PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM
Professional stakeholders
My Health Choices My Way: Step 1 Part 2 Interviews/focus groups
Chief Investigator: Professor Iva Strnadová

1. **What is the research study about?**
You are invited to take part in this research study. The research study aims to understand the experiences of people with intellectual disability, their supporters and the professionals involved in their care when they transition from paediatric to adult care, and develop resources to improve transition services.

2. **Who is conducting this research?**
The study is being carried out by the following researchers:

Professor Iva Strnadová	School of Education, UNSW
Associate Professor Elizabeth Emma Palmer	School of Clinical Medicine, UNSW
Mrs Julie Loblinzk Refalo OAM	School of Education, UNSW; Self-Advocacy Sydney Inc.

Research Funder: This research is being funded by the National Health and Medical Research Council.

3. **Inclusion/Exclusion Criteria**
Before you decide to participate in this research study, we need to ensure that it is ok for you to take part. The research study is looking recruit people who meet the following criteria:
    1. Professionals who have ever worked with children, adolescents and adults with an intellectual disability, including
        a. Healthcare professionals (e.g. GPs, paediatricians, adult subspecialists, psychiatrists, nurses, allied health, including medical students)
        b. Disability workers or leaders of advocacy organisations
        c. Educators (teachers and school leaders)
    2. Aged 18 years or over
    3. Currently live in Australia

4. **Do I have to take part in this research study?**
Participation in this research study is voluntary. If you do not want to take part, you do not have to. If you decide to take part and later change your mind, you are free to withdraw from the study at any stage.

    If you decide you want to take part in the research study, you will be asked to:
    - Read the information carefully (ask questions if necessary);
    - Sign and return the consent form if you decide to participate 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?**
If you agree to participate you will be asked to complete the following research procedures.

    You will be offered the opportunity of an interview or a focus group, during which you will be asked questions about your opinions and/or experiences about people with intellectual disability transitioning from paediatric to adult healthcare.

Interview: You can choose between taking part face-to-face, online (i.e., video-conferencing, using a platform of your choice), or via phone. If you prefer an interview, this will take place at an agreed location close to where you live (if it is feasible for a member of the research team to travel to this location) and will take approximately 45-60 minutes. With your permission the research team would like to audio record the interview. If you do not wish to be recorded but you would like to participate you can advise the research team and written notes will be taken.

Focus Group: All focus group sessions will take place either online or face-to-face in a community centre close to where you live (if it is feasible for a member of the research team to travel to this location) and will take approximately 90-120 minutes. The research team will audio record the focus group. If you would prefer not to be audio-recorded you can take part in an interview where the option of hand written notes can be offered.

If you participate in an interview, you may withdraw from the study at any time and request that your interview data be removed from the study dataset, provided data analysis has not yet commenced.

If you decide to participate in the focus group, your comments along with other participants will be recorded during the group discussions. Because of the way in which the focus group discussions are recorded, the research team will not be able to remove individual participant responses from the recording if you withdraw from the study. However, we will remove your comments from transcriptions and they will not be analysed.

Audio recordings from interviews and focus groups will be transcribed either using the in-built transcription within Microsoft Teams or Zoom, secure UNSW ChatGPT (under the UNSW ChatGPT-edu licence) or by a professional transcription service under a confidentiality agreement.

Recordings uploaded to UNSW ChatGPT-edu are used solely for the purpose of transcription and are not trained by OpenAI or used for model training or any other purpose, in accordance with the terms of the UNSW ChatGPT-edu licence.

Any professional transcription service used will be required to maintain confidentiality and securely handle your information.

Only authorised members of the research team will have access to audio recordings and transcripts, which will be stored securely in accordance with UNSW research data management requirements.

Further information about how UNSW ChatGPT-edu manages data can be found at: https://openai.com/enterprise-privacy/.

Additional Costs and Reimbursement: There are no costs associated with participating in this research project, nor will you be paid. However, you will receive a gift voucher to reimburse you for any reasonable travel, parking, meals and other expenses while completing the interview or focus group.

Psychological Distress: You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately. If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange for counselling or other appropriate support. Alternatively, several free contactable support services are included at section 9. 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.

6. What will happen to information about me?

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

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

- A minimum of 15 years after the completion of the research;

The information about you will be stored in a:

- Re-identifiable format where any identifiers such as your name, address, date of birth will be replaced with a unique code.

You will be asked to provide your consent for the research team to share or use the information collected from you in future research that:

- Will be an extension of, or closely related to, the original project; or is in the same general area of research.

Your information will only be shared in a format that will not identify you.

- Information collected from you in an electronic format will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators.
- Information collected from you using paper-based measures will be stored in the secure office of the Chief Investigator Professor Iva Strnadová at the School of Education, UNSW, and only the approved research investigators will have access to this information.
- Audio or video recordings will be stored on a UNSW password protected OneDrive only accessible to the approved research investigators and will be made available to a professional transcription service. Recordings will only be made available to the service after a confidentiality agreement has been signed.

The information 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 request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the PPIP Act. Further 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 intend to publish and/report the results of the research. All Information will be published in a way that will not identify you.

If you would like to receive a copy of the results you can let the research team know by inserting 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 from the research study?

If you do consent to participate, you 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 to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or the National Health and Medical Research Council. If you decide to leave the research study, the researchers will not collect additional information from you. You can request that any identifiable information about you be withdrawn from the research project.

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

If you have a complaint regarding 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	10582

10. 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 require further information regarding this study or if you have any problems which may be related to your involvement in the study, you can contact the following member of the research team:

Research Team Contact Details

Name	Natalie Roberts
Position	Program Manager
Telephone	02 9348 0718
Email	n.roberts@unsw.edu.au

Chief Investigator

Name	Professor Iva Strnadová
Position	Chief Investigator, Professor in Special Education and Disability Studies
Telephone	02 9065 1627
Email	i.strnadova@unsw.edu.au

Support Services Contact Details

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

Name/Organisation	Beyond Blue
Telephone	1300 224 636

Name/Organisation	13Yarn (Aboriginal or Torres Strait Islander Crisis Support Line)
Telephone	139276

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Professional stakeholders
My Health Choices My Way: Step 1 Part 2 Interviews/focus groups
Chief Investigator: Professor Iva Strnadová

Name/Organisation	People with Disability Australia
Telephone	(02) 9370 3100

Consent Form – Participant providing own consent

Declaration by the participant

- ☐ I understand I am being asked to provide consent to participate 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 record the interviews/focus groups; I agree to be recorded for this purpose.
- ☐ Transcription: I understand that the recording will be transcribed. This means the words people said will be typed up.
- ☐ UNSW ChatGPT-edu: I agree that the secure UNSW ChatGPT-edu may be used to transcribe the recording. I understand that it will only be used to type the words people said. The recording will not be used to train artificial intelligence or for any other purpose.
- ☐ 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 participate 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 understand that I will be given a signed copy of this document to keep.
- ☐ I understand that the results of the research will be made available on the My Health Choices My Way website.
- ☐ 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: _____

Optional Consent for reuse of data and future research:

- ☐ I provide my consent for my name and contact details to be retained in a register so I can be contacted about other research projects in the future.

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.

Form for Withdrawal of Participation

I wish to **WITHDRAW** my consent to participate in this research study described above and understand that such withdrawal **WILL NOT** affect my relationship with The University of New South Wales or the National Health and Medical Research Council.

☐ 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 am withdrawing my consent to participate in further components of this research and provide my permission for the research team to retain and/or use information collected about me which I have provided for the purpose of this research.

☐ I am withdrawing my consent and I understand that any information already published and/or not linked to my identity cannot be withdrawn from the research.

Participant Name

Name of Participant (please type)	
Date	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Professor Iva Strnadová
Email:	i.strnadova@unsw.edu.au
Phone:	02 9065 1627
Postal Address:	School of Education, Faculty of Arts, Design and Architecture Morven Brown G23 UNSW SYDNEY 2052