

Information sheet

Researcher introduction

Kia ora, Ko Sarah Knight tōku ingoa, Kei te noho au ki Horowhenua.

Kia ora, my name is Sarah Knight. I have a younger sibling with a whaikaha/disability. I grew up in the Horowhenua region. I am of mixed ethnicity, my ancestors came to Aotearoa/New Zealand as refugees, settlers, and immigrants from all over Europe. I am currently a postgraduate student at Massey University studying towards a Master of Arts (Psychology). I would like to invite you to participate in my research that aims to identify the unmet needs of siblings of children with either Autism Spectrum Disorder/Asperger's Syndrome/Takiwatanga, Cerebral Palsy/Hōkai Nukurangi and/or Down Syndrome/Pūira Kehi. Existing research has found that siblings of children with disabilities can have a range of unmet needs in a wide variety of areas including home, school and social activities. For some siblings these unmet needs can lead to feelings of isolation, frustration and sadness; for others, these needs may lead to a broad range of difficulties including mental distress. This research will contribute to the future development of support services to promote and encourage health and wellbeing in siblings.

Whaikaha - To have strength, to have ability, otherly abled, enabled.

Participant recruitment

We invite you to participate in this survey looking at the unmet needs of siblings of children with disabilities.

You will need to meet the following criteria:

- Be between 18 years old and 35 years old.

- Have a sibling (or someone who was like a sibling to you brother, sister, cousin, whāngai sibling) who is diagnosed with either Autism Spectrum Disorder/Asperger's Syndrome/Takiwatanga, Cerebral Palsy/Hōkai Nukurangi and/or Down Syndrome/Pūira Kehi.
- Grew up with your sibling who has a whaikaha/disability

Your participation will help me identify the unmet needs of siblings of children with whaikaha/disabilities. Results of this survey will be analysed, and the number and type of unmet needs identified. Differences and similarities between the unmet needs of siblings of children with Autism Spectrum Disorder/Asperger's Syndrome/Takiwatanga, Cerebral Palsy/Hōkai Nukurangi and Down Syndrome/Pūira Kehi will be compared. The research will also explore whether there are any different needs between different groups of siblings in this community.

Research Procedures

Research data will be collected through an online survey which is expected to take between 15 and 20 minutes to complete. In the first section you will be asked to provide demographic information. In the second section you will be asked questions about the experiences you and your family/whānau experienced; you will then be asked to select how often you felt your sibling's needs affected you during childhood ('never', 'rarely', 'sometime', 'quite frequently', or 'nearly always'). In the third section you will be asked about unmet needs you had during childhood. You will be asked to select whether you had 'no need', 'low need', 'moderate need', or 'strong need' across seven domains. These domains include: information about your sibling's whaikaha/disability; time out and recreation; practical assistance; support from friends and other young people; dealing with feelings; understanding from your family/whānau; and your relationship with your whaikaha/disabled sibling. You will also be asked a question about how your needs would have best been met.

Support

It is possible that you may experience some level of discomfort from looking back and reflecting on potentially difficult and distressing times in your childhood while completing the survey. You are welcome to leave a specific question unanswered or stop participating at any time. If you are currently receiving care for mental health issues from a hospital based mental health service, please carefully consider if participating in this research is right for you at this time, as thinking about the needs you had as a child may cause you distress. On completion of the survey, we will suggest some ways to access support should you need them, and they are also presented below.

- Social support: friends, family, whānau
- Visiting your GP, counsellor/therapist, or other health professional
- Youthline; Free text 234, Free call 0800 37 66 33, Email talk@youthline.co.nz, 7 days a week
- Free call or free text 1737 any time, 24 hours a day. Talk to (or text with) a trained counsellor or talk to a peer support worker.
- Depression Helpline, available 24/7. You can contact them free via; Phone 0800 111 757 or Text 4202.
- 0800 ANXIETY helpline 0800 269 4389 - 24 hours a day, 7 days a week
- 24/7 Helpline, 0800 LIFELINE (0800 54 33 54) or free text HELP (4357)
- Suicide Crisis Helpline, 0508 TAUTOKO (0508 82 88 65)

Data Management

The data collected will only be used for the purposes of research. All answers to the survey will be anonymous and your name will not be recorded. If the results of this research are published or given in presentations, no identifying information will be included.

If you would like to receive a summary of the findings from this study, you will need to provide your email address; however, this will be kept separate to your survey data, and this identifying data will

be deleted once the research has been completed. The data collected in this survey will be stored securely in both the Massey University cloud-based system and on a password protected computer. The data collected from this research (without any identifying information) may be shared with other researchers for future research upon request; after 5 years, this data will then be destroyed.

Participant's rights

Your participation in this research is completely voluntary. If you decide to participate, you can choose not to answer any particular question and you can stop doing the survey at any time. Completing the survey and submitting your answers implies consent and indicates that you are happy for your survey data to be included in the research.

Contacts

If you have any questions about the research, please contact me at

Sarah.Knight.10@uni.massey.ac.nz

Alternatively, you can contact my supervisor Dr Kirsty Ross, Associate Professor and Senior Clinical Psychologist at K.J.Ross@massey.ac.nz.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application SOB 22/62. If you have any concerns about the conduct of this research, please contact Dr Gerald Harrison, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83570, email humanethicsouthb@massey.ac.nz.