MONASH University

Explanatory Statement
Group 2 - Adult participants who require guardian/next of kin consent for research participation

Exploring participatory methods of inclusion in organisational research, decision-making and service design

The person you are a guardian/next of kin for is invited to take part in this research about how **organisations** and **people with cognitive disability** work together and share decisions.

Project ID: 49384

From the School of Primary and Allied Health Care, Faculty of Medicine, Nursing and Health Sciences, Monash University (Peninsula Campus) research team members are Natasha Layton, Jacinta Oakley, and Em Bould, and Ricky Buchanan.

Please read this Explanatory Statement in full before deciding whether or not the person you represent would like to participate in this research. If you have any questions about the research you can contact Jacinta Oakley (jacinta.oakley@monash.edu or 0401 019 067) or Natasha Layton (natasha.layton@monash.edu or 0405 310 266).

This study will form part of a Masters thesis being undertaken by Jacinta, who is an engagement practitioner with experience in organisational research, engagement, and co-design, with people with disability.

What are the project aims?

This project has the following aims, in relation to how organisations and people with cognitive disability work together and share decisions:

1. Build understanding of the current state of organisational practice in Australia
2. Explore perspectives and experiences of those involved
3. Identify barriers and enablers to meaningful and successful engagement

What does the research involve?

Given your next of kin or the person for whom you are an appointed guardian is invited to participate in this research project. As their next of kin / appointed guardian / proxy, you are invited to support them to contribute – or contribute as their proxy - to the research.

This research is designed to offer inclusive and accessible methods of participation.
Participants can choose to take part in the research in three ways. Participants are invited to:

1. Participate in an interview with a researcher that may take around 45 minutes to complete and can be held via a video call or over the phone.
2. Share their experience via a visual, video, audio or text response. For example, participants might write and/or draw about their experience, or record themselves talking out their experience.

Participants will be asked to share their experiences and perspectives of being involved in projects or activities where organisations and people with cognitive disability work together as partners and share power.

Interviews will be audio recorded for transcription purposes. Participants can choose to have a guardian/next of kin/support person support their participation by attending the interview with them, or helping them to share their experience in another way.

Who can participate in the research?

To be eligibility to take part, participants must

- be 18 years or older
- live in Australia and
- have been part of a project or activity where people with cognitive disability and organisations worked together and shared decisions.

Examples of this type of project or activity include: co-design, inclusive research, partnership, advisory groups, or other activities where decision-making and power is shared.

In the context of this project, organisations are considered different to universities. Organisation may include service providers, government, advocacy groups, community organisations, businesses and research organisations. Research organisations may be affiliated with universities but are distinct from them.

We want to hear from:

- People with **cognitive disability**, which includes anyone that has a disability that impacts their cognition (such as the ability to think, remember or make decisions). This may include but is not limited to people with intellectual disability, acquired brain injury, dementia, autism, neurodivergence or psychosocial disability.
- **Staff or volunteers at an organisations**
- **Support persons or representatives** for a person with cognitive disability (such as family members, carers, support persons or advocates)

Consent to take part in the research

Given your next of kin or the person for whom you are an appointed guardian requires support for decision making due to their disability, we are seeking your consent or decline of research participation as their nominated representative.

After reading this Explanatory Statement, if the person you are guardian/next of kin for is interested in taking part in the research, you can contact Jacinta Oakley (jacinta.oakley@monash.edu or 0401 019 067). Upon expression of interest, the researchers will confirm the participant's eligibility to take part, and preferred method of participation.

Withdrawal from the research

Yes. Participation is voluntary. A participant has every right to withdraw from this research at any stage by contacting the researchers, and there will be no negative implications from choosing to withdraw.

Possible benefits and risks to participants

Benefits include the provision of participant perspectives and experiences which will (1) build an understanding of the current state of practice, and; (2) identify barriers and enablers that influence practice and provide a foundation for future work to improve practices and support meaningful participatory engagement. There is no payment offered for participation in the research.

There is a small risk that the participant - or you as their nominated guardian/next of kin - may become upset when recalling and responding to questions about past experiences of participatory engagement activities, if the experiences were negative or challenging.

If you or the participant become upset, there are different options for each of you to receive support. You can choose to pause or end research participation at any time. If desired, the researcher can assist to connect you with support services, and help arrange a time to receive support. If preferred, you can make contact with a General Practitioner to discuss your concerns and connect with services. Alternatively, participants can contact the Beyond Blue Support service directly, or with the support of the researcher, on 1300 22 4636.

Confidentiality

All data will be de-identified. Reporting of findings will also be deidentified. Interview data will be audio recording and transcribed verbatim manually, or via Zoom transcript services in accordance with the Zoom privacy statement. Pseudonyms or codes will be used to de-identify transcripts.

Storage of data

Data (electronic and hard copy) will be stored in secure Monash storage systems for a period of 5 years after the final publication in this project, at which point electronic data will be permanently deleted or securely destroyed.

Reporting of results

You can request to be sent a copy of the report written about this research. The research findings will form the basis of a thesis, be presented at professional conferences, published in peer-reviewed journals and reports.

Research team contact details

If you would like further information regarding any aspect of this project, you are encouraged to contact the researchers via the phone number or email address listed below.

Jacinta Oakley
Student researcher
Phone: 0401 019 067
Email: Jacinta.oakley@monash.edu

Dr Natasha Layton
Associate Professor,
Rehabilitation, Ageing and Independent Living (RAIL) Research Centre
Chief investigator
Phone: 0405 310 266
Email: natasha.layton@monash.edu

Complaints

Should you have any concerns or complaints about the conduct of the project, you are welcome to contact the Executive Officer, Monash University Human Research Ethics Committee (MUHREC):

Executive Officer
Monash University Human Research Ethics Committee (MUHREC)

Office of Research Ethics and Integrity
Room 116, Administration Building B (3D)
26 Sports Walk, Clayton Campus
Monash University VIC 3800

Tel: +61 3 9905 2052

Email: muhrec@monash.edu

Thank you for considering participation in this project.