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# DANA / NDRP Collaborative/Co-design Research Scoping Project Report

## First Nations Engagement

March 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

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## Introduction

At the beginning of February 2025, I began groundwork to engage with First Nations specific, disability advocacy organisations, on behalf of Disability Advocacy Network Australia (DANA) and the National Disability Research Project (NDRP). The motivation for this work was to capture the involvement of disabled, First Nations people within leadership roles, their current, and potential future involvement with collaborative, co-designed, research.

The Department of Social Services website states that the First Peoples Disability Network (FPDN) are the only Indigenous peoples' specific, federally funded, Disability Representative Organisations (DRO). Upon starting this project I did confirm that FPDN had no capacity to engage with me in the initial stages, and I did reconfirm again in the latter part.

The Commonwealth's 2024 Annual Closing the Gap report, highlights FPDN having received funding since 2022, to develop and implement the National Disability Footprint (the Footprint). A foundational component of the Footprint is a drive to increase capacity, participation, and representation of First Nations people with disability, within all facets of research, policy, and governance.

Early on in the project it was noted that, there are a very low number of First Nations people with disability employed within leadership roles of non-government organisations (NGO), therefore, in an attempt to capture a more diverse range of voices, other organisations such as Aboriginal Community Controlled Health Organisations (ACCHOs) were considered for the purpose of the project.

Initial responses from some organisations showed that potential participants were interested in engaging in more collaborative research, however very few had staff members that were both Indigenous and identified as disabled.

After a long search, I was able to make contact with two individuals who are in leadership positions within an NGO.

## Leaders

Joshua Pether (Kalkadoon) is a multidisciplinary movement artist, with lived experience of disability, who recently became CEO at Arts Access Victoria. Along with his significant performance career, Josh is a seasoned disability advocate, and in 2019 he was a foundational artist for Alter State. Alter State is a disability arts festival with a vision to bring about significant cultural and social change for people living with disability.

Uncle Paul Constable Calcott (Wiradjuri) is an Elder, internationally showcased artist, and he has over 20 years' experience in various roles within NGOs and ACCHOs. Uncle Paul is currently serving on the board of Mob 4 Mob, a First Nations led, community based NGO who work collaboratively with state and national peak bodies, to ensure mob living with disability are supported, and represented in culturally appropriate ways.

First Nations people have been extensively researched, often in very extractive, and culturally inappropriate ways, with little to no benefit to them or their community, as a result of these interactions. When discussing co-designed and collaborative research with Josh and Uncle Paul, the overarching theme that became evident was how damaging research thus far has been for First Nations people, especially those living with disability.

When reflecting on their roles from a cultural perspective, both respondents felt responsibility to ensure the disabled, First Nations community did not feel they were again 'othered' throughout the research process.

While colonial ideas of disability are dominant amongst the larger community, First Nations people often view the separation into another marginalised group, as adding to their cultural load. Uncle Paul and Josh both stated that the communities they represent are often 'forced to choose' between being seen as disabled, or having their Indigeneity recognised.

Josh states that there is also a need for researchers and others in disability advocacy spaces, to recognise the significant cultural differences that exist within the disabled community in Australasia. Josh suggests that a Eurocentric view still dominates disability narratives, and that we need recognition and development of environments that reflect our true cultural needs.

Primarily, the concerns that the leaders had in regard to being involved in co-designed and collaborative research, was the ongoing funding needed to sustain it. Disability advocacy organisations have already seen a significant increase in their workload in recent years, with demand for services mounting, quality of life for Indigenous people declining still (as evidenced in the Closing the Gap targets not being met), and industry changes dominating their requests for support and advocacy.

These increases have not been met with anywhere near sufficient Federal funding to even allow some NGOs to remain operational, let alone develop, and then maintain a sustainable, intersectional, research team. The NGOs and ACCHOs that do receive finance from government, (either Federal, or State & Territory), were reported as being perpetually scrambling for funds relating to any facet of their work, with little to no ability to develop processes to support research, and with no capacity to be tasked with the role of securing

funding. The constant requirement to reapply for finance, takes up an intense amount of work and time.

## Disability advocates

In addition to speaking with First Nations leaders of NGOs, I engaged a group of 5 First Nations people with disability, who work within disability advocacy but weren't in leadership roles, to discuss possible barriers to participation in co-designed, collaborative research.

This discussion was held in a casual home-like space, over the course of 8 hours, and functioned similarly to an informal conversation but in line with cultural protocols.

The group consisted of respondents who identified their gender(s) as female, male, non-binary, and were aged between 18 and 60.

All respondents wished to remain anonymous, for fear of negative professional repercussions. Positions they hold included caseworker, research assistant, and artist.

Concerns that a lack of ongoing resources would negatively impact any capacity to engage in research, were reflected again by respondents who weren't in leadership roles but worked at NGOs.

Respondents linked reasons such as the abhorrent racism, gender based violence, and the worsening life experiences and outcomes that First Nations people face, as reasons for their lack of interaction with co-designed, or collaborative research. The participants in the focus group noted that their own quality of life overall had continued to worsen rapidly over the past 18 months. The Productivity Commissioner's 2025 report into the Government's (Closing the Gap) initiatives to improve socioeconomic outcomes for all First Nations people, cites an increase in death by suicide amongst some First Nations communities by almost 40%, with ever growing numbers of incarceration and child removals.

Respondents felt that many times they were seen as 'just data' and 'not really people' by researchers, due to the lack of community accountability and follow up.

The respondents felt that there is already a significant amount of data already available with regards to these life outcomes, but that the continued lack of funding and accountability by the Commonwealth, meant that improving these outcomes seemed hopeless. Consultation fatigue is another barrier facing researchers engaging with the First Nations disability community. If a participant is able to overcome all of the obstacles that were mentioned, and still engage with a researcher, they are often repeating answers to questions they've been asked many times before.

Every participant confirmed that they felt their responses and suggestions would not be taken into account when deciding the actions to result from the research.

This apparent ignorance of previous, well established data, and repetition of intergenerational traumas, is what influences the fatigue, and can be a catalyst for culturally disrespectful behavior.

Initially the challenges that seemed prominent when scoping the size and composition of potential research partnerships, was the lack of First Nations representation within disability organisations.

## Conclusion

After discussions with First Nations leaders with disability, what became evident was that there is an extremely limited number of disabled, First Nations people working within NGOs, or ACCHOs. The reason for this is that most of those people are navigating significant, non-modifiable circumstances to simply survive in life. Another factor suggested as reasons for the low number of staff identifying as disabled, were the cultural differences with respect to how chronic illness, disability, and neurodiversity was viewed in First Nations Communities.

To move towards building a sustainable, respectful, and non-extractive relationship with the First Nations communities at large, organisations must change their approaches dramatically. A secure, ongoing, bipartisan source of funding is required to allow the development of a First Nations led, research and co-design organisations and NGOs. First Nations people are not monolithic, and each community needs to be led by those most impacted by the decisions being made. Until there is a massive shift in the way the Government approaches, finances, researches, develops, and supports the practical application of governance, of First Nations people, specifically those with disability, their quality of life, and life outcomes will continue to decline. This decline will continue to permeate through every single facet of life, and remain ever present within the research itself.

## Recommendations:

Note, these recommendations are in conjunction with recommendations made

- 1.) The NDRP advocates for secure, ongoing funding for First Nations research that is led and designed by First Nations peoples. Specifically, First Nations research must be supported to lead research with their communities.
- 2.) The NDRP funds First Nations researcher and or First Nations organisations to develop and deliver training on intersectional experiences and cultural differences of disability. Such training should be mandatory to all NDRP researchers wanting to partner with First Nations communities.
- 3.) To minimise consultation fatigue, the NDRP works with First Nations organisations to ensure that a review of existing data and research on is conducted. This will minimise the extent to which First Nations people repeatedly tell their stories to researchers.

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