

Uncovering the hidden histories of late-diagnosed autistic adults

FINAL REPORT

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

December 2020



Australian Government
Department of Industry, Science,
Energy and Resources

Business
Cooperative Research
Centres Program

Uncovering the hidden histories of late-diagnosed autistic adults

Final Report

Liz Pellicano

Macquarie University | Autism CRC

Rozanna Lilley

Macquarie University | Autism CRC

Wenn Lawson

Macquarie University | Autism CRC

Samuel Arnold

University of New South Wales | Autism CRC

Gabrielle Hall

Macquarie University | Autism CRC

Julian Trollor

University of New South Wales | Autism CRC

Joanne Mahony

Macquarie University | Autism CRC

Michael Yudell

Drexel University

ISBN: 978-1-922365-18-7

Project number: 0.013RI

Citation: Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Arnold, S., Trollor, J., & Yudell, M. (2020). Uncovering the hidden histories of late-diagnosed autistic adults: Final Report. Brisbane, Australia. Autism CRC.

Copies of this report can be downloaded from the Autism CRC website autismcrc.com.au.

Copyright and disclaimer

The information contained in this report has been published by the Autism CRC to assist public knowledge and discussion to improve the outcomes for people on the autism spectrum through end-user driven research. To this end, Autism CRC grants permission for the general use of any or all of this information provided due acknowledgement is given to its source. Copyright in this report and all the information it contains vests in Autism CRC. You should seek independent professional, technical or legal (as required) advice before acting on any opinion, advice or information contained in this report. Autism CRC makes no warranties or assurances with respect to this report. Autism CRC and all persons associated with it exclude all liability (including liability for negligence) in relation to any opinion, advice or information contained in this report or for any consequences arising from the use of such opinion, advice or information.

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.

The authors acknowledge the financial support of the Cooperative Research Centre for Living with Autism (Autism CRC), established and supported under the Australian Government's Cooperative Research Centre Program. Staff and non-staff in kind were provided by Autism CRC participants.

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).

Table of contents

1. Executive Summary	4
2. Introduction.....	6
2.1 Background	6
2.1.1 Aims	7
3. Research methods and design	7
3.1 Ethical considerations	7
3.1.1 Informed consent.....	8
3.1.2 Confidentiality and anonymity	8
3.1.3 Power dynamics	8
3.1.4 Researching potentially sensitive topics	9
3.2 Community involvement.....	9
3.3 Participants.....	10
3.4 Procedure	11
3.5 Data analysis	13
4. Findings.....	13
5. Limitations.....	15
6. Implications for research and practice.....	16
7. Key recommendations.....	17
8. References	19

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, all conducted by one of two autistic researchers. 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. Even more strikingly, they also reported feeling empowered by being able to tell their stories in their own way and reported being more forthcoming because they were able to 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.

There are four key recommendations 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.

2. Introduction

2.1 Background

Autism was once an exceedingly rare diagnosis (Lotter, 1966). But this is no longer the case. Changes in the way that autism is diagnosed as well as greater public understanding of autism (Gernsbacher et al., 2005) has meant that autism is now a fairly commonplace diagnosis (Baio et al., 2018; May et al., 2020; see Lord et al., 2020). This means that, even in the recent past, many autistic children reached adulthood and worked through life without knowing anything about autism – growing up with a misdiagnosis or no diagnosis at all – leading to what some have referred to as the “lost generation” of autistic adults (Lai & Baron-Cohen, 2015).

While there is a growing body of work on the lived experiences of adults recently diagnosed as autistic, much of that work has focused on the diagnostic process and the benefits and pitfalls of that process (Arnold et al., 2020; Lewis, 2016; Leedham et al., 2019). Much less is known, however, about what late-diagnosed adults’ lives were like before they received an autism diagnosis – and especially how they survived, thrived and/or experienced distress. Listening to, and learning from, the life histories of those who went through childhood without a diagnosis could serve to better inform current diagnostic practices and ways of improving the lives of autistic people.

This qualitative study, co-produced with autistic people, sought to do just that. Critically, it aimed to build on existing research by adopting two key methodological approaches. The first was a *participatory approach*, in which autistic people are involved as partners in the research process (Fletcher-Watson et al., 2019; Nicolaidis et al., 2011; Pellicano & Stears, 2011). To this end, we had three autistic collaborators, two of whom were paid research assistants on the project, as well as an Autistic Advisory Group comprising three late-diagnosed autistic adults. Our autistic partners were actively involved in making decisions throughout the research process.

The second methodological approach was *oral history*. In oral history projects, the aim is to systematically record and preserve recollections deemed to be of historical significance. They allow for a multitude of points of view and give a voice to individuals and groups who have often been marginalized in conventional histories. While there is a burgeoning literature on qualitative research investigating the views and experiences of autistic people and their families, the use of

oral history – which situates peoples’ stories within a particular time and place in history – has rarely been used.

In this study, we specifically adopted a *disability* oral history approach (see Hirsch, 1995), recording the stories related to a person’s sense of self and their perceptions and actions set within a historical context. It is underpinned by the beliefs both that late-diagnosed autistic adults have unique experiential expertise – on how they survived, thrived and potentially experienced distress both before and after having received an autism diagnosis, and oral history methods provide the opportunity to explore shared experiences and group identity.

2.1.1 Aims

Using these approaches, we sought to address the following aims:

1. To conduct oral history interviews with late-diagnosed autistic adults in order to (a) understand better the consequences of living without a diagnosis for a significant portion of their adult lives; (b) elucidate what precipitates an autism diagnosis in mid-to-late adulthood; and (c) identify the impact that receiving a diagnosis has had on their lives.
2. To situate these adults’ views and experiences within a particular time and place in recent history.
3. To prepare these interviews for digital archiving and therefore access for future generations and communities.

3. Research methods and design

3.1 Ethical considerations

Ethical approval for the current study was obtained from Macquarie University’s Human Research Ethics Committee (Ref. no: 52019556310562). We identified – and addressed – four specific ethical issues for this project, including: (i) informed consent; (ii) confidentiality and anonymity; (iii) power dynamics; and (iv) researching potentially sensitive topics (see Pellicano et al., 2020, for full discussion).

3.1.1 Informed consent

Participants provided informed, written consent to: (i) take part in the interviews; (ii) identify themselves in the resulting outputs; (iii) digitally record the interviews; and (iv) preserve the interviews and other approved archival materials in a publicly-accessible online location. They were asked to provide consent in Session 1 and confirm it again in Sessions 2 and 3. Participants' interview recordings and transcripts, as well as any artefacts they provided, are retained in perpetuity (with participants' written, informed consent).

3.1.2 Confidentiality and anonymity

For the vast majority of published research on autism, de-identification is the norm. Our project followed the norms of oral history research, where it is common practice to identify participants. The decision to identify people reflects a deliberate effort to enable participants to claim ownership of their own history (Manning, 2009). To this end, participants could choose, during the consent process, to allow their identity and image(s) to be revealed. When participants chose to be anonymized (n=5), potential identifiers were omitted and a pseudonym (chosen by the participant themselves) was used.

3.1.3 Power dynamics

In autism research, autistic people and their families have reported feeling often disenfranchised by the research process (e.g., Pellicano et al., 2014). In this study, we sought to reduce the existing power imbalances between the researcher and the participant ("the researched") by effectively eliciting the views of seldom-heard voices and valuing them as experts by experience (Collins & Evans, 2002). We achieved this by (i) adopting oral history methods, which literally gives 'voice' to marginalized and seldom-heard communities (Thompson, 2017); (ii) adopting a participatory approach in which autistic partners have been involved – and thus shared power – in the project's decision making; (iii) providing participants with detailed information about each stage of the process to help address feelings of uncertainty and of being scrutinized; and (iv) having the oral history interviews conducted by late-diagnosed autistic research assistants, thus enabling more empathetic interactions.

3.1.4 Researching potentially sensitive topics

While people often feel a great deal of satisfaction from telling their life history (Manning, 2009; Thompson, 2017), we were aware that this process may be challenging for our autistic participants, despite being willing interviewees. This is partly because autistic adults frequently experience additional mental health issues, including suicidal ideation (Cassidy et al., 2018) and trauma (Fuld, 2018). We therefore implemented a series of procedures to mitigate this potential risk, including: inviting the participant to nominate a service provider (e.g., a local doctor) or trusted person who might be available to support them through the process; providing participants with a list of local psychological services and anonymized helplines; and creating a distress protocol (step-by-step procedure; Draucker et al., 2009) that interviewers needed to follow in order to manage any instances in which the participant showed distress during the interview (see Pellicano et al., 2020, for further detail).

We were also aware of the need, potentially, to support our autistic researchers, who also received late diagnoses, and might find it triggering to hear about the often-difficult experiences of others. They were therefore asked to consider specific ways of looking after themselves both before and after each interview; check-in with senior researchers (WL and LP); and seek external help and advice, when necessary.

3.2 Community involvement

This research was designed and implemented in partnership with autistic people, especially those with experiential expertise of receiving a late (adult) diagnosis. The research team included four autistic co-researchers (WL, CD, GH, JM), three of whom (WL, GH, JM) are late-diagnosed and two of whom (GH, JM) were employed as research assistants on the project. These autistic co-researchers were actively involved since the beginning of the project, resulting in collaborative decisions in regard to methodology, including eligibility criteria, sampling characteristics, the nature and content of each interview, the procedure itself and the analysis. Their involvement ensured that our methods were thorough, respectful and supportive of our autistic participants' needs and wishes.

The project also had input and oversight from an Autistic Advisory Group comprised of three autistic adults who were reimbursed for their time and expertise. The Group provided detailed feedback on the data collection methods and participant information (including inclusion criteria),

and all study information documents were significantly revised following their input. They also had input into the results of our preliminary analysis, including this final report.

The team, including our autistic research assistants (GH, JM), received training in oral history methods from the New South Wales Oral History Society. They prepared the team by providing essential teaching, guidance and hands-on training in digital recording, interviewing style/techniques and information for processing the interview.

3.3 Participants

The inclusion criteria for this study were derived in collaboration with our autistic co-researchers. To be eligible for our study, participants had to: (i) be born before 1975, that is, before autism appeared in the DSM-III (APA, 1980) and before the beginning of the surge of autism diagnoses in the 1980s; (ii) have received a clinical diagnosis of an autism spectrum condition after the age of 35; (iii) be English-speaking; (iv) have spent most of their childhood and adulthood living in Australia to allow their stories to be contextualized within the particular history of autism in Australia; and (v) provide written informed consent. It was felt that these criteria ensured that we included the life histories of those in mid-to-late adulthood, a particularly under-served group in autism research and practice (e.g., Happé & Charlton, 2012). It also sought to ensure that participants had spent their childhood and a significant portion of their adulthood living without an autism diagnosis and perhaps not knowing they were autistic and had grown up at a time when autism was unknown to clinicians, educators and the broader public.

We used convenience sampling (snowballing) methods to recruit participants. A social media campaign with a video and flyer were initially circulated via the Autism CRC's social media, which then generated additional participants through Australian self-advocacy groups, clinician and researcher networks and, especially, social media (Twitter, Facebook) and online forums. Within two weeks, we had received expressions of interest from 37 people – a number which far exceeded our target number ($n=24$) and which we believe is testament to the participatory approach adopted for this project.

Twenty-eight people met all five inclusion criteria for this project (see Appendix). They ranged in age from 45 to 72 years ($M=53.5$ years, $SD=7.6$). Fifteen people identified as female, 11 as male and one as non-binary (one preferred not to say). All had received an independent clinical diagnosis according to DSM-IV (APA, 2000) or DSM-5 (APA, 2013) late in life – at, on average, the age of 50 years. They had received this diagnosis, on average, three years prior to participation in

this study, although the duration between diagnosis and participation varied widely, from three months to 10 years.

Our participants came from diverse parts of Australia, including nine people from Victoria, six from New South Wales, six from Queensland, three from Western Australia, two from South Australia, one from the Northern Territory and one from Tasmania. Most (72%) were from cities and 28% from inner and outer regional communities. All were born in Australia except for one, who was born in the United Kingdom. All reported to be of White European ethnic background and one person identified as Aboriginal. Furthermore, all spoke English at home, with the exception of one participant who spoke Spanish.

Most of our participants were highly educated. Of the 28 participants, 22 (78%) reported having at least gained an undergraduate degree. Twenty-two (78%) of our participants were also currently employed in a range of occupations (see Appendix), while five (18%) were studying at the time of participation.

Most of our participants (n=24; 86%) reported co-occurring mental or physical health conditions (see Appendix), with half reporting having received at some point in their lives a diagnosis of anxiety disorder. Five participants (18%) reported being in receipt of a plan through the National Disability Insurance Scheme (NDIS), which gave them access to funding for supports and services.

3.4 Procedure

Participating in this project involved four separate sessions (see Figure 1 and Pellicano et al., 2020, for full details). In *Session 1* (~60 min), participants met with the interviewer (GH or JM) to establish rapport, provide informed consent to take part in the study, discuss the required paperwork and the main interview questions, and the potential inclusion of artefacts (photographs, objects) to prompt discussion during the main oral history interview. Following Session 1, participants were sent a list of the main interview questions, a personalised Support Person letter, and the contact details of local psychological support services/organisations in case of distress during the main interview.

Figure 1: Schematic of study design



Participants then met with the interviewer once again for *Session 2* (~1-3 hr). This session comprised the main, digitally-recorded oral history interview. The interviewer began by verbally re-checking participant consent. Participants were then asked questions about the different life stages (see Pellicano et al., 2020, for full details). The interview was semi-structured to ensure that the interviewee was able to tell their life history in their own way. Participants were also encouraged to incorporate any photos or personal objects into the telling of their life history, which were scanned for later archiving, alongside the digitised interview. The length of these interviews ranged from 67 to 201 minutes (Mean=129.1 minutes, SD=33.6).

Approximately one month after the main interview, the interviewer contacted the participant to take part in *Session 3* (~30 min). Prior to this session, the interviewer sent the interview transcript to the participant for review. At this point, they were able to remove details that they did not want included in the final record. After reviewing the materials, participants were asked to re-consent for digital release of the final, edited (if requested) materials. The majority gave their consent for their full name (n=15) or first name (n=8) to be identified, while five participants opted to use a pseudonym.

Finally, and soon after Session 3, the participant was invited to take part in *Session 4* (~20 min), during which they were asked to offer their thoughts and reflections on the experience of telling their life history, and on the research process itself.

The first three sessions were conducted by research assistants who are late-diagnosed autistics (GH, JM), and the final session by a senior researcher (EP, WL).

Participants were provided with a range of possible formats to conduct each of the sessions, including face-to-face, where feasible, over the phone, over high-quality web conferencing (Zoom: <https://zoom.us>) or via email. Most participants opted for the main interviews to take place via Zoom, although one interview was conducted over email and one face-to-face.

3.5 Data analysis

The key to successful oral history is to report the experiences, meanings and reality of the participants. All interviews have been transcribed verbatim. Members of the research team (LP, WL, JM, GH & RL) independently familiarised themselves with the data by listening to/watching the recordings, and/or (re-)reading the transcripts. The data are being analysed using reflexive thematic analysis (Braun & Clarke, 2006, 2019). Our analysis adopts an inductive (“bottom up”) approach (i.e., without integrating the themes within any preexisting coding schemes or preconceptions of the researchers) to identify patterned meanings in the dataset within an essentialist framework. Codes are assigned to data extracts. The analysis team have conferred weekly towards the end of the project to discuss the interviews and preliminary codes, review the themes and subthemes and resolve discrepancies.

4. Findings

Preliminary analysis of the transcripts has revealed an extraordinarily rich and subtle series of reflections from our participants, all of whom have been immensely generous with their time and candid in their accounts. Working with the Autism CRC, these oral histories will be made available through a digital platform at a major university library. The transcripts and analysis will also be written-up in academic form jointly with a historian of public health (MY), who has extensive experience with oral histories.

Our headline findings from the project flow both from the methodological approaches that were adopted and from the substance of the stories shared.

The key methodological finding emerged from the experience that participants had of engaging 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, both of which remain very rare in the field of autism research. When participants were asked how they felt as a result of engaging in this kind of research process – from responding to the call for participants, to completing the paperwork, to being given various ways to join the project, to having their needs met (breaks, interview times) throughout the project and so on – they responded overwhelmingly positively. While recounting their life history was often reported to be “exhausting” and “draining”, participants also reported feeling “supported all the way” and agreed that “it was made easier because I had an autistic researcher interviewing me”. They reported feeling a total lack of judgement, that they were

fully understood and their needs were met: “I don’t think I’d ever been asked to explain myself and to actually be heard”. 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”. Only one person said the ‘status’ of the researcher, autistic or not, made no difference to them. Such was the level of connection between the researchers and the participant that one individual even said their needs were over-catered for. Although, this person also added that they understood the protocol required checking in, and that other autistics might not be able to notice or access their own needs in the way that she was able to.

In terms of the substance of the stories that were shared, what emerged, overwhelmingly, 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: “I didn’t have it easy growing up”. Many participants recounted making substantial and highly intentional efforts to craft a life for themselves that reflected their own passions and interests while also attending to the sometimes-uncomfortable expectations and social requirements of others.

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

Particular emphasis emerged in these accounts of 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”. At other times, the key moments of personal challenge were those that are also often challenging for neurotypical individuals seeking to make sense of their own place in the world, including the loss of parents and the resulting personal grief, the making and breaking of personal friendships and the pursuit of intimate and loving relationships:

The fact that going through our life history and stuff like that, looking at especially the bits where it was quite apparent that we were different in some way, shape or form, whether that be social interactions as kids or teenage years and trying to have relationships, or even post teenage years. That constant realisation is that we’re not the same as everybody else.

Participants recalled in significant detail how they had to draw on their own personal resources in order to plot a path through these challenges, often feeling unable to rely on the support of others or to fall back on the established social conventions that can reassure neurotypical people at these moments of difficulty.

This absence of a sense of support at key moments also reinforced the relief that some participants reported when they were given an autism diagnosis in the later part of their lives. As one participant explained:

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.

Some spoke of taking considerable efforts to pursue such a diagnosis and even of being rebuffed by clinicians and other professionals at earlier points: “and every now and again, I’d go off and see a psychologist, and try and get an understanding of how I was not fitting in the same way that I could see that other people were... why I was just crashing and burning all the time”. Many spoke of being able to reinterpret earlier memories when equipped with a diagnosis, often finding emotional reassurance in being able to do so, although they also described frequently feeling as if they had “missed opportunities”: “well, there was relief when I was diagnosed in that it wasn’t my fault but, yes, sadness in the fact that there was so much more that I could have done in my life”. 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.

5. Limitations

This study is not without its limitations. First, our participants were predominantly of white ethnic background, were more likely to identify as female, and more than three quarters of the sample

were currently employed. It is therefore possible that a selection bias may have existed, particularly toward those who are willing to consent and able to convey their life history orally.

This in itself is not wholly surprising. Oral history projects are rarely fully representative as the method makes substantial demands on participants that not everyone is able or willing to meet. This is no doubt exacerbated in this case by the fact that qualitative, interview-based studies with autistic participants also have a tendency to over-represent those who are comfortable in extended conversation with researchers, whether those researchers are autistic themselves or not.

Moreover, given that the oral histories collected here specifically reflect the experiences of specific late-diagnosed autistic adults, they may not be straightforwardly generalizable to other autistic adults in Australia, other countries or cultural groups. The protocol itself, however, is designed to be used to gather comparative information about the experiences of late-diagnosed autistic adults in other countries and cultural groups and we look forward to seeing future oral history analyses that may collectively cast more light on the issues raised by this initial project.

6. Implications for research and practice

The study reveals the vital importance of deep and sustained efforts at genuine co-production in autism research; co-production which includes participation by autistic researchers in the design, conduct and analysis of the research. The research team is particularly grateful to the Autism CRC for its leadership in this regard, and notes that it is crucial that other funding bodies also invest in supporting co-production efforts of this kind. Such work is often more time-intensive than more conventional forms of autism research and requires expert management and support throughout, but it brings undoubted rewards seen most strikingly here in the sense of empowerment shared by those autistic people who were given the opportunity to reflect on their own lives directly with an autistic researcher.

In addition, the study also reveals a series of issues that require deeper investigation by scholars in the future. The autobiographical accounts collected demonstrated a deep capacity for self-reflection, providing a valuable resource for exploring the variability of autistic experiences and the socio-historical contexts that shape individual biographies, including experiences of exclusion and valued opportunities lost due to a lack of support and understanding. As described above, the oral histories also revealed the fundamental importance for many of autistic people's individual agency in enabling them to shape their own lives against the backdrop of sometimes unhelpful

neurotypical norms and expectations. Further exploration is required of the supports that new generations of autistic people may require in order to be able to develop similar skills of agency and self-direction.

Finally, the studies also reveal the potential importance of diagnostic opportunities provided to adults who have lived for many years without a diagnosis. The fact that many participants spoke so openly about the benefits they feel that they have personally derived from diagnosis underlined the need to ensure that such opportunities are continually available to others. The histories shared also demonstrated the role played by networks of peer support in enhancing the wellbeing of late-diagnosed autistic adults and further investigation is required into how those networks can best be fostered and sustained.

7. Key recommendations

Four key recommendations emerge from this work. They are:

1. Autistic researchers can play a crucial role in enhancing autism research. Funding agencies and research institutions need to continue to strive to give more opportunities for autistic people to play a major role in the design, conduct and analysis of autism research, including by providing greater financial support than is currently available and by adjusting time-horizons and project management expectations so that they better suit the needs and skills of autistic researchers. The creation of a peer-researcher mentoring network, in which senior autistic researchers could mentor more junior colleagues, is one additional way of supporting autistic partners involved in research.
2. Oral histories have much to tell us about the nature of autistic lives. We therefore recommend that efforts continue to be made to create a larger collection of autistic oral histories, to extend beyond the late-diagnosed adults included here.
3. Our participants spoke extensively about the important and positive effects of telling their stories and especially of telling them to other autistic people. We recommend, therefore, that efforts be made to foster networks of support between autistic people to enable them to tell their stories more frequently in more informal setting as well as in the formal research environments.

-
4. Diagnostic services for adults played an important role in many of our participants' lives, as retold in their oral histories. We recommend, therefore, that efforts continue to be made to protect, enhance, and increase existing diagnostic services for adults. Whether this needs further research or whether there is enough existing evidence to proceed is a matter beyond the scope of this project. However, the oral histories gathered for this project make it clear that establishing the best means of achieving that goal in a timely way across different health systems and policy jurisdictions is, literally, a matter of life or death for many adult autistics (Hirvikoski et al., 2016). Such learnings should feed into future revisions of the National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia in order to reduce the cost of, and lengthy waitlists for, an adult autism diagnosis.

8. References

- Arnold, S. R. C., Huang, Y., Hwang, Y. I., Richdale, A. L., Trollor, J. N., & Lawson, L. P. (2020). “The single most important thing that has happened to me in my life”: Development of the impact of diagnosis scale – Preliminary revision. *Autism in Adulthood*, 2, 34-41.
- Baio, J., Wiggins, L., Christensen, D. L., et al. (2018). Prevalence of autism spectrum disorder among children aged 8 years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR Surveillance Summaries*, 67, 1–23.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Cassidy, S., Bradley, L., & Shaw, R. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, 9, 42.
- Collins, H.M., & Evans, R. (2002). The third wave of science studies: Studies of expertise and experience. *Social Studies of Science*, 32, 235–296.
- Draucker, C. B., Martsof, D. S., & Poole, C. (2009). Developing distress protocols for research on sensitive topics. *Archives of Psychiatric Nursing*, 23, 343-350.
- Fletcher-Watson, S., Adams, J., Brook, K., Charman, T., Cusack, J., Crane, L., Leekam, S., Milton, D., Parr, J. R., & Pellicano, E. (2019). Making the future together: Shaping autism research through meaningful participation. *Autism*, 23, 943-953.
- Fuld, S. (2018). Autism spectrum disorder: The impact of stressful and traumatic life events and implications for clinical practice. *Clinical Social Work Journal*, 46, 210–219.
- Gernsbacher, M. A. (2017). The use of person-first language in scholarly writing may accentuate stigma. *Journal of Child Psychology and Psychiatry*, 58, 859–861.
- Gernsbacher, M. A., Dawson, M., & Goldsmith, H. H. (2005). Three reasons not to believe in an autism epidemic. *Current Directions in Psychological Science*, 14, 55-58.
- Happé, F., & Charlton, R. A. (2012). Aging in autism spectrum disorders: A mini-review. *Gerontology*, 58, 70 – 78.
- Hirsch, K. (1995). Culture and disability: The role of oral history. *The Oral History Review*, 22, 1-27.
- Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 208, 232–238.
- Kenny, L., Cribb, S., & Pellicano, E. (2019). Childhood executive function predicts later autistic features and adaptive behaviours in young autistic people: a 12-year prospective study. *Journal of Abnormal Child Psychology*, 47, 1089-1099.
- Lai, M-C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *Lancet Psychiatry*, 2, 1013–1027.

Leedham, A., Thompson, A., Smith, R., & Freeth, M. (2019). "I was exhausted trying to figure it out": The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, 1-12. doi:10.1177/1362361319853442

Lewis, L. F. (2016). Exploring the experience of self-diagnosis of autism spectrum disorder in adults. *Archives of Psychiatric Nursing*, 30, 575-580.

Lord, C., Brugha, T. S., Charman, T., Cusack, J., Dumas, G., Frazier, T., Jones, E. J H., Jones, R. M., Pickles, A., State, M W., Taylor, J. L., & Veenstra-VanderWeele, J. (2020). Autism spectrum disorder. *Nature Reviews*, 6, <https://doi.org/10.1038/s41572-019-0138-4>

Lotter, V. (1966). Epidemiology of autistic conditions in young children. *Social Psychiatry*, 1, 124–135.

May, T., Brignell, A., & Williams. K. (2020). Autism spectrum disorder prevalence in children aged 12-13 years from the Longitudinal Study of Australian Children. *Autism Research*, 13, 821-827.

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Ashkenazy, E., et al. (2011). Collaboration strategies in nontraditional community-based participatory research partnerships: Lessons from an academic-community partnership with autistic self-advocates. *Progress in Community Health Partnerships: Research, Education, and Action*, 5, 143–150.

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the UK. *Autism*, 18, 756-770.

Pellicano, E., Lawson, W., Hall, G., Mahony, J., Lilley, R., Davies, C., Arnold, S., Trollor, J., & Yudell, M. (2020). Understanding the untold histories of late-diagnosed autistic adults: an oral history protocol. *BMJ Open*, 10, e037968. doi:10.1136/bmjopen-2020-037968.

Pellicano, E., & Stears, M. (2011). Bridging autism, science and society: Moving towards an ethically-informed approach to autism research. *Autism Research*, 4, 271-282.

Sinclair, J. (1999). Why I dislike 'person-first' language. Retrieved from http://web.archive.org/web/20090210190652/http://web.syr.edu/~jsincla/person_first.htm

Thompson, P. (2017). *The voice of the past: Oral history (4th edition)*. Oxford University Press.

Appendix

Table 1: Participant characteristics

ID	Gender identity	Age at interview	Highest education level	Number of (autistic) children	Formal diagnosis	Age (years) at diagnosis	Time (years) since diagnosis	Lifetime psychiatric/ mental health conditions	Lifetime medical conditions
HH001	Female	56.7	Undergraduate degree	3 (2)	Autism	54	2.0	Anxiety disorder, Bipolar disorder	Obesity, Sleep issues, Thyroid problems
HH002	Female	50.9	Completed high school	3 (3)	Asperger's	48	2.0	Dyslexia, Dyspraxia, DC1N1 mutation, Anxiety disorder, Drug/alcohol dependence, PTSD	Hypertension
HH005	Female	59.2	Undergraduate degree	3 (0)	ASD	58	0.9	Anxiety disorder	Hypertension, Sleep issues
HH006	Male	55.7	College certificate	0	ASD	52	3.3		Sleep issues, Thyroid problems
HH007	Female	50.0	Graduate diploma	2 (0)	ASD	46	4.0		Thyroid problems, Rheumatoid Arthritis
HH008	Male	51.1	Postgraduate degree	1 (1)	ASD	48	2.2		Asthma
HH009	Male	49.9	Undergraduate degree	0	ASD	48	1.4	Attention Deficit Disorder	Sleep issues
HH010	Male	50.5	Undergraduate degree	2 (0)	ASD	48	0.8	Anxiety disorder, Post Traumatic Stress Disorder	
HH011	Female	45.5	Undergraduate degree	1 (1)	ASD	42	3.2		Obesity, Thyroid problems
HH014	Male	57.3	Undergraduate degree	2 (0)	ASD	56	0.6		Skin cancer
HH015	Female	47.9	Undergraduate degree	1 (1)	ASD	42	5.9		Asthma

HH016	Female	54.9	Undergraduate degree	2 (2)	ASD	54	0.2	Anxiety disorder	
HH017	Male	50.8	Undergraduate degree	2 (2)	ASD	43	7.6		
HH018	Non-binary	72.4	Undergraduate degree	0	Asperger's	62	10.2	Anxiety disorder, Chronic Fatigue Syndrome, Drug/alcohol dependence	Cancer, chronic pain, Gastrointestinal issues, Hepatitis, Hypertension, Sleep issues, Thyroid problems
HH019	Female	46.3	Undergraduate degree	1 (1)	ASD	45	0.8	AHDD, Anxiety disorder,	Chronic pain, Obesity, Hypermobility Spectrum Disorder
HH021	Female	54.4	Undergraduate degree	2 (0)	ASD	51	2.0	Anxiety disorder, Eating disorder,	Gastrointestinal issues, Obesity
HH022	Male	50.6	Undergraduate degree	0	Asperger's	39	10.8		
HH023	Female	50.5	Undergraduate degree	3 (1)	Asperger's	48	1.8	Anxiety disorder, Post Traumatic Stress Disorder	Chronic pain, Heart disease, Sleep issues
HH026	Male	72.9	Completed high school	3 (0)	ASD	72	0.8	Anxiety disorder	Heart disease, Sleep issues, Alport syndrome
HH027	Male	69.6	College diploma	3 (0)	Asperger's	68	1.2	Anxiety disorder	Hypertension, Stroke
HH028	Prefer not to say	45.3	Postgraduate degree	1 (1)	ASD	40	5.4	Anxiety disorder, Chronic Fatigue Syndrome	Gastrointestinal issues, Sleep issues
HH031	Female	52.8	Postgraduate degree	0	Asperger's	45	5.8	Anxiety disorder	Gastrointestinal issues, Hepatitis, Obesity, Sleep issues, Asthma
HH032	Male	47.5	Undergraduate degree	0	ASD	45	2.8	Anxiety disorder, Chronic Fatigue Syndrome	Sleep issues

HH033	Female	46.0	Postgraduate degree	2	ASD	43	2.3		
HH034	Female	47.3	Postgraduate diploma	1 (1)	ASD	46	1.2		
HH035	Female	59.3	Postgraduate degree	2 (0)	Asperger's	57	2.8		Sleep issues
HH036	Female (cisgender)	46.9	Postgraduate degree	0	Asperger's	43	2.0	Attention Deficit Hyperactivity Disorder	
HH037	Male	56.5	Started high school	1 (0)	ASD	56	0.2		Gastrointestinal issues
M (SD)		53.5 (7.6)				50.3 (8.2)	3.0 (2.8)		

**Autism CRC**

The University of Queensland
Long Pocket Precinct
Level 3, Foxtail Building
80 Meiers Road
Indooroopilly Qld 4068
T +61 7 3377 0600
E info@autismcrc.com.au
W autismcrc.com.au



@autismcrc

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



Australian Government
Department of Industry, Science,
Energy and Resources

Business
Cooperative Research
Centres Program