DISCOVER · PREVENT · CURE

Supporting the mental health of siblings of children with intellectual disability:

What are their support needs and preferences?

Dr Kate Dorozenko and Dr Emma Glasson - The Sibling Project

Our Purpose

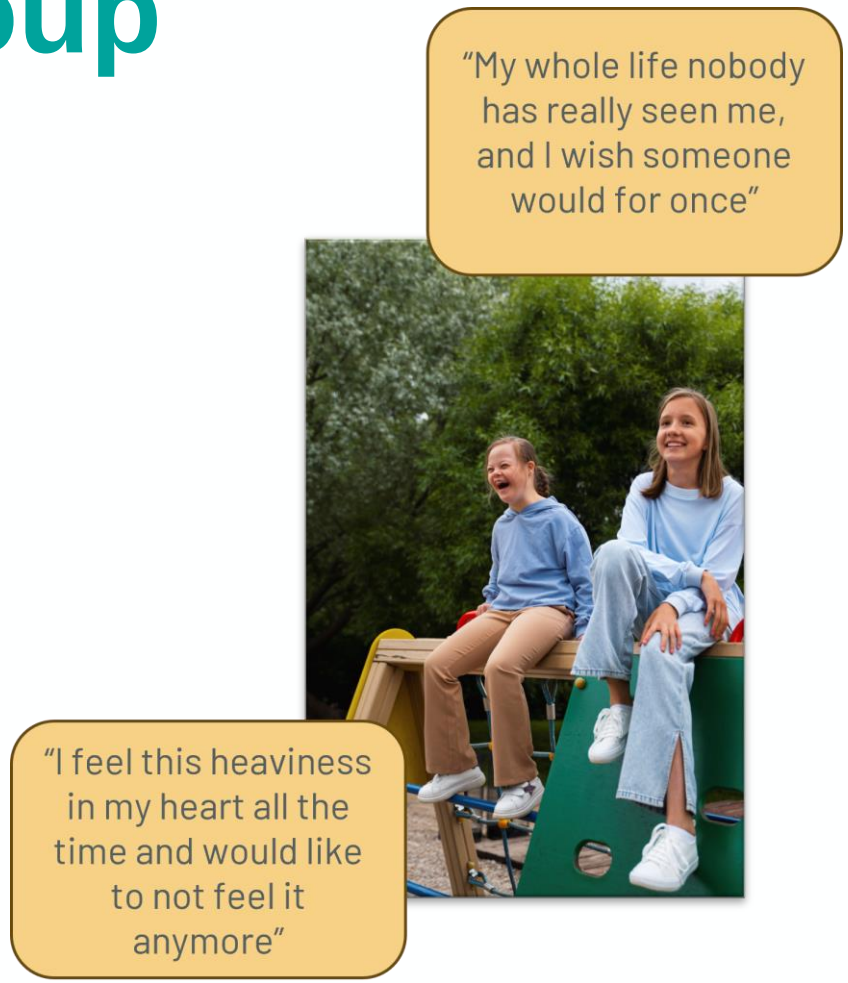
The aim of **The Sibling Project** is to increase the visibility of siblings, and develop and deliver resources that will support them and their families, so that they grow up with the opportunity to thrive and lead happy, healthy, fulfilling lives.

DISCOVER · PREVENT · CURE

https://www.facebook.com/share/r/174WmNZGLp/

Siblings: A hidden and often vulnerable group

- 10 000 children are born each year in Australia with a developmental disability.
- These families experience many challenges.
- The wellbeing of siblings is often overlooked, and mental health issues are common.



The KIDS RESEARCH INSTITUTE AUSTRALIA

Focus on Mental Health and Wellbeing

- Our survey of 715 children and young people found:
  - High depressive and anxiety scores among the sibling group and high self-reported psychiatric diagnosis (72%) vs controls (37%).
  - Sleep difficulties were much more common for siblings than controls (20% vs 5%).
  - Siblings had significantly higher rates of self harm (19% vs 14%), suicidal thoughts (26% vs 9%) and suicide attempts (18% vs 4%).

Wolff B, Franco, VF, Magiati, I, Cooper, MN, Roberts, R, Skoss, R, and Glasson, EJ (2023). Individual-Level Risk and Resilience Factors Associated with Mental Health in Siblings of Individuals with Neurodevelopmental Conditions: A Network Analysis. *Developmental Neuropsychology*, 48:112-134.

Wolff B, Franco, VR, Magiati, I, Pestell, CF, and Glasson, EJ (2023). Psychosocial and neurocognitive correlates of suicidal thoughts and behaviours amongst siblings of persons with and without neurodevelopmental conditions. *Res Development Disabil*, 139:104566

Wolff B, Franco, VF, Roberts, R, Skoss, R, Magiati, I, and Glasson, EJ (2024). Stability and change in self-reported risk and resilience factors associated with mental health of siblings of individuals with and without neurodevelopmental conditions over 15 months. *Adv Mental Health,* 22(3):653-681

Key Research Themes

Emotional Wellbeing

- Risk and protective factors

Sibling Relationships

- Family dynamics
- Sibling reciprocity

Social Inclusion

- Peer connection

Support Needs

- Key areas of concern
- Experiences of mental health services
- Sibling preferences for supports
- Accessing resources

Key Research Themes

Emotional Wellbeing

- Risk and protective factors

Sibling Relationships

- Family dynamics
- Sibling reciprocity

Social Inclusion

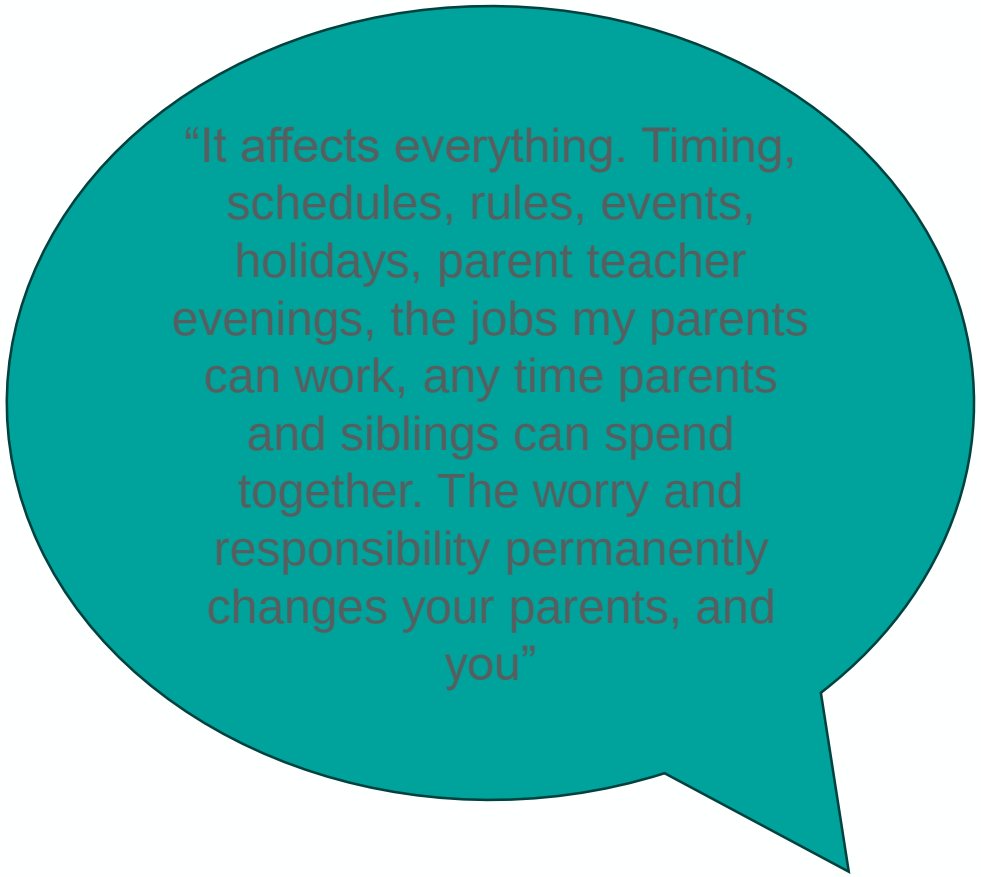
- Peer connection

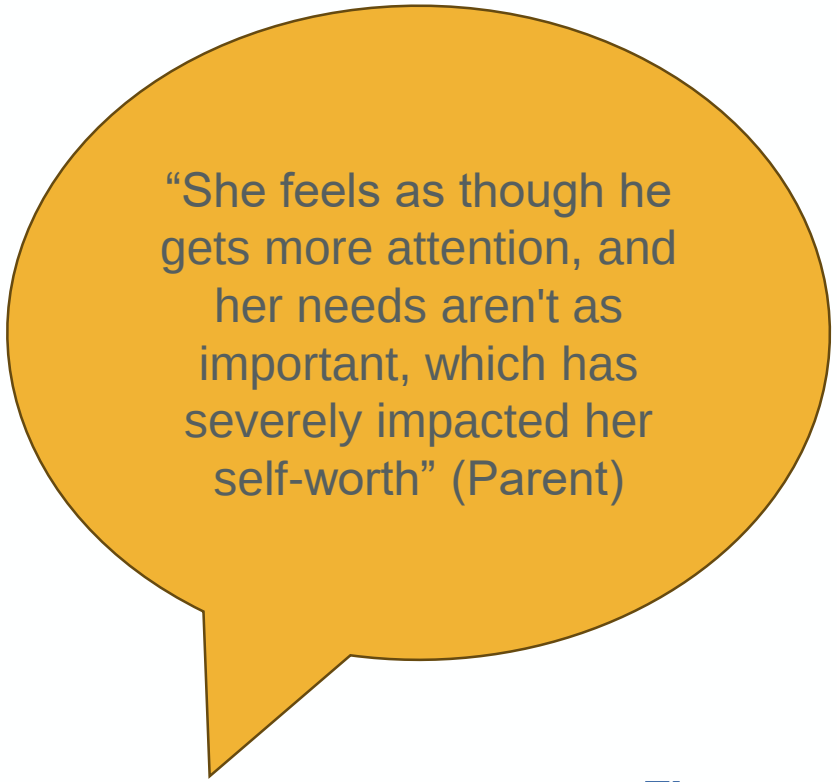
Support Needs

- **Key areas of concern**
- **Experiences of mental health services**
- **Sibling preferences for supports**
- **Accessing resources**

Sibling Perspectives

The KIDS RESEARCH INSTITUTE AUSTRALIA


“It affects everything. Timing, schedules, rules, events, holidays, parent teacher evenings, the jobs my parents can work, any time parents and siblings can spend together. The worry and responsibility permanently changes your parents, and you”


“She feels as though he gets more attention, and her needs aren't as important, which has severely impacted her self-worth” (Parent)

“Having siblings with a developmental disability has really opened my eyes and helped me further develop my patience and empathy. It has also strengthened the bond I have with my family”

“You see the world through a very unique lens... you're a lot more compassionate”

“I'm much more resilient and easily adaptable. Much less phases me and I'm able to keep my cool better that I would be without my siblings”

Current Mental Health Supports for Siblings

- **Siblings Australia** provide information and resources, and deliver a number of programs specifically for siblings, training to capacity build professionals, and also support for families.

- Our preliminary findings indicate:
  - Low awareness of mental health supports among siblings.
  - Difficulties accessing services and supports.
  - Supports may not always suit the emotional needs of siblings.

- Siblings shared their support preferences.

"For a very long time, I felt isolated in my experiences… (now) I know I'm not alone.
I get to have conversations with people who instantly understand".

The KIDS RESEARCH INSTITUTE AUSTRALIA

Illuminating Sibling Experiences

- We value lived experience perspectives and strive to make our research accessible to all.
- Intersectionality and the importance of including siblings with diverse experiences and identities.
    - Rural Siblings Study*
- Capturing the sibling population can be challenging.
- In our work, we use innovative and novel methods to reach siblings and guide our solutions.

*Antonio S, Jamieson K, Dorozenko KP, Glasson EJ & Maxwell-Smith C. (submitted). *Wellbeing and support preferences of siblings of individuals with a neurodevelopmental condition in regional and remote Australia: A mixed methods investigation*.

Get in touch!

Emma Glasson: emma.glasson@thekids.org.au

Kate Dorozenko: kate.dorozenko@thekids.org.au

Or email the team at: siblings@thekids.org.au

Visit **The Sibling Project** website: https://www.thekids.org.au/projects/siblings/