

## Uncovering the hidden histories of late-diagnosed autistic adults



### Background

A growing number of people have been receiving a diagnosis of autism during their 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 first three sessions were conducted by research assistants who are late-diagnosed autistics, and the final session by a senior researcher.



### Aim

This study aimed to:

- understand better the consequences of living without an autism diagnosis
- elucidate what instigates an autism diagnosis in mid-to-late adulthood
- identify 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

## Uncovering the hidden histories of late-diagnosed autistic adults



### 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.



### Acknowledgements

The authors are extremely grateful to all of our participants for taking part in this project. They are also very grateful to our Autistic Advisory Group, including Hayley Clapham, Melanie Heyworth and Michael Chan, as well as Catherine Davis at Drexel University, for their support and contribution throughout the research process, and to Shirleene Robinson and Andrew Host from the NSW Oral History Society for teaching us about oral history methods.



### Who did the research?



**MACQUARIE**  
University  
SYDNEY · AUSTRALIA



**UNSW**  
AUSTRALIA



DEPARTMENT OF  
DEVELOPMENTAL  
DISABILITY  
NEUROPSYCHIATRY

Liz Pellicano, Wenn Lawson, Joanne Mahony, Gabrielle Hall, Rozanna Lilley, Samuel Arnold, Julian Trollor and Michael Yudell.

### Find out more

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

