Participant information sheet

for siblings aged 13 years -17 years 11 months.

Invitation

Hi.

I am asking you to take part in my research study because you have a sibling (a brother or sister) with a disability.

Who am I?

My name is Nóirín Buckley and I am a Clinical Psychologist working with children with disabilities and their families in Ennis, Co Clare. I am also doing research with the University of Galway.

About my research

I have an interest in the brothers and sisters of children with disabilities. I'm doing my research study to find out more about what you think and how you feel about having a sibling with a disability. I am also interested in looking at your views on how your family gets along.

One of the main goals of this study is to find out if one of the questionnaires I am asking you to fill in would be useful for siblings like you in Ireland in the future.

I am asking hundreds of siblings to complete the questionnaires and I will look at the pattern of answers and figure out which questions work best.

What I am asking you to do

This research study is an online study. If you decide to take part in the study you will fill out two short questionnaires online.

They should take less than 10 minutes each to fill out.

The questionnaires contain a list of statements and you will be asked to click on a circle beside each statement indicating how much you agree with the statement.

If you decide when completing the questionnaires that you do not want to continue, you can just click out of the survey.

You will not be asked write anything about yourself or your brother or sister.

I will also be asking your parent to fill out one questionnaire.

When the questionnaires are completed they are returned to me **anonymously.** This means that I do not know who has completed the forms, so your information is completely private. Your name, e-mail or computer IP address is not available to me.

Do you have to take part?

No. You decide if you want to take part. If you don't want to, that is fine. After reading this leaflet you can think about whether you want to take part or not. The link to participate in the study is live for the next few weeks, so you have time to think about this. You can talk about it with your mum or dad and if you have any questions for me about the research they can contact me to get the answers.

Could the research help you?

The research will not help you directly. I will not be talking to you or to your parents about the questionnaires you filled out. I will be putting the scores together from all the children and parents who filled out the questionnaires.

I hope to learn from this research what siblings in Ireland think and feel about their brother or sister with a disability and about their family. I also want to see if the questionnaires are useful and if it would be a good idea for psychologists to ask siblings they meet in the clinic to fill these out.

If you have any worries or questions after filling out the questionnaires, please talk with your parents about these. They can get in touch with me to talk about these worries or questions if they need to. You can also find helpful information/ways to get support on these websites:

www.siblingsupport.org www.jigsaw.ie www.turn2me.ie

Assent

When adults participate in research, they are asked to consent to taking part. When children under the age of 18 take part in research, their parents need to consent to them taking part. However, if you decide to take part, you also need to let me know that you are happy to participate in the research. This is called assent.

To give your assent you will be asked to confirm

- that you have read this leaflet
- that you have spoken to your parent about it
- that you understand what you have to do
- that you want to take part

Thank you very much for reading this!