Siblings australia inc

25 YEARS

for siblings of children and adults with disability/illness

Prevalence, causes, and impacts of loneliness in NSW

Siblings Australia welcomes the opportunity to contribute to the Standing Committee on Social Issues in the inquiry into the prevalence, causes, and impacts of loneliness in NSW. Siblings Australia is a for-purpose organisation dedicated to supporting siblings of individuals living with disabilities, chronic health concerns, and mental health conditions. As a support organisation for siblings of all ages, we see firsthand how unique family dynamics can lead to profound loneliness and social isolation, often overlooked in public discussions on loneliness.

In particular, we wish to draw the Committee's attention to the experiences of both child and adult siblings, whose social isolation is often exacerbated by the unique nature of their roles and responsibilities.

Siblings Australia is the only national organisation to focus on siblings of children and adults with disability. For 25 years, we have developed a national and international reputation for our work with families and the professionals who support them, through our programs, supports, advocacy and research. In the last financial year, we provided in excess of 20,000 touchpoints for siblings and families seeking support for their role. Our feedback to this inquiry is informed by research, the input of our sibling-representative consultative committees, and members of our sibling community.

Experiences of Child Siblings

For many children who have siblings with disabilities or chronic health conditions, feelings of social isolation begin early. Children often feel that others - whether peers, extended family, or community members - do not fully understand the challenges they face. Common feelings include:

- Feeling like outsiders in social or family settings, where their sibling's needs or behaviours draw attention and may inadvertently lead to child siblings feeling sidelined.

- A lack of understanding from peers, which can prevent them from openly sharing their experiences or seeking support. Often, these children develop a sense of self-reliance that, while helpful, can inadvertently reinforce isolation.

- Loneliness during times of heightened sibling care, such as medical episodes or periods of intense caregiving from parents. During these times, their social connections may be disrupted as their sibling's needs take precedence.

Experiences of Adult Siblings

Adult siblings, too, face significant social isolation and loneliness, often as a result of increased caregiving responsibilities and a lack of understanding from others about their role.

As their parents age, adult siblings frequently step into caregiving roles without the formal supports or social recognition that traditional carers receive. The impacts are particularly pronounced in the following ways:

- Loss of social connections due to caregiving demands, which can limit an adult sibling's time and energy to engage with friends, colleagues, or other support networks.

- Feelings of being misunderstood by those who may not realise the demands of their caregiving role or its impact on their personal and professional lives.

- Lack of support networks specific to sibling carers, as much of the focus of existing support services is on parents or spouses of those with disabilities, not siblings who often fill these gaps.

- Lack of recognition of the primacy of sibling-relationships, which can cause service providers and professionals to not engage effectively with siblings.

The Need for Data and Supportive Interventions

To better understand and mitigate the loneliness experienced by siblings of people with disabilities and chronic health conditions, we propose the following actions:

- Inclusion of siblings in data collection efforts relating to social isolation and loneliness. Siblings remain an under-researched group whose needs are often overshadowed in disability-focused studies.

- Expansion of sibling-specific support programs that address both the psychological and social needs of child and adult siblings. This includes peer support programs, sibling networks, and workshops to help siblings build resilience and social skills, which have been developed and expanded by Siblings Australia in recent years based on community feedback.

- Training and resources for educators, healthcare providers, and community organisations on the unique needs of siblings, helping to foster empathy and understanding within the wider community. This should occur within a variety of settings, including schools and with disability-service providers.

- Exploration of further community-based and technology-supported initiatives that enable siblings to connect, share experiences, and support one another, thereby reducing the impacts of loneliness and fostering social cohesion.

Siblings Australia is able to assist with further information or consultation regarding the needs of siblings affected by loneliness and social isolation. We strongly encourage the Committee to consider the unique perspectives and challenges of siblings in shaping policies to reduce the impacts of loneliness in NSW.

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