

Adult Siblings Project Survey Results

Method of collection: Online Survey Monkey

Duration: 15th June - 10th July (3 weeks)

- A total of 82 responses were received. The majority of participants were female (79.3%), and were most commonly in the 18-24 years age group (34.1%). 19.5% were aged 55-64 years, and 18.3% were aged 45-54 years.
- 4.9% of participants identified as Aboriginal or Torres Strait Islander, and 19.5% were from a culturally or linguistically diverse background.
- Almost all participants lived in NSW (including rural and regional areas) and 47 of these participants were from Sydney, with a small number of participants from Queensland (3), Victoria (2), and Western Australia (1).
- The majority of participants were not their sibling's primary carer (18.3% were primary carers).
- There were slightly more caring for younger siblings (53.7%) than older siblings (45.1%), while the remaining 6.1% were the same age as their siblings.
- Most participants indicated that their sibling had an intellectual disability/development disability (ID/DD; 74.4%); whilst 31.7% reported a physical disability, and 17.1% reported both.
- Participants were able to provide comments on their siblings' disabilities, with the following identified: severe global developmental delay, mental illness/mental health diagnosis, acquired brain injury, Down syndrome, Asperger's, dyspraxia, autism, and motor neurone disease.
- Some participants also listed other health concerns within their families such as a parent living with cancer.
- The main issues and concerns about caring that were raised by siblings were:
 - ageing parents and having to take on the full-time caring role when parent(s) are no longer able;
 - lack of support, information, and access to services;
 - understanding their legal rights and financial guardianship;
 - health and wellbeing (including mental health such as depression and anxiety);

- future planning for their siblings; and
- social isolation.
- A majority of participants were unaware of any existing supports that specifically targeted adult sibling carers.
- Participants made the following suggestions for addressing existing service gaps:
 - establishing an outreach program that would help bridge the gap between service providers and siblings;
 - support groups or community social groups for adult siblings;
 - recognising the importance of including siblings in communications and distribution of information;
 - tailored information; and
 - transitional support for siblings accessing supports that are designed for under 25s.
- Although the majority of participants did not identify as the primary carer of their sibling, most were still involved in conversations about planning for their siblings' future in some capacity:

“I am 100% involved with planning for his future” (female, 18-24 y/o)

“High level – I instigated reviews in his group home, medical assessments, finances – I was his voice when my parents were too exhausted to keep fighting to ensure his group home continued to meet his needs” (female, 55-64 y/o)

- Participants described experiencing difficulties in maintaining their own individual identity and role as a sibling separate to caring for their siblings. They also suggested that it was important for service providers to recognise this difficulty.
- Some participants identified the importance of emotional support and access to counselling. Others suggested that service providers should be more open in their communication, instead of making assumptions about carers' needs:

“Try to listen without any preconceptions. Everyone has a unique situation which means their disability affects them in a unique way. If this is done, greater understanding can be achieved, and hence better help as a result” (male, 18-24 y/o)

“Service providers should never assume siblings know processes and have industry knowledge despite how competent a sibling may present” (female, 35-44 y/o)

- Participants completed a validated measure of personal wellbeing (the Personal Wellbeing Index). Siblings in this survey reported slightly higher wellbeing than a broader state-wide sample of carers in the Carers NSW 2016 Carer Survey, however, siblings' wellbeing was significantly lower than the general Australian population.