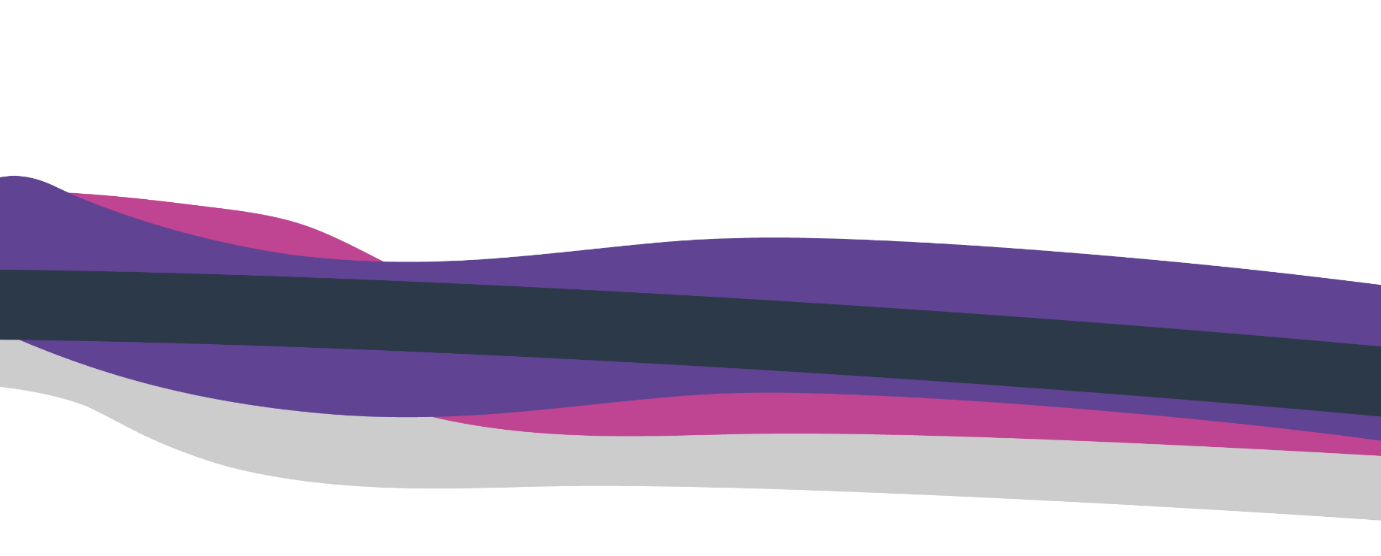


NDRP Resource Pack:

Co-design with people with intellectual disability





# Co-design with people with intellectual disability

## Be specific. Be respectful. Expect expertise.

### Why it matters

People with intellectual disability have been left out of research decisions for too long. Often, this happens because of unspoken assumptions, that people can’t understand complex ideas, contribute meaningfully, or "keep up."

These assumptions are wrong. People with intellectual disability bring insight, clarity, and lived experience that is essential to research that claims to be inclusive.

If your research is about systems that affect people with intellectual disability (like education, employment, housing, health, or justice), then it must be designed and conducted by and with people with intellectual disability.

### First: Be honest about bias

Before starting co-design, check your thinking:

* Are you assuming people need to prove they’re “capable” before being included?
* Are you asking if co-design is possible, or asking how to do it well?
* Are you planning for access and support, or seeing it as too hard?

The barrier is rarely the person. It’s the research systems and processes.

### What respectful co-design looks like

* Start with people, not just paperwork: Involve people with intellectual disability before the grant is written, not just after funding is secured.
* Use communication that works: Use Easy Read, plain language, visuals, and real examples. Say less, more clearly. Confirm understanding by checking in, not testing.
* Build in time and support: Allow more time to plan, meet, reflect, and adapt. People may need support people, transport, or breaks. Respect this as part of the process, not a barrier to it.
* Pay fairly: If you're paying consultants, you must pay co-design partners. This is not “volunteering”, this is skilled, lived experience expertise.
* Give choice and decision-making power: People with intellectual disability must help shape what the research is about, how it’s done, and how it’s shared. Not just reviewing documents, making decisions.
* Work on relationships: Work with advocacy organisations led by people with intellectual disability. If you don’t know how to begin, ask, and be ready to listen and change.

# Okay. I get the idea. How?

## How do I actually do co-design *by and with* people with intellectual disability?

### Examples of respectful co-design approaches

These approaches are:

* age-appropriate,
* presume competence, and
* offer choice and control.

**With children and young people:**

* Use storyboards, drawing, or role play to explore topics
* Let people choose how they participate, talking, pointing, moving, drawing
* Involve trusted adults or peers in supportive, not directive, roles
* Provide visuals, movement, and play as part of your methods
* Offer choice about when and how they contribute (e.g. one-on-one or group)

**With adults:**

* Run workshops with time for reflection and real decision-making
* Consider using digital tools with symbol support or voice navigation
* Involve people as co-presenters, co-authors, or co-facilitators
* Try creative methods like zines, photos, or videos, let people lead and direct

### Tips for building strong partnerships

* Allow time to prepare before and debrief after sessions
* Use consistent facilitators, relationships build trust
* Be ready to slow down, pivot, or adapt based on what people say they need
* Budget for access, support, and participation from the start

# Frequently asked questions (FAQ)

This list is informed by researcher questions, NDRP’s broader work and the goal of supporting inclusive, respectful partnerships between researchers and advocacy organisations.

## Engagement and ethics

### How do I pay people for their time or expertise if they’re not employed by a university?

You can usually pay individuals or organisations using invoices or honoraria. Talk to your university’s finance or grants team to set this up. Plan ahead, as payment processes can take time.

### What does shared decision-making really look like in practice?

It means that partners have a real say in how the research is done, not just being asked for feedback. This could include deciding on research questions, methods, analysis, or how results are shared.

### How can I avoid reinforcing power imbalances?

Be transparent, pay people fairly, and create space for different types of expertise, including lived experience. Don’t assume what people need, ask them. Take time to build trust, and check in regularly.

## Research design

### What if I already have a research idea, can I still do co-design?

Yes, but be upfront about what’s fixed and what can change. Even if your topic is set, you can still co-design methods, engagement approaches, and how findings are shared.

## Ongoing relationships and practice

### How do I keep relationships strong after the project ends?

Stay in touch, share results in accessible ways, and credit your partners in publications or presentations. Let them know about future projects early, and keep the door open for continued work.

### What happens if the partnership doesn’t go well?

Partnerships take work. If something’s not going well, talk about it early. Revisit your agreements, ask what support might help, or consider pausing to reflect. Learning from challenges is part of building better partnerships.

# Additional resources for inclusive and respectful research partnerships

These resources can support researchers, advocacy organisations, and co-design partners to deepen their understanding of inclusive research, lived experience leadership, and accessible practice.

| **Area** | **Description** | **Link** |
| --- | --- | --- |
| NDRP resources |  |  |
| ****National Disability Research Partnership (NDRP)****  ****Co-Designing Research**** | This resource explains the concept of co-design in disability research, emphasising collaboration with people with lived experience to shape research questions, methods, and outcomes. | [Explore Resource](https://www.ndrp.org.au/resources/co-design) |
| ****National Disability Research Partnership (NDRP)****  ****Co-Design Tools**** | A collection of templates, questions, and activities designed to facilitate co-production in real-world research settings, supporting inclusive practices. | [Access Tools](https://www.ndrp.org.au/resources/co-design/co-design-tools) |
| Advocacy organisations |  |  |
| Women with Disabilities Australia | What is advocacy? Standing up for your rights, Easy Read resource | [Easy Ready resource link](https://oursite-easyread.wwda.org.au/your-rights/standing-up-for-your-rights/what-is-advocacy/) |
| Inclusion Australia  Guide to Inclusion for Policy Makers | A guide developed with people with intellectual disabilities to assist policymakers in creating inclusive systems and processes. | [Download the guide](https://www.inclusionaustralia.org.au/wp-content/uploads/2023/04/Guide-to-Inclusion-for-Policy-Makers.pdf) |
| First Peoples Disability Network (FPDN) | A national organisation led by and for Australia's First Peoples with disabilities, offering resources and training. | [Visit FPDN](https://fpdn.org.au/) |
| People With Disability Australia (PWDA)  Consultancy Services | Information on PWDA's services helping organisations improve how they include people with disability in their research and events. | [Learn about the services](https://pwd.org.au/services/consultancy-services/) |
| Children and Young People with Disability Australia (CYDA) | Resources, made or co-designed by young people with disability, to help parents, caregivers and educators. | [Visit CYDA](https://cyda.org.au/resources/) |
| National Ethnic Disability Alliance (NEDA) | NEDA believes: People from non-English Speaking backgrounds (NESB) with disability, their families and carers are experts in knowing how they want to receive services and supports. | [Visit NEDA](https://neda.org.au/project/) |
| Australian Federation of Disability Organisations (AFDO) | Connect with Me Guide & Toolkit for organisations working & Co-designing with people with disability. | [Visit AFDO](https://www.pwdwa.org/our_campaigns/connect_with_me.html) |
| Disability Advocacy Network Australia (DANA) | National representative body for a network of independent disability advocacy organisations in Australia. They also host the National Centre for Disability Advocacy. | [Reports](https://dana.org.au/publications/) |
| Advocacy for Inclusion | Self-advocacy kit: This kit can be used by a person reading it on their own, in a group where ideas can be discussed, or in a workshop. | [The kit](https://www.advocacyforinclusion.org/self-advocacy-kit/) |
| Physical Disability Australia | PDA takes every opportunity that resources allow to provide formal submissions and consultations to the Government and NDIS. | [Submissions and campaigns](https://www.pda.org.au/projects-campaigns/) |
| Autism Alliance National | To strengthen our influence in legislation, policy and community attitudes we bring together perspectives from various disability representative organisations. | [Position statements](https://australianautismalliance.org.au/our-advocacy/policy-position-statements/) |
| Community Mental Health Australia | The coalition of peak community mental health organisations from States and Territories, established to promote the importance and benefits of community mental health and recovery services across Australia. | [Resources](https://www.qamh.org.au/our-work/resources/) |
| Deaf Australia | Deaf Australia's Accessibility & Inclusion Toolkit | [Toolkit](https://deafaustralia.org.au/aide-toolkit-home/) |
| Blind Citizens Australia | Policy and advocacy hub | [Hub](https://www.bca.org.au/advocacy/) |
| QLD | Queenslanders with Disability Network (QDN) outlines principles for co-designing with people with disability, emphasising authentic voice, respect, rights, resilience, and collective action. | [Access the Principles](https://qdn.org.au/wp-content/uploads/2022/02/QDN_Co-Design-Principles_FINAL_2022.pdf) |
| WA | Example of co-design of a local community disability advocacy model | [Information](https://www.cdaproject.org.au/build-a-network/co-design-of-the-model) |
| TAS | Disability Voices Tasmania project work | [Current projects](https://www.disabilityvoicestas.org.au/what-we-do/) |
| NSW | Disability Advocacy New South Wales resources  Family Advocacy supports people with disability and their families to promote and defend the rights and interests of people with developmental disability. | [Resources](https://www.da.org.au/resources)  [Inclusion Collection](https://family-advocacy.com/inclusion-library/) |
| VIC | Women with Disabilities Victoria’s guide promotes principled consultation and co-design with women with disabilities. It outlines a set of eight practices that enable ethical, effective work.  In this guide, the word refers to women with disabilities who are advocating for gender and disability equality. | [Download the Ask experts Guide](https://whe.org.au/tfer/margins-to-the-mainstream/wp-content/uploads/2023/09/ONLINE-10663-M2M-PVAWD-How-to-Guide.pdf)  [Download We are the experts Guide](https://whe.org.au/tfer/margins-to-the-mainstream/wp-content/uploads/2024/08/ONLINE-10997-M2M-Companion-Guide-%E2%80%93-We-are-the-Experts.pdf) |
| NT | Inclusion NT works to build a community in the Northern Territory that is inclusive of people with intellectual disability and provides opportunities for leadership. | [Link](https://inclusionnt.org.au/) |
| ACT | ACT Down Syndrome & Intellectual Disability (DSID) leads the way in building an inclusive community for people for people with intellectual disability. | [Link](https://www.downsyndrome.org.au/act/) |
| SA | Purple Orange’s example introduces co-design principles and practices, aiming to involve people with disability in decision-making processes.  SACID and Speak Out Advocacy co-designing improved pathways for people with intellectual disability to be leaders in organisations and communities | [Download Guide](https://purpleorange.org.au/application/files/7416/2510/1861/PO-CoDesign_Guide-Web-Accessible.pdf)  [Read more](https://sacid.org.au/respect-our-ability/) |
| Research organisations |  |  |
| ****UNSW Disability Innovation Institute**** | **Doing Research Inclusively: Guidelines for Co-Producing Research with People with Disability** provides practical strategies for co-producing research with people with disability, emphasising inclusive methodologies and ethical considerations. | [Access Guidelines](https://www.disabilityinnovation.unsw.edu.au/sites/default/files/documents/DIIU%20Doing%20Research%20Inclusively-Guidelines%20%2817%20pages%29.pdf) |
| The Commons Library | Offers examples and reflections on inclusive research practices, emphasising community-led approaches. | [Explore Examples](https://commonslibrary.org/what-is-inclusive-research/) |
| University of Sydney | Centre for Disability Research and Policy is producing collaborative research to influence policy and practice for people with disabilities. | [Explore the centre](https://www.sydney.edu.au/medicine-health/our-research/research-centres/centre-for-disability-research-and-policy.html) |
| Autism CRC | Inclusive Research Practice guides on participatory and inclusive research practices, promoting partnerships between researchers and community members.  Inclusive Research Practice: Engaging Autistic Individuals resource focuses on embedding inclusive practices within research organisations, ensuring adequate resources for involving end-users. | [Learn More](https://www.autismcrc.com.au/news/latest-news/latest-guides-participatory-and-inclusive-research-practices-released)  [Access Resource](https://www.autismcrc.com.au/knowledge-centre/resource/inclusive-research) |
| ****Melbourne Disability Institute**** | The Melbourne Disability Institute (MDI) deliver a collaborative and inclusive disability research program, led by and with people with disability, to build evidence for successful policy and practice. | [Link](https://disability.unimelb.edu.au/) |
| ****Centre of Research Excellence in Disability and Health (CRE-DH)**** | This centre brings together a national and international team of researchers to develop evidence for social and health policy reform to improve the health of people with disabilities. | [Link](https://credh.org.au/) |
| Centre for Disability Research and Policy (CDRP) | Located at The University of Sydney, the CDRP produces research that is community-driven and co-designed with people with disabilities to address emerging concerns in disability policy and practice. | [Link](https://www.sydney.edu.au/medicine-health/our-research/research-centres/centre-for-disability-research-and-policy.html) |
| National Centre of Excellence in Intellectual Disability Health | This national centre has a consortium of partner organisations and universities that contribute to its activities, aiming to improve health outcomes for people with intellectual disabilities. | [Link](https://nceidh.org.au/) |
| ****Deakin University**** | Guidelines for Inclusive Research provide strategies for conducting inclusive research, focusing on usability and accessibility for diverse populations, including people with disabilities.  Inclusive Research Practice for Research with Children with Disability guide offers principles and practical tips for conducting inclusive research with children with disability, including tool selection and ethical considerations. | [View Guidelines](https://blogs.deakin.edu.au/inclusivehealth/wp-content/uploads/sites/423/2024/02/Guidelines-for-Inclusive-Research-1.pdf)  [View Guide](https://voicesofchildrenwithdisability.com/wp-content/uploads/2015/03/DEA-Inclusive-Practice-Research_ACCESSIBLE.pdf) |
| Government resources |  |  |
| ****Disability Gateway**** | Good Practice Guidelines for Engaging with People with Disability guidelines are to assist you to engage with people with disability in an inclusive, respectful and appropriate way. | [View Guidelines](https://www.disabilitygateway.gov.au/good-practice-guidelines) |
| ****Local Government Association of South Australia**** | Six Tips for Good Engagement offers practical tips for effectively engaging with people with disability, aiming to improve inclusivity and accessibility in community consultations and decision-making processes. | [Read Tips](https://www.lga.sa.gov.au/members/community/disability/resources/six-tips-for-good-engagement) |
| ****NDIS Quality and Safeguards Commission**** | **Consulting with People with Disability During a Practice Review** fact sheet provides general guidelines for consulting and communicating with participants and other people with disabilities during a practice review, emphasising a person-centred approach. | [Download Fact Sheet](https://www.ndiscommission.gov.au/sites/default/files/2024-09/consulting-people-disability-during-practice-review-fact-sheet-practice-reviews.pdf) |
| ****NSW Agency for Clinical Innovation**** | **Library of Co-design Resources** is a collection of resources to support co-design in health services, including tools and templates. | [Explore Resources](https://aci.health.nsw.gov.au/projects/co-design/library-of-related-resources) |
| ****Good Practice Guidelines for Engaging with People with Disability**** | A practical tool for ensuring respectful, accessible, and meaningful engagement with people with disability. | [Access the Guidelines](https://www.disabilitygateway.gov.au/good-practice-guidelines) |
| ****Australia’s Disability Strategy Hub**** | Provides information on the strategy, including key actions, rights of people with disability, data, and research. | [Visit the Hub](https://www.disabilitygateway.gov.au/ads) |
| ****Co-design with People with Disability – Victorian Government**** | Details commitments to increase collaboration and co-design with people with disability on government policies, programs, and services. | [Read More](https://www.vic.gov.au/state-disability-plan/systemic-reform-commitments-actions-and-accountability/co-design-people) |
| ****NDIS – Working Towards Co-Design FAQ**** | Explains how the NDIA engages with participants and stakeholders through co-design workshops and other activities. | [View the FAQ](https://www.ndis.gov.au/community/making-ndis-stronger-together/working-towards-co-design-faq) |
| ****NDIS – Co-Designing Reform**** | Updates on the NDIA's co-design approach, focusing on critical reforms to the NDIS. | [Learn More](https://www.ndis.gov.au/community/making-ndis-stronger-together/co-designing-reform) |
| ****NDIA Co-Design Advisory Group Terms of Reference (2025)**** | Outlines the purpose, principles, and ways of working for the Co-Design Advisory Group. | [Download the Document](https://www.ndis.gov.au/media/7715/download?attachment=) |
| ****Disability Inclusion Planning – A Guide for Local Government**** | Assists councils across Australia in responding to legislation and proactively addressing cultural change. | [Access the Guide](https://humanrights.gov.au/sites/default/files/Disability%20Inclusion%20Planning%20-%20A%20Guide%20for%20Local%20Goverment%20%28FINAL%29.pdf) |
| ****Joint Australian, State and Territory Response to the Disability Royal Commission**** | Details commitments to review and update Australia's Disability Strategy in partnership with people with disability. | [Read the Response](https://www.dss.gov.au/system/files/documents/2024-10/jointaustralianstateandterritoryresponsetodrcjuly2024334720724_0.pdf) |
| ****Factsheet: Why is Co-Design Important? – Queensland Government**** | Highlights the importance of co-design, underpinned by human rights and the value of lived experience. | [View the Factsheet](https://www.dcssds.qld.gov.au/__data/assets/pdf_file/0021/7545/factsheet-1-why-is-co-design-important.pdf) |

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