

# PARENT PARTICIPANT INFORMATION SHEET

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## Research Project

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My research project is on the adjustment of siblings of children with disabilities.

By this I mean how they are doing emotionally and how they feel about their sibling. I am also looking at how parents and siblings view how their family gets on.

The formal title of the research is *An investigation of the factor structure and convergent validity of the Negative Adjustment Scale (NAS) in siblings of Irish children with disabilities.*

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## Who am I?

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My name is Nóirín Buckley. I am a Senior Clinical Psychologist with the Clare Children's Disability Network Team in Ennis. I am completing a research project as part of my Doctorate in Psychological Science for Qualified Clinicians at the University of Galway. My research supervisor is Prof Brian McGuire, School of Psychology, University of Galway.

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## Invitation

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You are invited to take part in this research study. You were contacted as you are the parent of a child attending a Children's Disability Network Team, who may also have another child/children who do not have a disability. This study is about siblings' experiences of having a brother or sister with a disability. Therefore, the siblings of your child who attends the service are also being invited to take part in this research study.

Before you decide, it is important that you understand why the research is being done and what it will involve. This *Participant Information Sheet* tells you about the purpose, risks and benefits of this research study. If you agree to your child/children taking part I will ask you to indicate *Consent* and your child/children to indicate *Assent* (assent is the agreement of someone not old enough to give legal consent) at the start of the online survey. You do not need to sign your names as participation is anonymous.

If there is anything that you are not clear about, I will be happy to explain it to you.

You should only consent to participate in this research study when you feel you understand what has been asked of you.

*If you are parenting child siblings who are in the care of the state, I do not have ethical approval to invite these siblings to participate. Many thanks for your interest in the study.*

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## Purpose of the Study

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The main goal of this study is to find out if a questionnaire, called the *Negative Adjustment Scale (NAS)*, is a useful and appropriate measure of adjustment of siblings of children with disabilities. This is done by asking hundreds of siblings to complete the questionnaire and looking at the overall scores and patterns of answers. I also want to look at your and the sibling's views on the strengths and challenges in your family, using a questionnaire called the SCORE-15. Once again, all responses are anonymous.

I hope that this research will lead to providing clinicians with a questionnaire that has been tested on Irish children and can be used in the future to help identify siblings who may benefit from support and interventions.

The study will start in January 2023 and finish in May 2023.

I hope to recruit a minimum of 200 sibling participants and an equal number of parents, as that number is needed for the type of statistical analysis I will be completing.

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## Taking Part – What it Involves

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### Do I and my child/children have to take part?

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It is up to you and your child/children to decide whether or not to take part. **There is no obligation to do so.** As the completed surveys will be anonymous, your choice to participate or not will not be known to me or to your Disability Network Team. Your decision will not impact the service you receive from them.

Please discuss the information leaflets with your child and chat about whether you would be interested in taking part. Please also consider how your child with a disability might feel about their sibling taking part.

As this research is focused on siblings, they can participate in the study even if you, their parent, does not want to participate also.

If the sibling chooses not to participate, parent participation is not possible.

**I only need parent participation if the sibling(s) is also taking part.**

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## What will we be asked to do?

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I am asking siblings, aged between 8 and 17 yrs, 11 months, to complete **two short questionnaires** (see below) and you, their parent(s), if you wish, to complete **one of these questionnaires** (the SCORE-15). If your child has more than one sibling, I am inviting 2 siblings to participate. However, if just one of the siblings decides to take part, that is fine.

Both questionnaires use a **Likert Scale**, which is a rating scale used to measure your opinions. They will contain a number of statements to which you rate your level of agreement.

**There are no questions in the survey that require you to write any answers: you will just need to click on appropriate boxes.**

The questionnaires take less than 10 minutes each to complete and can be filled out online, on your phone, laptop or tablet. I would ask that you are present with your child when they are completing the questionnaires (while giving them privacy to complete them) as you will need to answer the opening questions and give permission for the sibling to do the survey – and the survey also contains the parent questionnaire as the last item.

You will not be asked your name or any identifying details. You will be asked the following demographic questions only:

- Age and sex of your child in the service
- Age and sex of their sibling(s) completing the questionnaires
- Sex of parent/parents completing the questionnaire
- The category of the disability of your child in the service.

If you and the sibling(s) agree to take part, you can do so by pressing the link in the email. You will then be asked to give your consent and the sibling will be asked to give their assent. When this is done, the questionnaires will follow. **The link is live for the next few weeks, so you can participate at any time.**

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## How long will my part in the study last?

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Although the research will take place over a 4-month period, you and your child's part in the study should last less than 30 minutes, the length of time it takes to complete the questionnaires. You can withdraw from the study at any time before the final survey question - if you or your child decide while completing the questionnaires that you do not wish to continue, you can close the survey.

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## What are the possible benefits in taking part?

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There are no specific or immediate benefits to you or your child/children in taking part, as your scores will not be examined individually. They will form part of a set of scores for statistical analysis.

However, by your participation, this study will add to the body of research on siblings of children with disabilities. It will establish if the NAS is a useful questionnaire to use in Child Disability services in Ireland to help identify siblings who would benefit from sibling-specific interventions

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## What are the possible disadvantages and risks of taking part?

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Completing the questionnaires may raise some emotional issues for you or your child. Please check in with your child after they complete the questionnaires in relation to this. If completing the questionnaires raise issues for you or your child that you wish to discuss, please feel free to contact me at any point at the email or number below. Alternatively, you or your child may find helpful resources/books/support at the following websites:

[www.siblingsupport.org](http://www.siblingsupport.org) – publications and resources sections in particular

[www.sibshopireland.ie](http://www.sibshopireland.ie)

[www.jigsaw.ie](http://www.jigsaw.ie)

[www.inclusionireland.ie](http://www.inclusionireland.ie) -Connect Family Network

[www.AsIAm.ie](http://www.AsIAm.ie)

[www.onefamily.ie](http://www.onefamily.ie)

[www.parentline.ie](http://www.parentline.ie)

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## Confidentiality

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The questionnaires that are completed online are **completely anonymous**. When they are returned, they are not linked to your email address or your computer's IP address.

The questionnaires you complete will be seen and scored only by me and by my supervisor.

Your questionnaire scores will be added to the scores of all other participants for the purposes of statistical analysis.

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## What happens at the end of the study?

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At the end of the study, the research will be written up as a Doctoral thesis and submitted to the University of Galway. A research paper of the study will be written up to be submitted for publication.

I would be pleased to include you on an address list to receive any publications arising from the study, if you so wish.

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Who do I contact for more information or if I have further concerns?

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**Researcher: Nóirín Buckley at [n.buckley6@nuigalway.ie](mailto:n.buckley6@nuigalway.ie) Tel: 087-2687391**

**Researcher's Supervisor:** Professor Brian McGuire, School of Psychology, National University of Ireland at [brian.mcguire@universityofgalway.ie](mailto:brian.mcguire@universityofgalway.ie) or 091-493266

If you have any concerns about this study and wish to contact someone in confidence, you may contact the following: The Head of School (Dr. Pádraig MacNeela), School of Psychology, National University of Ireland, Galway at [padraig.macneela@universityofgalway.ie](mailto:padraig.macneela@universityofgalway.ie) or 091-495121

## Questionnaires in the online survey

Printed here for your information and reference only

Please complete the questionnaires by clicking the online survey link

### Negative Adjustment Scale

To be completed by siblings only, regardless of age

		Never	A little	Sometimes	A lot
1	I forget that my brother or sister has a disability.				
2	I feel sad because of my brother or sister's disability.				
3	I have too many household chores because of my brother/sister.				
4	I am scared of my brother or sister's disability.				
5	I think about my brother or sister's disability.				
6	I understand why my parents have to spend time on my brother or sister.				
7	I feel angry because of my brother or sister's disability.				
8	I wish I knew someone who understood how I am feeling.				
9	I talk to other adults about my brother or sister's disability.				
10	I wish that there was something I could do about my brother or sister's disability.				
11	I wonder why or how my brother or sister got their disability.				
12	I wish my parents could spend more time together with me.				
13	I'm worried about whether I can get the same disability as my brother or sister.				
14	My friends are worried that they can get my brother or sister's disability.				
15	My parents ignore me.				
16	Other people are more interested in my brother or sister than in me.				
17	Other people care about how I am.				
18	My brother or sister's disability change what we can do as a family.				

## CHILD SCORE-15

For completion by siblings between the ages of 8 and 12

Hello. We would like you to tell us about your family. We have written some sentences about families. For each sentence, please tell us how well it describes your family. This means how true you think it is.

For each line, tell us if you think the sentence describes your family:

1. Very well
2. Well
3. A bit
4. Not well
5. Not at all

For example, if a sentence was "Our family wants to stay together". If you feel this sentence is very true about your family, then it describes your family very well. You would put a tick in the box for Very Well, like this:

	<b><u>This describes our family:</u></b>				
	<b>Very Well</b>	<b>Well</b>	<b>A bit</b>	<b>Not well</b>	<b>Not at all</b>
Our family wants to stay together	✓				

Do not think for too long about any question, but do try to tick one of the boxes for each question. There are no right or wrong answers. It is about how you see things at the moment.

	This describes our family: Very Well	This describes our family: Well	This describes our family: A bit	This describes our family: Not Well	This describes our family: Not At All
1) In my family we talk to each other about things which matter to us					
2) In my family people often do not tell each other the truth					
3) In my family every person gets listened to					
4) In my family it feels risky or scary to disagree					
5) We find it hard to deal with everyday problems					
6) We trust each other					
7) It feels miserable in our family					
8) In my family when people get angry they ignore each other on purpose					
9) In my family we seem to go from one big problem to another					
10) When one of us is upset they get looked after in my family					
11) Things always seem to go wrong for my family					
12) People in the family are nasty to each other					
13) People in my family interfere or get involved <b>too much</b> in each other's lives					
14) In my family we blame each other when things go wrong					
15) We are good at finding new ways to deal with things that are difficult					



## SCORE-15

for completion by siblings aged 13 and over (and by parent if you choose to participate)

This questionnaire is almost identical to the Child-SCORE-15, but has a few different wordings and has 6 answers to choose from.

SCORE-15							
<p>This set of questions is about how you see your family <b>at the moment</b>. So we are asking for YOUR view of your family.</p> <p>When people say 'your family' they often mean the people who live in your house. But we want you to choose who you want to count as the family you are going to describe. All the questions are answered the same way- you give a rating between 1 and 6.</p> <p>1 means that describes my family very well and 6 means that does not describe my family at all.</p>							
		1 Extremely well	2 Very well	3 Well	4 A bit	5 Not well	6 Not at all
1	In my family we talk to each other about the things that matter to us	1	2	3	4	5	6
2	People often don't tell each other the truth in my family	1	2	3	4	5	6
3	Each of us gets listened to in our family	1	2	3	4	5	6
4	It feels risky to disagree in our family	1	2	3	4	5	6
5	We find it hard to deal with everyday problems	1	2	3	4	5	6
6	We trust each other	1	2	3	4	5	6
7	It feels miserable in our family	1	2	3	4	5	6
8	When people in my family get angry they ignore each other on purpose	1	2	3	4	5	6
9	We seem to go from one crisis to another in my family	1	2	3	4	5	6
10	When one of us is upset they get looked after within the family	1	2	3	4	5	6
11	Things always seem to go wrong for my family	1	2	3	4	5	6
12	People in the family are nasty to each other	1	2	3	4	5	6
13	People in my family interfere too much in each other's lives	1	2	3	4	5	6
14	In my family we blame each other when things go wrong	1	2	3	4	5	6
15	We are good at finding new ways to deal with things that are difficult	1	2	3	4	5	6