

AUTISM IN THE FAMILY CARERS' HEALTH AND WELLBEING OVER THE LIFESPAN

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Caring for someone on the autism spectrum has been associated with decreased social interaction, reduced workforce participation, and poor personal wellbeing outcomes. Alongside the growing evidence base regarding autism spectrum disorders (ASD) and their increasing prevalence, literature reports several unique challenges faced by families, due to the typical characteristics exhibited by individuals on the autism spectrum.

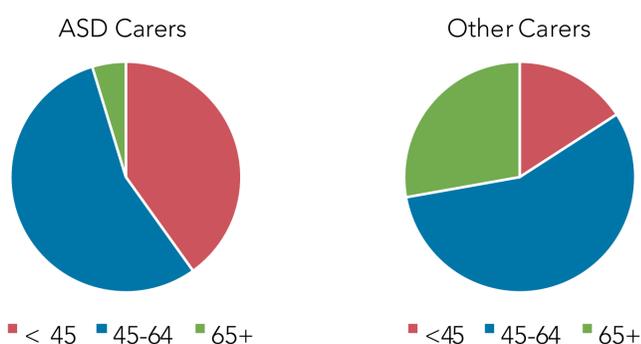


Figure 1. Age distribution (years) of ASD carers and other carers.

Carers from across New South Wales were invited to complete a survey regarding their caring experiences, support and service access, and wellbeing. A total of 359 who were caring for someone on the autism spectrum responded, 91.9% of whom were caring for their son or daughter. Their responses were compared with those of 605 other respondents who were caring for a son or daughter with any disability, mental illness, or chronic condition other than ASD.

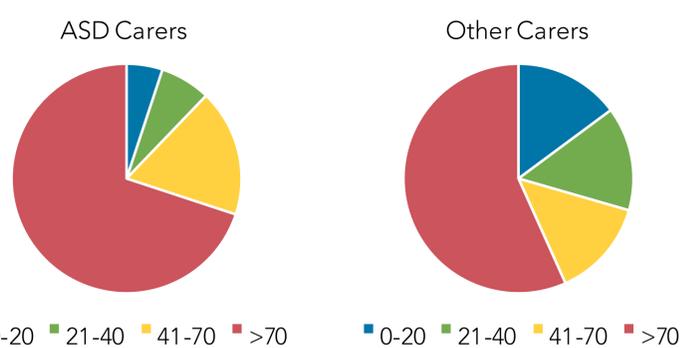


Figure 2. Hours of care per week provided by ASD carers and other carers

The vast majority of respondents were mothers (95.7% of ASD carers; 91.5% of other carers). On average, ASD carers were younger, and provided more hours of care per week than other carers (see Figure 1 and Figure 2).

Compared to other carers, ASD carers reported receiving less social support, poorer health, lower wellbeing, and higher levels of distress. Despite this, ASD carers reported experiencing more positive aspects of their caring roles than other carers (see Figure 3).

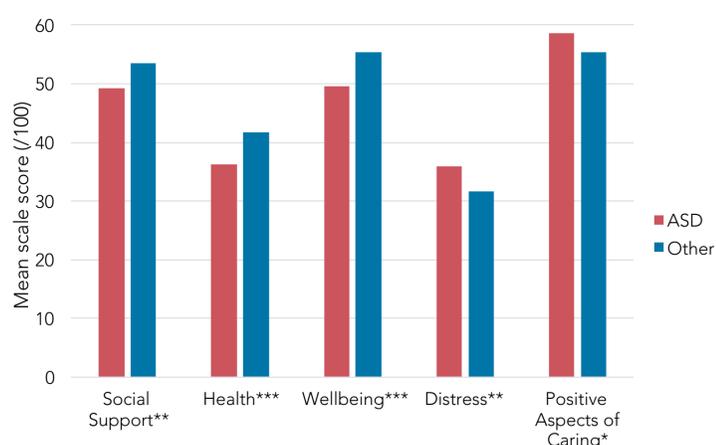


Figure 3. Comparisons between ASD carers and other carers

Important differences were evident in ASD carers' wellbeing and psychological distress over time. As demonstrated in Figure 4, those who had been caring for 11-15 years reported the lowest wellbeing and highest levels of psychological distress on average. It is noteworthy, however, that reports of wellbeing and distress significantly improved amongst those who had been in their caring roles for longer.

It must be noted that this survey employed a cross-sectional design, so causal relationships cannot be determined. It is nevertheless significant to note the positive personal outcomes that have been reported by carers of people on the autism spectrum.

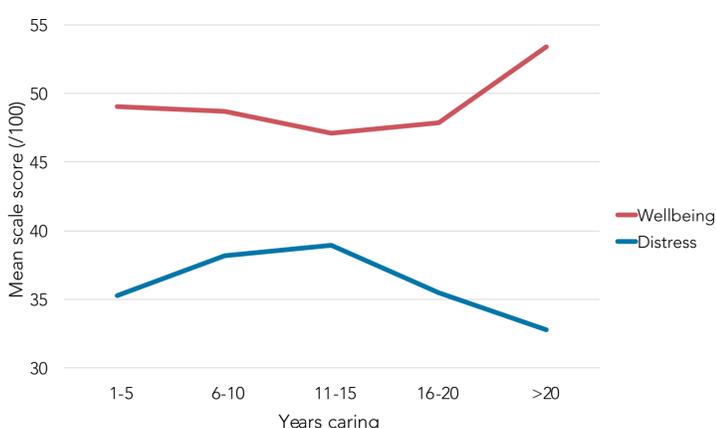


Figure 4. ASD carers' wellbeing and distress by years caring

Despite poorer reported social support, health, and wellbeing, ASD carers experienced more positive aspects of caring than other carers. Furthermore, after gradually decreasing personal wellbeing over the initial stages of caring, ASD carers reported substantial improvements in the much longer term. Further research is necessary to investigate potential causal factors behind these trends. Regardless, by focusing on the positive aspects of caring for a person on the autism spectrum, carers can be empowered to promote positive relationships and resilience throughout wider family networks.

For more information about the Carers NSW 2016 Carer Survey, visit www.carersnsw.org.au/research/survey or contact research@carersnsw.org.au.