

A place of my own: barriers and enablers to independent living for Autistic adults in Australia



Aspect Research Centre for Autism Practice (ARCAP) research team

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Project summary

Moving out of the family home to live independently is traditionally considered a marker of the transition to adult life in Australia. Despite the desire of Autistic adults to live independently, recent studies suggest that only about one in six Autistic adults live alone, with a partner or roommate - a rate lower than adults with other disabilities. This research aims to examine the moving out experiences of Autistic adults in Australia. In particular, the study investigated the importance of living independently, the associated challenges and required supports. To do this, Autistic adults, and parents of Autistic adults, who have moved out of home or want to move out were invited to participate in a short survey and express their interest to be interviewed. The results of the study are described in this report.

Working in partnership

Two Autistic staff members and one Autistic postdoctoral researcher were involved in the study design, development of measures, recruitment materials, data analysis and interpretation of findings.

Participants

A total of 37 participants completed the online survey:

- 28 Autistic adults
- 9 parents of Autistic adults
- 21 of the Autistic participants and Autistic children of parent participants identified as female, 12 identified as male and four as non-binary
- Average age of Autistic adults was 29 years (range: 18-52 years)
- 24.3% of Autistic adults were employed full time and 29.7% part time, 16.2% were studying and 13.5% were unemployed.



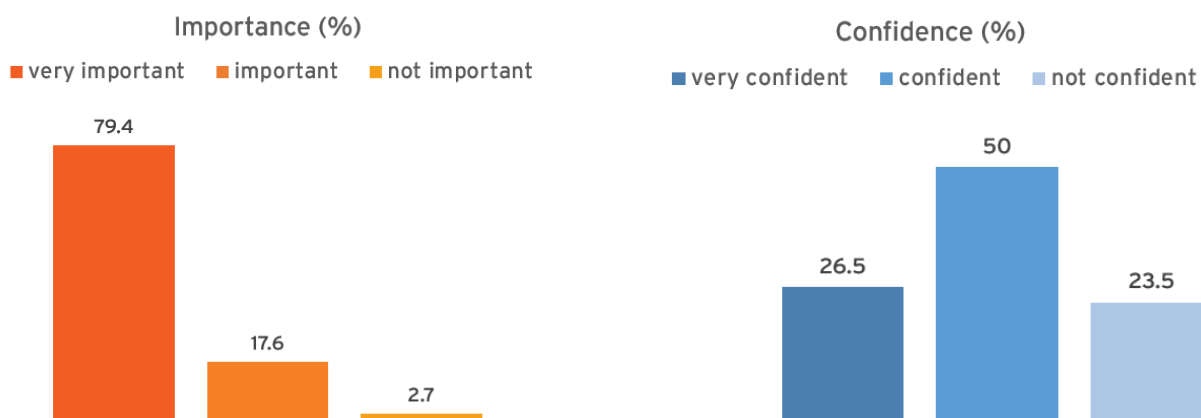
Eleven Autistic adults participated in follow-up interviews and shared their experiences of moving out of home and living independently.



Results


Online survey

Living independently was very important to the majority of Autistic adults (n = 27, 79.4%). Although the majority expressed confidence in their ability to live independently, about one quarter (n = 8, 23.5%) stated that they had no confidence at all about being able to do so.




Interviews

We identified three key themes from the interviews with Autistic adults:

Theme 1 **Independent living is important** 
"It's the most important thing in my life"

Participants spoke of the importance of independent living to their lives, reporting that it was "pretty high" on the priority list, and that "on a scale of one to ten, it's about a fifteen". Participants linked living independently to greater autonomy and control, being able to "choose what I wanted to do ... instead of what other people chose for me" and being able to "do whatever you want ... not having to ask for permission".

Independent living also provided opportunities for solitude. Participants viewed their homes as a "sanctuary away from the world" and a "safe little hiding hole from the rest of the world" which provided "lots of alone time", time and space that many Autistic participants required and valued.

Theme 2 **Moving out is challenging and there's limited support** 
"Literally every single aspect you can think of was a problem"

Despite the importance, participants informed us that they experienced challenges both during the moving out process and whilst living independently. Participants described being unsure about how to go about moving out of home. They had "no idea how you go about that - how you would find a suitable place" or how to "look for flatmates". Some participants sought support but when they "tried to get support, there just was none, really". Participants often did not know "what services are even out there?" and questioned if resources existed at all, "does that exist? I've never looked, does it exist?". Reflecting on their experience, one participant noted "I think if someone sat me down and said 'this is what it's going to be like' that would have helped because I would have been able to formulate a response to what I was faced with".

Participants also experienced administrative, logistical and communication challenges, particularly when dealing with utility providers, agents and removalists. However, financial challenges were highlighted as the biggest challenge. Participants felt that the cost of living was high, which impacted everyone, especially those with a disability, “the housing market sucks for people with a disability”. Participants perceived “rent being too damn high” and emphasised that “to live independently, you have to have a job”.

Mental health and burnout also impacted participants throughout the moving out and independent living processes and this was often linked to anxiety that occurred as a result of having to “step out of our comfort zone”. For some, living independently meant that “stress and anxiety and depression went up” with one participant being forced to return to the family home after their “health really crashed again” as a result of mental health issues.

In response to many of these challenges, some participants expressed that transitioning to independent living can be a gradual process. Participants perceived that a “slow transition is helpful” and that learning to manage a household such as cooking and cleaning, “was a six-year project”.

Theme 3

Early diagnosis may inform better choices

“I wish I had known when I was younger”



The majority of participants (9 out of 11) were diagnosed as adults and they reflected on the impact and importance of knowing they were Autistic in terms of their decision-making, experiences and supports received during the moving out process and while living independently. Participants shared that they “would have benefited from a lot more preparation before I ever moved out” and that being diagnosed would have “definitely influenced the type of house” they went into. For example, one participant shared that “if I had known I was Autistic ... I would want to live closer to my family” and another shared that “had I’ve known about such things, I wouldn’t have moved into that place” in reference to a house on a main street with loud flatmates.

Prior to diagnosis, participants were left with no knowledge of the supports, “I wasn’t aware how much support I would have needed or perhaps may have needed at the time ... so you go ahead and just try to figure these things out yourself”. But, following diagnosis “I am just sticking my hand up for every support out there”. They were able to “manage a lot better now because I understand what it is and I can do things to manage the sensory inputs and understand the social challenges and I can manage it a lot better” and they no longer tried to “power through everything myself to the detriment of my wellbeing”.

Conclusion and next steps

Living independently is important to Autistic people, however they require supports in order to be able to do so including:

- assistance in developing everyday living skills
- sourcing and selecting appropriate accommodation
- support to manage the organisational requirements of living independently.

Early diagnosis and provision of services or resources that can assist Autistic people and their families to navigate the processes associated with moving out of the family home would be beneficial. This could include:

- a checklist of the necessary logistical and administrative tasks and factors to consider when choosing a place to stay or a flatmate
- a service that provides Autistic people and their families with general guidance regarding the moving out process.



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