



# Experiences of Support Following Autism Diagnosis in Adulthood

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## Abstract

This study aimed to explore experiences of support after adulthood autism diagnosis. In this mixed-methods survey study of 137 adults, we found that most common formal supports received were counselling and mental health. Common unmet support needs were sensory sensitivities and accessing other services. Cost, lack of information, and fear of not being taken seriously were common barriers. Informal support was mainly helpful for self-understanding and emotions toward diagnosis. Qualitative findings included difficulties accessing formal support, need for practical quality-of-life supports and support from autistic peers and online communities. Based on these findings, future development of supportive interventions should address unmet needs, improve access, and explore the integration of autistic peer support and online support into formal services.

**Keywords** Autism · Adults · Health services · Support · Interventions · Diagnosis

## Introduction

Individuals on the autism spectrum can benefit greatly from early detection and support of their autism characteristics. However, many autistic people miss early detection due to lack of autism awareness, more restrictive past diagnostic criteria, and/or less visible autistic traits (Lai & Baron-Cohen, 2015). People receiving an autism diagnosis in adulthood have unique post-diagnosis support needs, but often experience difficulties accessing suitable services.

Many adulthood-diagnosed individuals have significant support needs, even those with relatively subtle autistic traits (Lai & Baron-Cohen, 2015; Lehnhardt et al., 2013). Studies of autistic<sup>1</sup> people diagnosed in adulthood reported problems with social interaction and relationships, poor mental health, and difficulties finding and maintaining employment (Griffith et al., 2012; Happé et al., 2016; Jones et al., 2014; Wilson et al., 2016). Studies also showed that despite average-to-high levels of education, autistic adults were likely to

experience significant unemployment and underemployment (Happé et al., 2016; Harvery et al., 2021; Hofvander et al., 2009). A UK-based survey of late-diagnosed adults reported a variety of support needs including social skills, education/employment, finances, and housing (Jones et al., 2014). These findings indicate significant unmet support needs in late-diagnosed adults, which are likely to negatively impact their quality of life and community participation.

Lack of formal post-diagnosis support is a pressing concern for individuals diagnosed in adulthood. Quantitative and qualitative studies of late-diagnosed adults (Crane et al., 2018; Jones et al., 2014; Lewis, 2016b) and families (Lewis, 2017; Raymond-Barker et al., 2018) described insufficient knowledge of services and frustration searching for suitable supports. Lack of autism-specific services led some autistic adults and support persons to seek support from mainstream mental health professionals, who were not always able to address autism-related concerns (Griffith et al., 2012; Lewis, 2017; Powell & Acker, 2016). Despite finding mainstream mental health services inadequate, some adults faced the dilemma of not having significant enough support needs to qualify for disability-specific services (Griffith et al., 2012). These gaps in post-diagnosis support severely limited the benefit of a professional diagnosis in adulthood and has discouraged some undiagnosed adults from pursuing assessment (Huang et al., 2021; Lewis, 2016a).

<sup>1</sup> We used Identity-first (“autistic person”) and neutral (“on the autism spectrum”) terminology throughout based on participants’ preferences (see Huang et al., 2021).

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Inadequate access to support services for autistic adults are also evident in available Australian data. The National Disability Insurance Scheme (NDIS) was introduced in 2016 to provide funding for people with disabilities to access support services (Buckmaster, 2017), with autism being the most common primary disability group in its participants (National Disability Insurance Agency, 2021a). The Survey of Disability, Ageing and Carers showed that over 85% of autistic people experience limitations in core activities or education/employment (Australian Bureau of Statistics, 2019). However, the 56,787 autistic NDIS participants aged 15 years and over only accounted for less than two-thirds of the conservative estimate of 94,600 autistic Australians in the same age category (National Disability Insurance Agency, 2021b). Although there is no data specific to autistic Australians diagnosed in adulthood, the relatively low percentage receiving NDIS funding suggest substantial gaps in formal support for this population.

New developments in supports and interventions for autistic adults have begun to address the gap in formal support. These include social skills training (Laugeson et al., 2015), employment training (Smith et al., 2014), support groups (Jantz, 2011), and arts-based programs (Koehne et al., 2016). Two reviews on supports and interventions for autistic adults found that most studies focused on addressing specific areas of difficulty such as social skills and employment, and that there was a lack of research into supports targeting holistic functioning, community participation and quality-of-life (Lorenc et al., 2017; Poon & Sidhu, 2017). More recently, Southby and Robinson (2018) reported on an innovative support service offering information, advice, and mentorship for autistic adults and carers who may not qualify for specialised support. Participants described the service as beneficial for autistic adults' career development, access to other services, wellbeing and everyday functioning. As research into adult interventions is in its early stages, more work is needed to develop support services that accommodate autistic adults' varied needs and preferences.

A few studies have explored informal support after adulthood autism diagnosis, defined as unpaid support received from family and social relationships (Cantor, 1979). Qualitative studies of late-diagnosed adults described both positive and negative experiences depending on the family member's level of autism understanding and acceptance (Crane et al., 2018; Punshon et al., 2009). Two studies focused on perspectives of late diagnosed adults' parents and partners, who sought to understand the autistic person and help them find professional support (Lewis, 2017; Raymond-Barker et al., 2018). Further research is needed to understand the functions of informal support and factors influencing the quality of experiences for adults and support persons.

Studies have highlighted autistic peers as a valuable source of support after adulthood autism diagnosis, which may

occur through formal support groups or informally through personal connections and online communities (Jantz, 2011; Tan, 2018). Since the 1990s, there has been an emergence of informal autistic peer communities offering social connection, support, and advocacy (Bagatell, 2010; Davidson, 2008). In these groups, autistic characteristics are normalised and accepted as part of a shared cultural identity (Bagatell, 2010; Davidson, 2008). In qualitative studies, late-diagnosed adults described informal connections with autistic peers as a positive consequence of diagnosis that helped foster a sense of belonging (Lewis, 2016b; Tan, 2018). Research into people with other conditions found that organised forms of peer support including peer support workers, mentoring programs, and support groups were beneficial for fostering self-acceptance and social connectedness (Repper & Carter, 2011; Richardson et al., 2020; Ussher et al., 2006). Emerging research into organised peer support for autistic adults identified receiving knowledge/advice and experiencing a shared sense of community as the main benefits (Crane et al., 2020; Jantz, 2011).

The internet is a popular yet under-researched source of post-diagnosis support for autistic adults. It offers convenient access to an overwhelming amount of multimedia content on various aspects of autism, including personal narratives from autistic authors (Davidson, 2008; Kollia et al., 2017; Reichow et al., 2012). Many autistic people find the internet is beneficial as it offers alternate modes of social interaction and allows them to connect with online autistic communities, where they can make social connections, share information, and exchange emotional support without the stress of face-to-face contact (Abel et al., 2019; Hassrick et al., 2021). However, studies also identified negative aspects of online autism spaces, including poor information quality, bullying, and contribution to reduced mental health (Hassrick et al., 2021; Reichow et al., 2012).

While the problem of inadequate formal support after adulthood autism diagnosis has been extensively discussed in the literature, much less is known about adults' preferred forms of professional support and experiences with informal sources of support. To better understand the roles of formal and informal support in Australian autistic adults' post-diagnosis experiences, this study aims to explore adults' support experiences, needs, and barriers in relation to professional, social, and self-directed sources using both quantitative and qualitative methods. We also aim to specifically explore the roles of autistic peer support and online support after diagnosis.

## Methods

This study is part of a larger project titled *Pathways, predictors and impact of receiving an autism spectrum diagnosis in adulthood*, approved by the UNSW Human Research Ethics

Committee, HC190582. This study used a data-validation variant of triangulation mixed methods design (Creswell & Plano Clark, 2007). In this approach, quantitative and qualitative data were collected simultaneously using a single survey instrument then analysed separately, using qualitative findings to illustrate and expand upon quantitative findings during interpretation.

## Participants and Procedure

Participants ( $N = 137$ ) were recruited via advertisements placed with existing research studies, autism and disability organisations, and service providers, with links to participant information and consent for the survey. For this study, participants were required to have received an autism spectrum diagnosis (including DSM-IV/ICD-10 subcategories) at or after age 18 to be included. Participants completed an online survey on their experiences during and after autism diagnosis, which involved questions related to usage of and satisfaction with formal, informal, and self-directed support sources. Detailed information on recruitment and procedure were outlined previously (Huang et al., 2021).

## Data Collection

Data for this study were collected in the online survey for the larger project (Huang et al., 2021). Online surveys with open-ended questions have been recommended as a qualitative data collection method that reduces participant burden and increases sample size without sacrificing depth (Braun et al., 2020). Supplementary Materials 1 contains the relevant survey sections.

## Measures

Below is a description of the relevant survey sections.

**About you:** This section contained questions on various demographic characteristics, including date of birth, gender, intellectual disability, autism diagnosis, ethnocultural background, other psychiatric diagnoses, family history of autism, current occupation, and geographic location. This section also asked participants to report details of their autism diagnosis including year of diagnosis, type of professional, and cost, which were described in a previous publication (Huang et al., 2021). Diagnosis age was calculated from birth year and year of diagnosis.

**Support after diagnosis:** Questions in this section addressed participants' usage, satisfaction, and areas addressed by formal, informal, and self-directed sources of support, as well as barriers to accessing external support. Satisfaction with support information and perceived helpfulness of support were both rated on a Likert scale of 1–5. Satisfaction was rated from “very dissatisfied” (1) to “very

satisfied” (5), while perceived helpfulness was rated from “not at all helpful” (1) to “extremely helpful” (5). This section also contained open-ended questions on experiences of autistic peer support and online support (if received), suggestions for support, and general comments.

## Data Analysis

Stata 15 was used for all quantitative data analysis. “Other (please describe)” responses that aligned with an existing category in multiple-choice questions were re-coded as that category. Descriptive statistics were used to summarize participant characteristics and response patterns. Chi-squared tests and t-tests were used to compare responses between groups such as gender or geographical location. Cramer's  $V$  was used to calculate the effect sizes of significant chi-squared test results. Only men and women were included in gender comparisons due to limited sample size of non-binary participants. For geographical location comparisons, participants reporting a “major city” postcode were compared against all participants whose postcodes were not labelled as “major city” given small numbers of remote residents and non-exclusive categories (see Table 1 note).

Sample sizes for questions with missing responses were indicated separately where applicable. The question on areas addressed by informal support was accidentally omitted from the initial survey and included later, resulting in a lower number of completed responses for that question ( $n = 117$ ).

Reflexive thematic analysis (Braun & Clarke, 2006, 2019) was used to analyse open-ended responses on support experiences and suggestions. We approached analysis from a primarily realist, inductive, and semantic perspective in order to faithfully reflect participants' experiences in the real world and allow for triangulation with quantitative data, while acknowledging the researcher's subjective interpretation in this process. Following Braun and Clarke's (2019) emphasis on personal engagement with the data, the first author generated codes during repeated reading of participants' responses, which were collated into broader themes based on shared meanings. The codes and themes were refined through an iterative process of re-examining coded data. The first author recorded reasoning and reflections behind coding and theme decisions to maintain rigour. Content and names of themes were discussed with co-authors for clarity and cohesion. NVivo 12 was used to manage data and assist qualitative analysis.

## Community Involvement

In addition to autistic and intellectual disability advisors' involvement in development of initial survey and consent

**Table 1** Participant Characteristics ( $N=137$ )

Characteristic	<i>n</i>	%
Gender		
Male	34	24.8
Female	86	62.8
Non-binary	14	10.2
Missing	3	2.2
Intellectual disability	8	5.8
Autism diagnosis		
Autism or Autism Spectrum Disorder/Condition	82	59.9
Asperger's syndrome	45	32.9
High-functioning autism	8	5.8
Missing	2	1.5
Ethnicity <sup>a</sup>		
Caucasian	122	89.1
Non-Caucasian	13	9.5
Missing	5	3.7
Country of birth		
Australia	119	86.9
Other	12	8.8
Missing	6	4.4
Language spoken at home <sup>a</sup>		
English	131	95.6
Other	11	8.0
Missing	5	3.6
Geographical remoteness <sup>a,b</sup>		
Major city	97	70.8
Regional	53	38.7
Remote	3	2.2
Any additional lifetime psychiatric diagnosis <sup>a</sup> ( <i>n</i> , %)	125	91.2
Depression	115	83.9
Anxiety disorders	112	81.8
Attention-deficit/hyperactivity disorder (ADHD)	57	41.6
Post-traumatic stress disorder	41	29.9
Other diagnoses	59	43.1
No additional diagnosis	7	5.1
Missing	5	3.7
Day activities <sup>a</sup> ( <i>n</i> , %)		
Open employment	82	59.9
Post-secondary study	31	22.6
Volunteer work	17	12.4
No structured activities	22	16.1
Other	24	17.5

<sup>a</sup>Categories are not mutually exclusive

<sup>b</sup>By postcode according to the Australian Statistical Geography Standard (Australian Bureau of Statistics, 2018), with inner/outer divisions collapsed for regional/remote categories

materials previously mentioned in Huang et al., (2021), four autistic advisors gave feedback on our interpretations of findings to ensure their relevance to lived experiences.

## Results

### Quantitative Findings

Table 1 shows participants' demographic characteristics. Participants' mean age was 41.91 years ( $SD=12.11$ , range 20–72) and mean age at autism diagnosis was 38.85 years ( $SD=12.47$ , range 18–70). Most participants ( $n=113$ , 82.5%) were diagnosed in 2013 or later. Although the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5), released in 2013, defined autism spectrum disorder as a single category (American Psychiatric Association, 2013), a significant percentage of our participants still reported receiving a diagnosis of Asperger's syndrome.

A minority of participants received information on support services at time of diagnosis delivery ( $n=65$ , 47.5%). Among those who did, mean satisfaction with the information given was 3.58 ( $SD=1.21$ ), with 56.9% ( $n=37$ ) giving a rating of "satisfied" (4) or "very satisfied" (5). Likelihood of receiving information did not differ significantly between those who received the diagnosis from a psychologist versus psychiatrist<sup>2</sup> ( $X^2(1)=2.50$ ,  $p=0.11$ ,  $N=124$ ).

Figure 1 shows the popularity of formal, informal, and self-directed sources of support included in this study. No significant differences in sources of support were found between male vs female gender or major city vs regional/remote.

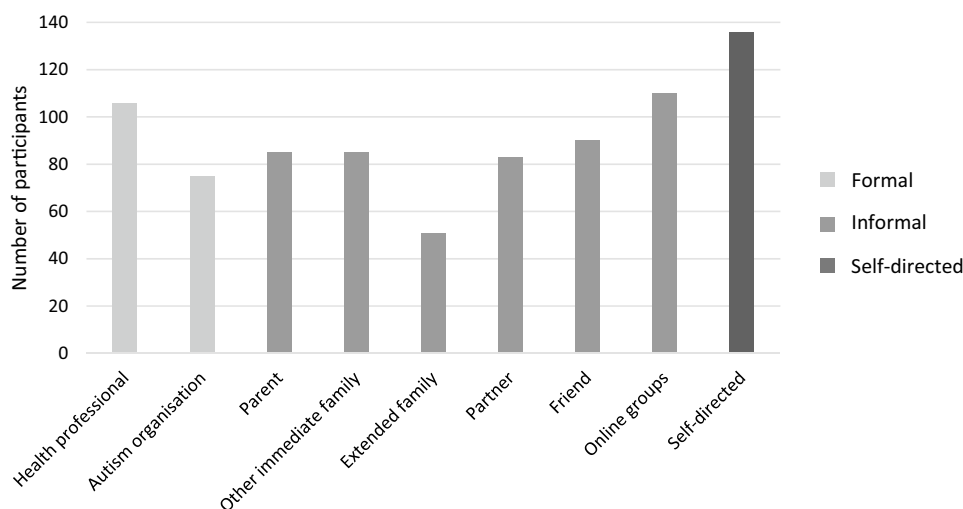
### Formal Support

Most participants received formal support ( $n=124$ , 90.5%). Of those participants receiving formal support, 85.5% received their support from a health professional ( $n=106$ ) and 60.5% from an autism organisation ( $n=75$ ). Participants rated their helpfulness as low-to-moderate, with mean ratings of 3.13 ( $SD=1.31$ ) for professionals and 2.55 ( $SD=1.31$ ) for organisations.

Among those who received formal support ( $n=124$ ), the most common types of professionals providing support were psychologists (62.9%), general practitioners (49.2%), and psychiatrists (32.3%). Only 23.4% received support from professionals other than the three most common categories (Table 2).

Figure 2 shows the percentage of participants who received formal support in each area versus those who did not but would like to. Compared to men, women were slightly less likely to have received behavioural support ( $X^2(1)=4.14$ ,  $p=0.04$ ,  $V=0.19$ ) or attended support groups ( $X^2(1)=5.11$ ,  $p=0.02$ ,  $V=0.21$ ). Women were also

<sup>2</sup> Excluding  $n=7$  who learned the diagnosis from both psychologists and psychiatrists, and  $n=6$  from other professionals.

**Fig. 1** Number of participants receiving each source of support**Table 2** Type of professional delivering formal support, as a percentage of whole sample ( $N=137$ )

Type of professional	$n$ (%)
Psychologist	78 (56.9)
General practitioner	61 (44.5)
Psychiatrist	40 (29)
Counsellor	8 (5.8)
Job coach	7 (5.1)
Occupational therapist	6 (4.4)
Disability support worker	6 (4.4)
Peer worker	5 (3.6)
Social worker	4 (2.9)
Mental health nurse	4 (2.9)
Speech pathologist	3 (2.2)
Other professional	6 (4.4)
Did not have professional support	13 (9.4)

more likely to want to attend support groups ( $X^2(1)=5.25$ ,  $p=0.02$ ,  $V=0.21$ ) than men. No significant differences in areas of support received and wanted were found between major city and regional/remote residents.

Table 3 shows perceived helpfulness ratings from participants who received support in each area. Mean perceived helpfulness for each area of support (excluding “other”) had a strong positive correlation with the number of participants who received this support ( $r(16)=0.84$ ,  $p<0.001$ ), but was unrelated to the number of participants who did not receive but desired this support ( $r(16)=-0.01$ ,  $p=0.96$ ).

Table 4 shows barriers to accessing formal support. Women were more likely to endorse “I don’t know what types of support would be suitable” ( $X^2(1)=5.17$ ,  $p=0.02$ ,  $V=0.21$ ), “I can’t find support suitable for my age” ( $X^2(1)=4.58$ ,  $p=0.03$ ,  $V=0.20$ ), and “I can’t find support

suitable for my gender” ( $X^2(1)=11.03$ ,  $p=0.001$ ,  $V=0.30$ ) than men. Compared to regional/remote participants, those living in major cities were less likely to report other barriers ( $X^2(1)=10.74$ ,  $p=0.001$ ,  $V=0.28$ ), of which  $n=8$  were related to lack of local support services. Participants who endorsed “I can’t find support suitable for my age” did not differ significantly in age ( $t(135)=0.18$ ,  $p=0.85$ ) from those who did not.

### Informal Support

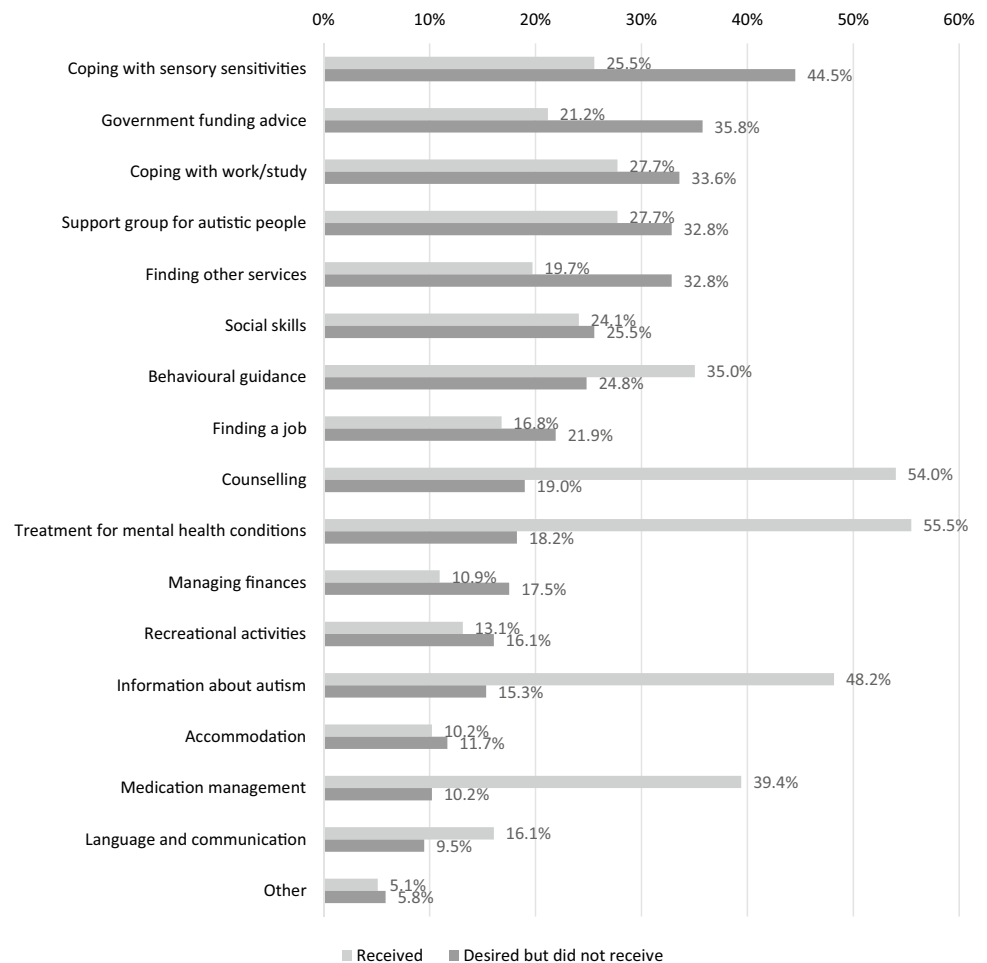
Most participants ( $n=135$ , 98.5%) received support from at least one informal source. Of those participants receiving at least one support, 81.5% received support from online groups/social media ( $n=110$ ), 66.7% from friends ( $n=90$ ), 63.0% from parents ( $n=85$ ), 63.0% from other immediate family ( $n=85$ ), 61.5% from an intimate partner ( $n=83$ ), and 37.8% from extended family ( $n=51$ ). On average, support from online groups was rated as the most helpful ( $M=3.65$ ,  $SD=1.27$ ), followed by partner ( $M=3.58$ ,  $SD=1.38$ ) and friend ( $M=3.03$ ,  $SD=1.30$ ).

Table 5 shows areas addressed by informal support ( $n=117$  due to missing data). The most common areas were also rated as the most helpful. No significant differences were found between men versus women or major city versus regional/remote residents.

Table 6 shows barriers to receiving informal support. Women were slightly more likely to endorse “I worry that others might respond negatively” ( $X^2(1)=6.36$ ,  $p=0.01$ ,  $V=0.23$ ), and “I feel too embarrassed to talk about my difficulties” ( $X^2(1)=5.39$ ,  $p=0.02$ ,  $V=0.21$ ) than men, but less likely to endorse “Other” ( $X^2(1)=4.67$ ,  $p=0.03$ ,  $V=0.20$ ). No differences were significant between major city and regional/remote residents.



**Fig. 2** Received versus desired areas of formal support (N = 137)



### Support from Autistic Peers

Over half of participants ( $n = 90$ , 65.7%) received support from other autistic people. Of those receiving support from other autistic people, 68.9% were supported by someone from an autism-related website or social media, 41.1% by a family member or friend, 17.8% by someone from an autism organisation in person, and 11.1% by others.

### Self-Directed Support

Almost all participants ( $n = 136$ , 99.3%) used self-directed learning to support their journey after autism diagnosis. It was also rated as the most helpful out of all sources of support ( $M = 4.26$ ,  $SD = 1.04$ ). Most common sources of information (Fig. 3) were online articles (used by 86.7% of participants), books explaining autism (86.0%), and YouTube videos (64.0%). Sources of information did not differ significantly by gender or geographical location. Participants who used self-directed learning were most likely to have viewed information produced by other autistic people

(89.7%), followed by professionals (87.5%), other authors (33.1%), and carers (26.5%).

### Qualitative Themes

One hundred and nineteen participants provided open-ended responses. Four themes were developed: Difficulty accessing support, Support for a better life, Belonging and autistic community, and Freedoms of online support.

### “I don’t feel disabled enough”- Obstacles to Receiving Support

Many participants were dissatisfied with the lack of professional support after diagnosis. They described financial and administrative barriers to professional support, including lengthy waiting times, lack of local service providers, and difficulty applying for government disability funding. Some mainstream health professionals had little knowledge of autistic adults and their needs, leaving participants to self-manage and “deal with it alone”. One participant recounted:

**Table 3** Formal support areas in order of perceived helpfulness ( $N=125$ )

Area of support	$n$	Perceived helpfulness	
		$M$	$SD$
Counselling	74	3.43	1.27
Treatment for mental health conditions	76	3.38	1.23
Information about autism	66	3.24	1.10
Social skills	33	3.12	1.34
Behavioural guidance	48	2.98	1.04
Support group for autistic people	38	2.97	1.64
Medication management	54	2.96	1.16
Language and communication	22	2.95	1.33
Coping with sensory sensitivities	35	2.89	1.25
Coping with work/study	38	2.84	1.20
Government funding advice	29	2.34	1.17
Recreational activities	18	2.33	1.46
Finding other services	27	2.26	1.16
Finding a job	23	2.26	1.29
Accommodation	14	2.07	1.27
Managing finances	15	1.80	1.21
Other	7	3.00	1.53

“I actually approached my state-based autism organisation... their response was ‘how old is the child?’. When I explained that I was the ‘child’, they looked very confused and then dismissively said, ‘oh, the only service we have for adults is supported accommodation’”.

**Table 4** Barriers to formal support in order of frequency ( $N=137$ )

Barrier	$n$	%
I can't afford to pay for support	79	57.7
I don't know what types of support would be suitable	79	57.7
My difficulties are not severe enough for the support services available	75	54.7
I'm worried that my difficulties won't be taken seriously	75	54.7
I can't find support suitable for my age	73	53.3
I find it hard to describe my difficulties to professionals	69	50.4
I don't know where to find support	68	49.6
I have had bad experiences with professionals in the past	65	47.4
I feel anxious about seeing professionals	57	41.6
I can't find support suitable for my gender	37	27.0
It takes too long to wait for support services	34	24.8
I find it hard to make and keep track of appointments	31	22.6
My existing physical/mental health conditions make it difficult to visit a health professional	22	16.1
My difficulties are too serious or complex for the support services available	14	10.2
I am doing well and don't need any extra support	14	10.2
Other	20	14.6

Participants also expressed dissatisfaction over lack of support from their families and social connections. They described being disbelieved, treated condescendingly, or rejected after their diagnosis was known, which added to their sense of isolation.

A major barrier to receiving support was the belief that one must be *sufficiently disabled* in order to access support. Some autistic adults did not view themselves as having enough support needs, and the idea of receiving professional support was patronising to them. Those who sought support reported that others would dismiss or minimise their support needs because of their apparent capabilities, even when performing those capabilities required great effort. One participant said:

“I don't feel disabled enough to seek out some of the other support stuff for autistic people - on the surface I seem normal (albeit odd), and so I think people assume I don't need help or support... I am so used to trying to mask and hold it together”.

Considering the difficulties in accessing support, many participants expressed the need for assistance to access and coordinate other support services, including assessment of support needs, information on support types and providers, support planning, and advocacy. Participants also highlighted the importance of resources on living with autism, especially those featuring autistic adults' experiences and perspectives. Participants varied in their desired level of autonomy in managing support. While some participants preferred to have information to “go through at one's own

pace”, others believed more direct guidance would be beneficial: “They really need help coordinating and communicating what they need to professionals... I think FREE case management and advocacy (available before qualifying for NDIS) is a key element missing”.

A smaller number of participants described positive support experiences with professionals and informal support

**Table 5** Frequency and perceived helpfulness of informal support by area (N = 117)

Area	n	%	Helpfulness (M(SD))
Understand strengths and difficulties	93	79.5	3.15 (1.21)
Feelings toward diagnosis	91	77.8	3.18 (1.30)
Information about autism	81	69.2	3.11 (1.25)
Advice on social interactions	80	68.4	2.73 (1.41)
Help getting autism assessment	77	65.8	2.71 (1.44)
Finding professional support	76	65.0	2.42 (1.40)
Daily living assistance	76	65.0	2.61 (1.41)
Meet other autistic people	66	56.4	2.29 (1.38)
Other	14	12.0	2.93 (2.02)

**Table 6** Frequency of barriers to informal support (N = 137)

Barrier	n	%
People I know don't understand autism very well	89	65.0
I worry that others might respond negatively	78	56.9
I find social interactions too difficult	64	46.7
I find it hard to talk about my autism with others	56	40.9
I don't have anyone who is close enough to talk to	53	38.7
I don't want other people's lives to be more difficult because of me	51	37.2
I feel too embarrassed to talk about my difficulties	34	24.8
I don't want others to know about my autism	28	20.4
Other	15	10.9

persons. These included tailored therapy sessions, improved workplace arrangements, emotional and daily living support from family members, and being understood by other autistic people. One participant described her experience with psychologists specialising in autism:

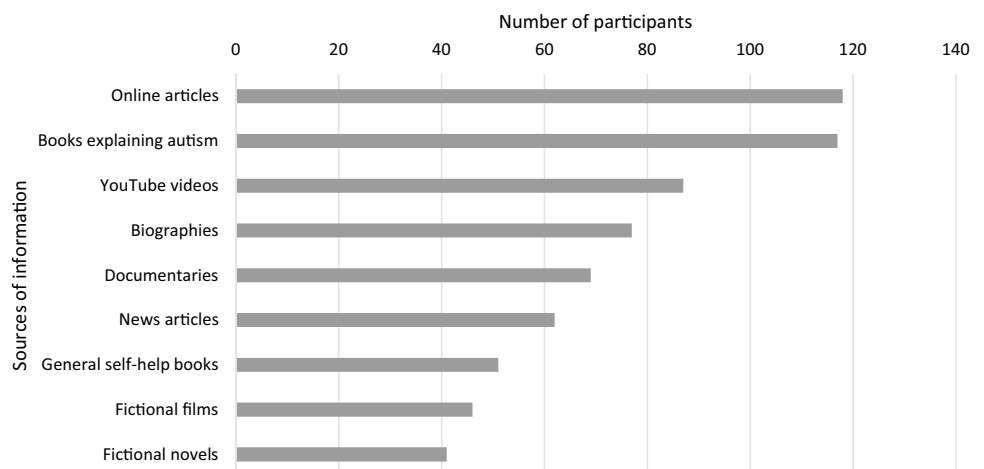
“It was a lot better structured to my needs than previous general psychologists (those who don't know about autism). The psychologists who work with autistic people often know how to tailor a session for someone who likes concrete things, and for those things to be in writing and in dot points and for the psychologist to do the majority of the talking”.

### “We too can have fulfilling lives”- Support for a Better Life

Participants' responses suggested a need for support that is practical, comprehensive and improves overall quality of life. While some participants suggested specific areas such as mental health or employment, many simply expressed a desire to better manage everyday tasks and overcome difficulties. A few participants proposed comprehensive support plans involving counselling, life skills, support groups, and hobbies to address adults' multifaceted needs. The desire for a better life was summarised by one participant: “...basically the support to learn how to do the things that come more naturally to those not on the spectrum so that we too can have fulfilling lives and positively contribute to society rather than being a burden”.

Another priority for support was to help the person develop a deeper understanding of what being autistic means for them. This includes understanding their strengths and difficulties, reflecting upon past experiences, and learning to communicate their needs. Participants believed professionals should empower autistic people to accept their differences and avoid viewing autism as a deficit. One participant said: “Reading and studying will

**Fig. 3** Sources of autism information for self-directed learning after diagnosis (n = 136)





always give you information and help in general, but real-life support allows you to feel more confident and comfortable about your diagnosis”.

### “People on the spectrum actually understand”- Belonging and Autistic Community

Participants received support from other autistic people in a variety of contexts including friends/acquaintances, real-life or online support groups, books or articles, and occasionally professional service providers. Participants’ suggestions for desired support also included support groups, one-on-one mentoring, and information written by autistic people.

Participants generally described interactions with other autistic people positively. They formed connections more easily due to shared experiences and similar communication styles. They also reported feeling accepted and more at ease among autistic peers, knowing they would not be judged for being different. Having similar experiences allowed for exchange of information and advice that aligned more closely with participants’ lives: “People on the spectrum actually understand. They can provide tips and information that others just don’t know about because they haven’t had to discover them”.

However, some participants expressed while the sense of belonging was helpful, it was not a substitute for structured professional support: “It’s been so helpful to not feel so alone, but I really need more formal supports to better integrate into society”. A few also described negative experiences with other autistic people due to differences in communication and social understanding.

### “Easier to communicate”- Freedoms of Online Support

Online information and discussion groups offered great autonomy and flexibility to adults seeking support after diagnosis. Participants often preferred online support to real-life as it was anonymous, could be accessed at any time, allowed them to find other autistic people more easily, and less stressful. For those who preferred written communication, online discussions allowed them to avoid the distraction of non-verbal cues and respond at their own pace. More importantly, it allowed adults to access information and informal support even in the absence of real-life support sources. One participant said:

“I can access online support as and how I need. I have more control over the pace and topics, etc. I can disengage and take a break more easily too. There is less extra information to have to sift through on the spot... I find it easier to communicate through writing than speaking”.

Online support also had disadvantages. For some participants, the anonymity and distance of online communication created a barrier to forming close connections. The relative lack of structure in online spaces also allowed negative attitudes, unhealthy group dynamics, and poor-quality information to take hold. One participant summarized positive and negative aspects of online support:

“Online is one of the few sources for adult-targeted supports. There seems to be very little available in person... As such, while there is some negativity, fatalism, and false information, there is still some good practical life advice re. handling adult responsibilities like work and household management”.

## Discussion

To our knowledge, our study was the first mixed-methods exploration of formal and informal support after autism diagnosis in adulthood. We found participants experienced multiple barriers in accessing post-diagnosis services, and these services were often inadequate for their needs. Results highlighted the importance of informal and self-directed support for self-understanding and wellbeing, including the unique roles of autistic peer support and online support. Our findings have significant implications for government agencies, service providers, and community organisations working to improve support experiences for autistic adults and their families after diagnosis. A summary of formal support areas and recommendations for practice are shown in Table 7.

Significant barriers to accessing formal support after diagnosis were identified. Results highlighted the need for assistance to find, coordinate and fund access to support services. This is consistent with international research calling for improved pathways to support after autism diagnosis (Crane et al., 2018; Lewis, 2016b; Raymond-Barker et al., 2018). Additionally, our findings identified cost considerations, inadequate knowledge on suitable supports, and trouble communicating with service providers as specific barriers to accessing formal support. There are a number of approaches that may help address these barriers. Diagnosis providers should give information on support options at time of diagnosis to ensure clients are linked with appropriate services. Autistic adults with more complex needs or difficulty making contact with service providers may benefit from individualised support planning and management with a trained worker. Measures to reduce cost and administrative barriers, such as government subsidies, streamlined application and referral processes, and shortened waiting times would also help improve access.

**Table 7** Summary of formal support areas and recommendations

Broad category	Support area	Availability <sup>a</sup>	Unmet need <sup>a</sup>	Notes
Core autism traits	Coping with sensory sensitivities	Medium	High	Greatest unmet need
	Social skills	Medium	Medium	Consider adult-specific adaptations of existing supports
	Behavioural guidance	Medium	Medium	
	Language and communication	Low	Low	Less desired but may be helpful for some
Mental health	Counselling	High	Low	Generally accessible
	Treatment for mental health conditions	High	Low	Benefit from tailoring to autism-specific needs
	Medication management	Medium	Low	
Productivity	Coping with work/study	Medium	Medium	Enhances community participation and independence
	Finding a job	Low	Medium	Can reduce financial barriers to other supports
Daily living	Managing finances	Low	Low	Enhances independence
	Recreational activities	Low	Low	Less desired but may be helpful for some
	Accommodation	Low	Low	
Self-understanding	Information about autism	High	Low	Lived experience perspectives are highly valuable Importance of strength-based framings of autism
	Support group for autistic people	Medium	Medium	Preferred by women Incorporate peer-led and professional-led elements Suited to online format
Service access	Government funding advice	Medium	Medium	Can reduce financial barriers to other supports
	Finding other services	Low	Medium	Information on suitable services is highly important Can reduce administrative barriers to other supports May be provided in a variety of formats and intensities

<sup>a</sup>Availability and unmet need categories were determined from the percentage of participants who received support versus those who did not receive but wanted support in each area. Category boundaries were devised based on the range of values in the data: high if  $\geq 40\%$ , medium if  $< 40\%$  and  $\geq 20\%$ , and low if  $< 20\%$

Although a large proportion of participants have received professional support, there was a mismatch between available services and support needs. It was common for adults to have accessed information and mental health support after autism diagnosis. However, they were much less likely to receive support addressing autism-specific (e.g., related to sensory sensitivities) and everyday functioning concerns, which may underlie their low-to-moderate satisfaction ratings. The same pattern of supports received versus wanted was observed in Jones et al. (2014), though only 58.1% of their participants reported receiving post-diagnosis support. Open-ended responses expressing dissatisfaction over the lack of professional support also demonstrated a mismatch between services and needs. While it appears to contradict quantitative data showing a high proportion receiving formal support, this may be explained by some participants not viewing services available prior to autism diagnosis and/or not addressing autism-related concerns as part of post-diagnosis support. These findings highlight the importance for support services to be both accessible and tailored to recipients' needs and priorities. To address adults' need for autism-specific support, it would be worthwhile for specialised autism services and researchers to explore how existing sensory, social, speech/

language and behavioural supports may be adapted to respect adults' need for autonomy and self-determination. In addition to specialised autism services for adults, equipping mainstream clinicians such as psychologists and counsellors to deliver autism-informed support would also help match available support to adults' needs.

Both quantitative and qualitative data showed adults' concerns over not being *disabled enough* to have their needs taken seriously and/or qualify for support, consistent with previous research (Griffith et al., 2012). This may be a reflection of broader misconceptions and prejudice towards people with invisible disabilities, whose disability status and support needs are often scrutinized and disbelieved (Kattari et al., 2018). This fear of being criticised or dismissed may have discouraged adults from pursuing disability-specific support options. Thus, it is important for professionals to take potential invisible difficulties into account when assessing autistic adults' support needs and suitability for services. These findings also suggest a gap in autism-specific support for adults with lower support needs. Services offering information, advice and mentoring as described in Southby and Robinson (2018) may help improve autism knowledge and

wellbeing in adults who do not qualify for more intensive disability services or prefer a self-directed approach.

Qualitative findings showed a preference for support that is self-paced, flexible, and addresses overall quality-of-life outcomes. This was supported by quantitative data on the variety of support areas desired by participants. Specifically, adults in both our study and Jones et al. (2014) desired support to participate in education and employment, areas important for self-determination and community participation. Supports such as resources for employers/educators, advocacy support for students/employees, and advice on managing workload would all be beneficial. A smaller proportion of participants in our study also wanted support for other aspects of daily living, such as managing finances, attending recreational activities, and finding accommodation. Consistent with recommendations in Lorenc et al. (2017), our findings demonstrate the need for formal support to address a range of independent living and community participation outcomes. Service providers would benefit greatly from ongoing consultations with autistic community members to ensure these supports are informed by lived experience and align with community needs.

Qualitative findings showed adults' preference for professional support that incorporates a strength-based view of autism and encourages self-understanding and acceptance. These sentiments are echoed in previous studies where late-diagnosed adults expressed positive views of autism and embraced it as part of their identity (Lewis, 2016b; Tan, 2018). While it is necessary for support to address perceived shortcomings, professionals should avoid framing autism as a flaw or deficit as it may be an important part of the client's identity. Considering the ubiquity of poor mental health in late-diagnosed adults (e.g., Hofvander et al., 2009), the strength-based approaches desired by our participants may have important benefits for self-esteem and wellbeing.

As a supplement to the more specialised functions of professional services, informal support from family and friends mainly served to assist the individual's self-understanding in the context of autism and offer emotional assistance. Unfortunately, some participants did not have positive experiences with the people in their lives. Both quantitative and qualitative data identified others' lack of autism knowledge and stigmatizing beliefs as major obstacles to seeking informal support, where disclosing the diagnosis may result in negative reactions rather than assistance. Quantitative findings also suggested that autistic adults' social communication challenges made it more difficult to maintain relationships with and reach out to potential support persons. Community stigma reduction approaches based in autism acceptance may be helpful for improving people's reactions to disclosure of an autism diagnosis. There is also a need for resources and services for support persons of newly diagnosed adults, such as self-help resources, individual and family counselling,

and support groups. These supports would help support persons develop a deeper understanding of autism, respond to the adult's needs more effectively, and manage their own wellbeing.

Women in this study were less likely to receive behavioural and group support and more likely to report difficulties finding suitable formal support. These findings suggest that available supports may be insufficiently sensitive to gender differences including gender-specific support needs. Recently, researchers have proposed the existence of a *female autism phenotype* involving greater social motivation, more socially acceptable special interests, and a greater tendency to camouflage autistic traits in social settings (Hull et al., 2020; Lai et al., 2015). Our finding of increased preference for support groups in female participants is also consistent with this profile. As gender differences in presentation are a contributor to delayed autism diagnosis in females (Hull et al., 2020; Shattuck et al., 2009), women diagnosed in adulthood may be especially likely to display these female-typical traits and require supports to be adapted to meet their needs. As increasing numbers of autistic women are identified and diagnosed, it has become increasingly important for professionals to be aware of gender-specific issues and ways to support women whose profile of autistic traits may appear atypical. More research is needed to confirm our findings on gender differences in post-diagnosis support due to the small number of male participants in our data.

Participants perceived support from other autistic people to be highly valuable. Quantitative data showed that information produced by autistic people was highly utilised in participants' self-directed support. This was echoed by qualitative findings where knowledge from peers with similar experiences was considered especially useful. In addition to practical information, the removal of mainstream societal expectations in autistic communities allowed participants to communicate more freely without fear of judgement. However, participants' open-ended responses also mentioned negative experiences with autistic peers, emphasising that informal peer support could not fulfill the need for structured and individualised formal supports. Organised forms of peer support could help incorporate benefits of autistic peer support in a more structured and goal-oriented format that extends beyond the usual functions of informal support. Support groups were highly desired in both our quantitative data and Jones et al. (2014). These groups may be organised with varying levels of structure and professional involvement based on member preferences and have been implemented successfully for autism and other conditions (Castelein et al., 2008; Jantz, 2011; Ussher et al., 2006). Based on existing research into mental health peer support, involvement of trained peer support workers alongside professional support may help promote empowerment and self-acceptance in clients (Repper & Carter, 2011). As late-diagnosed adults

have often experienced long periods of alienation and confusion prior to diagnosis (Huang et al., 2021; Lewis, 2016b), the mutual understanding and acceptance offered by peer support programs could be especially valuable.

Our quantitative data showed online resources to be a highly accessible form of self-directed support, while qualitative data highlighted its benefits in terms of autonomy and flexibility. These characteristics of online support made it especially suitable to participants who expressed discomfort with meeting professionals and preference for online communication. Online support also facilitates the exchange of informal peer support regardless of physical location. However, qualitative data highlighted potential shortcomings including unreliable information and unwanted behaviour from other users. This is consistent with past research suggesting the quality of online autism information to be highly variable (Reichow et al., 2012). As a relatively new support format, further research is needed to explore its usefulness as a free or low-cost supplement to traditional face-to-face support. Specifically, development of authoritative online resources designed to help adults navigate autism diagnosis and subsequent support would help address gaps in formal support and prevent individuals from being misled by low-quality information.

Our study had several limitations including the accidental omission of an informal support question during initial data collection, omission of non-binary gender from gender analyses, and reliance on self-report data. A major limitation is that although we aimed to include late-diagnosed adults with a variety of abilities and backgrounds, most participants did not have intellectual disability and were either studying or in open employment at time of survey. While this helps to demonstrate that supports are necessary even for those who appear to be well-integrated into mainstream society, their support needs and experiences are likely to be different to autistic adults with intellectual disability and/or who are unable to enter post-secondary education or competitive employment. Despite our efforts to recruit via intellectual disability organisations and offer Easy-read study information (Huang et al., 2021), some participants may have had difficulty completing the main survey even with support. To achieve better inclusion of these groups, researchers may need to improve targeted recruitment strategies and alter the study format for optimal accessibility. Future research should also extend our findings by exploring support persons and professionals' experiences of post-diagnosis support. Their perspectives as advocates and providers would help identify additional barriers to support and further inform the development of services.

Our survey of autistic people diagnosed in adulthood uncovered significant unmet support needs and barriers to accessing support. Findings also highlighted the unique benefits of autistic peer support and online support, as well

as ways to integrate them into service provision. We look forward to future developments in resources and services tailored to the diverse needs of autistic adults and their support persons.

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## Declarations

**Conflicts of interest** The authors have no relevant financial or non-financial interests to disclose.

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

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

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