*



## ● Considerations

- Measuring quality in co-production involves assessing the quality of the collaboration and the final products or outcomes of the research.
- Quality requires a demonstration of both the depth and breadth of power sharing and transparency as principles of co-production.
- Including opportunities for reflection can help research teams to evaluate their processes and identify strategies to improve co-production practice.
- Measurement of quality in co-production will vary depending on the specific context and aims of a project and the stakeholders involved.
- There will be aspects of quality in co-production that may only be observable and/or measurable once a project has been completed. The inclusion of plans for post-project reflection and evaluation is an important indicator of researchers' attention to quality in their projects.
- The quality of ethical review of applications is also a significant issue. It can be affected by factors such as whether the composition of the committee is fit for purpose in assessing co-production, the committee's level of knowledge about disability and co-production, and the loss of experience as members rotate off the committee.



### Ethics Committee Chair Insight

*"Ethics committees should be seen as more than an approval body, but as a resource for finding the right solution for ethical practice."*



## ● Strategies

When articulating and assessing the quality of co-production, researchers and ethics committees may consider some or all of the following as potential indicators. Note that the current lack of rigorous evidence about quality in co-production means the following points are necessarily provisional and will benefit from further development.

- **Adherence to the principles of co-production:** assessment of quality may be guided by evaluation of the ways that the principles of Power-sharing, Diversity, Accessibility, Reciprocity, Flexibility, and Transparency are effectively put into practice.
- **Clearly defined project aims and outcomes:** evaluation of quality can consider how well co-production aligns with the goals and objectives of a project, and whether the project serves its intended purpose and delivers the planned outcomes.
- **Stakeholder satisfaction:** to strengthen the evidence-base for co-production, research teams may seek feedback from the people and organisations involved in the co-production process including research partners, collaborators (academic researchers, co-researchers or community disability organisations) and any end users. This may be on an individual or a collective basis.
- **Communication and collaboration:** factors such as information accessibility and sharing, the effectiveness of project coordination activities, and the approach to power-sharing, decision-making, and teamwork, can all demonstrate quality in co-production.
- **Time and resource management:** whether the project is delivered within the anticipated timeframe and whether the resources are adequate and appropriately utilised can provide insights into the quality of the co-production approach.



- **Impact and sustainability:** considering the short- and long-term impact of the co-production approach on both the team and the outcomes of research, including an assessment of the sustainability of the co-production relationship, can provide insight into its quality. Developing a co-production impact strategy is one useful way of articulating the added value of co-production.
- **Adaptability and innovation:** the ways in which the co-production process is continuously assessed and adapted throughout the life of a project, and the resulting innovations that occur, can indicate the quality of co-production in a project.



# Building Better Practice in Ethical Co-Production

The issues identified in this document indicate ways in which researchers and ethics committees can improve their practice in ethical co-production. Researchers and committees however do not work in a vacuum, and there are changes that can be made at a systemic level to better support both researchers and ethics committees.

## Ethical Governance

Current national level approaches to governance and guidance for researchers and ethics committees in Australia fail to explicitly address many issues relevant to co-production research with people with disability.

- **Conceptions of capacity and vulnerability** do not reflect the spirit of the United Nations Convention on the Rights of Persons with Disabilities, which assumes capacity and promotes choice and supported decision-making. There is evidence of good practice in other jurisdictions, notably the New Zealand *National ethical standards for health and disability research and quality improvement*: these take the default position that people with disability have the capacity to consent, and that it is the responsibility of research teams to ensure information and processes are accessible for all parties involved<sup>47</sup>.
- **People with disability remain under-represented in ethics review bodies.** People with disability make up more than 20% of the Australian population. Additionally, disability research makes up a significant proportion of the research output of universities and other institutions. Thus, the absence of a systematic approach to their representation

in research governance and decision-making is striking. Currently, it is left to the discretion of individual ethics review bodies to address issues of representation through the composition of membership of committees and their own ad hoc education and training. Alongside Aboriginal and Torres Strait Islander peoples, people with disability have consistently called for “nothing about us without us”, yet oversight of the nature, quality, and impact of research relating to people with disability by people with disability themselves remains marginalised at a systemic level.

- **Co-production and its quality** are unaddressed in national guidance. There is currently no recognition of co-production as a core approach to disability research and other research. Current guidance focuses on issues raised by research participation rather than co-production. This leaves ethics committees and researchers tasked with assessing the novel ethical issues inherent in co-production relationships and processes to evaluate risks, benefits, and quality without explicit knowledge or guidance. There is also a lack of clarity about what constitutes quality in co-production. Quality indicators and metrics/measures to assess co-production are urgently needed for future research.
- **Knowledge development, education, and training** about co-production are currently left to the discretion of individual ethics committees. Given the diversity of disciplines represented on these committees and the workload demands on committee members it is likely that most will have little knowledge or experience of co-production. A systematic co-researcher-led and researcher-led approach to education that moves beyond the technical issues of consent and compliance would significantly enhance capacity of the ethics committee to effectively assess the ethical aspects of co-production.



## ● Research Cultures

As co-production is increasingly recognised, encouraged, and even required by some funding bodies, there is a need to nurture co-production research cultures locally and across universities and other research institutions. This can be done in many ways:

- **Knowledge and skills** relevant to co-production in disability research are currently developed and fostered by individual researchers and research teams. The development of broader supporting mechanisms could enable research teams engaged in co-production to share their learnings, successes, and challenges to enhance quality in co-production research practice.
- **Knowledge sharing** in the form of communities of practice and cross-university collaborative networks could:
  - share models of practice for co-production.
  - share templates, strategies, and outcomes from applications or other examples of how an application can be developed in co-production.
  - provide space for early career researchers or researchers new to co-production to find like-minded researchers.
  - foster mentoring and capacity building in co-production, such as experienced co-researchers responding to the questions of research teams who are just starting to engage in co-production.
- **Ethics committees** also have an important part to play in developing and promoting co-production research culture. Open communication and engagement between ethics committees and research teams before, during, and after approval processes can contribute to a positive culture that facilitates co-production research.



## ● Institutional Infrastructure

Researchers consistently cite institutional barriers to co-production as a major challenge to their practice. These centre primarily on inaccurate assumptions about or the inflexible application of existing policies to the appointment of people with disability (particularly people with intellectual disability) into academic or professional positions, and associated concerns with expenditure of project financial resources on co-researchers and co-production activities. These issues play out in multiple separate institutional and administrative contexts, with significant time cost to researchers and institutional research and administration staff. This could be avoided by:

- clear institutional policies establishing the rationale and agreed model for a standardised approach to determining salary levels for co-researchers.
- awareness raising for university Research Support, Human Resources, and Financial administrators about the role of co-researchers in research projects.
- provision of more flexible and accessible Human Resource and Finance systems and processes.



## ● Research Funding and Commissioning

There is growing recognition of the rights of people with disability to have a say in research that affects them. As a result, national competitive funding schemes and government and non-government tendering and commissioning of research increasingly require evidence of co-production in research applications. This incentivisation is agenda-setting and sends clear signals to researchers about the importance of integrating co-production into their disability research approaches. Being able to demonstrate that employing co-researchers is a requirement rather than a “nice to have” can also be useful to researchers in negotiating the institutional barriers outlined above.

In preparing tenders or commissions, Funders should provide clear guidance to potential applicants that clarify why co-production is needed and when it is required. This may include the following:

- **Objectives and outcomes:** explain why co-production is necessary or beneficial to achieving objectives and outcomes.
- **Definition of co-production:** include any specific requirements or principles to guide co-production to ensure a shared understanding of what is expected.
- **Scope and scale of co-production:** specify the extent to which co-production is expected, i.e. whether it is required throughout the life of project or at specific stages.
- **Identify co-production stakeholders:** outline expectations about who should be involved in co-production, the level of expected collaboration, and the approach to decision-making.
- **Evaluation and monitoring of co-production:** set out expectations about how the co-production process will be tracked and assessed, including where possible details of indicators and measures of quality and impact.



- **Support and resources:** plan for and make available appropriate funding allocation for co-production, including payment for co-researchers, potential accommodations, and training or capacity building.
- **Deliverables:** specify relevant milestones, deliverables, and reporting specifically related to co-production.
- **Documentation and dissemination:** outline expectations of how the co-production process should be documented in reports and encourage researchers to share knowledge and insights gained about co-production.

## ● Further Research

As co-production is a relatively new approach in disability research, it is important that research teams think not only about what worked well in their co-production projects but also about what did not go according to plan. The DIU Co-Production in Action guidelines recommends this be done in the Reflecting phase of research. What works and what does not work also needs to be shared beyond individual teams. Indeed, co-production as an approach to research will become stronger and more methodologically nuanced by sharing resources and experiences. Sharing lessons learnt about the co-production process is essential to further the development of the practice of co-production in disability research.

## ● Ethics Beyond the Application

The material presented in this Guide focuses primarily on issues relevant to researchers in articulating their co-production approaches for the purposes of ethical review in the university setting, and to university ethics committees in making their assessments. In reality, ethical co-production happens beyond the application process. Co-production itself provides the perfect vehicle for the open, critical, and real-time interrogation of its own ethics. Researchers are encouraged to ensure that discussion of what makes for ethical research is built into collaborative project decisions and so is part of co-production itself.

# Glossary

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<b>Academic researchers</b>	People involved in co-production research who have formal academic training and/or qualifications who are employed by universities and/or research institutes to conduct research and contribute new findings in their discipline.
<b>Co-production</b>	Co-production is defined as authentic collaboration, collective decision-making, and power-sharing in knowledge creation with a range of stakeholders. In disability research, co-production can involve people with disability, their families and supporters, representatives of disability organisations, practitioners, service providers, and professional researchers <sup>48 49</sup> .
<b>Co-researchers</b>	People involved in the co-production of research who represent any of the groups mentioned above, based outside of academic or research institutions. In this sense, ‘co’ suggests an equal but different contribution and has the implication of ‘collaborative’. Some other terms are used in Australia and internationally, such as ‘community researchers’, ‘participatory researchers’, and ‘lived experience researchers’.
<b>Ethics approval</b>	The successful outcome of an ethical review. Once an ethics committee has conducted a review of a prospective research project and concludes that the project meets the requirements of the National Standards and additional legislative requirements of the field of research, the project will be granted ethics approval. This allows the researchers to start their research. It is essential that ethics approval is obtained before commencement of a research project.
<b>Ethical assessment</b>	The process in which the individual members of an ethics committee examine whether each phase of the research project meets the standards of the National Statement and additional legislative requirements of the field of research. Ethics committees are made up of people with different backgrounds, professional experience, and research areas of expertise. Members apply their unique individual expertise when assessing a research project.



<b>Ethical review</b>	The process of initial review and monitoring of research projects that considers the ethical implications and determines whether or not the proposed research is acceptable by the ethical standards outlined in the National Statement and additional legislative requirements of the field of research. Any research study involving human participants requires ethical review.
<b>Ethics committees</b>	A group of people who reflect on the design and conduct of human research to ensure the research adheres to the National Statement and legislation related to the field of research. Ethics committees can be attached to different institutions that conduct human research, including universities, government departmental committees, research institutes, and Non-Government Organisations. Membership is specified in the National Statement and should include a mix of gender, professional and lay people, and at least two people with current research experience relevant to the research application under review <sup>50</sup> .
<b>Medical model of disability</b>	In this model, disability is seen as failure of body and/or mind that results in limited functioning that is perceived as an ‘individual deficit’. Disability is viewed as causing ‘limitations’ such that a person with disability is not comparable to a person without a disability. These ‘deficits’ are viewed as problems that need to be ‘solved’ or ‘fixed’ <sup>51 52</sup> .
<b>Research participants</b>	People who are engaged in a research project which is about them, in which their data is collected from them.
<b>Rights-based model of disability</b>	The primary focus in this model of disability is on the fundamental human rights and dignity of an individual. A person’s ‘medical characteristics’ (such as their disability) should be noted only if necessary. This model views disability as part of the human experience and asserts that society’s government, policies and laws need to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity” <sup>53</sup> as outlined in the United Nations Convention on the Rights of Persons with Disabilities <sup>54</sup> .
<b>Social model of disability</b>	In this model, disability is understood as a social construct, at least in part, in which a person’s disablement is caused by societal barriers that prevent their equal participation in society. Unlike the medical model, the social model sees disability not as an ‘individual deficit’ but as the result of barriers and obstacles created by society <sup>55</sup> . Therefore, society needs to adapt to ensure people with disability have full access.

# Useful Resources

## Co-production research with people with disability

Strnadová, I., Dowse, L., & Watfern, C. (2020). *Doing research inclusively: guidelines for co-producing research with people with disability*.

Open access link: [apo.org.au/node/310904](https://apo.org.au/node/310904)

*Doing research inclusively* is a set of guidelines that have been designed for academic researchers in the field of disability research, people with disability, disability organisations, and other stakeholders. This guide provides information about the benefits, principles and strategies of co-production research with people with disability. *Doing research inclusively* is a useful resource for those who wish to develop a better understanding of co-production research, its benefits and challenges, and how to undertake co-production research with people with disability.

Strnadová, I., Dowse, L., & Garcia-Lee, B. (2021). *Doing research inclusively: Co-production in action*. DIIU UNSW Sydney.

Open access link: [www.disabilityinnovation.unsw.edu.au/sites/default/files/documents/15661\\_UNSW\\_DIIU\\_CoProductionInAction\\_FA\\_Web.pdf](https://www.disabilityinnovation.unsw.edu.au/sites/default/files/documents/15661_UNSW_DIIU_CoProductionInAction_FA_Web.pdf)

*Co-production in action* is a set of guidelines that have been designed for academic researchers in the field of disability research, people with disability, disability organisations, and other stakeholders. This guide provides detailed consideration of co-production activities across the different stages of the research process. For those who are participating in co-production research, *Co-production in action* is a useful resource to help develop a better understanding of the process and key considerations of conducting co-production research with people with disability.

## Inclusive research with people with disability

RDI Network. (2020). *Research for all: Making research inclusive of people with disabilities*. CBM-Nossal Partnership for Disability-inclusive Development and Research for Development Impact Network.

Open access link: [rdinetwork.org.au/wp-content/uploads/2020/06/RDI-Network-R4All-Accessible-PDF-1.pdf](https://rdinetwork.org.au/wp-content/uploads/2020/06/RDI-Network-R4All-Accessible-PDF-1.pdf)

*Research for all* is designed for researchers, policy makers, and practitioners. It provides tools and resources for those conducting or evaluating research within the population or community to ensure that people with disability are not excluded. *Research for all* outlines principles of best practice and ethical considerations, and how these should be applied across the research cycle. As this guide has not been specifically designed solely for disability research, it can therefore be used in all research conducted with human participants.

den Houting, J. (2021). *Participatory and inclusive autism research practice guides*. Brisbane. Autism CRC.

Access to guide: [www.autismcrc.com.au/access/inclusive-research-guides](http://www.autismcrc.com.au/access/inclusive-research-guides)

*Participatory and inclusive autism research practice guides* contains six guides focused on participatory and inclusive research with autistic people. The guides outline research principles, concepts, and practices for conducting research with the autistic community to ensure authentic community engagement. The guides can be used by autistic people, researchers, policy makers, disability organisations and other stakeholders, to promote participatory research methodologies.

## Ethical research with community

Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement. (2022). *Community-based participatory research: A guide to ethical principles and practice (2nd edition)*. CSJCA & NCCPE, Durham and Bristol.

Open access link: [www.durham.ac.uk/media/durham-university/departments-/sociology/Community-Based-Participatory-Research-A-Guide-to-Ethical-Principles,-2nd-edition-\(2022\)-.pdf](http://www.durham.ac.uk/media/durham-university/departments-/sociology/Community-Based-Participatory-Research-A-Guide-to-Ethical-Principles,-2nd-edition-(2022)-.pdf)

*Community-based participatory research (2nd edition)* is a guide outlining how ethics should be applied to community-based participatory research (CBPR). This guide outlines ethical principles and guidance for how these principles are to be applied in practice. *Community-based participatory research (2nd edition)* can be applied by researchers, community members, community organisations and other stakeholders who engage in CBPR research, to ensure that research is conducted ethically throughout all phases of the research process.

## Co-design research with people with lived experience

Bellingham, B., Elder, E., Foxlewin, B., Gale, N., Rose, G, Sam, K., Thorburn, K., River, J. (2023) *Co-design kickstarter*. Community Mental Health Drug and Alcohol Research Network, Sydney.

Open access link: [cmhdaresearchnetwork.com.au/wp-content/uploads/2023/06/Co-design-kickstarter-FINAL-22.6.23-v4.pdf](http://cmhdaresearchnetwork.com.au/wp-content/uploads/2023/06/Co-design-kickstarter-FINAL-22.6.23-v4.pdf).

*Co-design kickstarter* is a resource for participation and co-design research in mental health, alcohol and other drugs (MHAOD) research. This guide outlines the different approaches to co-design research with specific focus on substantive co-design research where the research process is co-planned, co-defined, co-conducted, and co-disseminated. *Co-design kickstarter* can be used by a wide range of stakeholders involved in co-design in MHAOD research.

# References

- <sup>1</sup> Strnadová, I., Dowse, L., & Watfern, C. (2020). *Doing research inclusively: Guidelines for co-producing research with people with disability*. DIIU UNSW Sydney. [https://www.disabilityinnovation.unsw.edu.au/sites/default/files/documents/DIIU%20Doing%20Research%20Inclusively-Guidelines%20\(17%20pages\).pdf](https://www.disabilityinnovation.unsw.edu.au/sites/default/files/documents/DIIU%20Doing%20Research%20Inclusively-Guidelines%20(17%20pages).pdf)
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