Participant Information Sheet and Consent Form

Guardians

Sexual and reproductive rights for people with intellectual disability**:** Exploring stigma and attitudes toward contraceptive decision-making

Dr Maryann Barrington et al.

1. What is the research study about?

The person with intellectual disability that you support is invited to take part in this research study. The research study aims to improve access to inclusive contraceptive healthcare for people with intellectual disability. We are investigating experiences of contraceptive healthcare, focussing on decision-making and consent. This part of the project will communicate with people with intellectual disability.

Examples of contraception include:

- Oral pills that are taken each day
- An injection that is given once every 3 months
- An implant which is a small rod placed in the arm
- An intrauterine device which is a small device placed in the uterus

We will ask the person you support questions about whether they felt the contraceptive healthcare they received was inclusive, if they had enough information and the right support to make a decision, and how they think we can make contraceptive healthcare better.

2. Who is conducting this research?

The study is being carried out by the following researchers: Maryann Barrington, Julian Trollor, Patsie Frawley, and Tahli Hind at the National Centre of Excellence in Intellectual Disabiltiy Health (NCEIDH). We work at UNSW as part of the Faculty of Medicine & Health**.**

The study will also be supported by external investigators: Clare Boerma (Family Planning Australia), Bronwen Merner (University of Melbourne), Janelle Weise (University of Sydney), and Karen Fisher (UNSW Sydney).

Research Funder: This research is being funded by an Australian Human Rights Institute and Disability Innovation Institute joint seed grant.

3. Inclusion Criteria

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

- 14 years of age or older
- Lives in Australia
- Has an intellectual disability
- Has experience with contraceptive healthcare
- Understands what this research involves and can give informed consent

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/if they do not want to take part, they do not have to. If you agree that the person you support can take part and later change your mind, you are free to withdraw the person you support from the study at any stage.

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 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?

Screening: If the person you support would like to participate and you consent, they/you will be asked to take part in a short telephone screening interview. If you provide your consent for the person you support to participate in the screening process, they/you will be asked to provide contact details to allow the research team to contact the person you support/you and organise a time to complete the telephone interview (or they/you can call us). We will ask screening questions that will determine if the person you support is eligible to take part. Completing the screening questions will take 1-2 minutes. If they meet the criteria for inclusion, they will be able to participate in the research study and the research team will organise a convenient time for the person you support (and yourself) to participate in the research. If the screening questions show that they cannot be in the research study, we will destroy any information that has been collected about them/you.

Interview/focus group: If you agree for the person you support to take part they will be asked to participate in an interview or focus group.

Individuals can participate in an interview by themselves or with a support person present. Alternatively, they can choose to take part in a focus group with other people with intellectual disability (they can also have a support person present if they wish).

Information shared by people participating in focus groups must be kept confidential.

During a face to face, telephone or video conferencing interview or focus group, the person you support will be asked questions demographic questions. We will then ask them questions about their experience with contraceptive healthcare. Face to face interviews/focus groups will take place at UNSW Sydney. Video conferences will take place over Microsoft Teams or Zoom. Interviews will take approximately 1 hour, while focus groups will take approximately 2 hours. With your permission, the research team would like to audio record the interview/focus group. For interviews, if you do not want the person you support to be recorded but you would like them to participate you can advise the research team and written notes will be taken (this is not possible for focus groups). The person you support/ you will also have the option to turn off the video during a video conference (interview or focus group). If video is recorded, this will be promptly deleted and only the audio file will be kept.

Because of the way in which the focus group discussions are recorded, the research team will not be able to withdraw or destroy individual participant responses. However, we will not transcribe or include your data in the analysis if you withdraw from the study.

Additional Costs and Reimbursement: There are no costs associated with participating in this research study, nor will you be paid. However, the person you support will receive an $80 gift card voucher to reimburse them for any costs associated with participating in the study (e.g. pre-reading, time participating, travel (if in-person)).

Risks to Participants

Emotional Distress: The person you support may feel that some of the questions we ask are stressful or upsetting. If they do not wish to answer a question, they may skip it and go to the next question, or you may stop immediately. If the person you support/you become upset or distressed because of participation in the research study, the research team will be able to arrange for counselling or other appropriate support. Alternatively, a number of free contactable support services are included in section 11. 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.

Reputational Harm: The person you support may not want to answer some questions in front of their support person or in a focus group. Support them to identify if they would prefer to participate in an interview or focus group. Talk to them about what they can say if they do not want to answer a question in front of you (e.g., they can ask you to leave the room, they can ask to skip the question).

Risks to Guardians and Support Persons

Emotional Distress: You may feel upset or distressed by some of the questions asked, and some of the responses from the participant. If you are feeling distressed and want a break you can let the interviewer know. If you need to discontinue support in the interview, you can let the interviewer know.

Alternatively, a number of free contactable support services are included in section 11. 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 the person I support?

By signing the consent form, you consent 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/you for this research study for:

- A minimum of 5 years after the publication of the research results;

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

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

Your information will only be shared for the purposes of this project in a format that will not identify you or the person you support.

- 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 responses will be stored in the National Centre of Excellence in Intellectual Disability Health, Biolink Building E25 UNSW, NSW 2052 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. It will be made available to a professional transcription service. Recordings will only be made available after a confidentiality agreement has been signed.

The information the person you support/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 the person you support/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 for the person you support to participate, 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 to participate. Your decision not to participate or to withdraw from the study will not affect your relationship with UNSW Sydney or the project team. If the person you support decides to leave the research study, the researchers will not collect additional information from them. You can request that any identifiable information about the person you support be withdrawn from the research study.

If the person you support decides to withdraw part way through a focus group, information already collected about the person cannot be withdrawn given the nature of the focus group. However, we will not transcribe what you say or use your input in the data analysis.

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
HC Reference Number	9299

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 the person you support's involvement in the study, you can contact the following member of the research team:

Chief Investigator Contact Details

Name	Maryann Barrington
Position	Senior Research Fellow
Telephone	02 9065 4445
Email	maryann.barrington@unsw.edu.au

11. Support Services Contact Details

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

Name/Organisation	1800RESPECT
Telephone	1800 737 732
Website	https://www.1800respect.org.au/

Name/Organisation	Relationships Australia
Telephone	1300 364 277
Website	https://www.relationships.org.au/

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

Name/Organisation	Lifeline Australia
Telephone	13 11 14
Email	https://www.lifeline.org.au/

Consent Form – Parent/Guardian Consent

☐ I understand I am being asked to provide consent on behalf of the person with intellectual disability that is participating in this research study;

☐ I have read the Participant Information Statement, 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;

☐ 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 understand that the person that I support will need to maintain group confidentiality and not talk about what was said in the focus group.

☐ I provide my consent for the information collected about the person I support/myself 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 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 Participant (please print)	
Name of parent/ guardian (please print)	
Signature of parent/ guardian	
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 for the person I support to participate in this research study described above and understand that such withdrawal **WILL NOT** affect mine or the person I support's relationship with The University of New South Wales and the people and organisations involved in this project.

☐ I am withdrawing the person I support's consent and I would like any identifiable information collected about the person I support/myself which I have provided for the purpose of this research study withdrawn.
☐ I understand that the information collected about the person I support/myself during their participation in the focus groups cannot be withdrawn given the nature of the focus group. I understand the research team will not transcribe or include the data of the person I support/myself in the analysis if I withdraw from the study.

Participant Name

Name of Participant (please type)	
Date	
Name of parent/ guardian (please type)	

The section for Withdrawal of Participation should be forwarded to:

CI Name:	Dr Maryann Barrington
Email:	maryann.barrington@unsw.edu.au
Phone:	9065 9915
Postal Address:	Department of Developmental Disability Neuropsychiatry (3DN) Biolink Building E25 UNSW NSW 2052