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## Exploring the Experience of Seeking an Autism Diagnosis as an Adult

Matthew de Broize, BHlthSc(Hons)<sup>1,2</sup> Kiah Evans, BSc(OT)Hons, PhD,  
GradCert Research Commercialisation<sup>2–5</sup> Andrew J.O. Whitehouse, BSc(Speech Pathology)Hons, PhD<sup>2,3</sup>,  
John Wray, MBBS, FRACP<sup>6</sup> Valsamma Eapen, MBBS, PhD, FRCPsych, FRANZCP<sup>2,7,8</sup>,  
and Anna Urbanowicz, BSc(OT)Hons, PhD<sup>1,2,9</sup>

### Abstract

**Background:** Emerging research suggests that seeking an autism diagnosis as an adult is usually difficult and time-consuming but brings relief once a diagnosis is made. This study explored the experience of the pathway to an autism diagnosis during adulthood for adults living in Australia.

**Methods:** We conducted a qualitative phenomenological study and interviewed 13 adults who identified as autistic about their pathway to autism diagnosis in their mode of choice. Spoken interviews were transcribed verbatim, and transcripts were analyzed by using a thematic approach.

**Results:** Data analysis resulted in 6 themes and 20 meaning units that described the experiences of adults seeking an autism diagnosis in Australia. These themes involved two interwoven journeys that spanned before, during, and after the diagnostic process. The personal journey involved feeling different, considering autism, and living as autistic, whereas the clinical journey involved missed opportunities, varied diagnostic experiences, and absent supports.

**Conclusions:** Given the potential benefits for adults obtaining a formal autism diagnosis and accessing post-diagnostic supports, it is important that health professionals and governments collaborate to reduce access barriers and ensure adequate services are available. The findings from this study informed the development of Australia's national guideline for autism diagnosis.

**Keywords:** autism spectrum disorders, adults, diagnosis, health professionals, identification, supports

### Community Brief

#### *Why is this an important issue?*

The experience of being diagnosed as autistic as an adult is not well understood, particularly in Australia. Research from other places, such as New Zealand and the United Kingdom, suggests that receiving an autism diagnosis in adulthood is difficult and time-consuming, but brings relief. We do not know whether this is the same for adults in Australia.

<sup>1</sup>Queensland Centre for Intellectual and Developmental Disability, MRI-UQ, The University of Queensland The University of Queensland, South Brisbane, Australia.

<sup>2</sup>Cooperative Research Centre for Living with Autism (Autism CRC), The University of Queensland, Long Pocket Precinct, Indooroopilly, Australia.

<sup>3</sup>Telethon Kids Institute, The University of Western Australia, Perth Children's Hospital, Nedlands, Australia.

<sup>4</sup>School of Allied Health, Social Work and Speech Pathology, Curtin University, Bentley, Australia.

<sup>5</sup>School of Allied Health, University of Western Australia, Crawley, Australia.

<sup>6</sup>Child Development Service, Child and Adolescent Health Service, West Perth, Australia.

<sup>7</sup>Academic Unit of Child Psychiatry and South West Sydney Local Health District (AUCS) and Ingham Institute, Liverpool, Sydney, Australia.

<sup>8</sup>School of Psychiatry, Faculty of Medicine, University of New South Wales (UNSW), Kensington, Australia.

<sup>9</sup>Social and Global Studies Centre, School of Global, Urban and Social Studies, RMIT University, Melbourne, Australia.

*What was the purpose of this study?*

This study aimed at exploring the experience of seeking an autism diagnosis during adulthood in Australia.

*What did the researchers do?*

We conducted interviews with 13 adults who identified as autistic about their pathway to an autism diagnosis. Three sets of interview questions were used, depending on whether they had already obtained an autism diagnosis, were going through the assessment process, or were self-diagnosed. Adults completed the interview in their mode of choice. Spoken interviews were transcribed word-for-word, and the transcripts were analyzed to identify common themes.

*What were the results of the study?*

We identified six themes that described the experiences of adults seeking an autism diagnosis in Australia. These themes involved two related journeys that spanned before, during, and after the diagnostic process. The personal journey involved feeling different, considering autism, and living as autistic. The clinical journey involved missed opportunities, varied diagnostic experiences, and absent supports. Before starting the diagnostic process in adulthood, participants described always feeling different and many missed opportunities to receive an autism diagnosis in their younger years.

During the diagnostic process, participants described beginning to consider whether they were autistic and the varied pathways they underwent to confirm this. After the diagnostic process, participants described their experiences of living as autistic and a lack of post-diagnostic supports tailored to their needs.

*What do these findings add to what was already known?*

Our findings were similar to previous research findings from other countries, including the complex journey to diagnosis, relief and understanding on identifying as autistic, and lack of post-diagnostic services. However, to our knowledge, this is the first qualitative study to explore the experiences of adults seeking an autism diagnosis in Australia. Further, we included participants who did not have a formal diagnosis of autism. This group of people is often excluded from autism research, and their experiences of seeking an autism diagnosis are largely unknown.

*What are potential weaknesses in the study?*

The weaknesses of our study included recruiting a relatively small sample of mostly Caucasian females, and we did not consult with our study participants or other autistic adults to see whether our final themes aligned well with their experience. However, no new findings emerged in later interviews and our findings were similar to international literature. Future research should recruit more diverse groups of autistic adults and involve greater levels of autistic input.

*How will these findings help autistic adults now or in the future?*

Our findings informed the development of the “National Guideline for the Assessment and Diagnosis of Autism Spectrum Disorder in Australia,” a first step toward improving autism diagnosis in Australia.

**Introduction**

AUTISM DIAGNOSIS TYPICALLY occurs during early childhood, but several factors can contribute to people receiving an autism diagnosis later in life.<sup>1,2</sup> Changes to autism diagnostic criteria mean that individuals who may have not met the criteria in childhood, may now meet the criteria for diagnosis in adulthood.<sup>3</sup> Also, those who are now seeking an autism diagnosis as an adult may not have been identified during childhood due to a paucity of accessible diagnostic services and/or a lack of public and professional awareness about autism, which has increased over the past two decades.

Individuals with subtler or atypical presentations, including females, may not receive a diagnosis until adolescence or

adulthood when demands on communication, flexibility, and social interaction increase and surpass the individuals' abilities.<sup>4,5</sup> Further, camouflaging autistic traits, particularly among females, may also contribute to difficulties with receiving an autism diagnosis.<sup>6</sup>

Adults often experience barriers to accessing an autism diagnosis, with varied levels of satisfaction with the diagnostic process.<sup>7-9</sup> According to a large international study of more than 650 participants, many adults identify fear of not being believed by professionals as a barrier to autism diagnosis in adulthood.<sup>10</sup> Other barriers may include anxiety about appointments, lack of access to knowledgeable specialists, cost, communication difficulties, mistrust of professionals, stigma, and complexity of the health care system.<sup>9,10</sup>

One UK study of 128 autistic adults found that participants had varied levels of satisfaction with the diagnostic process, with 47% being “very/quite satisfied” and 40% being “very/quite dissatisfied.”<sup>11</sup> The authors found that the extent of delays, number of professionals seen, quality of information given at diagnosis, and level of post-diagnostic support predicted satisfaction levels.<sup>11</sup> We know little about the experience of adults seeking an autism diagnosis in Australia. In particular, we know very little of the experience of self-diagnosed adults, who may experience unique barriers to formal diagnosis, and who are frequently excluded from research.<sup>12</sup>

Adults most commonly report positive experiences when diagnosed as autistic, though a small proportion describe negative reactions. Receiving an autism diagnosis tends to provide the adult with a sense of self-discovery and identity formation and allows for connection with the autistic community.<sup>9,13–18</sup> In a study of 37 adults, these positive reactions were also found to extend to self-diagnosed individuals.<sup>19</sup> Participants in another study described autism as fundamental to their understanding of the world, and they rejected the idea that negative experiences such as suffering are intrinsically linked to autism.

Rather, it is something inseparable from them that affects how they process the world.<sup>20</sup> Although a diagnosis of autism can provide individuals with access to support services, such as government subsidized assistance programs,<sup>16</sup> many adults report a lack of appropriate post-diagnostic support services.<sup>9,13,15,21</sup> In some cases, individuals experienced negative reactions to their autism diagnosis, including feelings of anxiety, confusion, upset, anger,<sup>9,11,16</sup> and/or regret over not being diagnosed earlier.<sup>12,13,16</sup> The potential emotional benefit, combined with the dearth of research on the subject, highlights the need for further study in this area to inform autism diagnostic practices in adults.

Given the heterogeneity of autism diagnostic practices in different parts of the world, it is important to explore the experiences of adults seeking an autism diagnosis in a given place to inform practices in that area. At the time of this study, autism diagnostic practices varied within Australia, and there was no consistent standard applied to diagnostic assessments across the country.<sup>22,23</sup> Only two states, Western Australia and Victoria, had formal guidelines for adult autism diagnosis.<sup>24,25</sup> The aim of this study was to explore the experiences of seeking an autism diagnosis in adulthood from the perspective of adults who identify as autistic.

Research on the diagnostic experiences of autistic adults have largely been conducted outside of Australia,<sup>7,9,14,16</sup> included adults who were diagnosed in childhood or adolescence,<sup>11,13</sup> and excluded self-diagnosed adults.<sup>12,17</sup> We know very little about the experiences of adults (both formally- and self-diagnosed as autistic) who seek an autism diagnosis in adulthood, particularly in Australia. Therefore, this study aimed at answering the research question, “What is the experience of the pathway to an autism diagnosis in adulthood for adults living in Australia?”

## Methods

### Research design

This study took place as part of a larger program of research to inform the development of Australia’s first national

guideline for autism diagnosis.<sup>26</sup> We conducted a qualitative phenomenological study<sup>27</sup> collecting data through semi-structured interviews, with ethical approval from the University of Western Australia (RA/4/1/8711) and the University of Queensland (2017000472).

Although the findings outlined in this article focus on experiential aspects of the diagnostic journey, findings that focused on direct suggestions to ensure the guideline for autism diagnosis accommodated the needs of autistic adults have been published elsewhere.<sup>28,29</sup> The Cooperative Research Centre for Living with Autism (Autism CRC; funder and publisher of the guideline) is the world’s first national, cooperative research effort focused on autism and does not provide assessment or diagnostic services.

### Interviews

**Sample.** Participants ( $n=13$ ) were aged 18 years or older, and they met one of the following inclusion criteria: (1) had an autism diagnosis; (2) were currently undergoing an assessment for autism diagnosis; or (3) were self-diagnosed as autistic and had not yet sought an autism diagnosis. Adults who received a diagnosis of autism during childhood (0–17 years) were excluded. Potential participants were informed of the study through newsletters from the Autism CRC, the Queensland Centre for Intellectual and Developmental Disability, and social media.

Of the 19 individuals who expressed interest, 13 autistic adults proceeded to complete an interview by using their modality of choice (video conference  $n=6$ , telephone  $n=4$ , face-to-face  $n=1$  and email  $n=2$ ). Of our 13 interviewees, 10 had a confirmed diagnosis of autism, and 3 were self-diagnosed (Table 1).

**Data collection.** Three sets of semi-structured interview guides, consisting of key questions and prompts about the diagnostic journey, were developed to cater for the

TABLE 1. DEMOGRAPHIC DATA FOR PARTICIPANTS ( $n=13$ )

Demographic characteristic	n/N (%)
IRSAE decile, mean (SD) <sup>a</sup>	6.9 (3.0)
Age (years), mean (SD)	51.2 (15.7)
Age range (years)	30–80
Remoteness	
Major cities of Australia	10/13 (76.9%)
Inner Regional Australia	2/13 (15.4%)
Outer Regional Australia	1/13 (7.7%)
Gender	
Female	8/13 (61.5%)
Male	5/13 (38.5%)
Ethnicity	
Caucasian	11/13 (84.6%)
Asian	2/13 (15.4%)
Diagnosis	
Autism Spectrum Disorder	4/13 (30.8%)
Asperger’s Syndrome	6/13 (38.5%)
Self-Diagnosis	3/13 (30.8%)

<sup>a</sup>Data missing for one participant.

IRSAE, Index of Relative Socio-Economic Advantage or Disadvantage; SD, standard deviation.

participant's autism diagnosis status (Supplementary Data). Feedback on the interview guides was obtained from five researchers working in the autism field and three autistic adults. After feedback, amendments were made to the questions to both improve clarity for autistic adults and allow for a wider range of open-ended responses. Interview questions were organized into two phases.

The first phase involved asking participants to describe important considerations when developing a guideline for autism diagnosis. The second phase of the interview focused on three time periods: before a formal or self-diagnosis of autism, the diagnostic process (if relevant), and experiences after formal or self-diagnosis of autism. Data on participants' age, gender, ethnicity, postcode, and autism diagnosis were collected.

**Procedures.** The first author provided interested individuals with an information sheet and the relevant interview questions and obtained verbal or written consent before conducting each interview. The mean time taken for the spoken interviews was 57 minutes (standard deviation 26 minutes; range 33–121 minutes). Spoken interviews were audio-recorded and transcribed verbatim. The first author briefly discussed emerging findings, with each participant following their interview. During the final two interviews, no new findings emerged about participants' diagnostic experiences from which to draw themes.

#### *Data analysis*

A demographic profile of participants was created through descriptive statistics, including frequencies, means, and standard deviations. Participants' postcodes were used to determine their remoteness status by using the Australian Statistical Geography Survey,<sup>30</sup> as well as their Index of Relative Socio-Economic Advantage or Disadvantage (IRSAD) from the Socio-Economic Index Factor of Australia.<sup>31</sup> The Index uses 5-yearly census data to summarize the socioeconomic conditions of households within a postcode and assigns a corresponding score from 1 to 10. A higher IRSAD score represents greater levels of socioeconomic advantage, and a lower IRSAD score represents greater levels of relative disadvantage.<sup>31</sup>

We used reflexive thematic analysis to examine the interview responses through identifying repeating patterns to capture the essence of the participants' experiences of the autism diagnostic process.<sup>27,32,33</sup> This analytic approach was selected, as it is compatible with a phenomenological research design and the constructionist paradigm.<sup>27,32,33</sup> Interview transcripts were imported into NVivo,<sup>34</sup> and each transcript was read in full by at least two authors (M.d.B. and A.U. or K.E.).

Each of these authors inductively generated a set of preliminary meaning units and themes that were discussed, refined, and arranged to create a credible and dependable overarching thematic structure.<sup>32,33,35</sup> These three authors were each allocated two of the six themes for closer analysis, where final latent meaning units and themes were generated for the time periods before (M.d.B.), during (K.E.), and after (A.U.) an autism diagnosis.

Each author subsequently drafted a description for their allocated latent themes, after which they were refined by the

other two authors with familiarity with the interview transcripts and finally reviewed by the other authors (A.J.O.W., J.W., and V.E.). We have included numerous quotes from participants throughout to ensure our findings reflected the experiences portrayed by the autistic adults. We used pseudonyms throughout this publication.

Reflexivity was addressed throughout the data analysis process to ensure the findings were not the result of pre-conceived ideas by the authors.<sup>33,35</sup> The first author (M.d.B.) conducted the interviews while he was a health sciences honors student, at a time when he had no other experience working with autistic adults or conducting research, during which time he kept a field journal.<sup>35</sup> The first author engaged in the final data analysis process several years later while studying medicine (having not worked in an autism related field), and his further epistemological development was through mentorship during the data analysis process.

The research process was overseen by two authors (A.U. and K.E.) with occupational therapy backgrounds and prior experience in qualitative and quantitative research with autistic participants. A.U. and K.E. identified strongly with a constructivist paradigm, and this was subsequently the philosophical lens used during data analysis.<sup>32</sup> A.J.O.W., J.W., and V.E.'s contribution to planning the data collection methods and reviewing the findings was to contextualize the research study within the clinical landscape where they had experience as diagnosticians and leaders.

Four of the authors (A.J.O.W., J.W., K.E., and V.E.) comprised the Research Executive Committee for Australia's first national guideline for autism diagnosis.<sup>26</sup> To minimize the risk of investigator bias, the data analysis process for this article was delayed until after the guideline was published and intentional steps were taken to only include data that related to the essence of the participants' experiences.<sup>36</sup>

#### **Results**

Data analysis resulted in 6 themes and 20 meaning units that described the experiences of Australian autistic adults during their pathway to a formal or self-diagnosis of autism (see Fig. 1 and Table 2). These themes involved two interwoven journeys that spanned before, during, and after the diagnostic process. The personal journey involved feeling different, considering autism, and living as autistic, whereas the clinical journey involved missed opportunities, varied diagnostic experiences, and absent supports.

#### *Feeling different*

A long history of feeling "different" (Tara, Kate, Hayden), "awkward" (Angie, Kymberly), and like they "didn't fit in" (Angie) was frequently reported by participants. Despite having a long history of feeling different, many participants felt "people my whole life always told me I was different, but they could never tell me why..." (Kate). Several of the participants expressed that they could not understand why things seemed effortless for others, and this feeling often extended into adulthood.

Experiences of social isolation and difficulties forming friendships were common. Many participants reported that they had always found it difficult to interact with others, "I found it hard to make friends... I remember feeling socially isolated and not knowing how to behave with other children



**FIG. 1.** Themes illustrating the interwoven personal and clinical journeys.

my age around the age of four" (Helen). Others described difficulties socializing in later childhood, "about year three, year four was when I started to run into trouble and... struggle with friendships" (Nick).

These difficulties were commonly reported into adolescence and adulthood. Sometimes, these experiences included being "heavily bullied and eventually pulled out of school to do home schooling because my health and mental welfare were suffering badly" (Rebecca).

#### *Missed opportunities*

In many cases, mental health concerns distracted from a diagnosis of autism, such as "I had always received other diagnoses for all my challenges, but none were ever addressed adequately and my mental health has declined all my life" (Rebecca). Some participants were assessed during their youth for possible neurodivergence, but autism was not arrived at as the diagnosis. This was illustrated with "my parents did seek assistance for me in my mid teen years—[they took me] firstly to a paediatrician, then to an adolescent

psychologist, and then to an adolescent psychiatrist, but after... half a dozen sessions with each of them, they found they weren't really getting any answers" (Nick).

A lack of awareness on the part of families or teachers was described by several participants as an explanation for missed opportunities to recognize their autism. Many of the participants' families "acknowledged ... there was something wrong, but there was never ever a finger put on what it was" (Robert). Some participants expressed beliefs that at least one of their parents may have had undiagnosed autism, which some believed may have contributed to their own personal traits going unnoticed. Several participants came from large families and grew up with many siblings. According to them, this made it difficult for their parents to scrutinize their behaviors and subsequently autistic traits went unnoticed.

Finally, the ability to "adopt masking strategies" (Angie), "hide" autistic traits, and "pretend and copy" (Tara) was described by participants as influencing missed opportunities. This was explained further by Angie, with "a lot of my masking was pretty much copying what others did or said, and I kept a record of that mentally, so the more I observed

**TABLE 2. THEMES AND MEANING UNITS ORGANIZED TO ILLUSTRATE THE PERSONAL JOURNAL (THEMES 1, 3, AND 5) AND THE CLINICAL JOURNEY (THEMES 2, 4, AND 6) OVER TIME**

	<i>Personal journey</i>	<i>Clinical journey</i>
Before diagnostic process	Theme 1: Feeling Different <ul style="list-style-type: none"> <li>• A long history of feeling different</li> <li>• Social isolation and difficulties forming friendships</li> </ul>	Theme 2: Missed Opportunities <ul style="list-style-type: none"> <li>• Mental health concerns</li> <li>• Lack of awareness on the part of families or teachers</li> <li>• Ability to adopt masking strategies</li> </ul>
During diagnostic process	Theme 3: Considering Autism <ul style="list-style-type: none"> <li>• A real catalyst</li> <li>• A lot of research</li> </ul>	Theme 4: Varied Diagnostic Experiences <ul style="list-style-type: none"> <li><i>Clinician</i></li> <li>• The importance of trust</li> <li>• Expertise</li> <li><i>Conceptualizing Autism</i></li> <li>• Diagnostic criteria and assessment tools</li> <li>• Input from others</li> <li>• A more complex presentation</li> <li><i>Diagnostic Process</i></li> <li>• Navigating</li> <li>• Time taken</li> <li>• Cost</li> </ul>
After diagnostic process	Theme 5: Living as Autistic <ul style="list-style-type: none"> <li>• A sense of understanding, relief, and/or validation</li> <li>• Diagnosis is the start, not the finish</li> <li>• Being out about being autistic was an ongoing evolving situation</li> </ul>	Theme 6: Absent Supports <ul style="list-style-type: none"> <li>• Support was desired</li> <li>• Nonexistent or very few and overbooked</li> </ul>

and the more social experiences I had, then the more I had in my memory bank." Many of the participants felt that autistic girls and women were often better at adopting masking strategies.

### *Considering autism*

A "real catalyst" (Luke) where they started to consider autism as a possible diagnosis was described by participants. Several participants identified autistic traits in themselves after a child or grandchild was diagnosed as autistic, as illustrated with "seeing how my child mirrors myself" (Angie) and "recognised so many characteristics, so many similarities" (Kate). This led the participants to "question whether I'm also autistic" (Angie).

Other participants "stumbled across" (Rebecca) autism in other ways and the concept "just resonated" (Monika). This occurred when they heard of someone being diagnosed with autism, met an autistic individual, or read about autism (e.g., novel, magazine article, and academic literature). This stimulated "an intellectual curiosity" (Monika) and an initial information search, for example "I looked it up on Google" (Tara), so that they could "begin learning about autism" (Angie).

Participants also spent time with autistic individuals or their caregivers, where they found "it became clear to me that his personality type was similar to my own" (Tim). The final catalyst for considering autism was whether it was suggested by a health professional or someone else. Health professionals were generally consulted for other physical or mental health conditions, allowing them to "notice behaviour traits" (Robert) as co-occurring conditions resolved. Other participants reported that "friends and acquaintances ... initially suggested that I might have it" (Jenny), along with "work colleagues" (Nick) and "a complete stranger" (Kymberly). At first, some reacted by becoming a "little bit offended" (Kymberly), however once they had "reflected back then [they] thought, 'Yes, that may well be the case'" (Nick).

After the initial catalyst and realization that autism might be a relevant diagnostic label, participants "did a lot of research ..." (Monika) as part of the process of considering autism. This included reading "both in books and on-line" (Jenny), "evidence-based research" (Angie), "the DSM" (Hayden, Rebecca), past clinical "reports" (Hayden), "other people's accounts" (Monika), and "on-line discussion groups" (Jenny).

The intensity of this reading ranged from "I gradually read bits and pieces" (Jenny) through to "I read as much as I could" (Rebecca) and "it became a search for what was going on" (Hayden). One participant implied that this research was related to being autistic with "I have always dived obsessively into learning new things, and this became yet another" (Rebecca). Participants "started doing self-assessments online" (Kate) and "ticking off the boxes" (Angie) for diagnostic criteria. For some participants, their research confirmed their ideas that they may be autistic quite easily, expressed with "it sure looked like it" (Kate) and "every single one of them matched" (Kymberly).

For others, it was only after they read about lived experiences of autism that they felt sure they were autistic, as illustrated with "things really started resonating when I was reading ... other people's accounts of how they found being in the world and being autistic. And I [thought], 'I really get

that bit, that completely makes sense to me.'" (Monika). For other participants, they were still not sure at the conclusion of their research, for example "I knew I still didn't fit, but I couldn't work out why ... there were certain things that did fit in the definitions ..." (Hayden).

### *Varied diagnostic experiences*

**Clinicians.** Participants described varied experiences of clinician relationships; however, they collectively emphasized the importance of "trust" (e.g., Nick, Robert, Tara). The importance of trust was illustrated with "I really need to trust the person, or I won't let them see behind the mask" (Monika), which was contrasted with a description of when trust is achieved "I'm fully on board—whatever you need to know, you're getting the truth..." (Monika).

Although some participants entered the diagnostic process "willing to trust" (Monika) and "felt very much like [they] got it from the first phone call" (Monika), others reported that "it takes time for me to ... trust them and to build rapport" (Angie) so that you can "talk about your personal experiences" (Angie) and they need "a long time to settle in ... to feel safe with a person" (Tara).

Participants described several strategies that clinicians used to facilitate trust. Communication strategies included being able to "e-mail [them] rather than have to phone through a receptionist" (Monika), "[ringing] exactly when [they] said [they'd] ring, and then [their] e-mail was worded appropriately" (Monika), and "giving me very sensible, plain-spoken, practical advice" (Luke). Relationships were fostered through being "genuinely ... interested in people on the spectrum" (Monika) and having "awareness of how to deal with (especially) adults who are going through getting an autism ... diagnosis" (Luke). Further, being "considerate" (Monika), "gentle" (Monika), and "friendly and personable" (Rebecca) prevented intimidation.

Varied experiences of clinician expertise were also described by participants. Participants expressed greater confidence if they actively sought clinicians working in "a specialist autism centre" (Luke) or who were known to have "experience in diagnosing adult[s]" (Rebecca). This was further highlighted by negative experiences reported by some participants, such as "they admitted to knowing little about autism, but agreed to take me on and learn as we go, but 'fired' me as a client the next day via a text message because I was 'too complex'" (Rebecca).

**Conceptualization of autism.** Varied experiences in relation to how diagnostic criteria and assessment tools were used to conceptualize autism were described by participants. For some, "the way the levels are used to grade us doesn't feel entirely right ... we can be severely impacted in a number of ways, not just intellectually" (Rebecca). Assessment measures were often described as "extremely useless as many of us can use deductive reasoning and time to figure out the correct responses [and] it's also possible to find [the] test online and learn it perfectly" (Rebecca) and "a lot of it was tedious and difficult, and I found the questionnaires hard to answer a lot of the time because they're very black and white" (Monika). Participants were more accepting of assessment measures if the clinician were "open to interpreting the results, rather than using them as a ... blunt instrument" (Monika).

Varied experience in relation to the inclusion of input from others when conceptualizing autism was described by participants. This was specifically related to evaluating whether diagnostic indicators originated in the early developmental period, rather than just relying on self-report, with a recognition that “proving ‘lifelong’ is tricky” (Monika) for adult diagnosis.

Some participants felt that “having the information from people around me, that was more valuable to me, because I think they gave an honest opinion... so that was more honest to me than a self-report of myself” (Kymberly). In contrast, other participants raised concerns when they “don’t have my parents anymore ... when you don’t have anybody about who can vouch for what your behaviours as a child were, [they] said, ‘We’re kind of a bit stuffed’” (Luke) and “Mum and Dad didn’t fully understand [the parents’ observation sheet] ... it really wasn’t a true observation ... and some of the answers were just plain wrong” (Hayden).

Finally, varied experiences of conceptualizing autism when gender, age, and co-occurring conditions led to a more complex presentation were described by participants. There were concerns that “girls and women fly under the radar so easily with the current diagnostics because they are geared so heavily towards boys and men” (Rebecca). Further, there was a concern that “there actually isn’t a lot of awareness that adults can be autistic, and that children actually still grow up autistic” (Angie).

In addition, participants observed “the other thing which clouded the diagnostic process was my mood disorder [and it] definitely affected the answers I provided and would have confounded the assessment” (Nick) and “many people are fooled by my intelligence—maybe this is a reflection of their belief that autistic people are dumb” (Helen).

**Diagnostic process.** Varied experiences in relation to navigating the diagnostic process were described by participants, ranging from “it was an effort” (Nick) to “I basically just showed up with an open mind ... and I went through a series of questionnaires [and] tools ... for me it was comprehensive enough” (Angie). Accessing an assessment was described as “very difficult, even in [a capital city], to find an adult specialist clinician for autism spectrum disorders” (Nick), although participants received suggestions from existing and new networks, such as an “acquaintance who pointed me to [a suitable] specialist” (Nick) or through asking for “recommendations on social media” (Angie).

Even once the assessment process commenced, participants stated that “everything is very disjointed... It’s hard to ... just navigate your way through this whole lot, it’s a labyrinth...” (Kate). Challenges during the assessment included “I had to take hours of public transport ... which is very difficult for me from a sensory and anxiety point of view” (Rebecca) and “the building itself was not very autism friendly sensory-wise and I would be a mess of sensory overload before the sessions even began” (Rebecca).

Varied experiences related to their satisfaction with the time taken to complete the diagnostic process were described by participants. Some participants describe it as “a short period of time” (Tim) and were “very happy with the time it took” (Hayden) or “content to wait” (Rebecca), whereas others considered the process to be “a little bit time consuming” (Nick). Along with allowing time to build a trusting

relationship with the clinician where they “get to know me” (Monika), the participants described advantages of not rushing the diagnostic process. These included “we could break things up into one-hour blocks” (Nick) when it was “quite draining” (Monika) and a “dual focus—it wasn’t just about diagnosis, it was about counselling and supporting me” (Hayden).

Finally, varied experiences related to the cost of the diagnostic process were described by participants. Some participants expressed the sentiment that they were “lucky to have a little bit of money to go and get a proper diagnosis” (Tara) or the diagnostic appointments were scheduled to maximize government rebates, hence they “could more easily afford it via Medicare [Australia’s publicly-funded universal health care insurance scheme]” (Rebecca). The affordability of an autism diagnosis was related to the participants life stage, for example “now I can easily afford it, but previously, if I’d been thinking about getting an assessment, cost could well have been the consideration” (Jenny).

Cost sometimes acted as a deterrent, as illustrated with “we didn’t press too hard to get a formal diagnosis, [as my clinician] said ... it ... was going to be ... quite expensive, [and they] didn’t recommend it because [they] didn’t think that ... I would benefit” (Luke).

#### *Living as autistic*

Receiving a formal diagnosis or arriving at a self-diagnosis of autism brought a sense of understanding, relief, and/or validation for many participants. A diagnosis gave participants “something to explain who you were” (Angie) and “one of the pieces of the puzzle that had been missing all my life” (Rebecca). It helped them understand themselves better, to “understand why I was different” (Kate) and “understand that any minor difficulties I have are probably due to a difference of perception in the world” (Luke). For many “it just made my whole life make sense” (Tara) as illustrated by Angie:

...on the day I received my diagnosis, it’s funny, because I remember walking home, and immediately that the world just seemed different. It looked different, and I felt different, and it’s like the whole world just made sense, and I knew why I had these sensory difficulties that I have, and I knew why was different as a child, and I knew why I still struggle now, as an adult, with mental health issues, and a lot of things just suddenly made sense for me.

Some participants were “worried that I’d talked myself into thinking it was autism and that it wasn’t at all” (Rebecca), so receiving an official autism diagnosis came with a sense of relief and/or validation, “I cried because it had been quite a stressful process, and I said, ‘I’m not crying because I’m upset, I’m just, you know, relieved it’s over,’ ... I was right, you know, that I’m not stupid, that kind of validation. That was nice.” (Monika).

A couple of participants described disappointment after diagnosis, wanting to have been diagnosed with something else that they perceived could be managed with medication, such as attention deficit hyperactivity disorder, or desiring to have been diagnosed earlier in life, as a diagnosis in older adulthood meant life up until diagnosis was “wasted because I didn’t know who I was” (Tara).

The sentiment that “diagnosis is the start, not the finish, of the journey” (Hayden) was common across the participants. Participants described a “constant learning process and adapting process” (Nick) after diagnosis or self-diagnosis. This process involved “learn[ing] more about me and how I function and what I need, to do that well but with the least toll on myself” (Monika), “looking at where [autism has] impacted on my life and how can I change my behaviour” (Robert), and “figure[ing] out ways to make my life a bit easier” (Kymberly).

Many participants spoke about “challenges just being in the neurotypical world, in terms of people not understanding us” (Jenny) and how they had “learned a lot of coping mechanisms” (Kate) for living in such a world. Coping mechanisms included “self-help practices... like... practicing mindfulness and also having a sleep routine” (Angie), “learning to avoid situations.... when I recognised that situation the second time, I learned to avoid it, or I learned how to cope, how to navigate it” (Kate), and learning to manage fatigue associated with “the extra energy that it requires to process the world and deal with the world as it sits” (Hayden) by allowing more time for rest before, during or after social events.

For some participants, understanding their autistic strengths and difficulties improved their interpersonal relationships with family members and/or work colleagues, and came with decreased levels of anxiety and increased levels of confidence. For example, self-diagnosed Luke described feeling “lot less anxious about situations because I understand that any minor difficulties I have are probably due to a difference of perception in the world” and Hayden reported that since his diagnosis he has “so much more confidence in [his] abilities to deal correctly with people ... that itself has been empowering.”

“Being out about being autistic” was as “an ongoing evolving situation” (Monika) for participants, involving weighing up the benefits and disadvantages of disclosing their autism diagnosis. Many participants were not openly autistic with everyone in their lives. For disclosure to occur, participants needed “to feel really safe” (Monika). A couple of participants found that disclosing allowed them to stop “trying to hide my autistic things... it was empowering” (Hayden) and made it “easier to be me” (Monika). Nick described sharing his diagnosis with one or two close friends who were “understanding about it.”

Some felt reluctant to disclose, as “a lot of people are still really, really negative about [autism]” (Monika) and “they might think that people with Asperger’s are generally dumb, except for their special interests, or special abilities” (Jenny). Angie described not telling her parents “because I know they won’t accept it.” On disclosing they identified as Asperger’s, Jenny described feeling that people would expect her “not to understand things” and to “take things literally” and as a result she’s “gradually come to disclose less, and less....”

#### *Absent supports*

Post-diagnostic support was desired by most participants. Many expressed a desire for support that involved “someone they trust, and can relate to, who can help them through processing the diagnosis, and knowing where to turn to for help” (Angie) and “more life skills assistance... to deal with

the real-world situations like uni or workplaces and moving out of home, things like that.” (Nick). Participants spoke about the need for support “to be focused on the positive, not the negative ... to empower people to be able to take advantage of their diagnosis and use it to move forward” (Robert).

Support services were often “non-existent” or “very few and ... overbooked” (Kate). Participants felt “once I was given the diagnosis, I was then on my own with it to a large degree as there is almost no support and services for autistic adults.” (Rebecca). Some accessed support groups that were valuable and helped them feel “less of a freak” (Jenny). However, others “wouldn’t want to sit around a group of people and talk about it” (Kymberly).

A few participants stated that they desired to attend support groups, but were either unable to find them, or that the ones they found did not meet their needs, for example they did not cater to older adults. Some participants chose to continue individual psychological therapy with their diagnostician. However, psychological therapy after diagnosis did not always meet the needs of the individual as highlighted in Rebecca’s experience with “I found it distressing that the psychologist immediately wanted to start working on my ability to read social cues when it’s the least of my problems at this point.” Difficulty accessing the National Disability Insurance Scheme (NDIS) was common, as shown by Kate with “You can’t access them unless you’re willing to wait six months.”

#### **Discussion**

To our knowledge, this is the first qualitative study to explore the experiences of adults seeking an autism diagnosis in Australia and our findings provide insights into both the diagnostic and life experiences of these adults. Most participants expressed positive emotions such as relief, understanding, and/or confidence on receiving a diagnosis of autism or self-diagnosing autism. This supports previous work that found that the major reactions to an autism diagnosis in adulthood were relief and self-understanding.<sup>9,15,16</sup>

However, despite a diagnosis of autism generally being regarded as positive, our participants described varied and often complex journeys to diagnosis, along with a lack of post-diagnostic services and supports. This is in line with research from other countries that demonstrate that adult autism diagnostic and post-diagnostic services are often difficult to access and inadequate.<sup>9–11,16,21,37</sup> The positive perception of an autism diagnosis, and the varied experiences of the diagnostic process and post-diagnostic support, highlights the potential benefits of implementing national guidelines that makes autism diagnostic assessments and post-diagnostic supports more consistent and accessible to adults.

The clinical pathway outlined in the recently published Australian national guideline recommends that individuals are linked with supports at the time when the need is identified, rather than waiting on confirmation of a formal diagnosis to initiate a referral.<sup>26</sup>

Barriers to receiving a diagnosis created by the cost of assessment, difficulty accessing services and specialists, and anxiety were supported by an online study conducted on participants from 18 countries, including the United States, United Kingdom, and Canada.<sup>10</sup> Negative experiences with health professionals have also been highlighted in the

literature as a barrier to accessing a diagnosis.<sup>38</sup> This indicates that some barriers to adult autism diagnosis may be universal across health systems.

Our participants reported that the barriers they experienced either prevented them from pursuing a timely diagnosis or created significant stress when attempting to obtain a diagnosis. The sensory and communication needs of autistic people, and medical environments or professionals that do not accommodate appropriately, can cause autistic individuals to become overwhelmed.<sup>10</sup> This is particularly applicable to general practitioners, as they are often the first point of contact for individuals seeking an autism diagnosis and have the opportunity to facilitate adults accessing a potentially beneficial diagnosis.<sup>11</sup>

Due to the importance of accommodating the needs of autistic adults, diagnosis should be conducted by professionals with significant training on the needs of autistic people.<sup>39,40</sup> Although many participants in our study stated that diagnostic professionals lacked experience with autism in adulthood, participants reported satisfaction with their diagnosing health professionals when there was a sense of trust. This is in line with a 2014 UK study, which reported dissatisfaction with the diagnostic process, but satisfaction with diagnosing professionals.<sup>11</sup>

The lack of available post-diagnostic care is a common trend for autistic adults. Studies from the United Kingdom<sup>11,37,39</sup> and a study from New Zealand<sup>8</sup> showed that autistic adults reported a lack of post-diagnostic care. This lack of care was also expressed by diagnosticians in UK studies.<sup>11,39</sup> An Australian study on the experiences and needs of autistic women found that many wished that they received support earlier in life and wished for ongoing support.<sup>12</sup>

We found the majority of our participants desired more post-diagnostic support, but that preferences regarding the type and format of post-diagnostic support were individualized and would ideally not require a formal diagnostic label for access. Many expressed a desire for post-diagnostic support to involve someone they trusted and could relate to. Perhaps these roles could be fulfilled by autistic people with relevant expertise.

This idea is supported by recent research that highlights the benefits of autistic-led post-diagnostic support<sup>41</sup> and connectedness with the autistic community.<sup>42</sup> For individuals who favor social or collaborative experiences, support groups could also facilitate linkages with the autistic community,<sup>42</sup> however these were reported by participants to be unavailable or difficult to locate. For those who prefer a more solitary experience, their diagnostician could collaborate with the individual to co-design an appropriate post-diagnostic plan.

Beyond the assessment process, there is a need for government and community support programs to be autism-friendly so that it is easier for autistic adults to access these services. This is particularly relevant given the large proportion of disability services recipients who have an autism diagnosis,<sup>43</sup> and it is possible that there are other autistic adults who are not receiving support due to not meeting eligibility criteria, lack of awareness of available support, access difficulties, and/or self-diagnosis.<sup>19</sup>

#### **Limitations**

This is one of the first studies to examine the diagnostic experiences of autistic adults in an Australian context. The

use of interviews allowed us to develop a deep understanding of the personal experiences of the participants.<sup>44</sup> A limitation is that member checking was not performed on the themes as they emerged. However, the themes were developed by three authors and checked by the remaining authors after analysis.

The majority of participants in our study were Caucasian females. A further limitation for this study is that the sample size was relatively small ( $n=13$ ), however saturation was achieved during the data analysis process. It is possible that the six autistic adults lost to follow-up may have had different experiences of the autism diagnostic experience, for example they may have not felt comfortable participating in an interview if they had a particularly negative experience or if they had a complex life situation (such as multiple co-occurring conditions).

Future research should aim at recruiting more diverse samples, recruited through multiple organizations, to investigate whether the themes we found also emerge with people with different demographic characteristics and involve greater levels of autistic input. Unfortunately, this was not possible in the current study due to external time constraints related to the honors course (M.d.B.) and guideline development project.

#### **Conclusion**

Findings from this study serve to provide insights on Australian adults who have received or are considering an autism diagnosis. Our data generally indicate a positive psychological benefit associated with a formal or self-diagnosis of autism. However, the limitations of being unable to access support services with a self-diagnosis highlight the need to make obtaining an autism diagnosis more accessible for adults. This can be done by addressing the barriers that were reported by participants and increasing the autism awareness of health professionals. The data from this study have informed clinical practice and policy development in Australia<sup>26</sup> and may also be relevant internationally.

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A.U., K.E., and M.d.B. contributed to the study design, data collection, data analysis, and write-up. A.J.O.W., J.W., and V.E. contributed to the study design and write-up. All co-authors have reviewed and approved this article before submission. This article has been submitted solely to *Autism in Adulthood* and is not published, in press, or submitted elsewhere.

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## Supplementary Material

### Supplementary Data

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Address correspondence to:  
Anna Urbanowicz, BSc(OT)Hons, PhD  
Social and Global Studies Centre  
School of Global, Urban and Social Studies  
RMIT University  
GPO Box 2476  
Melbourne  
VIC 3001  
Australia

Email: anna.urbanowicz@rmit.edu.au