



PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

Someone supporting a person with intellectual disability
Understanding co-teaching preferences of people with intellectual disability and their support networks
Professor Julian Trollor

1. What is the research study about?

You have been invited to provide support for a research participant.

The research study aims to find out how people with intellectual disability and people who provide support to people with intellectual disability want to be involved in teaching health students about intellectual disability. The study also aims to find out what supports people with intellectual disability and their support networks need to be involved in teaching. This research will help us to give advice to universities about how to involve people with intellectual disability and support networks in teaching about intellectual disability.

2. Who is doing this research?

The study is being done by the following researchers: Professor Julian Trollor, Dr Jenna Zhao, Claire Eagleson, Dr Janelle Weise, Tahli Hind, Michaela Kobor, Dr Seeta Durvasula and Marianne Gibney-Quinteros from the Department of Developmental Disability Neuropsychiatry, UNSW Medicine and Health and Kat Davies and Zoe Hannah-Whitehouse from the Health and Disability Interface Section, Department of Health and Aged Care.

Research Funder: This research is being funded by the Department of Health and Aged Care.

3. Inclusion/Exclusion Criteria

You may be able to be a support person if you are:

- 18 years of age or older

4. Do I have to take part in this research study?

Participation in any research study is voluntary. If you do not want to take part, you do not have to.

5. What does participation in this research require, and are there any risks involved?

We are conducting online focus groups/interviews with people with intellectual disability.

As a support person, your role is to sit in on the focus group/interview with the person with intellectual disability and help them to communicate in the best way possible with the researcher. Your role as a support person in this research is to:

- Facilitate and interpret the person's speech or communication
- Rephrase questions in words or ways that the person will understand
- Give an example that might help the person understand better
- Provide technical assistance to participate in the online focus group/interview
- Alert the researcher to subtle signs of the person being upset or distressed
- Provide moral support and motivation

Your role as a support person is not answer the questions for the person with intellectual disability but, instead, to help that person answer themselves.

If you would like to participate in a focus group/interview for support networks to provide your own insights and experience on teaching, you can contact the research team for more information.

Additional Costs and Reimbursement: There are no costs associated with participating in this research project, nor will you receive any payment in your role as a support person.



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Psychological Distress: You or the person you are supporting may feel that some of the questions we ask are stressful or upsetting. If the person you are supporting does not want to answer a question, they may skip it. They may also stop being part of the focus group/interview at any time by letting the research team know.

If you or the person you are supporting become upset from taking part in the research project, the research team will be able to organise counselling or other support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge. We also include information about free contactable support services in Section 10.

6. What are my responsibilities as a supporter?

Your responsibilities as a supporter are:

- To help the person with intellectual disability communicate in the best way possible
- To assist in ways that are reflective of the person's opinion
- To be discrete about the information you hear from the person and other focus group members and to respect all members' confidentiality

7. What will happen to information about me and the person I am supporting?

By signing the consent form, you agree to the research team collecting and using information about you and the person you are supporting.

The research team will store the data collected from the person you are supporting/you for this research project for:

- At least 5 years after the publication of the research results

The information about the person you are supporting/you will be stored in a:

- Re-identifiable format where any information about them/you such as their/your name, address, date of birth will be replaced with a unique code.
- Information collected from the person you are supporting/you in an electronic format will be stored on a UNSW password protected OneDrive that only approved researchers can access.
- Audio or video recordings will be stored on a UNSW password protected OneDrive that only approved researchers will be able to access. The recordings will also be given to a professional transcription service. Recordings will only be given to the transcription service after they have signed a confidentiality agreement.

The information the person you are supporting/you provide is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). You have the right of access to personal information held about you by the University, the right to ask for the information to be corrected and changed, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. More information on how the University protects personal information is available in the [UNSW Privacy Management Plan](#).

8. What am I consenting for?

We would like to seek your permission to video record what you say during the focus group/interview.



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Please note that if the person you are supporting consents to the video recording but you don't, the focus group will still be recorded. However, we will not transcribe what you say or use your input in the data analysis. You can also discuss with the person you are supporting about your preferences for having or not having your face on camera. For example, you could support the person while sitting off-screen so that your face is not recorded.

9. How and when will I find out what the results of the research study are?

The research team plan to publish and/ report the results of the research in a variety of ways. All Information will be published in a way that will not identify you or the person you are supporting.

If you would like to receive a copy of the results you can let the research team know by putting your email or mailing address in the consent form. We will only use these details to send you the results of the research.

10. What if I want to withdraw from the research study?

You may withdraw from the study at any time. You can do so by completing the 'Withdrawal of Consent Form' which is provided at the end of this document or you can ring the research team and tell them you no longer want to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or the Department of Health and Aged Care. You can ask that any identifiable information about you be removed from the research project.

11. What if I have a complaint or any concerns about the research study?

If you have a complaint about any aspect of the study or the way it is being conducted, please contact the UNSW Human Ethics Coordinator:

Complaints Contact

Position	UNSW Human Research Ethics Coordinator
Telephone	+ 61 2 9385 6222
Email	humanethics@unsw.edu.au
Reference Number	iRECS5819

12. What should I do if I have further questions about my involvement in the research study?

The person you may need to contact will depend on the nature of your query. If you need further information about this study or if you have any problems which may be related to your involvement in the study, you can contact the following member/s of the research team:

Research Team Contact Details

Name	Dr Jenna Zhao
Position	Project Manager (Education)
Telephone	(02) 9065 1742
Email	jenna.zhao@unsw.edu.au

Chief Investigator

Name	Prof Julian Trollor
Position	Chair of Intellectual Disability Mental Health, Head of 3DN
Telephone	(02) 9348 2126
Email	j.trollor@unsw.edu.au



UNSW
Department of Developmental
Disability Neuropsychiatry



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Support Services Contact Details

If at any stage during the study, you or the person you are supporting become distressed or require additional support from someone not involved in the research please call:

Name/Organisation	Dr Rachael Cvejic
Position	Senior Research Fellow
Telephone	(02) 9065 1625
Email	r.cvejic@unsw.edu.au

You can also contact the Beyond Blue support line at any time on any day.

Name/Organisation	Beyond Blue
Telephone	1300 224 636
Email	www.beyondblue.org.au



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Consent Form – Support person

Declaration by the participant

- I understand I am being asked to provide consent to participate as a support person in this research project;
- I have read the Participant Information Sheet, or someone has read it to me in a language that I understand;
- I understand the purposes, study tasks and risks of the research described in the study;
- Recordings: I understand that the research team will audio/video record the interviews/focus groups; I agree to be recorded for this purpose.
- I agree not to disclose any information discussed during the focus group/interview and to maintain group confidentiality.
- I provide my consent for the information collected about me to be used for the purpose of this research study only.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received;
- I freely agree to take part in this research study as described and understand that I am free to withdraw at any time during the study and withdrawal will not affect my relationship with any of the named organisations and/or research team members;
- I would like to receive a copy of the study results via email or post, I have provided my details below and ask that they be used for this purpose only.

Name: _____

Address: _____

Email Address: _____

Participant Signature

Name of Participant (please print)	
Signature of Research Participant	
Date	

Declaration by Researcher*

- I have given a verbal explanation of the research study; its study activities and risks and I believe that the participant has understood that explanation.

Researcher Signature*

Name of Researcher (please print)	
Signature of Researcher	
Date	

***An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study.**

Note: All parties signing the consent section must date their own signature.



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Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to take part in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales and the Department of Health and Aged Care.

- I am withdrawing my consent and I would like any identifiable information collected about me which I have provided for the purpose of this research study withdrawn.

I understand that any information collected about me during participation in a focus group cannot be withdrawn given the nature of the focus group.

Participant Name

Name of Participant (please print)	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Prof Julian Trollor
Email:	j.trollor@unsw.edu.au
Phone:	(02) 9348 2126
Postal Address:	Rm 241, Level 2 Biolink Building (E25), UNSW Sydney, 2052