



Review of Supported Decision-Making in South Australia

Participant Information Sheet for Individuals with Lived Experience

PROJECT TITLE: The Need for New Solutions? Establishing a Legal Framework for Supported Decision-Making to Empower Individuals with Impaired Decision-Making

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2024-090

PRINCIPAL INVESTIGATOR: Professor John Williams

CO-INVESTIGATORS: Associate Professor David Plater, Associate Professor Beth Nosworthy, Associate Professor Sylvia Villios, Dr Mark Giancaspro, Dr Peta Spyrou, Ms Emily Conroy, Mr Simon Headland, Ms Brooke Washusen.

Dear Participant,

You are invited to participate in the research project described below.

What is the project about?

The South Australian Law Reform Institute ('SALRI') is investigating the suitability of various legal frameworks to promote supported decision-making ('SDM'). The ultimate aim is to identify and recommend the most appropriate legal structure or structures that ensure individuals with impaired decision-making capacity (IDMC) can effectively exercise their legal rights and make decisions about their own lives. In particular, we will examine the feasibility of the 'microboard' structure as one of the possible alternatives for SDM.

A microboard is an incorporated association set up to support and care for a person with decisionmaking support needs. A microboard is comprised of a small group of people who are usually the friends and family of the person with decision-making support needs. It is different to 'circles of support' which, though valuable, are informal structures that are not incorporated and are limited in what they can do.

Those with IDMC typically encounter barriers when making decisions for themselves or to participate fully in society. An appropriate SDM framework serves to guard against the exploitation of individuals with IDMC and enhances their ability to contribute to the community, achieve their goals, and lead a fulfilling life. Through consultation with a range of concerned stakeholders, including individuals with IDMC and their support networks, advocacy groups, industry experts, peak bodies, and the general public, SALRI will identify the most effective SDM framework for individuals with IDMC. This will enable SALRI to produce a final report for the South Australian Government containing possible recommendations for reforms to law and practice that cumulatively enable such a framework.

Who is undertaking the project?

This study is being conducted by a team of researchers from the University of Adelaide Law School (see 'Co-Investigators' listed above). The project is supported by a grant from the Law Foundation of South Australia, though they are not involved in any way with the project. It should be noted, however, that SALRI is an independent nonpartisan law reform body, and its findings are not in any way influenced by those persons or organisations enabling their work through financial or other support. SALRI does not, and cannot, provide you with legal advice. If you are in need of legal advice, you should speak to a lawyer and/or contact a community legal service.



Why am I being invited to participate?

You are being invited as you are aged 18 years or over, are resident in Australia, and are a concerned stakeholder in respect of this project. This means you may be a member of the disability community, a person with IDMC, a person with lived experiences of SDM, a carer, a peak body, an advocacy group, a member of the aged and disability care sector, an Aboriginal or Torres Strait Islander person, a legal professional, a person with relevant expertise, a potential member of a microboard, or an interested member of the general community.

What am I being invited to do?

You are being invited to participate in one or more ways. Specifically, you are invited to:

- a) participate in an online survey;
- b) Contribute your thoughts and respond to our fact sheets questions by providing a written submission by either:
 - sending an email to salri_sdm@adelaide.edu.au or
 - via post at: Ligertwood Building, The University of Adelaide SA 5005 , Australia

You may also register your interest in participating in consultations with members of the project team, through either a private interview and/or through a focus group discussion. Some guiding questions will be posed by the project team through circulated 'fact sheets' and during the consultations, meaning the project will be semi-structured in nature. You will not be required to answer any question that you do not wish to answer, nor will you be made to discuss any topic that you are not comfortable discussing.

How much time will my involvement in the project take?

This depends on your mode of engagement with us. If you participate in the online survey, you can take as much time as you like in completing it though we estimate a time commitment of 30-60 minutes. If you contribute by way of email or posted document to SALRI, you can, again, take as much time as you like in composing and submitting your correspondence before the closure date. If you participate in organised consultations with members of the project team, you can expect roundtable focus group discussions to run for approximately 60-120 minutes and interviews for approximately 60 minutes. You are welcome to withdraw from the consultation at any stage and to participate for as long as you like.

Are there any risks associated with participating in this project?

The risks of participation in this research project are minimal. Given the nature of the topic of SDM, it is possible that you may find some of the content of and themes raised within this project to be emotionally distressing. To mitigate this, we seek your informed consent to participation and allow you the right to withdraw at any stage prior to or during the project. The guiding questions we will ask are framed broadly to solicit input from a variety of concerned stakeholders and are not personal nor inherently sensitive in nature. Your responses will be anonymous unless you choose to be identified, and you can, up until 14 days following the completion of your consultation with the research team (inclusive of the consultation day), request that any views or information you provided not be included among the datasets. Accordingly, there are no foreseeable risks associated with your participation in this project.

Some participants with lived experience of IDMC, or their supporters, may experience emotional distress through engaging with some of the themes and questions raised during this project. For support in dealing with any distress arising from your participation in this project, please see the following list of available support services and their contact details:

- Lifeline
Ph: 13 11 14
W: <https://www.lifeline.org.au/about-lifeline/contact-us>



- Headspace Adelaide
Ph: 1800 063 267
Em: info@headspaceadelaide.org.au
W: <https://headspace.org.au/headspace-centres/adelaide/>
- Uniting Communities Adelaide
Ph: 1800 615 677
Em: enquiries@unitingcommunities.org
W: <https://www.unitingcommunities.org/service/disability>

For Aboriginal Australians, Nunkuwarrin Yunti of South Australia also offers a broad range of counselling services, including for disability, violence, neglect, abuse, or exploitation:

- Nunkuwarrin Yunti of South Australia Inc
Ph: (08) 8406 1600 (Wakefield St) or (08) 8254 5300 (Elizabeth Downs)
Em: <https://nunku.org.au/contact-us/contact-us-2/>
W: <https://nunku.org.au/our-services/social-emotional/psychology-counselling/>

What are the potential benefits of the research project?

This research project will contribute significantly to ensuring that those with IDMC can be supported by the most appropriate legal structures that cater for their needs and enable them to effectively exercise their legal rights, make decisions about their own lives without fear of exploitation, and actively participate in the community. Your input will inform our recommendations to the State Government as to how to reform law and practice so as to achieve these goals.

Can I withdraw from the project?

Participation in this project is completely voluntary. If you agree to participate, you can withdraw from consultations at any time. You may, up until 14 days following the completion of your consultation with the research team (inclusive of the consultation day), request that any views or information you provided not be included among the datasets.

What will happen to my information?

Any information you provide by way of online survey, written submission, or during consultations, will be completely de-identified (to the maximum possible extent) and securely stored in electronic format on the University of Adelaide's computer servers. Please note that the survey will be completely anonymous unless you provide your name and contact details.

For the interviews and focus groups, in light of the small number of participants, as well as the nature of the research and the locations in which consultations are conducted, total anonymity cannot be guaranteed.

Any notes or meeting minutes produced during interviews and focus groups will be stored in the same manner, except in the case of handwritten notes, which will be stored in a locked filing cabinet in a project team member's work office and accessible by them only. All data, irrespective of how it is stored, will be de-identified using a coding system. This will occur before the data is analysed, unless you tell the research team that you would like to be identified in its research outputs.

Only members of the project team and internally contracted research assistants will have access to your information. The data harvested will be used to inform the content of our final report to the State Government and the recommendations contained within the report. These will be submitted to and likely tabled within the South Australian Parliament to guide legal reform in the SDM space.

You should be aware that individuals and organisations can, in rare cases, be identifiable based on the work they perform or where this work occurs, as reported in the data. We will do all possible to minimise the risk of identification. You will be permitted, prior to publication of our final report, to review any input you have provided and which you are willing to have attributed to you by name.



The de-identified data collected through this project may be published in various forms, including SALRI's final report into the research project topic, journal articles, books, presentations, and the like. It may also be utilised in future research projects by University of Adelaide researchers that are an extension of, or closely related to, the original project.

The raw data collected will be retained for a period of 7 years following completion of the project.

Your information will only be used as described in this participant information sheet and it will only be disclosed according to the consent provided, except as required by law.

Who do I contact if I have questions about the project?

If you have any questions about the project, please contact one of the following members of the project team:

Primary contact:

Dr David Plater Phone: +61 8 8313 0921 Email: david.plater@adelaide.edu.au

Secondary contacts:

Professor John Williams john.williams@adelaide.edu.au +61 8 8313 1426

Associate Professor Beth Nosworthy beth.nosworthy@adelaide.edu.au +61 8 8313 5543

Associate Professor Sylvia Villios sylvia.villios@adelaide.edu.au +61 8 8313 7223

Dr Mark Giancaspro mark.giancaspro@adelaide.edu.au +61 8 8313 0879

Dr Peta Spyrou peta.spyrou@adelaide.edu.au +61 8 8313 1993

Mr Simon Headland simon.headland@adelaide.edu.au

Ms Emily Conroy

Ms Brooke Washusen brooke.washusen@adelaide.edu.au

Has this study been approved by a Human Research Ethics Committee?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2024-090). This research project will be conducted according to the NHMRC National Statement on Ethical Conduct in Human Research 2023.

What if I have a complaint or any concerns?

Questions

If you have questions about the study, you can contact the research team using the contact details listed above.

Insurance and Compensation

The study has been indemnified by The University of Adelaide which is enforceable by a participant to seek compensation in addition to your right to seek compensation under the common law through the legal system in legal proceedings.

Complaints

If you wish to speak with an independent person regarding concerns or a complaint about this study, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au



Post: Research Services, Level 3, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

If I want to participate, what do I do?

You can participate in this project by engaging with us in one or more of the formats listed below:

1. Complete the survey available at https://adelaideuniwide.qualtrics.com/jfe/form/SV_6QfXw3onPYWOZ6K.
2. Send SALRI a written submission or letter (formal or informal) via email at salri_sdm@adelaide.edu.au or via post to the South Australian Law Reform Institute, Ligertwood Building, University of Adelaide, North Terrace, ADELAIDE SA, 5005.
3. Attend a consultation (by invitation only). Contact us via email at salri_sdm@adelaide.edu.au to arrange a discussion.

SALRI's consultation process will open in July and close on 30 September 2024.

Yours sincerely,

Professor John Williams

Associate Professor David Plater

Associate Professor Beth Nosworthy Associate Professor Sylvia Villios

Dr Mark Giancaspro

Dr Peta Spyrou

Mr Simon Headland

Ms Emily Conroy

Ms Brooke Washusen