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ORIGINAL PAPER

A Qualitative Study of Adults' and Support Persons' Experiences of Support After Autism Diagnosis

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Abstract
Adulthood autism diagnosis has become increasingly common, but little is known about post-diagnosis support experiences and needs. We interviewed 19 autistic adults and 4 support persons on experiences of formal and informal post-diagnosis support. Reflexive thematic analysis was used to identify themes. Participants reported difficulties accessing suitable formal support, especially regarding education and employment. Informal support was helpful but created challenges in the relationships between autistic adults and support persons. For autistic adults, support from autistic peers fostered belonging and self-acceptance. We also identified complex interactions between adults' post-diagnosis identity development and support experiences as they resolved the dilemma between self-acceptance and a desire to change. Findings have important implications for services working with autistic adults and their families.

Keywords Autism · Adults · Qualitative research · Families · Support needs · Interventions

In recent years, a small number of mostly qualitative studies have explored the experiences of receiving an autism diagnosis in adulthood. Adults in these studies reported long histories of unexplained interpersonal difficulties and a sense of being different from others (Bargiela et al., 2016; Hickey et al., 2018; Punshon et al., 2009). For these adults, receiving the diagnosis led to re-interpretation of their strengths and difficulties (Hickey et al., 2018; Leedham et al., 2019; Lewis, 2016), accompanied by intense emotional reactions (Huang et al., 2021; Lewis, 2016; Powell & Acker, 2016). Despite having been diagnosed with a *disorder*, some adults embrace autism as a positive part of their identity (e.g. Lewis, 2016; Tan, 2018). Concerningly, adults often reported significant difficulties accessing support after diagnosis (Crane et al., 2018; Lewis, 2016). Most research into late diagnosis was focused on adults without intellectual disability, where delayed diagnosis was assumed to be due to more subtle autistic traits and fewer functional difficulties (Huang et al., 2020). Although several studies identified cases of previously-undiagnosed autism in adults with intellectual disability (Roy & Balaratnasingam, 2010; Saemundsen et al., 2010), relatively little is known about their subjective experiences or specific support needs. More research is needed to understand adults' support needs and experiences in the context of broader discourse on the dual status of autism as both a disability and social identity.

Views of Autism and Disability

Autism's complexity as a condition involving both strengths and vulnerabilities gave rise to disparate understandings with differing implications. Autism has traditionally been defined in terms of social and behavioural deficits in need of remediation (Baker, 2011; Kapp et al., 2013). These views are aligned with the medical model of disability, which regards disability to be the result of individual-level deficiencies that must be corrected to improve functioning (Chapman, 2019; Kapp et al., 2013). In contrast, the neurodiversity movement defines autism as a natural human variation and minority group identity deserving acceptance

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(Bagatell, 2010; Kapp et al., 2013). Neurodiversity proponents endorse the social model of disability, where disability is attributed to an unaccommodating society and should be remediated by efforts to reduce stigma and remove barriers to participation (Kapp et al., 2013; Shakespeare, 2017). However, neither medical nor social models fully account for the complex interaction between individual impairment and social barriers in autistic people's experiences. Studies found that many autistic adults endorse a combination of medical model and neurodiversity beliefs, where appreciation of autistic identity and strengths coexist with a desire to reduce deficits through interventions (Bagatell, 2010; Kapp et al., 2013). These disparate perspectives have important implications for the understanding of autistic adults' support needs and priorities.

Support for Autistic Adults

A key issue identified in studies of adulthood autism diagnosis is inadequate formal support (Arnold et al., 2020; Crane et al., 2018; Griffith et al., 2012). Adults reported receiving little to no guidance on navigating the gap between diagnostic and support services (Crane et al., 2018; Jones et al., 2014; Lewis, 2016). They were disappointed that autism services tend to focus on children or adults with higher support needs (Crane et al., 2018; Lewis, 2016), while mainstream mental health professionals are inadequate at addressing autism-related concerns (Griffith et al., 2012). Adults also described the dilemma of being considered too capable for disability services while still having significant support needs (Griffith et al., 2012). Studies reported a variety of desired supports including social skills, education/employment, self-care, and mental health, which are often unmet (Baldwin & Costley, 2016; Crane et al., 2018; Griffith et al., 2012; Jones et al., 2014). Studies of autistic adults with intellectual disability found them to have poorer adaptive functioning skills, more co-occurring psychiatric conditions, and more behaviours of concern compared to their non-autistic peers, suggesting greater support needs (Maguire et al., 2022; McCarthy et al., 2010; Totsika et al., 2010). Most research into supports and interventions for autistic adults with and without intellectual disability was focused on social skills (Lorenc et al., 2017; Walton & Ingersoll, 2013). There has also been a number of studies examining employment interventions for autistic adults with a range of intellectual abilities (Hedley et al., 2016).

Few studies have explored informal support from family, friends, and online communities. Autistic adults described varying responses from family and friends after their diagnosis, including acceptance, dismissiveness, and rejection (Crane et al., 2018; Lewis, 2016; Punshon et al., 2009). In these studies, support from other autistic people in real life and online allowed autistic adults to share experiences, feel accepted, and develop more positive views of autism (Hickey et al., 2018; Tan, 2018). Mothers and partners of late-diagnosed adults described significant difficulties coordinating formal support for their loved ones (Lewis, 2017; Raymond-Barker et al., 2018). Additionally, partners described a sometimes painful process of adjusting expectations and communication techniques (Lewis, 2017). These support persons reported wanting professional help to process their own feelings and learn to support their loved ones after diagnosis (Lewis, 2017; Raymond-Barker et al., 2018). Existing knowledge showed that while informal support can be highly valuable, the need to compensate for inadequate formal support may place undue burden on support persons.

Existing research on post-diagnosis support for adults are limited in both breadth and depth. With the exception of Griffith et al. (2012), most studies on adulthood autism diagnosis only involved cursory discussions of post-diagnosis support. Only a few studies addressed experiences of informal support. Additionally, most of these studies excluded adults with intellectual disability, with several older studies specifically focusing on the now-outdated diagnosis of Asperger's syndrome. While autistic people without intellectual disability do not necessarily have low support needs (Alvares et al., 2019), it is still likely that these studies have overlooked support needs and services specific to autistic adults with intellectual disability.

The present study aims to comprehensively explore adults' and support persons' experiences of formal and informal support after autism diagnosis in adulthood. To achieve this, we interviewed a diverse sample of adults and support persons to understand their perspectives on support needs, roles of formal and informal support, influence of support on identity development, and improving support experiences in the future.

Method

This study formed part of a larger mixed-methods project on experiences of autism diagnosis in adulthood, approved by the UNSW Human Research Ethics Committee, project number HC190582. The research design for this study was mostly guided by pragmatism, a theoretical paradigm which values usefulness of resultant knowledge over adherence to specific philosophical positions (Feilzer, 2009). Our methodological approach was also informed by phenomenology, which aims to understand the essence of a phenomenon by studying individual experiences (Patton, 1990). Combining these theoretical orientations allowed this study to explore

Table 1 Participant Information

Number	Participant group	Age	Gender	Intellectual disability	State	Interview mode	Notes
1	Autistic adult	65+	Male	No	Victoria	Email	
2	Autistic adult	25–34	Non-binary	No	New South Wales	Email	
3	Autistic adult	25–34	Female	No	Queensland	Video	
4	Autistic adult	65+	Male	No	Victoria	Phone	
5	Autistic adult	55–64	Male	No	New South Wales	Face-to-face	
6	Autistic adult	25–34	Female	No	New South Wales	Phone	
7	Autistic adult	35–44	Female	No	Australian Capital Territory	Instant message	
8	Autistic adult	55–64	Male	No	Australian Capital Territory	Video	
9	Autistic adult	55–64	Female	No	New South Wales	Video	
10	Autistic adult	35–44	Female	No	Western Australia	Instant message	
11	Autistic adult	25–34	Female	Yes	Victoria	Email	
12	Autistic adult	45–54	Female	Yes	Queensland	Email	
13	Autistic adult	35–44	Non-binary	Yes	New South Wales	Email	
14	Autistic adult	25–34	Female	No	Queensland	Video	
15	Support person	45–54	Female	No	Queensland	Video	Mother of Participant 14
16	Autistic adult	25–34	Male	Yes	New South Wales	Video	
17	Support person	55–64	Female	No	New South Wales	Video	Mother of Participant 16
18	Autistic adult	18–24	Non-binary	No	Western Australia	Video	
19	Autistic adult	25–34	Male	No	Queensland	Video	
20	Support person	55–64	Female	No	Australian Capital Territory	Video	Wife of Participant 8
21	Autistic adult	55–64	Female	No	New South Wales	Phone	
22	Autistic adult	35–44	Male	No	Tasmania	Phone	
23	Support person	35–44	Female	No	Tasmania	Phone	Wife of Participant 22

individual experiences and perspectives while situating them within the broader social context.

Participants

Advertisement for this study was distributed alongside a survey component via participant newsletters of existing research studies and various autism and disability organisations and service providers in Australia (see Huang et al., 2021 for details). The survey also contained an option for expressing interest in being interviewed. Additionally, we asked participants to distribute study information to any interested parties. Participants were required to be 18 or over, have received an autism spectrum diagnosis in adulthood (age ≥ 18), or have supported someone diagnosed in adulthood during and after their diagnosis.

To capture a variety of support experiences, we purposively sampled for maximum demographic variation (Sandelowski, 1995) in age, gender, intellectual disability, geographical location, and interview format. To achieve this, we initially prioritized emailing/phoning participants from less represented or unrepresented demographics from the list of all potential participants who expressed interest.

Nineteen autistic adults (7 male, 9 female, 3 non-binary) and four support persons (all female) were interviewed. Autistic adults had a mean age of 44.37 years ($SD = 17.84$) and were diagnosed between 2000 and 2019. Four adults self-reported mild to moderate intellectual disability. Support persons were mothers ($n = 2$) or wives ($n = 2$) of autistic adults who also participated in the study. Several other autistic adults had support persons who did not respond to invitation or chose not to participate in this study. There was at least one participant from each state/territory of Australia except South Australia and Northern Territory. See Table 1 for detailed participant information.

Data Collection and Procedure

An online expression of interest form asked participants to provide informed consent, demographic information (date of birth, gender, intellectual disability, state/territory) and interview preferences. Participants who expressed interest via other means (such as contacting the researcher via telephone) completed the consent form via email or post. Participant information and consent documents were provided in both standard and easy-read formats. YH then contacted suitable participants and arranged interview times.

The first author developed a semi-structured interview guide (Supplementary material 1) involving seven questions on initial diagnosis, supports received/ wanted, meaning of diagnosis, and future suggestions in consultation with co-authors and autistic research advisors. Interview questions were piloted with several colleagues and associates including an advisor with intellectual disability. Prior to the interview, participants were provided with an accessible document with plain language and supporting images explaining the interview process and a copy of interview questions.

The interview was offered via online video conferencing ($n = 10$), email ($n = 5$), telephone ($n = 5$), instant messaging ($n = 2$), and face-to-face ($n = 1$) to accommodate participants' locations and preferences, as recommended by Nicolaidis et al. (2019). Using a variety of data collection approaches helped reduce barriers to participation and recruit a more diverse sample, though not all methods resulted in the same level of richness and detail. The face-to-face interview was conducted at a university meeting room. Only one interview occurred face-to-face as these were discontinued following the outbreak of COVID-19 in 2020. Autistic adults and their support persons were given the option to be interviewed together or in separate sessions. All pairs chose to be interviewed separately. Participants were reimbursed with a $60 AUD gift card for remote interviews and $80 for the face-to-face interview to account for travel expenses and time. Participants who participated in member checking (see Data Analysis) received an additional $35.

The first author conducted all interviews between October 2019 and June 2020 and kept a journal of reflections and possible directions for analysis. The length of spoken interviews ranged from 34 to 148 min ($M = 75.23$), while typed interviews ranged from 693 to 4,636 words ($M = 2{,}327$). Recordings were transcribed verbatim by the first author and a professional transcriber, then checked for accuracy by the first and second authors. All transcripts were edited to remove identifying information.

Data Analysis

We used reflexive thematic analysis (Braun & Clarke, 2006, 2019), where the researcher develops patterns of meaning from active engagement with the data. Although our analytic approach was primarily data-driven and semantic, analysis of participants' beliefs about autism and the self was conducted at a more latent level, informed by discourse on models of disability and neurodiversity. Analysis commenced shortly after the first interview and was conducted concurrently with data collection. Using NVivo 12 to manage data, YH read the transcripts repeatedly and generated initial codes. YH then developed themes from connections between frequent and/or thematically important codes, revisiting the initial codes and reorganising them as necessary. Throughout this process, YH used a reflexive journal to document the rationales for decisions and process of refining themes. All of the authors then met to discuss the proposed themes, correspondence between themes and codes, and relevance to the research question. To enhance authenticity of research findings, participants were given an opportunity to comment on a summary of themes with selected quotes, as recommended by Birt et al. (2016). Quotes were edited for clarity and the participant was given an opportunity to make changes before inclusion. We incorporated participants' feedback into the final list of themes and discussion of their implications for practice.

Reflexivity and Position of the Researcher

YH is a doctoral student with personal connections to autism via family and social relationships, bringing aspects of both academic and real-life understandings to the project. Having conducted a literature review and other studies in the larger project, YH began this study with knowledge of autistic adults' difficulties accessing formal post-diagnosis support and concerns around disclosing their diagnosis to others. YH also had pre-existing knowledge of the popularity of autistic self-advocacy and neurodiversity movements in autistic communities. While YH expected these ideas to emerge in participants' interviews, she also paid attention to participants' varied opinions on these topics and new or unexpected ideas. YH kept a reflexive journal throughout interview and analysis to maintain awareness of her own perspectives and influence on the research process. YH mainly presented herself as an outsider to participants while mentioning that she has some relevant personal experiences. This allowed her to connect with participants more closely while encouraging participants to elaborate on ideas that might be assumed or taken for granted within their communities. However, her outsider status may have motivated some participants to present themselves and their communities in a more socially desirable manner (Bergen & Labonté, 2019). While being a researcher naturally gave YH authority over participants, her young age and outsider status resulted in more fluid power dynamics as participants could *educate* the researcher on insider issues and life experiences.

SA, KF, and JT are experienced in the dual roles of researcher and clinician in the field of autism and developmental disabilities, who gave guidance based on academic expertise and reflections from clinical experience.

Community Involvement

Consultation with autistic people during the project helped promote authentic portrayal of the community and its interests. Autistic research advisors provided feedback on interview questions at the start of the project. Additionally, two non-autistic research advisors with intellectual disability reviewed Easy-read documents for accessibility. Preliminary themes were shared with interview participants for feedback. Autistic research advisors then provided feedback on the interpretations and implications of the findings.

Financial reimbursement was offered to all participants and research advisors who gave feedback.

Results

Seven themes were developed from participants' interview data. These themes captured autistic adults' and support persons' perspectives on professional support, informal support including autistic peer support, and identity formation as an autistic person.

Theme 1: Difficulty Accessing Support

Autistic adults and support persons found the system of formal support services confusing to navigate as they received little information at the time of diagnosis. Not knowing what services would be suitable or where to find them caused adults to miss out on support: "I really don't know what to ask for. I'm unsure what's available, especially for adults, and what will help me" (Participant 7, autistic adult).

Adults and support persons encountered numerous obstacles in the process of finding and organising formal support. Few autism services accepted adult clients, and those that did often came with prohibitive fees. This made them inaccessible to many participants:

> "[Diagnosis provider] would like me to come back to see them, to get my health services there, but I live about an hour out of the city and again, they're very expensive. So unless I'm really, really desperate for mental health services, I'm not going there" (Participant 3, autistic adult).

Although avenues of government funding such as the National Disability Insurance Scheme helped ease financial burdens, not all participants were eligible to receive such assistance. Many autistic adults and support persons who applied for government funding found the steps required to demonstrate eligibility and provide ongoing documentation to be stressful. Both mothers interviewed were heavily involved in managing funding and services for their adult children. One mother said:

> "I have to tell them how to do their work like that. Like the speech therapist and the occupational therapist... I have to ring them like several times, send emails… that is their job" (Participant 17, support person).

The contrast between autistic adults' apparent capabilities and significant support needs meant they were seen as both *too disabled* and *not disabled enough*. Some adults were reluctant to seek formal support for fear that others would underestimate their capabilities, while others struggled to have their support needs taken seriously. Although this was most apparent in the experiences of autistic adults without intellectual disability, the mother of a participant with mild intellectual disability also described the dilemma of being stuck between mainstream and disability-specific services: "He's not there as a mainstream, he's not totally disabled, so the gap's there… They see what he can do, but there are some hidden things which they are not aware" (Participant 17, support person).

Personal factors also impacted autistic adults' ability to seek and receive formal support. Adults found the process of searching for and contacting services difficult and stressful, which discouraged them from pursuing support. This was especially the case for adults with co-occurring physical or mental health conditions: "Between autism, depression and chronic fatigue, the few times I have the energy to ring up, cause ringing people up in the first place is challenging… every time you ring up, you get told 'we're not taking new patients'" (Participant 22, autistic adult).

Another factor raised mainly by support persons was their perception that adults were uncomfortable with aspects of formal support that require change. This was sometimes due to a fear of unfamiliar people, places, or ideas: "For him, anything new would be quite anxiety-producing" (Participant 20, support person). Other times, autistic adults and support persons had different views on whether certain characteristics or behaviours should be changed or accepted as part of the autism. An autistic adult, who did not have a support person participating in the study, was concerned that learning ways to mitigate negative aspects of autism would mean losing the positive aspects: "I was offered by [diagnosis provider] to work through some of my behavioural problems… I think I do need it… but I just don't want to give up what gives me good sensations" (Participant 9, autistic adult).

In light of these barriers, both autistic adults and support persons wanted more information, advice and professional assistance on finding formal support after diagnosis: "I think somebody who could walk you through some of the processes… Somebody to give you a starting point to go, 'You know what? I've been there'" (Participant 15, support person).

Theme 2: Support to Empower Growth

Most autistic adults' experiences of professional support consisted of counselling and psychotherapy from mental health professionals, often during treatment for co-occurring mental illnesses. Both adults and support persons desired a greater variety of services to address adults' individual needs.

Adults and support persons emphasised the importance of having autism-informed professional support. These professionals helped adults understand their strengths and difficulties, taught practical coping strategies, and adapted their treatment of co-occurring mental health conditions with autism in mind. For support persons, autism-informed professionals gave them greater insight into the adult's behaviour and helped them respond more effectively. Unsurprisingly, both adults and support persons considered autism-informed professionals an indispensable part of good post-diagnosis support:

> "I would strongly recommend go to psychologists who specialise in treating autism spectrum disorders and get some strategies, because you might find stuff that you didn't even know before" (Participant 19, autistic adult)

Although a few autistic adults were uninterested in social connections, most adults wanted to learn to connect with others more easily. Adults' experiences of social skills advice from professionals included both simple rules such as "don't speak for more than thirty seconds" (Participant 8, autistic adult) and more in-depth explanations of other people's behaviours in social situations. Both were regarded as helpful, though one participant emphasised the latter helped them break away from superficial imitation of socially acceptable behaviour and respond more naturally:

> "I feel like there's a difference between basing for example, body language on 'this is what people do in this situation' and basing body language on 'this situation's happening, what's going on?'. I'm gonna react how I'm gonna react, but I'm going to know that my reaction isn't gonna hurt anyone" (Participant 18, autistic adult)

Both adults and support persons expressed a need for more holistic support services addressing independence and community participation, including managing everyday tasks, attending events and activities, education, and employment. This was especially important for adults with intellectual disability who received professional assistance to manage their finances and participate in recreational activities, though other adults also desired support in these areas. A participant with intellectual disability described the benefits of having a support worker: "Accessing the community… like just have an outing in the park and do roller skating. It was quite easy together side by side" (Participant 16, autistic adult).

Younger autistic adults and their support persons were particularly concerned about the transition to adult life. Although young adults expressed a strong desire to become more independent, they found social isolation and lack of stable income to be major barriers to achieving their goals. Participant 14 reported wanting to move out of the parental home, though her mother feared that not having enough family support would worsen the daughter's mental health. The mother said:

> "My fear was if she moves out without support that she would be at risk… Ideally I would like her to be able to move out into almost like a halfway house type program, but I don't know of any" (Participant 15, support person).

On a deeper level, adults wanted to be accepted as they are, while being supported to work towards individualised goals. Adults believed it was important for professionals to embrace a positive understanding of autism and treat them as an equal partner. They also wanted to choose the goals of support based on their own values and needs, which may be different from what mainstream society would expect: "It is essential for support services to be directed by my values and my priorities. Not what my spouse wants, or my parents, or my doctor. It's not even about what my peers, or community, or culture wants. It's about what I want" (Participant 21, autistic adult).

Theme 3: Supporting Learning and Vocation

Although working-age autistic adults generally wanted to learn new skills and financially support themselves through paid work, they often needed support to cope with the demands of education and employment. Adults reported that social challenges of job interviews and workplace communication hindered their job prospects: "I've never been good at an interview… The only reason I've always had a job is because doctors were scarce in my time" (Participant 9, autistic adult). Autistic adults also found themselves confused and frustrated by vague instructions, unclear expectations and others' unwillingness to follow rules in universities and workplaces. Additionally, some adults with co-occurring physical and/or mental health conditions desired greater flexibility in hours and tasks to help maintain wellbeing while studying or working.

Two adults with intellectual disability had received disability-specific employment support services, including disability job agencies, supported open employment and sheltered employment. Although both expressed a strong desire to work in open employment, the support offered by mainstream workplaces was often inadequate: "I have faced a lot of struggles because workplaces in Australia and New Zealand were not yet fully equipped for this kind of support… many corporate companies do all talk and no action which didn't help me at all to stay on in the role" (Participant 11, autistic adult). Participant 16 found working at a disability enterprise to be mentally unstimulating and preferred an "office job" where he could use his skills more.

Despite challenges, adults found that certain aspects of autism gave them unique advantages in the workplace, such as being detail-oriented, focused, and rule-abiding: "I suspect being an Aspie actually makes me better at my job rather than worse, because of my ability to remember lots of information and stay task-focused" (Participant 5, autistic adult). Both adults and support persons hoped for more opportunities where autistic adults' skills would be recognised and valued, "Because when they do something, they do it 110%" (Participant 23, support person).

Theme 4: Wanting to be Understood

After diagnosis, autistic adults wanted to share their newfound knowledge with friends and family, hoping others would understand them better. Adults explained that having an official label helped them communicate their experiences and needs to others. In many instances, disclosing the diagnosis resulted in improved understanding, acceptance, and informal support. One adult explained how disclosing the diagnosis allowed her to avoid eye contact, which made communication feel easier:

> "I just look away and I listen. I'm much better now at taking things in and remembering them… But to do that, I have to tell people I'm autistic, so they don't ask me… and I can really concentrate on what they're saying" (Participant 9, autistic adult).

In other instances, disclosing the autism diagnosis resulted in negative reactions, which added to adults' sense of social isolation. Others often doubted whether the adult was really autistic due to their apparent lack of visible difficulties. Sometimes, the dismissiveness was coupled with a general lack of awareness of psychiatric conditions, which made it difficult for adults to communicate their needs. One adult described how she felt when a friend questioned her diagnosis: "It was frustrating and invalidating, and it did make me question it a bit, you know. I mean, it is also a bit of an abstract thing. It's not like a blood test. It's not something definitive like that." (Participant 14, autistic adult).

Adults and support persons reported that some relatives and acquaintances would avoid the subject of autism after learning of the adult's diagnosis. This reaction left adults wondering whether these people lacked autism knowledge, did not know how to respond, or simply did not care: "They sort of heard the news and then went 'oh' and then sort of didn't visit it any further. So I don't know if it's because it doesn't really matter to them or that they don't want to 'pry' or what" (Participant 7, autistic adult).

Both adults and support persons believed the wider community needed to adopt more positive understandings of autism in adulthood and reject stigmatizing stereotypes, so that others would be more likely to respond positively to the diagnosis and offer informal support. They were pleased that public attitudes appeared to be improving: "It's educating the public, so people don't go up and say, "You don't look autistic', 'You don't act autistic'. And I think that must be happening, cause the young people are so much better" (Participant 9, autistic adult).

Theme 5: To Care and be Cared for

Following diagnosis, adults and support persons underwent a mutual process of understanding and adjustment. While some support persons quickly accepted the diagnosis, others were initially resistant due to not wanting to view their loved one as impaired. One adult described his mother's reluctance and eventual acceptance:

"Well, I spoke to her about it, probably more of a defence mechanism to say, 'no, my son doesn't have this', you know, 'my son is not defective'… maybe just the feeling of shame that 'I put that in the world and that's not possible'… But then when my dad and I gave her more information. She then realized, 'oh yeah, actually that made sense, and this is what it is'" (Participant 19, autistic adult).

Diagnosis and subsequent support alerted support persons to previously hidden support needs such as sensory sensitivities and a need for predictability. Improved understanding also helped support persons interpret the adult's behaviours differently, reframing them as autism-related difficulties rather than personality flaws:

> "Since his diagnosis, the first thing that came to my mind was: I can't leave, here's somebody with something that he can't help doing, I've got to stay and work it out with him" (Participant 20, support person).

An important aspect of mutual understanding was adapting to each other's communication styles. Some autistic adults' direct communication style was sometimes perceived as offensive, while support persons' attempts at subtle communication resulted in misunderstandings. One support person described how using direct communication helped her husband understand her better:

> "Just tell him what's not acceptable to you and that'll help him… He's very good with clear, one-sentence requests, whereas I talk around the block and try and make it really sweet and soft, and then he says, 'What are you talking about? I don't understand'" (Participant 20, support person).

Support persons helped adults navigate many aspects of life after diagnosis. Autistic adults appreciated having someone who could help them understand social situations in real time: "If I'm wondering why somebody said this or why somebody acted in that way, she can translate for me in a way that I'll understand, which is such a unique skill" (Participant 3, autistic adult). Support persons also helped link autistic adults with professional services. Several younger adults reported that their parents took on the responsibility of managing professional support for them:

> "My parents, especially my mother; helped me to get into these support groups to meet other people. I was not mature enough to care about doing these activities at the time, but looking back, I realise I should have made the effort myself" (Participant 11, autistic adult).

The autistic adult's needs resulted in additional responsibilities for the support person, which led to a deviation from expected relationship dynamics. While this was less of a problem for adults supported by their parents, receiving informal support from siblings, partners, or children created discomfort for both the adult and the support person. Participant 9 was deeply embarrassed at the realization that her daughter had been helping her interpret social situations for years: "My daughter is so emotionally intelligent and she's also very bright. I'm almost a child to her now. And it's embarrassing cause she's right. She's interpreted for me, and I never listen" (Participant 9, autistic adult). Support persons also found it stressful to manage the autistic adult's needs in addition to other responsibilities. This was particularly difficult in intimate relationships where both partners were expected to support each other. Participant 20 described the responsibility of helping her husband in social settings:

> "As a communication person, I feel a very, very heavy burden that I'm the only person who can notice and say things, because I'm the one who sees him every day, 24 hours, one-on-one as well as in social settings" (Participant 20, support person).

Despite challenges, support persons valued their relationship with the autistic adult. Both autistic adults and support persons wanted more resources and services for loved ones of newly diagnosed autistic adults, such as information packs, one-on-one consultations, and support groups. One participant commented on the lack of existing services: "It does leave a lot of adults struggling and their families struggling too, because they have to support people on the spectrum… They don't have any resources any more than we do, and they need support too" (Participant 3, autistic adult).

Theme 6: Being Different Together

Autistic adults valued connections with other autistic people both in-person and online, through friendships and autism-specific support groups. Adults described feeling more understood and accepted by autistic people who shared their experiences. They also found interactions less stressful due to similar thinking and communication styles. An autistic adult with intellectual disability described her friendship with two other autistic people: "We are just nice to each other and don't need to deal with small chat and useless talk" (Participant 12, autistic adult).

These similarities made other autistic people a good source of knowledge and advice for newly diagnosed adults. Adults reported that suggestions from autistic peers helped them understand themselves and develop coping strategies. Adults also offered advice to people who were struggling with various issues. The exchange of informal support helped strengthen adults' sense of belonging in an autistic community. Participant 21 considered connections with the autistic community or "tribe" to be an essential aspect of post-diagnosis support:

> "The most helpful thing to do after diagnosis is to find an Autistic community to help orientate your identity. It is important to get validation from shared idiosyncrasies and experiences, but also vital for personal growth to have opportunities to discover unique differences, be it within one's own tribe or not" (Participant 21, autistic adult).

Meeting other autistic people with a variety of autistic traits, interests, personalities and support needs helped broaden participants' understandings of autism. However, some adults found it difficult to relate to autistic people who were very different from them, and preferred those who matched their gender, interests, and support needs. Some women who had attended autistic adult support groups reported difficulties connecting with other group attendees who were mostly young men. An autistic adult with intellectual disability was disappointed by online autism communities' tendency to overlook people with intellectual disability and higher support needs:

> "We are people just like any autistic. We grow up. We're not children forever. We have different experiences but we want to make friends and connect to others too. Just because we may not understand or we take longer to learn or we can't learn something doesn't make our value less. Our voice matters too" (Participant 13, autistic adult).

Some autistic adults found it unhelpful when people in online autism groups became fixated on pessimistic complaints without offering solutions. They also wanted to avoid the emotionally charged and argumentative discussions that often occur in these groups. One participant described an online forum she was a part of:

> "People post every day about their difficulties to see who else experiences the same thing. I used to read but I stopped responding because I would get some negative feedback… I don't dare to be a positive voice or to defend neurotypical people" (Participant 3, autistic adult).

While only a few autistic adults had attended organised support groups, many were interested in attending one. Participants differed greatly on the preferred format and goals of their ideal support group. Some adults were primarily interested in making social connections at their own pace, while others wanted to focus on problem-solving strategies in a more structured setting. Adults also had different opinions on the level of involvement from non-autistic professionals and community members. While some participants preferred an autistic-only group free from external authority and mainstream social expectations, others saw an opportunity to bridge the gap between autistic and non-autistic people. One participant explained that although his ideal group would include neurotypical people, "the neurotypical would need to be in a position where they understand the autism, and not ram their own ideas of healing down your throat" (Participant 4, autistic adult).

Theme 7: Negotiating Autistic Identity

For many adults, diagnosis and subsequent support led them onto a pathway of self-discovery as they sought to learn more about autism in relation to their lives and relationships, resulting in deeper changes in how they perceived their identity and relationship with the world.

An important aspect of post-diagnosis self-reflection is self-acceptance. Letting go of the expectation to act neurotypical helped adults reduce self-blame and view themselves more positively: "It meant that things weren't all my fault… I wasn't just a problem, there were things that I couldn't actually control" (Participant 14, autistic adult). They remarked that autism not only explained their difficulties, but also their strengths such as honesty, intense focus, and rational thinking. Thus, many adults accepted autism as a permanent and positive part of themselves that should not be erased: "It's not an impediment. It's just a different way of doing things" (Participant 8, autistic adult).

Acceptance of autism also included accepting autism-related difficulties, which led to feelings of self-doubt and inadequacy in some participants. However, adults found ways to reconcile their difficulties with a positive view of autism. Some had adapted their interests and activities to minimise the effects of difficulties, while others considered certain difficulties not central to their identity as an autistic person. In general, adults considered it more helpful to focus on special interests and strengths rather than dwelling on deficits. An adult with intellectual disability said, "Don't feel bad about yourself. And autism makes you special, I mean, you could have special skills" (Participant 16, autistic adult).

For many adults, autism acceptance coexisted with a desire to change certain aspects of themselves through professional support. Participants' perspectives on balancing acceptance and change were deeply personal and varied. Some believed in primarily adapting the environment to the person, favouring minor adjustments that allow them to be themselves as much as possible. Others were highly motivated to learn new skills and sought constant self-improvement. Although adults' opinions varied, most agreed that self-acceptance can co-exist with a desire to change: "I feel less pressured to change how I approach things, but at the same time I recognise that maybe I can approach things in a different way, recognising that I can be overly direct and overly blunt" (Participant 5, autistic adult).

For many adults, the importance of autism as part of their identity changed over time. Several adults experienced a strengthening of autistic identification as their self-understanding and involvement with the autistic community increased. However, others described that autism became less prominent as they integrated the diagnosis into their identities over time: "For a while, when I thought about myself, there would be this 'and I'm autistic' along with other things… but as I've come to terms with them more, they've become just part of the landscape" (Participant 18, autistic adult).

Autism diagnosis also changed how adults viewed their place in society. The sense of kinship with other autistic people was accompanied by feelings of being out of place in the wider neurotypical world. It was common for participants to depict autistic and non-autistic people as two *tribes* or communities with complementary abilities and preferences, where the dominance of non-autistic norms led to autistic people's alienation from mainstream society: "Three-quarters of the problem that people who are on the spectrum have with other people is that we're not them. And they don't like it. They can't accept it" (Participant 21, autistic adult). However, adults also expressed a desire for mutual understanding and connection: "I wanted to find more ways to come together with people, to help other people understand me and to understand them better, because it's a two-way street" (Participant 3, autistic adult).

Discussion

Our qualitative study aimed to understand experiences of support after adulthood autism diagnosis. Findings revealed significant unmet need for formal support after adulthood autism diagnosis. By interviewing autistic adults and support persons, we were able to identify key benefits and challenges of informal support from both perspectives. Additionally, our study uncovered interesting interactions between adults' experiences of support and development of autistic identity. These findings have important implications for improving post-diagnosis experiences of autistic adults and support persons.

Adults and support persons in our study reported a shortage of available formal support and significant barriers to access, consistent with previous research (e.g., Crane et al., 2018; Jones et al., 2014). Navigating the gap between diagnosis and support required significant knowledge, time, finances and personal resources, which was especially challenging considering adults' reported difficulties with social communication, mental health, and employment. Support persons who helped their loved ones find services encountered many of the same barriers. Our findings indicate a need for diagnosing clinicians to provide comprehensive information, advice, and personalised guidance to help bridge the path to post-diagnosis support for adults. It is also important to increase the availability and range of services for autistic adults, including those who may not qualify for more intensive disability support. Services that offer information, general support, and links to external providers such as described in Southby and Robinson (2018) may be a candidate for broader implementation. Autism training for mainstream health professionals would also help them to either directly support autistic adults or refer them to appropriate services more effectively. Furthermore, it may be necessary for providers to explore additional formal supports or links to existing services to ensure that specific populations such as transition-age youth or people with co-occurring mental health conditions are adequately supported.

The theme *Supporting Learning and Vocation* was originally conceptualised as part of *Support to Empower Growth* but was separated after participants' feedback highlighted its importance to working-age autistic adults and their support persons. A major concern for autistic adults was how to make use of their abilities in paid employment without being held back by social challenges. Our findings are consistent with previous research highlighting social difficulties and unaccommodating workplaces as major barriers to positive employment experiences in autistic adults (Anderson et al., 2021; Baldwin et al., 2014; Harvery et al., 2021). Additionally, adults with intellectual disability in our study faced a unique challenge, where they found sheltered employment unfulfilling but did not have enough support to transition to open employment. This was in line with past research showing supported open employment to be superior to sheltered employment in terms of job satisfaction and income for people with intellectual disability (Cimera, 2011; Jiranek & Kirby, 1990). Our research supports the call for more diverse employment opportunities that meet the social and financial needs of people with intellectual disability, with examples including non-segregated social enterprises and a combination of open and sheltered employment (Meltzer et al., 2018; Rustad & Kassah, 2021)., Formal supports including autism and disability-specific employment programs (Brooke et al., 2018), career planning (Hatfield et al., 2017), and training for employees and employers (Wehman et al., 2016) have shown promise for improving autistic adults' workplace experiences and independence as well as lessening the economic impact of autism on society (Hedley et al., 2016; Scott et al., 2018).

The apparent dilemma between acceptance and change was developed from the interweaving of positive feelings about autism diagnosis with the desire to remediate certain aspects in autistic adults' interviews. We then applied the dynamics of acceptance and change to interpret individual variations in autistic identity development and support preferences. The coexistence of acceptance and change is reminiscent of Kapp et al.'s (2013) deficit-as-difference view, which reflect the complexity of autism as both a disability and identity. Most of our participants endorsed the neurodiversity movement's view of autism as a positive neurological difference, which encouraged self-acceptance and positive self-esteem. Contrary to the assertions of Jaarsma and Welin (2012, p. 27), neurodiversity-aligned views were not limited to "high-functioning" individuals but were also shared by participants with intellectual disability. However, this acceptance did not hinder participants' recognition of their difficulties or their practical desire to improve the lives of themselves and those around them through change. Autistic adults' highly varied perspectives on whether certain aspects of the autistic experience should be accepted or changed shaped their preferences and goals for formal support, which are sometimes incongruent with support persons' expectations. Considering the diversity of autistic people's beliefs and support needs, it is important for formal support to respect each individual's balance between acceptance and change, fostering positive self-esteem through autism acceptance while empowering the individual to make necessary changes to achieve their goals. It is also important for professionals to explore possible differences in autistic adults and support persons' expectations when devising support goals, and ensure that needs for autonomy, wellbeing, and healthy relationships are accounted for.

Our findings on informal support mostly confirmed existing research on support person experiences (Lewis, 2017; Raymond-Barker et al., 2018). Additionally, exploration of autistic adults' perspectives allowed us to gain a fuller understanding of the benefits of and barriers to informal support, especially in cases where loved ones are unable or unwilling to provide much assistance. Although informal support persons played a valuable role in autistic adults' lives after diagnosis, our data highlighted a number of challenges including support persons' inadequate autism knowledge, mutual miscommunication, and changes in relationship dynamics. If left unaddressed, these challenges may have a significant negative impact on both parties' wellbeing and relationship quality. Newly diagnosed adults may benefit from advice on disclosing their diagnosis and take-home resources to help loved ones understand their diagnosis and support needs. For support persons, autism-informed individual counselling, family and relationship counselling, and support groups may help them improve wellbeing, maintain healthy relationships, and better support their loved ones.

Informal support from other autistic people helped fulfill adults' need for social connection and belonging, consistent with Tan (2018). Autistic peers also provided knowledge and advice that helped fill the gap in autism-informed formal support. Somewhat unexpectedly, our participants reported some dissatisfactory experiences with informal autistic peer support, where people's tendency to commiserate over negative experiences shifted the focus away from problem-solving. This has seldom been mentioned in previous research involving late-diagnosed adults, which tended to emphasize positive aspects of community and identity formation (Bargiela et al., 2016; Tan, 2018). Research in the general population suggested that while sharing negative emotions with others produced immediate relief and facilitated interpersonal bonding, it had little benefit for emotional recovery and may even promote negative emotions through rumination (Choi & Toma, 2014; Rimé, 2009). Anonymity has also been found to contribute to verbal aggression in online settings (Zimmerman & Ybarra, 2016). As support groups were highly desired by our participants, formal, structured group-based support co-led by professionals and autistic adults may help combine the benefits of autistic peer support with professional knowledge, while minimising unhelpful venting and conflict. Considering the variation in participants' preferences and goals for attending a group, group facilitators need to work closely with members to ensure their needs are met, with the option of starting subgroups for people with specific needs or preferences if required.

Although the interview did not specifically mention societal attitudes, participants' experiences of formal and informal support were often shaped by other people's level of autism knowledge and acceptance. A common thread across both autistic adults' and support persons' responses was the need for positive autism awareness in society, which may have wide-reaching benefits for adults' social relationships, formal and informal support, and employment. Misconceptions and overly narrow understandings of autism contributed to adults' experiences of not having their needs taken seriously by professionals and social connections, preventing them from receiving support. As late diagnosis may be a result of having subtle or atypical autistic traits (Lai & Baron-Cohen, 2015), increasing community awareness of diverse presentations of autism may be especially important for individuals diagnosed in adulthood. Our data also highlighted consequences of autism stigma, where associating autism with incompetence made support persons reluctant to accept the diagnosis and adults less willing to seek support. As knowledge alone may have limited effectiveness at improving attitudes towards autistic people (Mac Cárthaigh & López, 2020), interventions incorporating components such as increased contact with autistic people (Shand et al., 2020) may be more effective at promoting positive understandings of autism in the wider community.

Our study highlighted several key differences in the experiences of autistic adults with and without intellectual disability. Adults with intellectual disability accessed a greater variety of formal support compared to adults without intellectual disability. This is consistent with quantitative research indicating that autistic individuals with intellectual disability had greater access to services than those without (Lai & Weiss, 2017; Zablotsky et al., 2015). Our participants with intellectual disability also received more informal assistance from family members, which often included managing formal support services. Although participants with intellectual disability enjoyed friendships with other autistic people, they were not always included or comfortable in autistic communities dominated by people without intellectual disability. This is consistent with research showing few social connections between people with intellectual disability and people without intellectual disability who were not staff or family members (Verdonschot et al., 2009). Our findings highlight the need for further research on the social needs and experiences of autistic adults with intellectual disability, with the goal of supporting their social participation and inclusion in a range of autism-specific and general settings.

Our study had several limitations. Although we reached out to intellectual disability organisations during recruitment, we were only able to interview a small number of adults with intellectual disability. The small sample size limited our ability to explore the support needs and experiences of late-diagnosed adults with intellectual disability in detail and compare them to adults without intellectual disability. Considering the under-representation of people with intellectual disability in autism research, further exploration of these adults' experiences of autism diagnosis and subsequent support would help ensure their needs are addressed by diagnosticians and support services. Our sample of support persons was also small and only involved women. Some autistic adults in this study received no informal support, while others received low-level support from several individuals, meaning there was no designated support person role. In the case of autistic adults receiving significant informal support, it may have been difficult for support persons to find the time and energy to take part in an interview-based study. Less intensive data collection methods such as brief online surveys may be more suitable for this population.

The use of text-based and asynchronous modes of data collection in addition to traditional spoken interviews had both benefits and drawbacks. This was most evident in email interviews, where the letter format and time gaps between replies limited rapport-building and amount of detail in the data. However, the asynchronous nature gave participants more time to produce considered responses that conveyed their ideas more succinctly. It also allowed us to reach participants who may not have time or feel comfortable enough for a traditional interview. To compensate for the reduced amount of detail, future researchers may wish to expand sample sizes accordingly when using email-based interviews.

The small number of support persons in our study meant we were unable to explore relationship dynamics between autistic adults and support persons in detail. Future researchers examining informal support may wish to use autistic adult-support person dyads rather than individuals as the unit of analysis. Dyadic analysis would allow the researcher to triangulate both parties' perspectives in relation to the same event or phenomenon (Eisikovits & Koren, 2010). Researchers will need to consider the choice of joint versus separate interviews carefully with regards to participant comfort, richness of data, and equal opportunities to contribute. This is especially important in autism research considering the historical dominance of parental narratives over autistic self-advocacy (Ward & Meyer, 1999).

Our study highlighted autistic adults' and their loved ones' difficulties finding suitable formal support after adulthood autism diagnosis. We also uncovered unique rewards and challenges of informal support from family, friends, and autistic peers. We look forward to future developments in research and practice that help address the diverse needs of late-diagnosed adults and their support persons.

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Declarations

Conflict of interest The authors declare that there is no conflict of interest.

Ethics Approval This study was approved by the UNSW Human Research Ethics Committee, number HC190582.

Consent to Participate/Publish All participants provided informed consent to participate in the study and for the results to be published in a journal.

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