



Representative advocacy & children with disabilities in Ireland

Children's Focus Group Information Sheet

Thank you for your interest in our research project. This document is to give you more information about the project and to help you decide if you are happy for your child to take part.

What is the research about?

An independent advocate can help a child and their family to find out more information about their rights and entitlements, understand or navigate the system, attend meetings with them and make sure their views are heard. The project team wants to learn if children with intellectual disabilities get the help they need to speak up for their rights. They also want to know what type of advocacy services children with intellectual disabilities and their families would like to have in Ireland.

Who can take part?

Children with intellectual disabilities in Ireland can take part. For this research children includes those aged between 9 and 17 years of age.

What will people taking part have to do?

Participants will have to attend a focus group and talk about what could help them speak up for their rights. They will be asked about who could help them do this, what a person who does this kind of work should be like and what a new advocacy service could help with.

There will be focus group for children aged 9 – 12 and aged 13 – 17. While parents are welcome to attend these sessions to support their child, these focus groups are just for children. The project also held focus groups for parents and guardians.

Who is working on this?

Inclusion Ireland commissioned the research. The Centre for Disability Law and Policy at the University of Galway are the ones carrying out the research. The researchers working on it are Emma Burns, Dr. Clíona de Bhailís and Professor Eilionóir Flynn.

Do I have to take part?

No, taking part in this research is completely voluntary. If your child would like to take part and you agree, we will need you to sign a consent form. Your child will also need to sign a consent form or agree to take part and have this recorded verbally or by some other means. The consent form is available in Easy Read, and we can help them to understand this if necessary.

Confidentiality

Confidentiality is a really important part of this research. Emma, Clíona and Eilionóir will be the only ones who will have access to any personal data collected. They will be working with an advisory group of young people with intellectual disabilities. However, the group will not have access to any of the information about participants.

At the start of the focus group the facilitator (Emma, or Clíona) will ask everyone if they are happy to have the session recorded. They will only record it if everyone agrees. They will use the recording to take notes and remember what people said. They will delete the recording when they are finished working on the project.

If you have concerns about how your child's data is stored or managed you can contact the University of Galway Data Protection Officer at dataprotection@universityofgalway.ie or Tel: (091) 524411. The best way to contact Data Protection Commission (Ireland) is through their online webform available at <https://www.dataprotection.ie/en/contact/how-contact-us>

Accessibility

It is important to the researchers that all those invited and who are interested in the research can be involved or simply have easy ways to contact them to find out more. Please let us 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.

We understand that the focus group format will not work for every child, and we are eager to ensure that every child that would like to take part can. We are particularly interested in making sure that the views or experiences of children who use communication supports or non-traditional communication are included in the research.

Please contact us and we will work together to find a way for them to participate.

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

If you have any questions, you should contact us by email or phone. You can contact Emma at emma.burns@universityofgalway.ie or Clíona cliona.debhailis@universityofgalway.ie or 0860081153.

If you wish to contact a neutral third party, you can email ethics@universityofgalway.ie to talk to the Research Ethics Coordinator or the Chair of the University of Galway Research Ethics Committee.

What should I do if my child wants to take part?

You can contact Emma at emma.burns@universityofgalway.ie or Clíona cliona.debhailis@universityofgalway.ie or 0860081153 and they will provide the links and all information about taking part.