Report

Co-design partnerships: A mutual exchange

August 2025

About DANA

DANA is the national representative body for a network of independent disability advocacy organisations throughout Australia.

Our Vision

DANA's vision is of a nation that includes and values people with disabilities and respects human rights for all.

Our Purpose

DANA's purpose is to strengthen, support and provide a collective voice for independent disability advocacy organisations across Australia that advocates for and with people with disability.

We achieve this by:

- promoting the role and value of independent disability advocacy
- providing a collective voice for our members
- providing communication and information sharing between disability advocacy organisations
- providing support and development for members, staff and volunteers of disability advocacy organisations
- building the evidence base to demonstrate the value of disability advocacy
- promoting the human rights, needs, value and diversity of people with disabilities

Contact:

David Petherick, Interim CEO

Email: comms@dana.org.au

Authors:

Dr Cherry Baylosis, Alana Starr, Tori Haar

DANA is a disability-led organisation and the scoping project work team reflects this. The project was undertaken by a dedicated project team of people with disability and psychosocial disability. Specialist contractors included a Project lead, Data Analyst and Report Writer, lived experience CALD Facilitator, a First Nations lead for First Nations project components, and a young person employed as a Research Assistant, who co-facilitated the Children and Young People working group and was responsible for specific outputs on research formats for dissemination. Team members were supported by DANA's Project Coordinator, Policy Coordination Manager, and Deputy CEO.

Introduction

Research overview

DANA was funded by the National Disability Research Partnership (NDRP) to undertake this project. The NDRP funds research led by and with people with disability. It supports a collaborative and inclusive disability research program that builds evidence for successful policy and practice. The NDRP is an independent not-for-profit organisation governed, led and staffed by majority people with disability. This project was funded by the NDRP through a grant from the Australian Government as an initiative under Australia's Disability Strategy 2021 - 2031.

The purpose of the project was to create clarity around what is needed for disability representative and carer organisations (DRCOs)[1] , disability advocacy organisations (DAOs)[2] and other consumer-led and disability capacity strengthening organisations, to be able to be meaningfully involved in disability research, in a sustainable way. These organisations are at the forefront of understanding the key issues impacting on people with disability through their day-to-day work, and the complex policy and practice issues and systemic and individual barriers and discrimination people with disability face. What makes them unique is they are formed to represent and support people with disability to uphold their human rights, and they are independent, in that they are not linked to or operated by service delivery providers. Therefore, for research to be led by and with people with disability, involvement of these organisations is crucial across the research continuum.

The aim of this project was to co-develop an understanding of, and recommendations for, the kinds of activities, good practices, and resourcing the NDRP, researchers and their institutions, governments and other relevant stakeholders could need to support, to enable this meaningful and ongoing involvement in research. We suggest our findings may be of use more broadly; for co-designers – researchers, consultants, and partners who want to adopt participatory and inclusive research approaches.

We spoke and worked with selected DCROs and DROs. We used a mix-methods co-designed approach that involved CEO interviews, working groups and a survey. Together, we identified three key needs that were centred on mutuality:

- **Two-way learning:** An exchange of information and knowledge occurs between researchers and DRCOs and DAOs. For researchers, this begins with a minimum of standard of knowledge and skills, including reflexive practice, listening through difference, and trauma informed approaches that can make them more receptive to learning. DRCOs and DAOs in exchange would benefit from learning to assess the value of research.

- **Co-define, co-design, co-create**: Mutual learning informs shared decision-making that takes place at every stage of research, including how research problems are identified and defined, the research design, and the production of research outputs.

- **Distribution of resources:** Shared decision making is enabled through a fairer distribution of time, money, and data. This distribution of resources must benefit community partners and their communities.

These three key needs are entangled, and in practice are hard to separate. Mutual learning, for instance, occurs at each stage of research and during the process where resources are distributed. However, for the purpose of providing clarity for each need, we address these individually to inform our recommendations (listed below).

Recommendations

Two-way learning:

- The NDRP works with DRCOs and DAOs to develop minimum standard guidelines for researchers that position reflexive practice, listening through difference, and trauma-informed approaches as essential in research.

- NDRP works with DRCOs and DAOs to develop accessible information to support organisations that have not been involved in research to assess if they want to and have the capacity to be involved in a project. This should cover how to determine, realistically, how much time and which commitments are required.

- The NDRP develops tools and/or resources with DRCO and DAOs that enable potential partners to better assess collaboration opportunities with researchers. These could also provide information for potential partners to calculate resources needed and provide information so that partners can approach researchers (or funders) with ideas for research.

Co-define, co-design, co-create:

- The NDRP creates structures, policies and processes for its research funding and evidence to action initiatives that prioritise the involvement of DRCOs and DAOs in shared decision-making at every stage. Mutual learning can support this. Through its capacity strengthening work, this might include identifying and defining problems through an exchange of information between researchers and DRCOs and or DAOs.

- Coproduce information with and for people with disability**:** The NDRP collaborates with disability organisations and communities to co-produce a co-design research template for partners to engage in research. This template supports researchers to build a key resource with all necessary information needed by DRCOs to give informed consent to involvement in, or sharing research.

- The NDRP works with DRCOs and DAOs to make research evidence accessible. This may include providing DRCO and DAOs with university honorary relationships where they are granted access to both research software and library databases.

Distribution of resources: Time, funding, and data

- The NDRP funds an environmental scan of DRCOs and DAOs to understand the current volume of research requests received by organisations to inform future engagements. This is particularly necessary for research with First Nations communities (see separate report [insert link]). Specifically, this needs to include the levels of funding offered, timelines and how research data will be directly beneficial to the disability community.

- The NDRP supports its funded research teams to co-design the knowledge mobilisation activities at each stage of the research. This should include a dissemination plan that ensures research is shared in accessible ways, with a specific focus on the communities that the research is about and those that have been systemically excluded from research (e.g., regional rural communities, Culturally and Linguistically Diverse communities, First Nations communities, and people with intellectual disability).

- The NDRP co-authors a set of guidelines or an information sheet about timeframes needed for proper co-design with DRCOs, DAOs and/or the disability community. This resource may require discussions with over-researched communities such as representative organisations for people with an intellectual disability.

Is this really co-design?

To situate this research, we must firstly address the conflicting meanings and uses of 'co-design'. It has become a ubiquitous term used across governments, the disability sector and academia, often with different meanings. It has led to tensions and a frequent questioning of people asking researchers, 'are you *really* doing co-design' (see Moll et al, 2020, emphasis added). Arguably, the widespread use of this concept has fuelled a healthy scepticism of co-design research (Blomkamp, 2018; Kaethler et al., 2017).

At the most basic level, co-design can be described as a user-centric inquiry in order to approach problems then develop solutions. Within the disability community, this approach is often criticised and viewed instead as consultations masquerading as co-design in disguise. This basic approach stands at odds with the definition used in disability studies, which argues that co-design unsettles and redistributes power in research (Barbour, et al, 2025; Benz et al., 2024). Co-design, in this sense, challenges longstanding hierarchies of non-disabled people doing research *on* people with disability, instead of *with* (Benz et al., 2024).

We follow the definition of co-design as used within disability studies. Rooted in the history of the social model of disability, co-design is a methodology that elevates experiential knowledge, recognising lived experience as authoritative knowledge in its own right (Nind (2017). Importantly, co-design sees that people with disability play a key role in decision-making at each of stage of research (Durose et al., 2017; Fraser-Barbour et al., 2025). In doing so, co-design destabilises power relations between the researcher and participants. Co-design, in this regard, problematises tendencies in traditional research approaches that exclude people with disability from having their own say, and voice, in research (Farr, 2018;

Higgins et al., 2019). Instead, co-design aims to position participants, such as people with disability, as 'partners' in research, elevating them to equal status (Rutter et al., 2004).

A co-design partnership: What we mean by community partners and research partners

We refer to people from DRCOs and DAOs who contributed to this project as 'community partners.' This reflects two-way mutual learning where partners inform each other to develop new insights (Hendriks et al., 2015). However, to distinguish between the two, we refer to 'research partners' as the people who facilitated interviews and working groups and 'community partners' as the people with expertise whom we sought to learn from.

We adapt this definition to the findings of community working groups and interviews we facilitated for this project and add to the meanings of co-design. Importantly, this definition was co-produced with the organisations who partnered in this work and told us what they want to see in co-design research:

- Co-design begins at the very first moment that a project begins – even before the questions to research are settled. Importantly, people with disability are at the centre of designing the methodology

- People with disability and researchers decide on the problem that needs solving and the potential solution to solve it together

- A process where people with disability and researchers share decision-making power about the project for the duration of the whole project

- Ensures that all project contributors are of equal value and importance and are treated equally

- Continues all the way through a project until the end, including any post-project communications, reporting or information sharing, including information on impact

Co-design as a standard on the horizon

The definition we adopt was not without its hurdles within this project. Specifically, it was a challenge to use co-design methods as defined above in time-bound project with a time-pressed community. The project aims and questions were co-developed by our project team with NDRP staff. Collectively, this group was majority persons with disability with experience across various roles in university-led and community-led research, co-design projects, and operations and leadership of DROs, DAOs and consumer-led organisations. The aims and questions were developed prior to speaking with this project's community partners. Our project team designed the project methods, incorporating some feedback provided by the NDRP on our initial proposal. Our project team alone interpreted the data. Time and resources were a key issue here. But as will be discussed later in further detail, this inadvertently contributed to our findings where we argue that the context of doing co-design is a significant factor.

We raise this to not criticise the efforts of attempting to do co-design research, nor do we suggest that co-design – as described in our definition - is impossible. Rather, we highlight our definition of co-design as the standard on the horizon that we can all work toward. Indeed, acknowledging the limitations and hurdles within this study, means that other co-design practitioners can build upon this to develop more robust approaches.

The community partners

We had seven focus areas of lived expertise that we sought to learn from:

1. Advocacy (non-systemic advocacy)

2. Children and young people with disability

3. Culturally and Linguistically Diverse (CALD) people with disability

4. First Nations people with disability*

5. People with an intellectual disability

6. LGBTQIA+ people with disability

7. Women and girls with disability

* First Nations working groups, interviews and a separate report on this work was led by a First Nations consultant. Whilst the findings are also integrated within this report, there are specific recommendations for co-design research with First Nations communities outlined separately.

Each specific area of expertise had a DRCO and or DOA organisation invited to attend interviews and working groups. This was to represent intersecting forms of differences - at both individual and structural levels - that can impact on co-design research capacity.

Types of organisations

Community partners worked within a variety of different organisations in the disability sector. Each had different advocacy priorities, funding arrangements, operating environments and resource availability within the scope of this work. A variety of organisational types represented different facets of the disability sector's ecosystem that pointed to structural and systemic impacts on co-design research. The types of organisations included:

- Disability Representative and Carers Organisations (DRCOs): These are peak body organisations that work the NDIA toward NDIS reform and improvements.

- The National Centre for Disability Advocacy (NCDA): They build the capacity of independent disability advocacy organisations nationwide.

- Independent disability advocacy services (DAOs): This included individual and self-advocacy that receive either/and state and national funding.

- Organisations that deliver Information, Linkages and Capacity Building (ILC) programs.

- Organisations involved in auspice arrangements.

All organisations had established relationships with DANA through its secretariat programs[3], as DANA members, or through previous funding or grant arrangements. Data collection and exchange occurred from November 2024 and February 2025.

Methods

Centring lived experience

While working within the scope of this project, we placed experiential knowledge at the forefront of our research methods wherever possible. As noted earlier, this project had pre-defined aims and research focus areas. To bring lived experience to the fore, we used a mixed-methods approach that relied on qualitative methods. This included exploratory interviews, working groups, and a survey with open ended questions. This approach permitted flexibility to deviate away from predetermined focus areas toward areas of interest of co-design partners.

Leadership interviews

One-on-one interviews were conducted to allow for in-depth and nuanced exploration into individual experience with co-design research. This approach maximised individual voice as there was less potential for group dynamics to influence responses. Community partners who were interviewed were CEOs or equivalent leaders of organisations who were experts in the focus areas outlined above. Many of whom also had lived experience of disability too.

Interviews were semi-structured to ensure that key areas were addressed while allowing flexibility for leaders to raise issues and areas of interest that may not have been addressed within the confines of a structured interview.

In total, nine CEO interviews were completed using a 30-minute base timeframe, with interviews ranging from 25 – 53 minutes in duration and an average of 41 minutes. The research team offered to extend the 30-minute time if interviewees were comfortable and available to do so when in conversation, and most CEOs chose to extend the timeframe to continue the discussion.

Working groups

Working groups were facilitated to further gather in-depth insights into cohort and community experiences, perspectives and attitudes toward co-design research. Specifically, group dynamics can stimulate discussion and generate ideas among community partners, where they can leverage, build, or even challenge perspectives. This has the potential to uncover insights that may not emerge in one-on-one interviews.

Working groups were based on specific cohorts' expertise and lived experience, with some of the key areas of expertise identified (listed on page before). Working groups used open-

ended questions to collect data on specific themes. Similar to interviews, the working groups were semi-structured to ensure group discussions remained on track, while allowing for flexibility to discuss areas that the groups raised.

A total of five working groups were run for this project[4]. Each working group ran for 60-90 minutes. Each working group had between two and four attendees, and attendees were typically policy team members, projects team members, and subject matter specialists on area of expertise. Working groups were run using a modified question set in comparison to CEO interviews after a preliminary analysis of CEO transcripts to capture key data gaps.

Survey

A survey was used to capture a broader reach of perspectives on co-design research within the disability sector. The use of a survey allowed people who were not able to contribute to an interview or working group to offer their experiences, and perspectives on co-design research. An invitation to complete the survey was disseminated via DANA's newsletter, as well as a direct email from DANA's Deputy CEO, inviting DRCO and DANA members to complete the survey.

The survey was designed on Survey Monkey. The survey featured 17 questions. There were primarily simple response questions with multiple option tick boxes, and with optional open-ended questions and took approximately 10 minutes to complete. The survey was open from December 2024 to February 2025 to support this project. Survey respondents were not renumerated for their participation.

The survey received 24 responses from people who work in DRCOs or DROs. We suspect that the response rate was relatively low because targeted organisations had already participated in the work, the summer holiday timeframe of the project, and the heavy workload experienced by the independent disability advocacy sector. At the time, the sector had competing survey requests and calls for consultation across many different areas and topics in its systemic advocacy work. Ongoing disability reforms requiring significant consultation, specialised advocacy work and information dissemination were adding additional pressure to sectoral organisations' already stretched workloads. However, many in the sample provided written responses - which was optional - to the survey items.

Research partners: A disability led team

Following the principles of co-design, we amplified experiential knowledge within our research team. They were all people who had lived experience of disability and or psychosocial disability. The research design was developed by a mad studies researcher (see Baylosis, 2020), and the facilitators were specialist co-design facilitators, with some having expertise in intersectional experiences (discussed more below) of disability. Again, this brought experiential knowledge of disability to the forefront while drawing on previous research within mad studies and disability studies.

A shared sense of community

As discussed above, lived experience experts both designed and conducted this project. DANA used specialist lived experience practitioners to work with specific groups to ensure

cultural safety and accessibility was upheld. Specialist consultants for this project also included a First Nations lead, a CALD specialist facilitator, and a young person with disability who co-facilitated several consultations.

Research partners disclosed relevant lived experience (by choice) during interviews and working groups, encouraging a safe space for people to disclose, ask for what they needed, and to contribute. This was unlike dominant methods where the researcher generally remains separate, and in the background as an objective neutral observer studying the 'other' (Mayer, 2005). Instead, this approach placed the researchers within – as part of the same community – to address imbalances that have commonly plagued disability research (Lewis, 2013). Indeed, many organisations sent people with relevant lived experience to the working groups, allowing community and research partners to share and examine similar experiences.

Working from within: Sector experience

Lived experience expertise was further complemented by professional experience immersed within the disability sector. The research partners had previously and similarly participated in co-design consultations themselves as people with disability. In an ethnographic vein, this positioned research partners where they not only observed, but indeed, experienced everyday phenomena (see Pink, 2012) within the disability sector shared among people working in the same field.

All the research partners had experience working in organisations within the disability sector. They were either currently employed within a disability organisation or had previous experience working with a disability organisation. This meant that research and community partners shared tacit knowledge and similar experiences of working within the disability sector. For instance, they shared similar lexicon, and knowledge of funding and reporting complexities, or accessibility needs. This shared knowledge and experiences of working in the same environment provided a solid foundation to create a sameness and reduce power imbalances.

Ethical symmetry

Working as insiders within this project allowed us to adopt 'ethical symmetry' (Slater, 2013). This meant we equally privileged knowledge. Specifically, we worked in alignment with co-design principles (Fraser-Barbour et al., 2025), and elevated lived experience as authoritative knowledge. Rather than merely treating community partners as 'participants' or objects for analysis on which research is done, we worked with community partners to collaboratively produce knowledge. We moved from the individual to collective levels of knowledge and worked together to build a critical understanding of shared experiences – where there are points of intersections and departure, and where there are interconnections and implications at broader levels (Sweeny, 2016). This collaborative approach allowed for a deep reflection and pooling of knowledge and interest shared among people with different background and experiences (Steen, 2013)

Ethical considerations: Respect and rights

> *[C]learing research through an ethics process or committee doesn't mean that it's ethical for our community. And so that's another issue where something has passed through, like ethics approval, but it's through a university that doesn't have a disability rights lens. (WWDA interview).*

We provided the following measures to support safety and well-being of community partners who contributed to the working groups and interviews. We had a dedicated wellbeing fund available for all community partners who contributed to the working groups and interviews. They had the option to access wellbeing support of their choice if participating in this project raised distress. Allowing community partners to select the wellbeing support was a crucial aspect of offering this support. Doing so recognised the varying needs of individuals (e.g., cultural and individual preferences).

Each organisation was paid $1000 for participating in this work - involving a commitment of approximately four hours across the organisations with 1-3 people from organisations. This was offered in recognition of both organisational expertise and current sector pressures. Many organisations are funded to do specific work and cannot necessarily make time to do 'unpaid' research work without reducing time spent on funded work. Thus, payment for time spent was important to recognise DRCOs' and DAOs' contributions.

To promote agency, community partners were able to select how they were represented in this report. All community partners were sent the first draft of this report. Those with anonymised quotes had these highlighted in their copy. They were asked if they wanted to remain anonymous or have these quotes attributed to them by first name, position and organisation. They were also given the opportunity to edit quotes to make sure that the report accurately conveyed their views. Therefore, there are varied attributions of quotes in this report from working group members and interviewees. This was not an option provided to survey respondents as they completed the survey anonymously.

Data analysis

The project team used SurveyMonkey's in-built analytical software to analyse survey data. Transcripts and field notes from working groups and interviews were reviewed by the project team (including research partners), who developed preliminary observations. Data and analysis Lead (CB) led a thematic analysis to identify the themes outlined as our findings.

Limitations

Contextualising co-design in a time pressured sector

This data exchange occurred at an extremely busy time in the disability sector, with disability reform consultations and announcements occurring through December 2024 and commencing again in January 2025. We were not able to secure the involvement of all requested organisations due to these pressures, and we wish to acknowledge the expertise that was both available and absent to us during this project.

Time is a key factor when partnering with people with disability and their respective organisations. This project was a short-term project and as such, operated on a highly condensed schedule with most consultations occurring within a period of three weeks. This naturally excluded organisations and individuals who could not respond within the allocated timeframe, leading to less organisations' involvement than anticipated. As will be discussed in the findings, more timing and resourcing are required to partner with the most marginalised people with disability, who are frequently and inadvertently excluded from research.

Capturing the expertise of people with an intellectual disability and their representative organisations

One particular area of concern is that we have not included the expertise of people with intellectual disability. We were unable to organise an Intellectual Disability working group within the project timeline. The time of data exchange occurred during a time that overlapped with the 'Having a Say' Conference in late January – a seminal conference for people with intellectual disability. However, we spoke with a CEO of a peak organisation that represent people with intellectual disability. They shared that both people with an intellectual disability and their respective organisations in research are left out of research. Therefore, they recommended that research partners engage with organisations to harness this expertise to better connect representative and advocacy organisations with intellectual disability researchers.

The *Towards Inclusive Practice* project by Inclusion Australia – a project about meeting with, consulting with, and creating accessible information for people with disability aimed at a government audience - includes a fact sheet on time[5], stepping out the different phases of projects and consultation where time investment is needed and the impact taking time has on doing consultations well. We recommend this resource as a key reference point to support future timing of consultation projects.

Findings

The importance of mutuality

This project explored the question, 'what do disability organisations need to partner meaningfully in co-design research?'. We analysed transcripts from working groups, interviews and survey responses to identify consistent themes across data sets. This yielded three needs based on mutuality that were strongly discussed among community partners from DRCOs and DAOs:

- **Two-way learning:** Co-design research begins with a minimum standard of knowledge and skills that researcher partners must have to increase their receptivity to learning. This includes listening through difference, reflexive practice, and trauma informed research. These skills are developed through learning *with* community partners where there is a mutual exchange of knowledge. In return, DRCOs and DAOs may gain benefit from learning about how to assess value in research to support their decision-making around undertaking and contributing to research.

- **Co-define, co-design, co-create:** Mutual learning takes place at each stage of 'co-design' research, and it enables shared decision-making - from the conception of a research project to the dissemination and actioning of research findings.
- **Distribution of resources:** Shared decision making is enabled through a fairer distribution of time, funding, and data. Significantly, the distribution of resources must benefit community partners and their communities.

While we address these needs individually, it is important to emphasise that these three key areas are entangled and in practice are hard to separate. However, for the purpose of analysis and explanation, we address them individually next.

Two-way learning:

> *[F]lip it on its head and actually train the researchers to be ready to work with us (Clare, women and girls working group)*

Before entering the field, co-design researchers must develop a set of core skills, capacities, knowledge and mindsets to work with people with disability. These involve listening to learn, practicing reflexivity, as well as being trauma informed. As the quote above suggests, researchers tend to focus on capacity building of people with disability. However, as commonly discussed among community partners, this needs to shift focus to researchers understanding they need to 'skill up'. Importantly, this learning must be guided by people with disabilities as highlighted in the quote below.

> *Some researchers feel like they are the experts, and they're extracting something that is an objective reality from conversations with us, instead of realising they're learning as well, and they're not learning because of the disciplinary background that they acquired in a classroom. They're learning*

Listening to learn

Many community partners spoke about listening as an important starting place that takes place through dialogue. One community partner described it as 'deep listening', a practice that they also do within their own work and personal life which involves listening to people who hold different views. These differences open up opportunities to learn, and it is what Dreher (2009) refers to as 'listening though difference'.

> *[You] really have to learn to listen to people who have a different view than you. So, like, if we're going to resolve some of the issues…we really have to talk (IA interview)*

Focusing on listening shifts focus to 'the other side' of the conversation (Thill, 2014). In doing so, it directs the onus of responsibility on those who speak and instead it pays close attention to the role that people - as listeners (and researchers) - have when marginalised people speak.

Reflexive practice

In addition to listening, reflexivity was an important practice that community partners spoke about as being crucial to managing power imbalances. As one community described:

> *Owning your subjectivity and naming it and then trying to work out how to include it or exclude it from a research project is all we've actually got (Lenie Bourke, Capacity Building Advocate, QAI[6], LGBTQIA working group)*

The above quote exemplified a common concern among community partners about researchers' subjectivities and biases.

These can form beliefs and perceptions that shape a researchers' interactions with communities and how they interpret results. As Finlay (2002) described 'outing' the researcher through analysing how 'subjective and intersubjective elements influence their research' is 'part of laying claim to integrity and trustworthiness' (p. 531). Research engagements require an awareness of emotions, thoughts, and beliefs that can arise through interpersonal interactions (Varela, 1999). Managing uncomfortable experiences - that arise through rubbing up against one's biases - reflects a commitment to creating a safe place for an ongoing dialogue. Importantly, these exchanges foster not only an openness to difference, but also to learning through difference. Engaging in reflexive practice, encourages an interrogation of one's own power and privilege, and it make time and space to listen, share and learn (Hankivsky, 2014).

Trauma informed researchers: creating safe spaces for partners

Co-design researchers must be trauma informed and receive tailored training for specific cohorts and individuals. We emphasise that this training is not generalist and must be specialised for different cohorts and potentially individual projects. As noted in the First Nations scoping report intergenerational traumas can largely impact on First Nations people's capacity to interreact with co-design research. Research partners should seek guidance from community partners about who may be able to provide training and or provide direction on what training is needed to work with specific cohorts.

Within co-design research, being trauma informed requires a constant examination and correction of research practices that maintain uneven power imbalances. We suggest that this starts with listening and reflexivity where researcher partners closely assess how their engagements can impact on people with disability:

> *So think about the trauma informed approach. Think about making sure that you're creating really safe spaces and giving people access to support during and after that process. And it even comes… right down to who's asking the questions. Is the right person asking the questions, or is there the wrong person asking the questions, which could lead unintentionally to a power imbalance that will prevent you from participating or prevent researchers from getting the right information (Clare, women and girls working group)*

As the quote above indicates, being trauma informed involves being aware of how relationship dynamics can unintentionally contribute to distress. In this, researchers need to understand how their intersecting forms of identity and position (e.g., gender, age, race, role as a researcher) may affect working with specific cohorts and individuals. Specifically, it is important for researchers to have a strong critical understanding of the tangled history of research that has unintentionally perpetuated trauma of people with disability (Liasidou, 2023).

Having this understanding forms this foundation for adopting a trauma informed approach within co-design. In this, there is a focus for researchers to address longstanding power imbalances in which they no longer assume expertise but seek to build expertise *with* people with disability (Slater, 2013; Steen, 2013). There is a recognition that both sides of the research partnership have equal expertise that can inform each other's learning during the research process.

Exchanging knowledge: Assessing the value of research

For community partners, a specific exchange of expertise that may be useful is research knowledge and project planning. Community partners frequently advised that many organisations are focused on their day-to-day activities, and knowing how to assess research value without an immediate impact is challenging. This is a particular issue when community partners are unclear on how research will directly impact on their communities.

> *A lot of smaller organisations don't have that level of planning, don't have that level of strategy in their organisation, and it's sort of anything that*

> *comes across their desk, whether they'll engage with it is determined by an ad hoc sort of approach…And so I think a lot could be said if there was a really clear understanding of what the purpose of research was, and what sort of cohort would be best represented in this research and the reason why this research is being undertaken (advocacy working group).*

Many community partners saw value in research that could support their work in advocating for change in their communities:

> *[R]esearch actually can be a tool for us to build momentum and to build a case for change proactively, rather than reacting to a question that the government's putting to us…(WWDA, women and girls working group)*

Many DRCOs and DAOs may choose to not partner in research as it is not clearly aligned with what they value in research – that is, research must demonstrate that it will directly benefit their organisations and or communities. Therefore, research partners must work with potential community partners to assess and identify together what is of value for both sides of a partnership. As the next section will discuss, this can begin with mutual learning at the conception of a research project, and at all stages of research.

Co-define, co-design, and co-create

> *[G]enuine partnership involves…the sharing of knowledge and power through every stage of a research process, not just…identifying an issue, but up to the translation and the analysis and narratives that are formed for sure (WWDA interview).*

For community partners, meaningful co-design research involves shared decision-making at all stages of research. From the beginning, this involves making decisions to identify priorities and to define problems. This then leads to shared decision making to develop the research design and to develop innovative methods to collect data. Lastly, co-creation and co-production was seen as an important element of shared decision-making in co-design partnerships. This enables people with disability to co-author, and to also have a say in how, where, when and what is communicated back to their communities.

Co-defining the problem

There was a strong theme among community partners for the research project to be developed with community partners from the very beginning, at the 'embryonic stage' of research (WWDA interview):

> *[I]n terms of picking a research topic, if we were to engage young people, for example, we would want the young people empowered to inform that decision about what the research is about. So like, right from the start, being able to identify their priority for the research, which may actually be different, to the priority of the government or to the organisation that's engaged them, which can be challenging (CYDA interview)*

Ideally, we would be given the opportunity to be involved in the research development process and be given the opportunity to review and provide advice and input on the proposed research plan (Anonymous survey respondent)

As the quotes above indicate, there may be a mismatch in priorities between the disability community, and governments and universities. However, greater efforts are needed to build that bridge between differing priority areas. Community partners also highlighted that enabling shared decision-making at the start can minimise hurdles (e.g., organising accessibility requirements) as reflected in the quote below. Here, they lament that co-design often appears like an afterthought:

Like a tack on at the end, rather than as really part of the process. And so I think they [the researchers] would have a greater understanding and respect for access. And I think it would make the projects much, much better if they did it from the start… I think how difficult researchers can find it when they haven't done that (SARU interview)

Collecting data

Several community partners recommended that data collection involve inclusive and diverse communication methods - beyond surveys and interviews - to capture people's preferred or primary forms of expression:

I'm curious about the different research methods available and whether, if I were to contribute to a project, there would be opportunities to express myself in more creative ways—perhaps through storytelling or other interactive formats (Iga[7], CALD working group)

Allowing for non-ableist forms of expression

Traditional forms of research can feel limiting in terms of how people with disability prefer to communicate. Moreover, allowing for more flexibility in research approaches can create safety because it is adaptive and sensitive to person's needs:

Different people groups will have sensitivity to past traumas, past issues and being not being so rigid in your research approach that you can't be flexible, and you can't be person led in the way that you capture the data you need to capture, maybe that means you don't do a face-to-face interview. Maybe it means you draw pictures with the person around what their idea of great life is, or something like that. I think it's being creative in how you capture what you need to capture in a way that's sensitive to the person and what their needs are, so pretty much it just means be person led throughout the process (Advocacy working group)

Co-designing methodologies must begin with recognising diverse communication methods are valid, central ways of sharing knowledge, not deviations from the 'norm'. A key issue here is that researchers may take for granted communication preferences that are deeply ingrained in research methods such as interviews and working group, that rely on verbal and

or written communication. However, the intersecting experiences of disability in particular can be difficult to capture in language and words, and can prevent people who try and describe their embodied experiences and feelings (Brown, 2018). Allowing for more innovative and creative ways to capture tacit and experiences beyond words, as part of data collection, can add depth and nuance to research that may be lost in more mainstream approaches (Baylosis, 2017).

Co-facilitation

Several community partners highlighted that sharing facilitation with people with lived experience was an important element to encourage safe participation through having a shared understanding:

> *When conversations are facilitated by people with shared lived experience—who understand what it means to move through the world as both LGBTQIA+ and disabled—it creates a sense of safety that no amount of academic expertise can replicate. I've been in spaces where a well-meaning 50-year-old professor was leading the session, and despite their credentials, they simply couldn't connect. The room shut down. Contrast that with a session led by a queer disabled peer—suddenly the space opens up, people lean in, and real trust is built. That kind of facilitation isn't a nice-to-have—it's essential (Sebastian Zagarella, CEO PWDA[8], LGBTQIA+ working group)*

Similarly, another community partner explained it creates a sense of community, and researcher accountability:

> *[B]ecause you've got that co-convener that is a part of the community, they bring the sense of community with it. And then like this, this aspect of skin in the game of like, I can't let you* as the researcher, mistreat or dehumanise my community and my cohort of people to make us fit into your square box (Advocacy working group).

As noted earlier, this project's facilitators were all people with disability. This creates ethical symmetry (Slater, 2013), where research partners worked with communities partners to collaboratively explore and develop ways of understanding. While it may not be necessary to have only people with lived experience as facilitators, sharing facilitation is important to establish trust – based on a shared sense of community - and connection with community partners.

Co-interpretation: Shared sense-making

Ensuring that people with disability are part of the data analysis makes sure that ableist biases do not go unchecked in the interpretation of data. Sharing the sense-making of data with community partners challenges power relation between the researcher and participants, where researchers have been privileged in telling the stories of others (Couldry, 2010).

> *[B]eing part of the analysis and how things are interpreted and how things are expressed…We helped at the start, and now we're going to put it back*

into the black box of the researchers own life experiences and perceptions of things… (WWDA interview)

Shared sense-making may bring to light points of divergences among research partners and community partners, exposing unconscious biases. These points of difference can create opportunities for learning and correcting misrepresentations of data. It also allows for the recognition of multiple truths, and a platform to share multiple – and equally privileged - ways of interpreting phenomena (Lippa & Shalin, 2007). An example provided by one community partner was language, and how different words can take on different meanings, and may require translation across communities:

This is why you get us to do the translating, because only we can tell you what it really means, because language and words…in the disability community, words don't always mean the same thing to different communities (PWDA interview)

Co-authoring and dissemination

Co-authoring is an important part of shared sense-making and representation. However, for many community partners 'the write up' and sharing research findings need to include multiple formats:

…non-traditional outputs, we need to think of more. I'm really into animation at the moment because I think it is so accessible to a broad community. There's the audio components that are accessible to people who aren't visual communicators. There's the visual components that are more accessible for people who need that to support the information they're receiving, and it's just an easy way to make complex ideas more understandable. So that's the sort of innovation I want to see in knowledge translation (WWDA, women and girls working group)

The above statement highlights the importance of co-producing research outputs in a variety of formats. These must be accessible for multiple communities with differing communications preferences and needs.

Co-producing accessible materials

Accessibility is significant issue. There was a strong theme among community partners where several advised that both research methods and communication approaches often exclude people with disabilities through inaccessible communications. This reflects the failure of research systems to be accessible to diverse audiences, including people with cognitive disabilities and those without formal academic training. Many community partners stressed the need for accessible language, plain English summaries, and multiple formats to ensure that research is genuinely inclusive:

[M]ake sure the information is there, like if it is in writing…[then] it has been translated, if there is a language other than English, that would make it more accessible, if literacy is an issue, making sure there is that time to verbally go through the information beforehand, identifying sort of any

*visual prompts or other things that would help…that all goes to… the idea
of removing barriers to their participation (CYDA interview)*

Closing the loop: Sharing the benefits of research

Lastly, some community partners spoke about sharing information as a way of sharing benefits of research and closing the loop. A key issue raised among community partners, including our First Nations community partners is the burden on people with disabilities to repeatedly share personal and sometimes traumatic experiences without clear pathways for how their insights will be used or whether they will drive change. They highlighted the dangers of potentially contributing to trauma, where people share deeply personal experiences and then have no clear mutual benefit. As one community partner described, it can be:

*[C]ompletely extractive, and so there is a piece around coming [to] a close,
like a closing a feedback loop, and letting people know. Well, this is what
we learned, and here's how you can use it to make your life better. Not just
keep me in a peer reviewed article, it's really important (Clare, women and
girls working group).*

As will further be discussed in the following section, sharing research data with the broader disability sector was seen as a benefit for not only community partners, but more broadly the disability sector. This includes organisations that may not be involved directly in research and may be impacted and benefit from the research findings.

Distribution of resources: Time, money, data

Funding, time, and access to data are crucial enablers for more balanced partnerships. While it is now commonplace for research partners to offer renumeration for research participation, these agreements often impose ableist expectations in terms of time and resources. Specifically, people with disability are often expected to produce and participate in research at the same pace as non-disabled researchers, and often with less (financial and informational) resources. Research partners must acknowledge and allow for 'doing' research with longer timeframes – particularly for people with intellectual disability, whom also require more tailored resource allocation.

A time pressured and under-resourced disability sector

*There needs to be an awareness of how often individuals within our
communities are asked to participate in research- research fatigue needs
to be taken into account and proper incentives for research participants
with disability arrange for them to participate in research (Anonymous
survey respondent)*

Many organisations across the disability sector are stretched beyond their limits, with many functioning at or beyond capacity. The First Nations community partners also shared that they had seen an increase in the volume of consultation but without an adequate increase in

resourcing. This project took place during a significant period of reform. Following the release of the findings of NDIS review and the Disability Royal Commission (DRC), the Federal Government announced significant reforms across numerous service systems and public services that support people with disability. To implement these reforms government bodies were tasked to conduct 'co-design' work with DRCOs and advocacy organisation. This largely impact on this research project.

This project took place within an environment of systemic fatigue and scarcity, with time and expertise in constant demand and rarely met with corresponding support. It meant that we needed to work within these constraints and ensure that contributing to working groups and interviews were not an additional burden on already overstretched organisations. As one community partner explained:

> *[K]nowing that if you are going to work with in a co-design way, in research with people with cognitive disability, it's going to take longer than you thought so you're going to need much more time, and you will, you'll have to build a relationship with those people, even in that one because that's the way that's going to create accessible environment, that's going to create better communication channels. So working with people, particularly people with intellectual disability, you need to slow it down and you need to allow more time (SARU interview)*

Furthermore, disability organisations are often under resourced. To partner in research often means that they need to pool together other projects to make it economically viable within an organisation, which in turn, can impact on time available:

> *And so an understanding that it may take…organisations longer to get things done, because we will be looking to try and add more work into an existing sort of research resource pool who's already balancing a number of…projects and priorities, and it's not only those external things that they're working on, but internal things (CYDA interview)*

Research partners must be aware of how ableist timeframes can create systemic barriers for people with disabilities to meaningfully partner in research (Kafer, 2013; Kuppers, 2014; Pierre & Peers, 2016). If unaware, unrealistic ableist timeframes can prevent some of the most marginalised people from partnering in research. Mutual learning, and in particular, reflexive practice is important here for researchers to address the biases they may have around conventional project norms, such as time and pace, that are often taken for granted (Nario-Redmond, 2019). In addition, research partners must take into account that disability organisations may not be able prioritise co-design research when significant reforms are taking place. These changes will have a direct impact on their disability organisation's community and or organisation, and therefore often prioritised over research that does not have clear immediate impact on their day-to-day business:

> *I think the reality is most advocacy organisations are just getting there on the day and trying to deal with what's in front of them, right there, and then there is a bit of a trickle-down effect (Advocacy working group)*

Funding: The hidden costs of disabilities

Community partners spoke of the additional costs that some cohorts and communities have. For smaller organisations, particularly those with specialisation or who work with specific groups of people with disability, dedicating time to consultation without additional resources is unrealistic. Universities and research institutions frequently seek their input—as one organisational leader noted, sometimes up to five times per month—expecting contributions in kind without recognising the financial and operational burden this creates. Beyond time constraints, these demands also require additional staff support, debriefing, and supervision, increasing internal workload.

There's this over reliance on the already stretched resources of small organisations...Giving them $1,000 is great for something like this, right?...but often, they're not getting enough money to actually cover the staff member's time needed for genuine accessible engagement or value the skill set of the staff members providing support to this. The reimbursement is often not enough to make it worthwhile for the org. (SARU Interview)

So you can't expect small organisation with two or three staff to spend hours consulting people at the same public research project (Advocacy working group)

Additionally, accessibility and support for people to partner in research must be factored into budgets. Often the responsibility is placed on DRCOs and DAOs or people with disability to make accessibility requests (e.g., Auslan, captioning, interpreters). However, a more equitable balance is needed - research partners must also invest in strengthening their own capacity to provide support to DRCOs, DAOs and people with disability:

We've engaged with a research project with an external organisation, and it became very clear very quickly that they had very little understanding about access and inclusion, which meant that the resources that we thought we needed to allocate to participate in that project, we severely underestimated that, because it just took so much more time to upskill the researchers on these things, and then the support we were providing to the young people we'd linked into the project had to be a lot more than we thought (CYDA interview)

Funding constraints are a further barrier to participation. Many organisations operate with limited resources, yet researchers frequently expect them to contribute with inadequate renumeration. There are often hidden costs associated with disability that are invisible to researchers, such as accessing transport (regional areas have unreliable and inconsistent public transport) having support workers and/or support people available, and accessible materials (Soltani, 2018). Even when funding is available, it rarely covers the full costs of research participation, leaving organisations to absorb the additional time, staffing and resources.

> *We like to be fully included - our organisation has been involved in research for many years... we would like to receive funding for our time and effort, which might include a funded position, which we do not currently have. We are a trusted and expert organisation in the community, and this should be recognised through opportunities and appropriate resources (Down Syndrome Australia representative, survey response)*

Sharing data: A mutual exchange

Finally, research should be actionable, providing clear and timely insights that can be used for advocacy and policy change. Many community partners expressed frustration with research that takes years to publish, which is when the opportunity to use research to influence policy on systemic issues has passed. Specifically, community partners often spoke about wanting to see their contributions have made an impact:

> *I think that there's often a lack of ownership and responsibility to the community, to give back and to provide accessible summaries so that people, one, want to be more involved, and two, can see how their contributions has an ongoing and on lasting positive effect (LGTQIA+ working group)*

In this, many community partners recognised that having access to research findings enabled them better advocate for and with their communities to influence policy:

> *We can tell all of the stories. But, you know, increasingly, it's the data and that comes through the research and things like that. So for us, it's actually an incredibly valuable tool that we can use to advocate on behalf of the people that we represent, that we can use to show why a policy is good or why a policy is not going to work or hasn't worked, to influence the way that people are doing things (WWDA interview)*

As reflected above, having access to research findings and data can provide DRCOs and DAOs with evidence and information to support their work (e.g., writing submission, demonstrating need). However, there is often an issue with access as research articles are often behind paywalls. As noted above, co-production that involves producing research outputs in variety of formats in multiple locations can increase access. Importantly, this creates improved mutuality in the research process where the benefit of research better extends to DRCOs, DAOs and people in the community.

Conclusion

This report underscores the critical importance of mutuality in co-design partnerships between researcher partners and DRCOs and or DAOs. The findings and recommendations highlight several key areas that need attention to ensure these partnerships are effective, inclusive, and beneficial for all parties involved. These include two-way learning, shared decision-making at all stages of research and a fair distribution of resources to partner in co-design projects.

References

Baylosis, C. (2017). Mad Practices and Mobilities: Bringing Voices to Digital Ethnography. *Digital Culture & Society*, *3*(2), 229 - 236.

Benz, C., Scott-Jeffs, W., McKercher, K. A., Welsh, M., Norman, R., Hendrie, D., & Robinson, S. (2024). Community-based participatory-research through co-design: supporting collaboration from all sides of disability. *Research Involvement and Engagement*, *10*(47), 1 -12.

Blomkamp, E. (2018). The promise of co-design for public policy 1. In *In Routledge handbook of policy design* (pp. 59 - 73). Routledge.

Brown, N. (2018). Exploring the lived experience of fibromyalgia using creative data collection methods. *Cogent Social Sciences*, *4*(1), 1 - 17.

Couldry, N. (2010). *Why Voice Matters: Culture and Politics After Neoliberalism*. Sage.

Dreher, T. (2009). Listening across difference: Media and multiculturalism

beyond the politics of voice. *Continuum*, *23*(445 - 458).

Durose, C., Needham, C., Mangan, C., & Rees, J. (2017). Generating 'good enough' evidence for co-production. *Evidence & Policy*, *13*(1), 135 - 151.

Farr, M. (2018). Power dynamics and collaborative mechanisms in co-production and co-design processes. *Critical social policy*, *38*(4), 623 - 644.

Finlay, L. (2002). "Outing" the researcher: the provenance, process, and practice of reflexivity. *Qualitative Health Research*, *12*(4), 531 - 545.

Fraser-Barbour, E., Robinson, S., Gendera, S., Burton-Clark, K., Fisher, R., Alexander, J., & Howe, K. (2025). Shifting power to people with disability in co-designed research. *Disability & Society*, *40*(2), 259 - 280.

Hankivsky, O. (2014). *Intersectionality 101*. Intersectionality Research and Policy, Simon Fraser University,.

Hendriks, N., Slegers, K., & Duysburgh, P. (2015). Codesign with people living with cognitive or sensory impairments: a case for method stories and uniqueness. *CoDesign*, *11*(1), 70 - 82.

Higgins, D., Dennis, A., Stoddard, A., Maier, A. G., & Howitt, S. (2019). 'Power to empower': conceptions of teaching and learning in a pedagogical co-design partnership. *Higher Education Research & Development*, *38*(6), 1154 - 1167.

Kaethler, M., De Blust, S., & Devos, T. (2017). Ambiguity as Agency: Critical Opportunists in the Neoliberal City. *CoDesign*, *13*, 175-186.

Kafer, A. (2013). *Feminist, Queer, Crip*. Indian University Press.

Kuppers, P. (2014). Crip Time. *Tikkun*, *24*(4), 29 - 30.

Liasidou, A. (2023). Trauma-informed disability politics: interdisciplinary navigations and implications. *Disability & Society*, *38*(683 - 699).

Lippa, K., & Shalin, V. (2007). Sensemaking in disability management. Conference on Technology-based Learning with Disability,

Nario-Redmond, M. R. (2019). *Ableism: The Causes and Consequences of Disability Prejudice*. John Wiley and Sons.

Nind, M. (2017). The practical wisdom of inclusive research. *Qualitative Research*, *17*(3), 278 -288.

Pierre, J. S., & Peers, D. (2016). Telling ourselves sideways, crooked, crip: An introduction In *Canadian Journal of Disability Studies* (Vol. 3, pp. 1 - 11). 5.

Pink, S. (2012). *Situating Everday Life: Practices and Places*. Sage.

Rutter, D., Manley, C., Weaver, T., Crawford, M. J., & Fulop, N. (2004). Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science & Medicine*, *58*(1973 - 1984).

Slater, D. (2013). *New Media Development and Globalization: Making Connection in the Global South*. Polity Press.

Soltani, S. (2018). Hidden cost of disability: What policy makers usually forget. *Journal of Research in Medical Sciences*, *23*, 15 - 16.

Steen, M. (2013). Co-Design as a process of joint inquiry and imagination. *Design Issues*, *29*(2), 16 - 28.

Thill, C. (2014). Listening for policy change: How the voices of disabled people

shaped Australia's National Disability Insurance Scheme. *Disability & Society*, *30*(1), 15 - 28.

Varela, F. (1999). *Ethical know-how: Action, wisdom, cognition*. Stanford University Press.

Endnotes

[1]   DRCOs comprise 27 organisations that are members of the NDIA DRCO group that work closely with the NDIA on changes, reforms and improvements to the NDIS. We worked with selected DRCOs as part of this project.

[2] DAOs were independent disability advocacy organisations, which receive federal and or state funding to deliver advocacy services.

[3] DANA currently delivers two secretariat programs - the National Coordination Function with Disability Representative Organisations, and the NDIA DRCO program.

[4] The 5 working groups were CALD, LGBTQIA+, women and girls, advocacy, and First Nations. As noted, the First Nations working group was led by First Nations Lead and reported separately.

[5] Inclusion Australia (2023). Inclusion: take the time, make the time., available at: https://www.inclusionaustralia.org.au/wp-content/uploads/2023/04/Take-the-time-make-the-time.pdf

[6] Community partner self-selected to disclose name, position, and organisation.

[7] Community partner selected to disclose their first name

[8] Community partner nominated to disclose identifiable information alongside quote