

Uncovering the hidden histories of late-diagnosed autistic adults

EXECUTIVE SUMMARY

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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

autismcrc.com.au

A note on terminology

We use 'identify-first' language ('autistic person') rather than person-first language ('person with autism'), because it is the preferred term of our autistic co-researchers and Advisory Group members, of autistic activists (e.g., Sinclair, 1999) and many autistic people and their families (Bury et al., 2020; Kenny et al., 2016) and is less associated with stigma (Gernsbacher, 2017).

1. Executive Summary

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. While emerging work has started to demonstrate the perceived benefits and pitfalls of gaining an autism diagnosis late in life, there is little research on 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.

This study sought to change that. To do so, we put together a team of autistic and non-autistic researchers to co-design and co-produce a study that would be thorough, respectful and supportive of our autistic participants. Our autistic partners, including members of our Advisory Group, actively contributed their experience and expertise throughout the study.

We then deployed *oral history methods* to investigate the life stories of 28 autistic people, aged between 45 and 72 years from diverse parts of Australia, all of whom had been diagnosed after the age of 35. In oral history, an interviewer elicits the memories of people's unique life experiences and records them in order to preserve their voices and stories. These methods have often been used to uncover overlooked and marginalised voices and, critically, allow people's views and experiences to be understood within a particular time and place in history.

Our study used these approaches to:

1. understand better the consequences of living without an autism diagnosis,
2. elucidate what instigates an autism diagnosis in mid-to-late adulthood and
3. identify the perceived impact of receiving that diagnosis.

Participants took part in four sessions, including the main oral history interview, through a range of possible formats to facilitate inclusion. The first three sessions were conducted by research assistants who are late-diagnosed autistics, and the final session by a senior researcher (see figure below). The interview data are being analysed using reflexive thematic analysis.



The main interviews produced an enormously rich set of life histories. Participants shared detailed stories of their lives, highlighting a number of overlapping interests. What emerged, overwhelming,

from the life histories was the sense of individuals recalling feeling “out of step” with their peers and their broader communities at various points of their lives.

For 40 years, I felt bad and different but not able to put that into words.

Participants also emphasised key moments of “transition” in life. These were sometimes moments where established neurotypical conventions seemed ill-suited to the wellbeing of our participants, including the move from one school to another or the end of school and the beginning of working life.

The struggles that we went through in school, and the struggles we go through with relationships, and the struggles we go through with work

Some spoke of taking considerable efforts to pursue such a diagnosis and even of being rebuffed by clinicians and other professionals at earlier points. Participants also discussed at length the ability to discover community with other autistic people – to “find my tribe” – once they had a diagnosis.

With the autistic community it’s not just the connection of things you do together... but it’s a connection of the way we think.

Even more strikingly, 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. One participant went so far as to say that they “probably would have dropped out [of the project] if it was run by people who weren’t autistic”.

Four key recommendations emerge from this research, including that sustained efforts be made to:

1. Create greater institutional and structural supports to ensure that autistic researchers are able to play a crucial role in enhancing autism research.
2. Build a larger collection of autistic oral histories, to extend beyond the late-diagnosed adults included here, in other countries across the world.
3. Foster networks of support between autistic people to enable them to tell their stories more frequently in more informal settings as well as in the formal research environments.
4. Protect, enhance, and increase existing diagnostic services for adults.

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Our values

**Inclusion**

Working together with those with the lived experience of autism in all we do

**Innovation**

New solutions for long term challenges

**Independence**

Guided by evidence based research, integrity and peer review

**Cooperation**

Bringing benefits to our partners; capturing opportunities they cannot capture alone



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