**Ethical Issues in Co-Production Research with People with Disability: Background paper to Guidance for Researchers and Ethics Committees**



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# About this background paper

People with disability are experts in their own lives through experience. Co-production is an approach that enables people with disability to inform and work collaboratively with researchers to conceptualise, design and implement research that addresses issues of importance to people with disability. As a research approach, co-production is built on respect and acknowledgment of the life experience of the person with disability. Its methodology is flexible, responsive and open, and the details of how it is done will vary between projects. Australia’s National Health and Medical Research Council provides the National Statement on Ethical Conduct in Human Research 2007 (updated 2018) to guide human research, but this document does not explicitly address co-production. This means that researchers are currently without clear guidance on how to articulate co-production in their proposals, and ethics committees are similarly unsupported in how to assess the ethical implications of proposed co-production.

This paper provides background information relevant to ethical issues in co-production research with people with disability in the university context in Australia. It is a companion to *Doing Research Inclusively: Guidance on Ethical Issues in Co-Production*,which provides strategies for academic researchers in the preparation of applications for ethics approval for proposed co-produced research, and for ethics committees in the review and approval of those proposals. This document describes the approach used for information gathering to support the development of guidance for ethics committees and researchers. It briefly summarises the findings of a review of contemporary research literature and existing guidance, and findings from interviews with inclusive research teams and chairs of ethics committees at Australian universities.

# Review of literature and guidance

A review of contemporary research literature and existing guidance was conducted to ensure the identification of key issues and the development of suggested strategies for researchers and ethics committee that is grounded in the best available current evidence. This review and scoping covered: (i) peer-reviewed literature, (ii) grey literature, and (iii) ethics guidance in English-speaking countries. The date range for inclusion of resources span 20 years from 2003-2023, including the years in which Australia adopted and ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

## 2.1 Peer-reviewed literature

### 2.1.1 Approach

Relevant academic literature was identified, focusing on: a) research using co-production/co-design research methods, b) research including people with disability in co-production/co-design processes, and c) ethical issues or reflections on conducting co-production/co-design research methodologies with people with disability. Detailed information about the search strategy is available in Appendix A.

Articles were excluded if they a) included people with disability solely as participants and not as part of the research team, b) discussed ethics in relation to gaining ethics approval or following ethics protocols, with no elaboration about ethical considerations or reflections on co-production/co-design with people with disability, and c) if people with disability were not included in research.

Based on these criteria, 63 articles were included in the literature review and then read, focusing on two key questions:

a) How are the roles of people with disability within research teams named? and

b) What ethical issues are identified in co-produced disability research?

### 2.1.2 Key findings

#### Naming the roles of people with disability within research teams

The roles of people with disability within research teams are often not explicitly named. Where they are named, there is little consistency.

* Where people with disability within research teams are referred to, they are often identified with their diagnostic label, such as “people with a learning disability” (Inglis & Cook, 2011, p.99).
* People with disability may also be referred to in broader terms, such as “marginalised groups” (Fiske et al., 2019, p.617), “disabled participants” (van der Heijden et al., 2019, p.738) and “previously disempowered groups” (Northway et al., 2015, p.574).
* Where the role of the person with disability is defined, the most consistently used term is “co-researcher” (Ajodhia-Andrews, 2015; Brady & Franklin, 2019; Chown et al., 2017; Tilley et al., 2021), with descriptions being strength-based (Tilley et al., 2021) and focusing on decision-making (Brady & Franklin, 2019).
* Less commonly used terms are “participant researcher” (Cook & Inglis, 2012), “citizen scientist” (Chesser et al., 2020, p.498) and “colleagues, knowledge users, and partners” (Cascio et al. 2020, p.1677).

#### Identified ethical issues in co-produced disability research

A diverse range of ethical issues in co-produced disability research was identified in the peer-reviewed literature. These could be grouped into distinct categories, with the most frequently mentioned being vulnerability, followed by research design, procedural ethics, and safety. It should be noted however that the authors of the peer-reviewed literature described here are principally researchers, and although some may have been part of ethics committees, this was not stated. No literature was found that specifically examines issues for those assessing ethical issues (such as members of ethics committees).

*Vulnerability*

Discussions of the issue of vulnerability examine capacity, as well as consent and power differentials. The potential risks of research are acknowledged and are recommended to be contextualised and balanced against benefits.

* The widespread notion that people with disability are too vulnerable and lack capacity to participate in research is disputed as being over-protectionist and paternalistic, leading to exclusion and a “denigration of their autonomy” (Gombert et al., 2016, p. 593; Gustafon & Brunger, 2014; Kuper et al., 2021; Northway et al., 2013, van de Heijen et al., 2019).
* Children and young people with disability are highlighted as a group where the balance between research involvement and safeguards is particularly important (Ajodhia-Andrews, 2015; Brady & Franklin, 2019).
* Informed and ongoing consent is recognised as vital to co-produced research (Ajodhia-Andrews, 2015; Cook & Inglis, 2012), noting that people with disability may feel obliged to consent (Coons & Watson, 2013; Gombert et al., 2016).
* Power imbalances and the potential risk of coercion can be addressed by establishing processes for power-sharing and using arms-length recruitment (Marshall et al., 2012; Nicolaidis et al., 2019).

*Research design*

The second most common category of ethical issues identified in the literature relates to research design. Specific issues span diverse areas of research design including timelines, accessibility, accommodations, reasonable adjustments and renumeration.

* It can be an ethical issue if timelines do not account for the time needed to obtain informed consent, to establish trust between research team members, to provide the team with training and capacity building, and to reflect on the research (Ajodhia-Andrews, 2015; Banks et al., 2022; Coons & Watson, 2013; Dee-Price, 2020; Gabriel et al., 2017; Gombert et al., 2016; Inglis & Cook, 2011; Mintz et al., 2022; Northway et al., 2015; Tilley et al., 2021; van der Heijen et al., 2019).
* Accessibility can be an issue at all levels of research design, including recruitment and research dissemination, such as providing accessible documents for ethics approval, consent forms, and information sheets, and the use of visual aids and augmentative and alternative communication (Banks et al., 2022; Brady & Franklin, 2019; Cook & Inglis, 2012; Marshall et al., 2012; Northway et al., 2015).
* Research design should provide for accommodations and reasonable adjustments such as research sessions of appropriate duration, greater flexibility and support workers that enable co-researchers to have an equal opportunity to participate and engage in research (Carmichael & Carmichael, 2014; Chesser et al., 2020; Dee-Price, 2020; Gilbert, 2004; Goodwin & Tiderington, 2022; Inglis & Cook, 2011; Marshall et al., 2012; Morgan et al., 2014; Northway et al., 2015).
* There are potential issues related to renumeration such as unpaid labour in co-produced research and the difficulty of renumerating people with disability if it impacts their pensions and welfare benefits (Northway et al., 2015; Rickard & Purtell, 2011).

*Procedural ethics*

Procedural ethics, the formal processes of ethical evaluation and approval such as those set out by ethics committees, is perceived to be an issue in co-production research (Guillemin & Gillam, 2004). Procedural ethics may not recognise the nuances and everyday ethical issues that researchers and co-researchers negotiate while undertaking co-produced disability research.

* Ethics committees require up-skilling in their understanding of people with disability and co-produced disability research and its related methodologies, as it may be ethically problematic if disability and co-produced disability research is not accurately comprehended or valued (Dorozenko et al., 2016; Goodyear-Smith et al., 2015; Horowitz et al., 2009; Tee & Lathlean, 2004).
* Traditional ethics approval processes can mean that co-researchers cannot participate in research teams from the beginning if their participation requires approval, an issue further exacerbated by often lengthy ethical assessment and approval processes (Fleming et al., 2014; Northway et al., 2013; Taylor & Balandin, 2020).
* Ethics committees may request that their standards be applied without flexibility, which can make research inaccessible such as the inclusion of complex information (Kong et al., 2020; Morgan et al., 2014).
* The difficulties of negotiating procedural ethics are increased by the lack of guidance on ethical inclusive practices, particularly for specific populations of people with disability (Lam et al., 2020; Newbutt & Bradley, 2022).

*Safety*

A number of other ethical issues that relate to safety in ethical co-production are identified in the peer-reviewed literature. These concern the safety of researchers and co-researchers in relation to disclosure, confidentiality, and misconduct.

* Disclosure of traumatic events can be ethically challenging if appropriate services and referrals cannot be offered or are unavailable (Kyegombe et al., 2019).
* Maintaining confidentiality can be an issue in cases where there is disclosure of criminal actions or inconsistent accounts (Marshall et al., 2012; Kyegombe et al., 2019).
* Misconduct by researchers and co-researchers may arise for example due to pressure to meet recruitment goals (True et al., 2011).
* To maintain ethical conduct, True et al. (2011) recommend that the members of the research team be well connected to each other, have knowledge of the research protocol and underlying rationale, and be supported by a supervisor.

## Grey literature

### 2.2.1 Approach

Scoping of grey literature was conducted to identify existing advice developed by universities, organisations, institutions, and government agencies about co-production research with people with disability. Relevant documents was identified in the grey literature, focusing on: a) guidelines for research using co-production/co-design research methods, b) research including people with disability in co-production/co-design processes, and c) ethical issues or reflections on conducting co-production/co-design research methodologies with people with disability.

The search strategy used is presented in Appendix B. Based on these criteria, 14 documents were included in the final set of grey literature reviewed. These guidelines were read focusing on: a) How are the roles of people with disability within research teams named? and b) What ethical issues are identified in co-produced disability research?

### 2.2.2 Key findings

#### Naming the roles of people with disability within research teams

Findings from the review of grey literature were similar to those from the peer-reviewed literature identified above.

* There is little consistency in how the roles of people with disability within research teams are named.
* People with disability within research teams are generally referred to with their diagnostic label (Clifton, 2020).
* “Co-researcher” is the most frequently used designation (Durham Community Research Team, 2011; Wilson et al., 2020).

#### Identified ethical issues in co-produced disability research

Comparable categories of ethical issues in co-produced disability research were identified in the review of grey literature and peer-reviewed literature. However, the frequency at which different categories of ethical issues were mentioned varied. In the grey literature, the most common categories of ethical issues were research design followed by data management and ownership, and vulnerability. As in the case of the peer-reviewed literature, the vast majority of authors were researchers, though some guidelines were authored by organisational entities such as ethics committees or bodies with which ethics committees are registered. This lack of commentary from ethics committees further emphasises the need for a greater understanding of the perspectives of ethics committees on co-produced disability research.

*Accessible design*

Similar points about accessibility as an ethical issue are raised across grey and peer-reviewed literature. The importance of implementing accessible research design across all phases of research is emphasised (Research for Development Impact Network [RDIN], 2020).

* Meaningful representation and respectful relationships with co-researchers and disability organisations are considered ethical concerns and can be improved through disability training and professional development (Kaur & Kerrigan, 2020; RDIN, 2020; Research for Development Impact Network & Australian Council for International Development [RDIN & ACID], 2021).
* Research design should allow for reflection, including the establishment of appropriate channels for co-researchers to provide feedback and to assess the impact of research decisions (den Houting, 2021; RDIN, 2020).
* Accessibility of materials and methods across communication, data collection, and dissemination, as well as reasonable adjustments, are all identified as important to research involvement (RDIN, 2020; RDIN & ACID, 2021).
* Appropriate budgeting for inclusive accommodations is highlighted as an ethical issue (RDIN, 2020).

*Data management*

The second most common category of ethical issue is data management and ownership. Interestingly this issue is not similarly raised within the peer-reviewed literature.

* Maintaining confidentiality and preserving anonymity are considered important ethical safeguards for respect (Kaur & Kerringan, 2020).
* However, data management is often not considered seriously and anonymity may not be possible in cases of controversial research (Durham University, n. d.; RDIN & ACID, 2021).
* Discussion of ownership of research data and intellectual property is an ethical issue related to rights (den Houting, 2021).
* As an example, the co-ownership or ownership of intellectual property for Aboriginal and Torres Strait Islander Peoples is linked to the right to their heritage and traditional knowledge and culture, all the more significant given their historical lack of recognition and exclusion (National Health and Medical Research Council, 2018).

*Vulnerability*

Lastly, the category of vulnerability is recognised as being of ethical concern. As in the peer-reviewed literature, a reframing of the vulnerability of people with disability is suggested (Clifton, 2020).

* Power dynamics within research teams can be managed through attention to power imbalances, sharing leadership roles, and respecting lived experience expertise (den Houting, 2021; Durham University, n.d.).
* Accessible consent processes for people with disability to facilitate informed decision making is discussed as an ethical issue alongside vulnerability (RDIN, 2020)

## 2.3 Existing ethics guidance

### 2.3.1 Approach

A scoping of existing ethics guidance was conducted to establish the expectations of and recommendations for the ethical conduct of co-production/co-design research with people with disability in English-speaking countries. The objective was to review international and national research guidelines used by researchers globally that are equivalent to the National Statement. The search strategy used is presented in Appendix C which includes Table 1 Existing Ethics Guidance Characteristics.

Eleven guidelines were identified based on the above criteria and were analysed, focusing on: a) whether people with disability within research teams are acknowledged, b) whether people with disability are perceived as ‘vulnerable’ or as having capacity, and c) how co-production with people with disability is discussed.

### 2.3.2 Key findings

#### Acknowledgement of people with disability within research teams

Most international and national research guidelines reference people with disability as participants, but only a minority acknowledge people with disability within research teams. There is variation in the level of information provided about people with disability as participants.

* People with disability are commonly identified as participants without any further information.
* There are references to the notion that people with disability should be included in research and not excluded because of their disability (Canada Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council, 2018; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).
* Considerations of accessibility, including in communication, location, and format of research information such as large print and Easy Read, are discussed (National Disability Authority, 2009).
* People with disability are sometimes acknowledged as a population group who can be involved in and contribute positively to co-production research when social barriers to their involvement are addressed and removed (National Ethics Advisory Committee, 2019).

#### Perceptions of vulnerability and capacity

Most guidelines do not make explicit reference to or discuss vulnerability or capacity in relation to people with disability. The few guidelines that do, adopt varied standpoints about whether people with disability are vulnerable or have capacity.

* People with disability are sometimes considered to be vulnerable due to their assumed limited capacity to, for example, consent to participation in research (Canada Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council, 2018; National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). In these cases, it was advised that third party consent, risk and benefits, and engagement with community and community leaders be considered.
* Conversely it is argued that vulnerability in people with disability should not be assumed as vulnerability is complex and can vary based on the individual’s characteristics, life stage, and context as well as the nature of the research they are involved in (National Disability Authority, 2009; National Ethics Advisory Committee, 2019)
* It is suggested that excessive concern in the form of gatekeeping to protect those considered vulnerable can be paradoxically harmful as it leads to their exclusion from research and further marginalisation (Atkinson, 2007).

#### Examination of co-production with people with disability

Most guidelines do not make specific mention of co-production in general nor co-production with people with disability. Those that do, focus on:

* Ethical principles related to co-production such as mutual respect, everyone being equally valued, sharing and understanding power, addressing and challenging inequality, and considerations of accessibility (Hickey et al., 2018; Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement, 2022).
* Concepts related to social justice such as making a difference, collective action, and personal integrity (Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement, 2022).
* Relational elements, including the need for reciprocity of benefits and building and maintaining relationships (Hickey et al., 2018).
* Practical aspects of co-production, including adaptations and adjustments to support researchers with disabilities, appropriate funding allocation, and a longer timeline for research (National Ethics Advisory Committee, 2019).

# Interviews

In order to identify current challenges in ethics in co-production in the Australian context, we interviewed a range of inclusive researchers/research teams based at Australian universities and ethics committees who are tasked with reviewing applications for ethics approval, to draw on their knowledge and experience.

## 3.1 Approach

Online interviews were conducted with selected researchers and/or inclusive research teams and with Chairs of ethics committees from Australian universities. All interviews were digitally recorded and transcribed. Appendix D presents the list of contributors and their institutional affiliations. Ethics approval was granted by UNSW Human Research Ethics Committee (HREC).

*Australian academic researchers and co-researchers with disability*

Researchers were identified for interview based on their track record, identified through their publications, of working in co-production research with people with disability. These were long-listed and discussed with project funders to ensure representation across university location and disciplinary area. Interviewees were approached by email. In total, 27 academic researchers and 8 co-researchers, from 13 research teams across 10 universities, were interviewed alone or in groups. The semi-structured interviews canvassed experience in inclusive research and co-production; barriers, challenges and strategies when making successful ethics applications for co-production projects; views on the concepts of vulnerability and capacity in co-production; the accessibility of ethics application processes; and specific advice for researchers, ethics committees and research governance bodies to build better practice in ethical review.

*Chairs of Australian university ethics committees*

Chairs of Australian university HRECs were identified via online search and email invitations were issued to universities based on size, location, and experience in assessing co-production proposals, inferred from researcher profiles. Interviews were conducted with HREC Chairs from three universities. The low number reflects the limited availability of interviewees within project timeframes. Semi-structured interviews covered experience assessing co-production applications; issues and challenges in the assessment and review of co-production projects and disability inclusive research proposals; the accessibility of ethics application processes; and any specific advice for researchers, for ethics committees and research governance bodies to build better practice in ethical review of co-production projects with people with disability. Some researchers interviewed had also served as members of ethics committees and thus were able to bring additional insights from their experience.

Thematic analysis of all de-identified transcripts was conducted, following the iterative approach established by Braun and Clarke (2006). This process involved familiarisation with the transcripts through repeated reading and then summarising the salient points in each interview via deductive coding using interview questions as a guide for organisation. Inductive coding was then applied, based on themes identified via the literature review. Codes were subsumed into interpretative themes that were relevant across the entire dataset. These aligned with insights from the literature and other relevant guidance, giving rise to the core factors and key ethical issues and associated strategies outlined below.

## 3.2 Key findings

The following key findings emerged from the thematic analysis of the interviews.

* ***Co-production enhances integrity*:** A co-production approach is a positive ethical safeguard in disability research and helps to mitigate ethical concerns. Co-production, when appropriate and done well, enhances the integrity and quality of a project and may contribute to better research outcomes. Most importantly co-production advances recognition of the roles that previously marginalised people can play in research.
* ***Inaccessible application processes*:** The ethics application process can exclude co-researchers. The complexity of format and language of the application process may be inaccessible and can marginalise co-researchers and as a result exclude them from decision-making related to the research.
* ***Harm in the application process:*** Lack of understanding can mean ethics committees apply a ‘medical model’ interpretation of disability as a deficit when considering co-production research, resulting in a more ‘protectionist’ approach to assessment. Co-researchers can experience harm and insult because of the requirement in the application process to identify certain people with disability 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. It also presents a professional and moral dilemma for inclusive 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 or assume that co-production is a red flag for ethics committees, attracting a level of scrutiny that makes co-production ‘too much trouble’. Ethics committees may assume that co-production adds ethical complexity rather than ethical rigour to a proposal.
* ***Conflicting ethical principles****:* Limited ethical guidance can mean that ethical principles may be in conflict when applied to co-produced disability research. This may then require researchers and members of ethics committees to make individual judgments, which are inevitably influenced by their personal experiences of and attitudes toward disability.
* ***Familiarity with the process****:* Researchers may be unfamiliar with ethics processes and the terminology needed. A sound understanding of the National Statement will ensure that co-produced projects are well explained 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 proposals.
* ***Variability in experience and motivation:*** Researchers come to co-production in different ways, from different disciplines, and will have varying levels of 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.
* ***Educational rather than confrontational:*** 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 disability research. These tensions can be exacerbated by the increasingly technical nature of the application process itself. Direct personal relationships and open lines of communication between inclusive researchers and ethics committees can enable all parties to learn from each other and support the development of co-production research with people with disability.

# Appendices

## Appendix A Peer Reviewed Literature Search Strategy

Search terms used were: “co-produc\* research” OR “co-design\* research” OR “inclusive research” OR “participatory research” OR “emancipatory research” OR “action research" AND “disab\*” OR “neurodivers\*” OR “learning difficult\*” OR “autis\*” OR “marginali\*” OR “vulnerabl\*” AND "ethic\*".

Three databases were selected based on their scope of academic literature relevant to the research focus: PsychINFO, Scopus, and CINAHL.

There were 338 records found from applying the search terms, dates, and peer reviewed journal criteria. After duplicates were removed and abstracts read, there were 107 articles. These articles were read against inclusion criteria to determine relevancy and a final total of 63 articles included in the literature review.

## Appendix B Grey Literature Search Strategy

Search terms used were: (co-production research OR co-design research OR inclusive research OR participatory research OR emancipatory research OR action research) AND (disability OR neurodiverse OR autistic OR marginalised OR vulnerable) AND ethic.

Google Advance was used to compile existing relevant guidance. To ensure that government, educational, organisations and health specific publications were captured in these searches, specific adjustments such as .org or .govt.nz were used. This scoping of grey literature focused on English-speaking countries including the United States, the United Kingdom, Canada, and New Zealand. There were 141 records found. This was reduced to 56 publications based on reading of the abstract. The text was then read against the inclusion criteria and a final total of 14 documents included as part of the grey literature.

##

## Appendix C Existing Ethics Guidance Search Strategy

Searches were conducted using Google Advance and Google, and focused on international guidelines, national guidelines, and guidance used by universities and health organisations when conducting research on human subjects. The focus was on international guidelines and guidelines available in the United States, United Kingdom, Ireland, Canada, and New Zealand. Eleven existing items of ethics guidance were included.

**Table 1 Existing Ethics Guidance Characteristics**

|  |  |  |  |
| --- | --- | --- | --- |
| Authors  | Date | Guidance | Location |
| Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council | 2018 | Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans. | Canada  |
| National Ethics Advisory Committee | 2019 | National Ethical Standards for Health and Disability Research and Quality Improvement | New Zealand |
| United Kingdom Research and Innovation  | 2022 | Revised UKRI Policy on the Governance of Good Research Practice | United Kingdom |
| National Health Service Health Research Authority | 2017 | UK Policy Framework for Health and Social Care Research | United Kingdom |
| Centre for Social Justice and Community, Action and National Co-ordinating Centre for Public Engagement  | 2012 | Community-based Participatory Research: A Guide to Ethical Principles and Practice | United Kingdom |
| Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., Staniszewska, S., Tembo, D., Torok, K., and Turner, K. | 2018 | Guidance on Co-producing a Research Project | United Kingdom |
| National Disability Authority | 2009 | Ethical Guidance for Research with People with Disabilities | United Kingdom |
| United States Environmental Protection Agency | 2016 | Policy and Procedures on Protection of Human Subjects in EPA Conducted or Supported Research | United States |
| National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research | 1979 | The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research | United States |
| World Health Organization | 2011 | Standards and Operational Guidance for Ethics Review of Health-related Research with Human Participants | International |
| United Nations Educational, Scientific and Cultural Organisation | 2006 | Universal Declaration on Bioethics and Human Rights | International |

## Appendix D List of Contributors

|  |  |
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| Dr Alexandra Devine | University of Melbourne |
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# References

Ajodhia-Andrews, A. (2015). Reflexively conducting research with ethnically diverse children with disabilities. *Qualitative Report*, *21*(2), 252–287. <https://nsuworks.nova.edu/tqr/vol21/iss2/6/>

Atkinson, J. (2007). Protecting or empowering the vulnerable: Mental Illness, communication and the research process. *Research Ethics Review,* 3(4), 134–138. <https://doi.org/10.1177/174701610700300410>

Banks, L. M., Willan, S., Inglis-Jassiem, G., Dunkle, K., Ganle, J., Shakespeare, T., Khan, R. S., Hameed, S., Machisa, M., Watson, N., Carpenter, B., Smythe, T., Mthethwa, N., Seketi, Q., Wilbur, J., Nzuza, A., İlkkurşun, Z., Tetali, S., Huq, L., Clyde, A., & Hanass-Hancock, J. (2022). Adapting disability research methods and practices during the covid-19 pandemic: Experiences from the field. *IDS Bulletin*, *53*(3), 129–152. <https://doi.org/10.19088/1968-2022.130>

Brady, G., & Franklin, A. (2019). Challenging dominant notions of participation and protection through a co-led disabled young researcher study. *Journal of Children’s Services*, *14*(3), 174–185. <https://doi.org/10.1108/JCS-03-2019-0016>

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. https://doi:10.1191/1478088706qp063oa

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council. (2018).  *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Secretariat on Responsible Conduct of Research. <https://ethics.gc.ca/eng/documents/tcps2-2018-en-interactive-final.pdf>

Carmichael, C., & Carmichael, P. (2014). BNCI systems as a potential assistive technology: Ethical issues and participatory research in the BrainAble project. *Disability & Rehabilitation: Assistive Technology*, *9*(1), 41–47. <https://doi.org/10.3109/17483107.2013.867372>

Cascio, M. A., Weiss, J. A., & Racine, E. (2020). Person-oriented ethics for autism research: Creating best practices through engagement with autism and autistic communities. *Autism: The International Journal of Research & Practice*, *24*(7), 1676–1690. <https://doi.org/10.1177/162361320918763>

Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement. (2022). C*ommunity-based participatory research: A guide to ethical principles and practice (2nd edition).* Centre for Social Justice and Community Action. [https://www.durham.ac.uk/media/durham-university/departments-/sociology/Community-Based-Participatory-Research-A-Guide-to-Ethical-Principles,-2nd-edition-(2022)-.pdf](https://www.durham.ac.uk/media/durham-university/departments-/sociology/Community-Based-Participatory-Research-A-Guide-to-Ethical-Principles%2C-2nd-edition-%282022%29-.pdf)

Chesser, S., Porter, M. M., & Tuckett, A. G. (2020). Cultivating citizen science for all: Ethical considerations for research projects involving diverse and marginalized populations. *International Journal of Social Research Methodology: Theory & Practice*, *23*(5), 497–508. <https://doi.org/10.1080/13645579.2019.1704355>

Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L., & MacGregor, D. (2017). Improving research about us, with us: A draft framework for inclusive autism research. *Disability & Society*, *32*(5), 720–734. <https://doi.org/10.1080/09687599.2017.1320273>

Clifton, S. (2020). *Hierarchies of power: Disability theories and models and their implications for violence against, and abuse, neglect, and exploitation of, people with disability*. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. <https://disability.royalcommission.gov.au/system/files/2020-10/Research%20Report%20-%20Hierarchies%20of%20power_Disability%20theories%20and%20models%20and%20their%20implications%20for%20violence%20against%2C%20and%20abuse%2C%20neglect%2C%20and%20exploitation%20of%2C%20people%20with%20disability.pdf>

Cook, T., & Inglis, P. (2012). Participatory research with men with learning disability: Informed consent. *Tizard Learning Disability Review*, *17*(2), 92–101. <https://doi.org/10.1108/13595471211218875>

Coons, K. D., & Watson, S. L. (2013). Conducting research with individuals who have intellectual disabilities: Ethical and practical implications for qualitative research. *Journal on Developmental Disabilities*, *19*(2), 14–24. <https://www.proquest.com/scholarly-journals/conducting-research-with-individuals-who-have/docview/1460847872/se-2?accountid=12763>

Dee-Price, B-J. M. (2020). Social researchers and participants with intellectual disabilities and complex communication (access) needs. Whose capacity? Whose competence? *Research and Practice in Intellectual and Developmental Disabilities*, *7*(2), 132–143. <https://doi.org/10.1080/23297018.2020.1788418>

den Houting, J. (2021). *Participatory and inclusive autism research practice guides.* Autism CRC. <https://research-management.mq.edu.au/ws/portalfiles/portal/217708443/217471379.pdf>

Dorozenko, K. P., Bishop, B. J., & Roberts, L. D. (2016). Fumblings and faux pas: Reflections on attempting to engage in participatory research with people with an intellectual disability. *Journal of Intellectual & Developmental Disability*, *41*(3), 197–208. <https://doi.org/10.3109/13668250.2016.1175551>

Durham Community Research Team. (2011). *Community-based Participatory Research: Ethical Challenges.* Centre for Social Justice and Community Action. <https://www.durham.ac.uk/media/durham-university/research-/research-centres/social-justice-amp-community-action-centre-for/documents/Community-Based-Participatory-Research---Ethical-Challenges.pdf>

Durham University. (n.d.). *Co-inquiry toolkit: Community-university participatory research partnerships: co-inquiry and related approaches*. Beacons. <https://www.durham.ac.uk/media/durham-university/research-/research-centres/social-justice-amp-community-action-centre-for/documents/toolkits-guides-and-case-studies/Co-Inquiry-Toolkit.pdf>

Fiske, A., Prainsack, B., & Buyx, A. (2019). Meeting the needs of underserved populations: Setting the agenda for more inclusive citizen science of medicine. *Journal of Medical Ethics*, *45*(9), 1–6. <https://doi.org/10.1136/medethics-2018-105253>

Fleming, J., Beresford, P., Bewley, C., Croft, S., Branfield, F., Postle, K., & Turner, M. (2014). Working together – innovative collaboration in social care research. *Qualitative Social Work*, *13*(5), 706–722. <https://doi.org/10.1177/1473325013506929>

Gabriel, L., James, H., Cronin-Davis, J., Tizro, Z., Beetham, T., Hullock, A., & Raynar, A. (2017). Reflexive research with mothers and children victims of domestic violence. *Counselling & Psychotherapy Research*, *17*(2), 157–165. <https://doi.org/10.1002/capr.12117>

Gilbert, T. (2004). Involving people with learning disabilities in research: Issues and possibilities. *Health & Social Care in the Community*, *12*(4), 298–308. <https://doi.org/10.1111/j.1365-2524.2004.00499.x>

Gombert, K., Douglas, F., McArdle, K., & Carlisle, S. (2016). Reflections on ethical dilemmas in working with so-called ‘vulnerable’ and ‘hard-to-reach’ groups: Experiences from the Foodways and Futures project. *Educational Action Research*, *24*(4), 583–597. <https://doi.org/10.1080/09650792.2015.1106958>

Goodwin, J., & Tiderington, E. (2022). Building trauma-informed research competencies in social work education. *Social Work Education*, *41*(2), 143–156. <https://doi.org/10.1080/02615479.2020.1820977>

Goodyear-Smith, F., Jackson, C., & Greenhalgh, T. (2015). Co-design and implementation research: Challenges and solutions for ethics committees. *BMC Medical Ethics*, *16*, 1–5. <https://doi.org/10.1186/s12910-015-0072-2>

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Inquiry*, *10*(2), 261–280. https://doi.org/10.1177/1077800403262360

Gustafson, D. L., & Brunger, F. (2014). Ethics, “vulnerability,” and feminist participatory action research with a disability community. *Qualitative Health Research*, *24*(7), 997–1005. <https://doi.org/10.1177/1049732314538122>

Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., Staniszewska, S., Tembo, D., Torok, K., & Turner, K. (2018). *Guidance on Co-producing a Research Project.* INVOLVE. <https://www.invo.org.uk/wp-content/uploads/2019/04/Copro_Guidance_Feb19.pdf>

Horowitz, C.R., Robinson, M., Seifer, S., Horowitz, C. R., Robinson, M., & Seifer, S. (2009). Community-based participatory research from the margin to the mainstream: Are researchers prepared? *Circulation*, *119*(19), 2633–2642. <https://doi.org/10.1161/CIRCULATIONAHA.107.729863>

Inglis, P., & Cook, T. (2011). Ten top tips for effectively involving people with a learning disability in research. *Journal of Learning Disabilities & Offending Behaviour*, *2*(2), 98–104. <https://doi.org/10.1108/20420921111152441>

Kaur, H., & Kerrigan, P. (2020). *Stronger together: a guide for co-researchers working on co-produced research projects.* University of York. <https://www.york.ac.uk/media/future-health/CoProductionResearch_Booklet_WebFinal.pdf>

Kong, S. T., Banks, S., Brandon, T., Chappell, S., Charnley, H., Hwang, S. K., Rudd, D., Shaw, S., Slatcher, S., & Ward, N. (2020). Extending voice and autonomy through participatory action research: Ethical and practical issues. *Ethics and Social Welfare*, *14*(2), 220–229. <https://doi.org/10.1080/17496535.2020.1758413>

Kuper, H., Hameed, S., Reichenberger, V., Scherer, N., Wilbur, J., Zuurmond, M., Mactaggart, I., Bright, T., & Shakespeare, T. (2021). Participatory research in disability in low-and middle-income countries: What have we learnt and what should we do? *Scandinavian Journal of Disability Research*, *23*(1), 328–337. <https://doi.org/10.16993/sjdr.814>

Kyegombe, N., Banks, L. M., Kelly, S., Kuper, H., & Devries, K. M. (2019). How to conduct good quality research on violence against children with disabilities: Key ethical, measurement, and research principles. *BMC Public Health*, *19*(1), 1–14. <https://doi.org/10.1186/s12889-019-7456-z>

Lam, G. Y. H., Holden, E., Fitzpatrick, M., Raffaele Mendez, L., & Berkman, K. (2020). ‘Different but connected’: Participatory action research using Photovoice to explore well-being in autistic young adults. *Autism: The International Journal of Research & Practice*, *24*(5), 1246–1259. <https://doi.org/10.1177/1362361319898961>

Marshall, Z., Nixon, S., Nepveux, D., Vo, T., Wilson, C., Flicker, S., McClelland, A., & Proudfoot, D. (2012). Navigating risks and professional roles: Research with lesbian, gay, bisexual, trans, and queer young people with intellectual disabilities. *Journal of Empirical Research on Human Research Ethics*, *7*(4), 20–33. <https://doi.org/10.1525/jer.2012.7.4.20>

Mintz, K. T., Gammer, B., Khan, A. J., Shaub, G., Levine, S., & Sisti, D. (2022). Physical disability and psychedelic therapies: An agenda for inclusive research and practice. *Frontiers in Psychiatry*, *13*, 1–7. <https://doi.org/10.3389/fpsyt.2022.914458>

Morgan, M. F., Cuskelly, M., & Moni, K. B. (2014). Unanticipated ethical issues in a participatory research project with individuals with intellectual disability. *Disability & Society*, *29*(8), 1305–1318. <https://doi.org/10.1080/09687599.2014.934440>

National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1979). *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. U.S. Department of Health and Human Services. <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html>

National Disability Authority. (2009). *Ethical Guidance for Research with People with Disabilities.* National Disability Authority. <https://nda.ie/publications/ethical-guidance-for-research-with-people-with-disabilities-report>

National Ethics Advisory Committee. (2019). *National Ethical Standards for Health and Disability Research and Quality Improvement.* Ministry of Health. <https://neac.health.govt.nz/assets/Uploads/NEAC/publications/national-ethical-standards-health-disability-research-quality-improvement-2019-v3.pdf>

National Health and Medical Research Council. (2018). *Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for Researchers and Stakeholders.* Commonwealth of Australia. <https://www.nhmrc.gov.au/about-us/resources/ethical-conduct-research-aboriginal-and-torres-strait-islander-peoples-and-communities>

National Health Service Health Research Authority. (2017). *UK Policy Framework for Health and Social Care Research.* National Health Service Health Research Authority. <https://s3.eu-west-2.amazonaws.com/www.hra.nhs.uk/media/documents/Final_Accessibility_uk-policy-framework-health-social-care-research_.pdf>

National Health and Medical Research Council, the Australian Research Council and Universities Australia. (2007). *National Statement on Ethical Conduct in Human Research 2007 (Updated 2018)*. Commonwealth of Australia. [www.nhmrc.gov.au/guidelines/publications/e72](http://www.nhmrc.gov.au/guidelines/publications/e72)

Newbutt, N., & Bradley, R. (2022). Using immersive virtual reality with autistic pupils: Moving towards greater inclusion and co-participation through ethical practices. *Journal of Enabling Technologies*, *16*(2), 124–140. <https://doi.org/10.1108/JET-01-2022-0010>

Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, *23*(8), 2007–2019. [https://doi.org/10.1177/ 1362361319830523](https://doi.org/10.1177/%201362361319830523)

Northway, R., Jenkins, R., Jones, V., Howarth, J., & Hodges, Z. (2013). Researching policy and practice to safeguard people with intellectual disabilities from abuse: Some methodological challenges. *Journal of Policy and Practice in Intellectual Disabilities*, *10*(3), 188–195. <https://doi.org/10.1111/jppi.12037>

Northway, R., Howarth, J., & Evans, L. (2015). Participatory research, people with intellectual disabilities and ethical approval: Making reasonable adjustments to enable participation. *Journal of Clinical Nursing, 24*(3–4), 573–581. <https://doi.org/10.1111/jocn.12702>

Research for Development Impact 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. <https://rdinetwork.org.au/wp-content/uploads/2020/06/RDI-Network-R4All-Accessible-PDF-1.pdf>

Research for Development Impact Network & Australian Council for International Development. (2021). *Principles and Guidelines for Ethical Research and Evaluation in International Development*. Research for Development Impact Network. <https://rdinetwork.org.au/wp-content/uploads/2021/08/Updated-Aug-2021_ACFID-RDI-Network-Ethical-Principles_Accessible.pdf>

Rickard, W., & Purtell, R. (2011). Finding a way to pay in the UK: Methods and mechanisms for paying service users involved in research. *Disability & Society*, *26*(1), 33–48. <https://doi.org/10.1080/09687599.2011.529665>

Taylor, S., & Balandin, S. (2020). The ethics of inclusion in AAC research of participants with complex communication needs. *Scandinavian Journal of Disability Research*, *22*(1), 108–115. <https://doi.org/10.16993/sjdr.637>

Tee, S. R., & Lathlean, J. A. (2004). The ethics of conducting a co-operative inquiry with vulnerable people. *Journal of Advanced Nursing*, *47*(5), 536–543. <https://doi.org/10.1111/j.1365-2648.2004.03130.x>

Tilley, E., Strnadová, I., Ledger, S., Walmsley, J., Loblinzk, J., Christian, P. A., & Arnold, Z. J. (2021). ‘Working together is like a partnership of entangled knowledge’: Exploring the sensitivities of doing participatory data analysis with people with learning disabilities. *International Journal of Social Research Methodology*, *24*(5), 567–579. <https://doi.org/10.1080/13645579.2020.1857970>

True, G., Alexander, L. B., & Richman, K. A. (2011). Misbehaviors of front-line research personnel and the integrity of community-based research. *Journal of Empirical Research on Human Research Ethics*, *6*(2), 3–12. <https://doi.org/10.1525/jer.2011.6.2.3>

United Kingdom Research and Innovation. (2022). *Revised UKRI* p*olicy on the Governance of Good Research Practice.* UK Research and Innovation.https://www.ukri.org/publications/ukri-policy-on-the-governance-of-good-research-practice/

United Nations Educational, Scientific and Cultural Organisation. (2006). *Universal Declaration on Bioethics and Human Rights.* UNESCO.  [https://unesdoc.unesco.org/ark:/48223/pf0000142825.page=80](https://unesdoc.unesco.org/ark%3A/48223/pf0000142825.page%3D80)

United States Environmental Protection Agency. (2016). *Policy and Procedures on Protection of Human Subjects in EPA Conducted or Supported Research.* EPA.  <https://www.epa.gov/sites/default/files/2016-06/documents/2016_policy_order_revision_6-10-16.pdf>

Wilson, O., Daxenberger, L., Dieudonne, L., Eustace, J., Hanard, A., Krishnamurthi, A., Quigley, P., Vergou, A. (2020). *A Rapid Evidence Review of Young People’s Involvement in Health Research*. Wellcome <https://cms.wellcome.org/sites/default/files/2021-02/a-rapid-evidence-review-of-young-peoples-involvement-in-health-research.pdf>

World Health Organization. (2011). *Standards and Operational Guidance for Ethics Review of Health-related Research with Human Participants*. World Health Organization. <https://iris.who.int/bitstream/handle/10665/44783/9789241502948_eng.pdf?sequence=1>

van der Heijden, I., Harries, J., & Abrahams, N. (2019). Ethical considerations for disability-inclusive gender-based violence research: Reflections from a South African qualitative case study. *Global Public Health*, *14*(5), 737–749. <https://doi.org/10.1080/17441692.2018.1542015>