Disability Advocacy
Network Australia

2025

Report

Partnering with Disability Representative and Advocacy Organisations in Research

Plain language summary

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Introduction

This report, prepared by Disability Advocacy Network Australia (DANA), explores how to effectively partner with disability representative and advocacy organisations in research. The goal is to ensure these partnerships are meaningful and beneficial for all involved.

Who We Are

DANA is a national body representing independent disability advocacy organisations across Australia. Our vision is to create a nation that values people with disabilities and respects their human rights. We aim to strengthen and support these organisations, providing a collective voice and promoting the value of disability advocacy.

Research Overview

The project was conducted for the National Disability Research Partnership (NDRP). It involved speaking with selected disability representative and carer organisations (DRCOs) and disability advocacy organisations (DAOs) to understand their needs for meaningful research partnerships. The methods used included interviews, working groups, and surveys.

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Key Findings

1. Two-Way Learning

a. **Listening to learn:** Researchers should actively listen to the experiences and perspectives of people with disabilities. This involves being open to different viewpoints and understanding the unique challenges faced by people with disabilities.
b. **Reflexive practice:** Researchers need to regularly reflect on their own biases and assumptions. This helps them understand how their perspectives might affect the research process and outcomes.

c. **Trauma-informed approaches:** Researchers must be aware of the potential for trauma in the lives of people with disabilities. They should use approaches that minimise harm and create safe spaces for participants to share their experiences.

d. **Exchanging knowledge**: Just as researchers learn from advocacy organisations, organisations can benefit from learning how to judge the value of research and how findings might help their communities.

2. Co-Define, Co-Design, Co-Create

a. **Identifying problems together**: Researchers and community partners should work together from the very beginning to identify the research problems. This ensures that the research addresses issues that are important to the disability community.
b. **Designing research together**: Community partners should be involved in designing the research methods and processes. This includes deciding how data will be collected and analysed.
c. **Producing outputs together:** The final research outputs, such as reports and presentations, should be co-created with community partners. This ensures that the findings are relevant and accessible to the disability community.

3. Distribution of Resources

Partnerships must include fair sharing of time, money, and data.

a. **Time**: Research projects should allow enough time for meaningful participation from community partners. This includes time for building relationships, conducting the research, and sharing the findings.
b. **Money**: Adequate funding should be provided to support the participation of community partners. This includes compensation for their time and expertise, as well as covering any additional costs related to accessibility.
c. **Data:** The data collected during the research should be shared with community partners. This allows them to use the findings to advocate for change and improve their own practices.

Recommendations

Two-Way Learning

1. **Develop Guidelines for Researchers**
    - The NDRP works with DRCOs and DAOs to create guidelines that to help researchers build important skills. These skills include reflective practice (thinking about their own biases and assumptions), listening through differences (understanding different viewpoints), and trauma-informed research (being aware of and minimizing harm to participants).
2. **Create Accessible Information Resources**:
    - NDRP works with DRCOs and DAOs to develop easy-to-use resources to help disability organisations decide if they want to be involved in a research project. These resources should explain how much time and commitment is likely to be needed, so organisations can make an informed choice.
3. **Develop a Toolkit for Collaboration**:
    - The NDRP develops tools and/or resources with DRCO and DAOs to help potential partners assess collaboration opportunities. This toolkit should include information on how to evaluate the benefits of research partnerships, calculate the resources needed, and approach researchers or funders with research ideas.

2. Co-Define, Co-Design, Co-Create

1. **Enable Shared Decision-Making**:
    - 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.
2. **Co-Produce Accessible Information Resources:**
    - The NDRP work with the disability community to create accessible information resources. These resources should help organisations that have not been involved in research before understanding what is required and decide if they want to participate.
3. **Collaborate on a Co-Design Research Template**:
    - 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

1. **Fund an Environmental Scan**:
    - The NDRP funds an environmental scan of DRCOs and DAOs to understand the current level of research requests they receive. This scan should evaluate appropriate levels of funding, timelines, and how research data can directly benefit the disability community.
2. **Co-Design a Dissemination Plan**:
    - The NDRP supports its funded research teams to co-design the knowledge mobilisation activities at each stage of the research. This dissemination plan should ensure that research findings are shared in accessible ways, especially with hard-to-reach communities such as regional and rural areas, culturally and linguistically diverse communities, First Nations communities, and people with intellectual disabilities.
3. **Co-Author Guidelines on Timeframes**:
    - The NDRP co-authors a set of guidelines on the timeframes needed for proper co-design with DRCOs, DAOs, and the disability community. These guidelines may require discussions with over-researched communities such as representative organisations for people with an intellectual disability.

Ethical Considerations:

- Emphasis on trauma-informed approaches and creating safe spaces for participants.
- Payment for participation and additional support for wellbeing were provided to acknowledge the expertise and time of the organisations involved.

Conclusion

The report highlights the importance of mutuality in co-design partnerships. It advocates for shared decision-making, fair resource distribution, and the elevation of lived experience as authoritative knowledge. By addressing these needs, research partnerships can become more inclusive and effective.