



## **NDIS Participant Voice project - Summary of Seed Funding**

**Melbourne Disability Institute (MDI)**

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### **Introduction**

In Dec 2021, Mark Considine, Carmel Larargy, Rae West obtained a seed funding grant from Melbourne Disability Institute (MDI) to examine the possible role of codesign in a disability research project on participant voice within the NDIS and to better understand system responsiveness. Specifically, this pre-study was to support our methodology of disability inclusive research approaches for an ARC Discovery grant application. The grant application was submitted on 11 May. The codesign methodology required engagement with the disability community, specifically within the design creation phase. This is in order to inform the community of the topic of the research and to ensure the project's research design meets community expectations in relation to research on their group. Those expectations include the core questions being addressed and the proposed activities and engagements to be used. For ARC grants, this predesign stage of community engagement as a part of a codesign research methodology is currently not funded.

The title of the ARC application has now evolved to Strengthening the role of Service Users in the Continuing Co-design of Public Services: The NDIS Case. Its aims are to examine continuing codesign elements of the NDIS. Varying levels of codesign were built into the NDIS scheme, which included an Independent Advisory Council, avenues for appeal and complaints pathways and feedback consultations on varying design elements of the scheme. This design of running the scheme based on individualised funding within a marketised system at a national scale was transformational in terms of service-user design and control of services. Nine years down the track from the NDIS Act (2013) and the beginning of onboarding in 2016, where is the participant positioned now in relation to codesign? In looking at the broad codesign elements of the NDIS we will examine how and to what level do participants continue to coproduce their own service map? If problems emerge, how do they use voice or innovate within the scheme to resolve these? Is the scheme responsive to this voice? And ultimately, where and through what means might this voice lead to continuous improvement in scheme design (and hence ongoing coproduction by participants in terms of scheme design)?

### **Codesign methodology**

Methodologies of disability research have historically conducted research 'on' or 'about' people with disabilities. In the main, this research was conducted by objective, mostly able-bodied researchers, conducting clinical, medical-condition based research on physical or intellectual difference, or ethnographic sociological-styled studies where people with disability were 'observed'.

The design of the ARC research specifically aims to incorporate principles of codesign and coproduction as prescribed by the discourse of the disability studies field (Walmsley and Johnson 2003, Walmsley 2004; Bigby and Frawley 2010, Bigby et al 2014, Robinson et al 2014, Gaudion et al 2015, Hendriks et al 2015, Puyalto et al 2016, SCIE 2015, Warr et al 2017, RDI 2020, Strnadová et al 2020, Fisher et al 2022). It will utilise disability inclusive research approaches, recognising the full participation of people with disability, including people with intellectual disability, throughout the research process - from the beginning of the research design through to translation of knowledge and findings to stakeholders. As noted by Puyalto et al (2016:147), people with relevant experience in relation to the studied topic should be included in the research and their participation facilitated in all phases of it.

The codesign methodology specifically seeks to engage with the community in which the research is being undertaken in, providing ownership and reciprocity of the research project with the community for the participants involved, supporting the principle of 'nothing about us without us'. The codesign methodology allows for community expectations of research undertaken in the field to be reviewed by the disability community. As highlighted by Bigby et al. (2014) in their scoping of the peer-reviewed literature on inclusive research, collaborative approaches in research need to be utilised '*...where people with and without disabilities work together on a research process in which each contributes their skills and experience to generate new knowledge together*'.

Coproduction approaches also seek to actively drawback inherent power imbalances between the researchers and participants within interactions, and seek to create more balanced forms of interaction and knowledge creation that can more effectively draw-out lived experience and service user knowledge (Cataldo et al 2021). As noted in Cataldo et al (2021:16) '*...learning how to share power and partner with people with diverse lived experiences opens space for meaningful inclusion and unlikeminded partnership. ...decision-makers must learn how to share — and give away — their institutional and positional power with people with diverse lived experiences who are passionate about co-creating and realising change* (Cataldo et al 2021:16).

### **Pre design engagement with disability community**

The pre-study community engagement involved consultation with people with a disability, advocates, parents and supporters from within the disability field before the research design was completed. This enabled us to incorporate learning, understanding and knowledge of the best way to conduct the research into the research design, and consider the best ways to explore the concept and phenomena of our research topic in line with the community's expectations of engagement and participation in research on their own population group.

Nine engagement-on-design meetings were conducted: seven with advocacy organisations, and two that included the Office of the Public Advocate and a meeting with a single NDIS representative. This was followed by engagement with people with disabilities themselves and discussion on research concepts and methodology.

The disability community told us that codesign and coproduction approaches utilised for disability inclusive research will require extended time and resources in order to undertake pre meetings to prepare participants for focus groups and interviews, and supports for advocacy management staff and facilitators to brief participants on the research topic. It might require communication and accessibility supports such as formal captioning supports and translator supports, support worker time for each participant, translation of participant information and consent form documentation into easy read to ensure understanding by participants and additional time (double to triple the normal time)

for interviews and focus groups to ensure understanding and clarity of communication. We identified that a variety of communication methods will need to be used to obtain data. We also identified that the research team will be required to take a variety of roles to support participants throughout the research to obtain meaningful, longterm inclusion of people with disabilities as participants.

People with disability communicated that they often preferred speaking with other people with disabilities as they felt there was some level of implicit understanding of lived experience and shared understanding of issues. In taking on board this feedback it was determined that in addition to an academic with a disability, that community researchers should be included in the research team. The community researchers will have lived experience of interacting with the NDIS system and knowledge of disability community culture, but will not necessarily be qualified academics. Their value is recognised in the differing knowledge and perspective that they will bring to the study from their personal experiences and from personally interacting with this scheme.

The following meetings were undertaken as a part of this community engagement:

20 Jan 2022 PurpleOrange  
21 Jan 2022 Inclusion Melb  
24 Jan 2022 Down Syndrome Australia  
25 Jan 2022 Office of the Public Advocate (OPA)  
4 Feb 2022 Women with Disabilities Vic (WDV)  
15 Feb 2022 PurpleOrange - Elders Group facilitator  
24 Feb 2022 PurpleOrange - OurVoice Group  
24 Mar 2022 AMIDA [Action for More Independence and Dignity in Accommodation]  
5 May 2022 NDIS senior staff member

The project's design has involved significant interaction and engagement with disability advocacy organisations and the disability community more broadly. This has played significant role in how the research has been designed, timelines, data collection, thinking on who should be members of the research team, budgeting of resources and in thinking around forms of knowledge translation of findings.

In summary, the seed funding obtained from MDI was highly effective in giving us resources that allowed us time to effectively engage with the disability community and undertake a comprehensive codesign methodology. The disability community provided great insight at numerous levels of thought and thinking on parameters of the study, how communication methods should occur, varying elements of how data collection should be undertaken and scale, the use of community researchers within the research team and expectations for our research.

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