

Uncovering the hidden histories of late-diagnosed autistic adults



Background

A growing number of people have been receiving a diagnosis of autism during adulthood, previously having either been misdiagnosed in childhood or missed out on a diagnosis altogether. We know little about what late-diagnosed adults' lives were like before they received an autism diagnosis and especially how they survived, thrived and/or experienced distress as the result of not having a diagnosis.



How we did the research

This qualitative study was co-designed and co-produced with autistic and non-autistic researchers. We used oral history methods, where an interviewer elicits the memories of people's unique life experiences and records them in order to preserve their voices and stories. In the current study, the main oral history interviews were conducted by autistic researchers, who were late diagnosed themselves.



Aim

This study aimed to understand:

- the consequences of living without an autism diagnosis
- what instigates an autism diagnosis in mid-to-late adulthood
- the perceived impact of receiving that diagnosis.



Who took part?

28

people in mid-to-late adulthood, from all over Australia, who received a diagnosis late in life (after the age of 35).

"I had a context in which to view my life. My life had been all these different bits and pieces which seem to be chaotic, or, failure, or god knows what, particularly in a social situation. But with the diagnosis, it turned, it gave me a centre, a core, from which, that unified all of these things that I had considered or related to separately. But they weren't separate. They were all part and parcel of this one thing, autism."

Participant quote

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What did we find?

The main interviews produced an enormously rich set of life histories. Participants shared detailed stories of their lives.



People recalled feeling “out of step” with their peers and their broader communities at various points of their lives.



Participants also emphasised key moments of “transition” in life (e.g., primary to highschool, highschool to working life), which were often fraught with difficulties.



People discussed at length the ability to discover community with other autistic people – to “find my tribe” – once they had a diagnosis.



Most strikingly, however, participants also reported feeling empowered by being able to tell their stories in their own way and reported feeling being more able to do so

because they could engage in a project that was co-produced between a team of non-autistic and autistic researchers and where the main interviews were conducted by autistic researchers.



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Who did the research?



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Find out more

Download the final report and executive summary on the Autism CRC website:
autismcrc.com.au/reports/hidden-histories



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