



## **Information Sheet for Data Collection Participants**

Young people with disabilities from 15 – 20 years of age are invited to answer some questions for a research project about decision making.

### **What is it about?**

This research wants to learn about decision making and young people with disabilities in Ireland. It wants to find out what stops young people from making decisions and if young people with disabilities use support to make decisions or what helps them to make decisions. These could be decisions about school, work, money, health and medical treatment, hobbies or socialising. The term support comes from Article 12 of the UNCRPD. It can cover lots of different things that help someone make a decision and everyone's idea of support can be different. For example, support could be talking to a friend or parent about something, getting information in an accessible way or taking more time to think and ask questions.

### **Who can take part?**

People with disabilities aged between 15 and 20 years of age can take part. The project is looking for young people with all kinds of disabilities and experiences. This includes experience of

- physical disability (wheelchair user, limited mobility or people whose arms or legs don't work in the same way as other people)
- sensory disability including blind, low vision, deaf or hard of hearing
- intellectual disability,
- learning disability (dyslexia, dyscalculia etc.),
- Neurodiversity (Autism, DCD/Dyspraxia, ADD, ADHD),
- psycho-social disability or experience of the mental health services.

### **Who is working on this?**

This project is based at the Centre for Disability Law and Policy in NUI Galway. Clíona de Bhailís is the lead researcher on this project. She is doing this research as part of her PhD. Her PhD supervisor is Professor Eilionóir Flynn. Before starting on her PhD, Clíona was a Research Assistant on the VOICES project. The VOICES project looked at people with disabilities experiences of being denied the right to make decisions or using support to make decisions. It had participants from over 11 countries and 5 continents.

### **What will people taking part have to do?**

People taking part in this research will have to answer questions about a good experience of decision making or a time they felt listened to, a bad experience or a time they were not listened to or supported and what helps them make decisions. They will have to be happy for Clíona to use this information in her research.

These questions will be on a form that Clíona will send to you by email. You can answer the questions online using Microsoft Forms or by filling in a Microsoft Word document and sending it to Clíona by email. Clíona can also help you fill in the form.

### **How much time will this take?**

Filling in the questionnaire should only take around 20 - 30 minutes. It might take longer for some people depending on the support they need. Before filling in the form, Clíona will talk to you (phone call, video call with interpretation if needed, email etc.,) about what you need to do and explain the project and the consent form. At the end you can decide if you would like to hear more about the project or if you would be interested in being contacted about more research.

### **Confidentiality**

Confidentiality is a really important part of this research. Clíona will be working with a group of young people with disabilities for advice on the research and with her supervisor, Professor Eilionóir Flynn. However, they will not have access to any of the information about participants. Pseudonyms or 'fake names' will be used when referring to the participants in the research at all times.

### **Do I have to take part?**

No, taking part in this research is completely voluntary. If you do decide to take part, you will be asked to sign a consent form. If you are under 18 your parent or guardian will also have to sign a consent form.

You can also change your mind even after you have agreed to take part and up until Clíona finishes working on this part of her PhD in December 2020. If you do change your mind Clíona will delete all the information she has about you.

### **Accessibility**

It is important to Clíona that young people with disabilities who are interested in the research can be involved or simply have easy ways to contact her to find out more. Please let me know what would help you to take part. You can contact me by phone, email, text and information about the project is available in multiple formats – plain language, EasyRead, large text etc. Please also let me know if you need sign language interpretation or other supports.

### **I have more questions that you don't answer here. Who should I talk to?**

If you have any questions, you should contact Clíona at [c.debhailis1@nuigalway.ie](mailto:c.debhailis1@nuigalway.ie) or 086-6032755 (call and text).

### **Where can I find the questionnaire, I would like to or I know someone who would like to take part?**

If you are interested in taking part, you should contact Clíona at [c.debhailis1@nuigalway.ie](mailto:c.debhailis1@nuigalway.ie) or 086-6032755 (call and text).