



**PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM**

*Parent/Guardian*

*Understanding co-teaching preferences of people with intellectual disability and their support networks*  
*Professor Julian Trollor*

**1. What is the research study about?**

The person with intellectual disability you support is invited to take part in this research study. 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**

Before you decide to allow the person you support to take part in this research study, we need to make sure that it is ok for the person you support to take part. The research study is looking for people who meet the following criteria:

- Are 18 years of age or older
- Have an intellectual disability
- Live in Australia
- Have experience with teaching students about intellectual disability or an interest in teaching
- Can use Zoom to be part of the study.

Participants who meet the following criteria will not be able to take part in the study:

- Participants who do not meet the above criteria

**4. Does the person I support have to take part in this research study?**

Participation in this research study is voluntary. If you do not want the person you support to take part, they do not have to. If you agree for the person you support to take part and later change your mind, you are free to withdraw the person from the study at any time.

If you decide you want the person you support to take part in the research study, you will be asked to:

- Read the information carefully (ask questions if you need to);
- Sign and send back the consent form if you decide you want the person you support to take part in the study;
- Take a copy of this form with you to keep.

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

**Screening:** If you agree for the person you support to participate, they/you will be asked to complete a screening process by email or phone depending on how the research team is contacted. The screening questions will determine if the person you support is eligible to take part. Completing the screening questions will take 1-2 minutes. If the person you support meets the criteria for inclusion, they will be able to participate in the research study and the research team will organise a convenient



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time for the person you support to participate. If the screening questions show that the person you support cannot be in the research project, we will let them/you know and destroy any information that has been collected about them/you.

**Focus group/interview:** If you agree for the person you support to participate, they will be asked to be part of a focus group. If the person you support is not able to join one of the focus group times or would prefer not to share their ideas in front of other people, they can do an interview instead. The focus group/interview will take place on Zoom. The focus group/interview will take approximately 1.5 hours.

During the focus group/interview, the person you support will be asked questions about how they would like to be involved in teaching health students about intellectual disability and what support they would need from universities to be involved. The person you support will also be asked questions about any experiences they already have with teaching students about intellectual disability.

With your permission, the research team would like to video record the focus group/interview. If you decide to allow the person you support to take part in a focus group, their comments along with other people in the group will be recorded during the group discussions. If you do not want the person you support's face to be recorded, they may turn off their camera during the focus group. Because of the way the focus group discussions are recorded, the research team will not be able to remove the things that the person you support have said.

If you decide to allow the person you support to take part in an interview and do not want us to record what they say, the research team can take notes instead.

Before the focus group/interview, the person you support will receive an email to let them know their focus group/interview time and how to join the session. We will also send some information about what we will be discussing so that the person you support can prepare. Two days before the focus group/interview, they will receive a reminder.

**Additional Costs and Reimbursement:** There are no costs associated with participating in this research project. We will pay the person you support a \$150 Coles or Coles-Myer gift card to thank them for taking part.

**Psychological Distress:** The person you support may feel that some of the questions we ask are stressful or upsetting. If they do 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 the person you support becomes upset from taking part in the research project, the research team will be able to organise counselling or other support for them. 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.

**Confidentiality:** If the person you support takes part in a focus group, there is a very small chance that other members may share information from the focus group with others outside of the group. The research team will remind all participants at the beginning and end of each focus group not to repeat information to people who were not part of the group. The person you support can also choose not to answer a question if they are worried about their answer being repeated to people outside of the group.



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**6. What will happen to information about me?**

By signing the consent form, you agree to the research team collecting and using information about the person you support for the research study.

The research team will store the data collected from the person you support for this research project for:

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

The information about the person you support will be stored in a:

- Re-identifiable format where any information about them such as their name, address, date of birth will be replaced with a unique code.
- Information collected from the person you support 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 support provides is personal information for the purposes of the Privacy and Personal Information Protection Act 1998 (NSW). The person you support has the right of access to personal information held about them 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](#).

**7. 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. All Information will be published in a way that will not identify the person you support.

If you or the person you support 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.

**8. What if I want to withdraw the person I support from the research study?**

If you do consent for the person you support to take part in the research study, you or the person you support may withdraw 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 the person you support to take part. Your decision not to take part or to withdraw from the study will not affect your relationship with UNSW Sydney or the Department of Health and Aged Care. If you or the person you support decide to leave the research study, the researchers will not collect additional information from the person you support. You or the person you support can ask that any identifiable information about the person you support be withdrawn from the research project.

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



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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**

<b>Position</b>	UNSW Human Research Ethics Coordinator
<b>Telephone</b>	+ 61 2 9385 6222
<b>Email</b>	<a href="mailto:humanethics@unsw.edu.au">humanethics@unsw.edu.au</a>
<b>Reference Number</b>	iRECS5819

**10. What should I do if I have further questions about the person I support's 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 the person you support's involvement in the study, you can contact the following member/s of the research team:

**Research Team Contact Details**

<b>Name</b>	Dr Jenna Zhao
<b>Position</b>	Project Manager (Education)
<b>Telephone</b>	(02) 9065 1742
<b>Email</b>	<a href="mailto:jenna.zhao@unsw.edu.au">jenna.zhao@unsw.edu.au</a>

**Chief Investigator**

<b>Name</b>	Prof Julian Trollor
<b>Position</b>	Chair of Intellectual Disability Mental Health, Head of 3DN
<b>Telephone</b>	(02) 9348 2126
<b>Email</b>	<a href="mailto:j.trollor@unsw.edu.au">j.trollor@unsw.edu.au</a>

**Support Services Contact Details**

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

<b>Name/Organisation</b>	Dr Rachael Cvejic
<b>Position</b>	Senior Research Fellow
<b>Telephone</b>	(02) 9065 1625
<b>Email</b>	<a href="mailto:r.cvejic@unsw.edu.au">r.cvejic@unsw.edu.au</a>

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

<b>Name/Organisation</b>	Beyond Blue
<b>Telephone</b>	1300 224 636
<b>Email</b>	<a href="http://www.beyondblue.org.au">www.beyondblue.org.au</a>



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## Consent Form – Parent/guardian consent

### Declaration by the participant

- I understand I am being asked to provide consent for the person I support to take part in this research study;
- 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 for the person I support to be recorded for this purpose.
- I provide my consent for the information collected about the person I support 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 for the person I support 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:** \_\_\_\_\_

### Parent/Guardian Signature

Name of person providing consent (please print)	
Signature of person providing consent	
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 for the person I support 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 the person I support's consent and I would like any identifiable information collected about the person I support which they have provided for the purpose of this research study withdrawn.

I understand that any information collected about the person I support during their 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:	<a href="mailto:j.trollor@unsw.edu.au">j.trollor@unsw.edu.au</a>
Phone:	(02) 9348 2126
Postal Address:	Rm 241, Level 2 Biolink Building (E25), UNSW Sydney, 2052