



Information Sheet for Data Collection Participants

Young people with disabilities from 15 – 20 years of age are invited to take part in a research project about decision making.

What is it about?

This research wants to learn about how people with disabilities in Ireland between the ages of 15 and 20 years old make decisions. It wants to know if the law or people around them stops or supports them to make decisions or if they feel it doesn't take the decisions they make seriously. These could be decisions could be about school, work, money, health and medical treatment, hobbies or socialising. It also wants to know if young people with disabilities use support to make decisions and what kinds of things this might be. For example, support could be talking to a friend or parent about something or getting information about the decision in an accessible way.

Who is working on this?

This project is based at the Centre for Disability Law and Policy in NUI Galway. Clóna de Bhailís is the lead researcher on this project. She is doing this research as part of her PhD and is supervised by Professor Eilionóir Flynn. Before working on this project Clóna was a Research Assistant on the VOICES project which looked at people with disabilities from over 11 countries and 5 continents have been denied the right to make decisions or have used support to make decisions.

Who can take part?

People with disabilities aged between 15 and 20 years of age can take part. We are looking for young people with all kinds of disabilities and experiences including people with physical disabilities, sensory disabilities, intellectual disabilities, autism or psycho-social disabilities e.g. experience of the mental health services.

What will people taking part have to do?

People taking part in this research will have to agree to keep a record, either a diary, a recording or some other notes, for 12 weeks about the decisions they made, the decisions someone stopped them making or didn't listen to them about and if they used support to make a decision. They will have to be happy for Clóna to use this information in her research.

How much time will this take?

Recording the information about the decisions you make will only take around 10 – 15 minutes each week for 12 weeks.

Outside of this there will be one meeting, phone call or Skype call with interpretation etc. with Clíona at the start to talk about what you need to do. Clíona can also contact you every few weeks to check in if you like.

She will also contact you when she has put all the information together to explain what she has learned and ask what you think others (parents, doctors, teachers, social workers, politicians, support staff etc.) should learn from this research. You do not have to take part in this if you do not want to.

Confidentiality

Confidentiality is a really important part of this research and although Clíona will be working with a group of young people with disabilities for advice on the research and with her supervisor, Professor Eilionóir Flynn, they will not have access to any of the information about participants. Pseudonyms or ‘false 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. Even after you have agreed and up until Clíona finishes writing about her work you can change your mind. If you do change your mind Clíona will take out all the information about you and delete any recordings, documents or other information she has about you up until July 2020.

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 or you are interested in taking part, you should contact Clíona at c.debhailis1@nuigalway.ie or 086-6032755.