

**Autistic Adults' Experiences Seeking and Receiving Support for Mental Health and Suicidality**

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## **Author Note**

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### **Language Use**

In this manuscript we use identity-first language (IFL). IFL is preferred by the study advisory group as well as the study's autistic authors. We acknowledge that some people with a diagnosis of autism prefer person-first language.

### **Conflict of Interest Statement**

At the time of the study, D.H. was supported by a Suicide Prevention Australia National Suicide Prevention Research Fellowship. C.M.B is currently supported by a Suicide Prevention Australia National Suicide Prevention Post-Doctoral Research Fellowship. We declare no actual or potential conflict of interest.

### **Data Access**

Requests for access to the data sample should be directed to Darren Hedley, PhD, Olga Tennison Autism Research Centre, School of Psychology and Public Health, La Trobe University, Melbourne 3086, VIC, Australia; e-mail: d.hedley@latrobe.edu.au.

**Ethics Statement**

The research was approved by La Trobe University Human Research Ethics Committee HEC20235. All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from participants after the nature of the study was explained.

**Authorship Statement**

D.H., M.S., and D.N. designed the study. D.H. collected the data with the assistance of a research assistant. J.W. analyzed the data. D.H. and J.W. wrote the manuscript with input from all authors. All authors reviewed and approved the final version of the manuscript.

## **Abstract**

### **Background**

Autistic adults have a high incidence of mental health challenges and suicidality, with a correspondingly increased mortality risk. Considering the serious risk to autistic people posed by mental health challenges, our objective was to gain a nuanced understanding of autistic adults' experiences in seeking and receiving support for their mental health and experiences of suicidality.

### **Method**

Acknowledging autistic people as the experts on their own lives, we applied an integrated co-design approach to our study design, involving autistic adults at every stage. Thirty-three autistic adults with a history of suicidal behavior participated in semi-structured narrative interviews, discussing their experiences seeking and receiving formal and informal support for their mental health. The data generated were analyzed using reflexive thematic analysis.

### **Results**

We constructed an overarching theme that “We Don’t Know What We Don’t Know”, enclosing four central themes: (1) Communicate with Me; (2) Understand Me; (3) Help Me to Understand Myself; and (4) Support Me.

### **Conclusion**

Our findings demonstrate an urgent need to remove barriers to access mental healthcare services and improve effectiveness of service utilization for autistic adults. Our thematic map provides a framework to inform approach for service providers engaging with autistic adults.

*Keywords:* autism, mental health, suicidality, service access, barriers, lived experience, qualitative research, reflexive thematic analysis

## **Community Brief**

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

Autistic adults face serious barriers to access and effective utilization of services to support their mental health and treat co-occurring mental health conditions. This is important because autistic adults are much more likely to have a co-occurring mental illness, and are more likely to die from suicide, compared with the general population.

### **What was the purpose of this study?**

To better understand the lived experiences of autistic adults when they access and use healthcare services for their mental health, and to use the understanding gained to help inform better ways for service providers to support autistic people.

### **What did the researchers do?**

We asked thirty-three adults with a history of suicidal behavior to share their experiences seeking and receiving support for their mental health challenges. Specifically, we asked them who they reached out to for support, what the experience was like, and if they had any suggestions to improve the process. An autistic researcher analyzed the conversations to find the common factors, both positive and negative, that might impact autistic adults accessing and using healthcare services. In addition, we built from the pool of information received to see if we could find any additional, unspoken problems that might be impacting autistic adults when engaging with healthcare services.

### **What were the results of the study?**

Study participants told us that their challenges accessing healthcare services included communication with service providers, the (mis)understanding of autism and autistic people held by many service providers, the difficulties autistic adults experience in understanding themselves and their support needs, and the difficulties autistic adults face in finding and using the right services and supports. We were able to identify a wider, overarching problem of misunderstanding between autistic adults and healthcare service providers.

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

This is the first study to ask autistic adults with lived experience of suicidality about their experiences accessing support for their mental health. We found there were many misunderstandings between autistic adults and healthcare service providers that affected the level of care autistic people received. We also asked participants about positive experiences and things that helped them when they were in crisis. Our research findings can be used to redesign services to better support autistic adults.

**What are potential weaknesses in the study?**

The study participants didn't include any autistic adults with a co-occurring intellectual disability, or with complex communication support needs, so the information might not apply to autistic people who have those challenges.

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

Our findings will help service providers adapt their services and approaches to better serve the needs of autistic adults.

**Autistic Adults' Experiences Seeking and Receiving Support for Mental Health and Suicidality**

There is strong evidence that autistic adults are at increased risk of co-occurring mental health conditions.<sup>1-3</sup> Given that co-occurring mental health conditions are significant risk markers for suicidal thoughts and behaviors in both autistic<sup>4-6</sup> and non-autistic<sup>7,8</sup> adult populations, it is unsurprising that suicidality (encompassing suicide-related ideations, behaviors, and communications<sup>9,10</sup>) occurs at significantly elevated rates in autistic individual compared to the general population, and comparable to other clinical groups<sup>2,11,12</sup>. Indeed, a recent meta-analysis and comparison to Global Burden of Disease (GBD) data, identified the mortality risk due to suicide in autistic adults as more than three-fold that of the non-autistic population.<sup>5</sup> In addition, there is emerging evidence that autistic individuals may experience additional, more severe, and sometimes unique, sources of distress across the lifespan compared with non-autistic individuals.<sup>13-16</sup> Epidemiological evidence suggests that increasing distress increases the likelihood that an individual may progress from suicidal thoughts to a suicide attempt, particularly if that individual has a co-occurring mood disorder;<sup>17</sup> and this is consistent with findings regarding the interplay of stressors, psychopathology and suicide rates in the autistic population.<sup>14</sup> Indeed, autistic adults consider accessing and receiving effective services for mental healthcare a priority,<sup>18</sup> a finding echoed by a recent roundtable focused on mental health and suicidality in autism.<sup>19</sup>

In direct contrast to this priority, there is an increasing body of evidence suggesting significant barriers to service access and utilization for and by autistic people.<sup>20-23</sup> These studies have examined autistic adults' service experiences via focus groups<sup>22</sup> and online surveys,<sup>21,23</sup> and have identified multiple barriers to both accessing and utilizing services for treatment of co-occurring mental health conditions. Furthermore, lack of or difficulty accessing appropriate mental healthcare can increase suicidal ideation.<sup>21</sup> Barriers to the effectiveness of mental healthcare therapy for autistic adults identified by participants in the current study followed similar themes to other recent studies examining service access barriers (see Results section).<sup>23</sup> Thus, there is urgent need to

explore the experiences of autistic adults accessing mental healthcare services that can subsequently inform service improvements.<sup>20</sup>

Provision of services to the autistic population comes at considerable economic cost to both the families of autistic people and governments.<sup>24-26</sup> In Australia, for example, National Disability Insurance Scheme (NDIS) funding for participants with a diagnosis of autism exceeded \$2.3 billion in the six months to 30 June, 2021.<sup>27</sup> Similar government costs as a percentage of gross domestic product are reported in the United Kingdom, Canada and the United States.<sup>24-26</sup> Given the economic impact of provision of care for autistic individuals, it is imperative that healthcare services are designed, accessed, and provided, in ways that maximize effectiveness.

### **Current Study**

In this qualitative study we interviewed autistic adults with a history of suicidal thoughts and behaviors to improve our understanding of the experiences of autistic adults seeking and receiving support for their mental health, including co-occurring mental health conditions, and suicidality.

### **Method**

Interviews were conducted between August and December 2021. The interview guide, can be found in the supplementary materials (Appendix 1), as can the guiding research questions (Appendix 2).

### **Participants**

Thirty-three autistic adults (16 women, 14 men, 3 non-binary) aged 21 to 68 years ( $M_{\text{age}} = 41.72$ ,  $SD = 11.49$  years), without co-occurring intellectual disability and who had previously participated in a longitudinal study investigating mental health in autistic adults, participated in the study. Primary inclusion criteria were: history of one or more suicidal attempts ( $n = 20$ ), interrupted attempts ( $n = 1$ ), or suicidal ideation ( $n = 12$ ) on the Columbia-Suicide Severity Rating Scale (C-SSRS),<sup>28</sup> and were not considered to be at immediate risk of suicide (as assessed by a psychologist on the research team). Other inclusion criteria were the ability to communicate in English, aged 18 years or older, and reporting a formal diagnosis of autism by a qualified health professional.



***Procedure***

The study was approved by the La Trobe University Human Research Ethics Committee (HEC20235). All participants provided written informed consent. The study was advertised in an emailed newsletter sent to all participants from one of two Australian longitudinal studies on autism.<sup>29,30</sup> Individuals who had participated in two previous phases of the research study indicated if they would be willing to participate in a subsequent qualitative interview. We reviewed their C-SSRS scores and other data to determine eligibility, with a goal of recruiting up to 40 participants with a history of suicidality. We then invited participants beginning with those with history of an attempt first, to those reporting suicidal ideation on the C-SSRS, until we reached 40 participants or had exhausted the participant pool. In this case, we exhausted the participant pool when we reached 33 participants. A detailed risk assessment procedure based on an existing protocol<sup>31</sup> was developed for the study. All participants were provided with links to mental healthcare resources; those identified with any level of suicidal risk based on their responses to survey items were followed up according to the risk management protocol. Participants were reimbursed AUD \$100 in shopping vouchers upon completion of all phases of the research program.

***Co-Design Statement***

Community members (autistic and non-autistic researchers, clinicians, family members, and autistic adults) collaborated in all three of the ‘design, development, implement’ phases of this research. This integrative co-design approach<sup>32</sup> was applied during design of research questions, epistemological approach, interview design, data coding, theme generation, and interpretation of results, as well as authorship of the paper. As one concrete example, prior to developing the interview guide and questions, we invited community members including research participants from the broader study to (anonymously) contribute questions, suggestions, and ideas they felt we should ask to “better understand and support mental health and suicide prevention” within the autistic community. We subsequently incorporated these suggestions into the interview guide.

***Data Analysis***

J.W. analyzed the open-ended narrative survey responses using a reflexive thematic analysis (RTA) approach.<sup>33-35</sup> RTA explicitly acknowledges, highlights, and emphasizes, the researcher's role in knowledge production as an active process, and highlights the need to document and understand the researcher's engagement with their data and analytical process.<sup>34</sup> We applied a constructivist epistemology and experiential orientation to the data, in line with Braun and Clarke's approach to RTA.<sup>34</sup> J.W. performed an iterative, inductive analysis, with both latent and semantic coding of data.<sup>35</sup> RTA was chosen because this approach aims "to provide a coherent and compelling interpretation of the data, grounded in the data".<sup>36</sup> In RTA, the researcher is positioned as a storyteller, with active engagement in generating shared meaning; it acknowledges that data are interpreted through the lens of the researcher's own positionality in terms of their lived experience, background and knowledge.<sup>34,36-38</sup> We agreed that this approach would allow us to draw on our team's strengths and do justice to the generosity of study participants in sharing their experiences. We noted that, in a departure from the convention of reporting results in a 'Results' section, then contextualizing findings and synthesizing analysis in a 'Discussion' section, the appropriate reporting style for RTA is to contextualize data and synthesize analysis as data are reported, in a combined 'Results and Discussion' section.<sup>35,39,40</sup> We agreed to adhere to the preferred reporting style for RTA, thereby maximizing the analytical potential of the methodology.

### ***Researcher Positionality***

Braun and Clarke conceptualize researcher subjectivity as a resource rather than a threat to credibility".<sup>38</sup> As such, we have embraced the RTA paradigm, and utilized lived experience of autism as a resource to enhance understanding of our dataset, with the data analysis for this paper performed by an autistic researcher. By explicitly and transparently stating the subjective connection with the context we are investigating, we feel we add richness to our analysis, rather than detracting from it. Specific details on approach and researcher positionality are provided in the supplementary materials (Appendix 3, Supplement Table S1, and Supplement Table S2).

### ***Participant Demographics***

Participants reported basic demographic and diagnostic information. Most participants were born in Australia ( $n = 23$ , 69.7%) and primarily spoke English in the home ( $n = 29$ , 87.9%).

Participants reported a diagnosis of autism spectrum disorder (ASD;  $n = 17$ , 51.5%) or Asperger's syndrome ( $n = 16$ , 48.5%). Participants tended to be highly educated, 42.4% ( $n = 14$ ) had gained a bachelor's level qualification, 24.2% ( $n = 8$ ) had a master's level degree, and 9.1% ( $n = 3$ ) had obtained a PhD. Most participants ( $n = 21$ , 63.6%) reported being in a relationship, 51.5% ( $n = 17$ ) lived with a spouse or partner, 18.2% ( $n = 6$ ) lived with a parent or relative. Common co-occurring diagnoses included anxiety and depression (both  $n = 23$ , 69.7%) and attention deficit hyperactivity disorder ( $n = 10$ , 30.3%); no participants reported intellectual disability.

## Results and Discussion

### Reflexive Thematic Analysis

Participants discussed their experiences accessing and utilizing both formal and informal supports for their mental health generally, as well as specifically during periods of mental illness and suicidality. In addition, study participants were asked for their suggestions to improve service provision for autistic adults in the future. A single, overarching theme was generated from analysis of the interview transcripts and recordings: 'We Don't Know What We Don't Know'. Under this theme sat four central themes: 'Communicate with Me', 'Understand Me', 'Help Me Understand Myself', and 'Support Me'. These themes and the associated sub-themes are mapped in Figure 1. Details of the researcher's conceptualizations of these themes are supplied in the supplementary material (Supplement Table S3).

[Insert Figure 1 about here]

### ***Overarching Theme: We Don't Know What We Don't Know***

Negative experiences in the mental healthcare system were commonly reported by participants, both in the current study and more widely in the literature<sup>41</sup>. These experiences speak to a culture of shared misunderstandings, a case where both mental healthcare professionals and autistic adults "don't know what we don't know" about the other party's understandings, beliefs,

motivations, and needs. Not knowing in an age of information would appear to be only mildly problematic, whereas not knowing what we don't know is more likely to represent a true barrier to understanding, as it may lead us to consider our knowledge of a topic complete<sup>42</sup>. In addition, not knowing that we don't know, and acting on that (lack of) knowledge, may lead to harm via acts of omission or commission<sup>43-45</sup>. These acts of harm may be both unintentional and un-noticed by the perpetrator,<sup>46,47</sup> leading the victim of harm to feel invalidated and unseen<sup>42</sup>, and further perpetuating the divide of "we don't know what we don't know".

**Theme 1: Communicate With Me.** Communication difficulties and misunderstandings were a common element of many participants' narratives when describing their attempts to access and utilize healthcare supports. Two discrete sub-themes were constructed: 'Be Explicit' and 'Understand I Might Communicate Differently'.

**Be Explicit.** Explicitness in communication helps to ensure the meaning received is the meaning intended. Participants suggested that this can be enacted both by direct communication, without the use of vague metaphor and hidden meaning, and by providing information with sufficient detail to ensure there are no doubts about expectations, procedures, and requirements. Several participants expressed feeling relieved when provided with explicit, detailed communication prior to participating in a stressful situation: "It takes a lot of the mental load off me, because I don't have to make all the social decisions on the fly, because I know what they are, because I know what I'm supposed to be doing." (P016)

**Understand I Might Communicate Differently.** Study participants shared many experiences involving miscommunication and misunderstanding when attempting to access or use mental healthcare services. Notable is the fact that persistent challenges in social communication and interaction is one of the diagnostic criteria for autism,<sup>48</sup> yet in the participant narratives, it appeared that very little effort was being made on the part of service providers to accommodate for, or even understand, these challenges.

Study participants identified several communication factors that led to difficulties in making appointments. Executive function difficulties such as remembering during business hours to make the appointment and difficulties with multi-step processes were common factors, as was uncertainty around social rules (e.g., how long one should wait for a promised call back before following up). In addition, many participants expressed a dislike of telephone calls. Participants described how these challenges were not accommodated for by service providers:

[The GP] yelled at me, because I hadn't called the psych, and that was obviously the most sensible thing to do. I don't call anybody. I don't want to call anybody. Unless it's like an absolute [expletive] emergency. (P016)

A frequent suggestion for improvement was ensuring that supports and service providers are aware of, and willing to accommodate, the additional needs many autistic adults have in terms of communication. Most notable was the request for patience and extra time to ensure understanding.

I'm quite emotional, which is something that's improved a bit as I've aged, but just people who won't get angry at me if I'm going slowly or getting emotional. (P001)

Several participants suggested that having information available in multiple formats (e.g., oral instructions, written instructions, video, social stories) would be helpful to allow them to improve comprehension.

**Theme 2: Understand Me.** The need for service providers to truly understand the autistic people they are supporting is a universal theme, identified in the narrative of every participant in the current study. Four sub-themes were constructed under 'Understand Me'.

***I Am Valid as a Whole Person.*** Study participants identified several factors that ranged from unhelpful to potentially harmful when healthcare services interact with autistic adults. Participants reported that “pathologization of difference” was a widespread problem, particularly when that difference underpins an autistic adult’s identity. Pathologization of characteristics inherent to autistic adults (e.g., by care providers) may result in ‘othering’ due to a power imbalance.<sup>49</sup> Members of the dominant group may characterize differences shared by members of the subordinate group as undesirable. Members of the subordinate group may find it difficult to reject this characterization and may not be able to replace it with a more positive view of themselves.<sup>50</sup> Michael suggests that ‘being othered’ could be considered a co-occurring condition of autism,<sup>51</sup> a position supported in the narratives of several of study participants, e.g., “It would be nice if there was room in the world for people like me” (P003); “I already thought that there was something wrong with me and I felt bad already. [She] was reinforcing that idea that there was something wrong” (P013).

Participants’ experiences of invalidation (e.g., of one’s lived experiences or autism diagnosis) were common. Invalidation occurs when a service provider fails to accept an individual’s own experiences of their life because it differs from the caregiver’s experiences and understanding of the world.<sup>52</sup> Invalidation is likely to have significant and long-term impacts on one’s health and wellbeing, including internalizing invalidation,<sup>53</sup> overcompensating for the perceived problem,<sup>52</sup> and rejecting or avoiding care.<sup>54</sup> Moreover, invalidation can lead to worsening of psychological distress and subsequent intensification of mental illness.<sup>52,54-56</sup>

Furthermore, invalidation of diagnosis had significant reported negative impacts on participants’ self-identity. Many autistic individuals consider that autism underpins their way of being, and thus their identity.<sup>57,58</sup> “When people just say, well, obviously you’re not autistic, it feels like they’re taking away a big part of who I am, as well as invalidating a lot of the struggles that I have” (P007). Many participants felt that invalidation of diagnosis by (often well-meaning) caregivers was a barrier to both access and utilization of services and impacted the caregiver’s ability to support the autistic person effectively: “It’s an integral part of my mental health. I can’t not be who I

am and that's just part of who I am" (P004). In a further example of the complexity of navigating healthcare services, participants also shared their understanding that while disclosure of diagnosis often led to invalidation, disclosure was essential to effective utilization of supports:

[Disclosure] helps [service providers], because autistic people have different thinking processes and sometimes different ways of behaving. (P029)

***My Context is a Complex System.*** Human beings are, and exist in, complex systems.<sup>59</sup>

Logically, any additional points requiring integration into the system increase the complexity of that system, e.g., an autistic adult attempting to function in a non-autistic world. Given the high levels of co-occurring mental health and physical health conditions in the autistic population<sup>1-3,60,61</sup>, it seems reasonable to conclude that many autistic adults inhabit an extremely complex system. One of the characteristics of a complex system is its interconnectedness, meaning that making any change to the system can have unexpected, unplanned, and disproportionate repercussions on parts of the system that are seemingly unrelated.<sup>59,62</sup> It is unsurprising that the challenges of understanding such a complex system and managing changes (and the often unexpected repercussions of those changes), appear to be quite problematic for many participants: "I felt like things were fine until they weren't and then things would get really, really bad really quickly and it was always when the psychologist thought I was doing well" (P019); "[I can't] comprehend in my head how people just can't follow the rules" (P021).

***Sometimes I'm a Chameleon.*** Masking (also described as 'camouflaging' or 'compensating') refers to behaviors that may be employed by autistic individuals to hide autistic traits and behaviors that may be considered socially unacceptable, as well describing artificial social behaviors that are employed to fit into non-autistic society.<sup>63</sup> Masking can be a barrier to access and use of healthcare services, in terms of not appearing 'autistic enough' to qualify for supports: "Because I present pretty normally, on the surface, they don't really take me seriously" (P009); conversely, masking can

be an asset in terms of caregivers assuming competence due to the masked presentation of the autistic person: “I suspect that my experience of working with psychiatrists in particular would have been remarkably much worse if I were not good at masking.” (P001)

Regardless of the effect on accessing and utilizing supports, there was consensus amongst study participants that masking had a cost for the autistic person’s self-esteem and identity. Additionally, there were costs both in terms of draining emotional resources: “If I go to a conference, or something like that, and I have to be a normal human being for a week, then [I] will have a meltdown for days when I get home” (P007); as well greater demands on cognitive processes: “You’re constantly having to translate what you’re thinking into something that somebody else is going to understand or not react to” (P026). Participants also reported that their ability to mask could be unreliable: “I try and blend in and sometimes I fail” (P024).

***I am Not a Stereotype.*** A common theme in the narratives of study participants was the stereotypical (mis)understanding of autism held by many service providers. Participants reported having their competence or capabilities assumed based on their autism diagnosis: “I feel like [because of my diagnosis] both of them were approaching me like I was a child. I didn’t have autonomy and I didn’t have the right to choose what was happening with me” (P016). Study participants also reported having their diagnosis brought into question based on the caregiver’s poor understanding of autism: “She completely disregarded everything I said and [told me] if you’re autistic you’d have problems with sensory issues that you could have no way of understanding as a normal person.” (P019)

**Theme 3: Help Me Understand Myself.** Many participants in the current study expressed that developing an understanding of oneself and one’s needs could mitigate feelings of failure and shame and reduce the associated distress, leading to more successful navigation of supports. Strategies used included metacognition to understand one’s thoughts and behaviors as indicators of mental health challenges: “when I have a lot of trouble navigating small changes in routine and things like that, [...] that’s when I’m probably having some extra problems [with my mental health].”



(P033); understanding how to choose the best person to support them: “I need less, and I need calm, so I would go to my boyfriend. I would not go to my mother. Despite the fact that their intentions are exactly the same, the delivery is very different” (P007); and having simple, concrete solutions: “Keeping it clear and simple and doable, concrete, in terms of, like, go to the beach, or do something action orientated like have a bath” (P006).

Conversely, participants shared that experiencing difficulties in understanding themselves, their support needs, and their place in the world, added to challenges in accessing and utilizing supports. As one study participant said, when asked what supports might help them where previous tactics had failed, “I honestly don't know [what supports are available]. It's one of these things, we don't know what we don't know.” (P005)

***Getting My Diagnosis Disrupted My World.*** For those study participants who discussed being diagnosed as an adult, there was consensus that the diagnosis changed how they viewed the world and their place in it. The diagnosis often challenged the commonly held self-belief that the participant was a ‘failed neurotypical person’ and validated their experiences as real rather than imaginary: “It makes sense, it's changed my self-concept. I'm not a freak, it's not my fault and it's not something I have to fix with bloody mindfulness” (P031).

***I May Not Understand My Own Needs Without Assistance.*** It can be difficult for an autistic person to recognize their own basic needs (often due to alexithymia and poor interoception), let alone find ways to meet them, especially if one needs support to do so.<sup>64</sup> Many participants in the current study expressed their difficulties in understanding how they were feeling, how to support optimal functioning, and what their support needs were: “I think this is a very classic autistic thing where we don't realize that we're feeling bad, until we're feeling horrible.” (P007)

Several participants also expressed an awareness of choosing maladaptive coping strategies, but not knowing how or where to look for support to choose better strategies: “I would probably just try and cope, in a dysfunctional way. Like drink too much. I might have a relapse of an eating

disorder.” (P006); “Nothing positive. I self-medicate with alcohol, basically, switches the brain off and get some sleep.” (P012).

***Help Me Imagine a Positive Future.*** Rigid, black and white thinking is often a characteristic of autism.<sup>65</sup> Many study participants described thinking about themselves and the future in a way that was rigid and negative: “I’ve grown towards the position that there’s pretty much nothing that can be done to improve my communication abilities from the life stage I’m at. I’ve given up a bit.” (P003). Another study participant shared their difficulty finding meaning and value when considering how they fit in the world:

You get up. You go to work. You come home. You do schoolwork and clean the house. You go to bed and then you do it all again tomorrow. I’m not having a profound impact on anything. I’m not creating a cure for cancer. I’m not making meaningful differences to the human species. So, what is the point of me? (P021)

Study participants also described that it is possible, with the right support and an understanding of themselves, to develop a positive appraisal of oneself: “Something is kicking in from knowing - having the information about how my brain is wired is really helping me” (P008). Beyond a simple understanding of one’s own cognition, participants reported the development of increased psychological flexibility, including strategies similar to cognitive diffusion and acceptance.<sup>66,67</sup> “[What helped was] understanding that the feeling was transitory and even though I had suicidal thoughts I had no intention of acting on them” (P023).

***I Need to be a Person Beyond My Diagnosis.*** Many study participants described positive aspects of their lives in terms of opportunities to contribute meaningfully to the world, and the benefits that brings to the individual making the contribution. Study participants expressed that meaningful contribution was worthwhile, even when it came at a significant cost to the person making the contribution:

I'm happy to talk and I find meaning if the rubbish I say to you will help someone like my kid. Because I've spent 35, 40 years feeling different until I found out I *was* different. It would have been good if smart people like you and your team, would find a way to help kids like mine. So, a momentary sadness or pain [*for me*] for the betterment of kids like my son is worth it. (P021)

**Theme 4: Support Me.** Previously discussed themes and subthemes constructed from our data are inextricably entwined in our fourth theme, 'Support Me'. Participants discussed that when caregivers understand the support needs and strengths of individuals they support, as well as the context inhabited by those individuals, and when the two parties can communicate with each other in ways that foster understanding, the support is most effective. When the individual receiving support understands themselves and their own needs, they gain the most benefit from that support.

***Help Me to Remove the Known Barriers.*** The common barriers to access both formal and informal mental healthcare supports identified by participants are summarized in the supplementary material (Supplement Table S4). It is notable that many study participants described characteristics of autism itself, and its commonly co-occurring conditions (e.g., mood disorders and personality disorders),<sup>68</sup> as barriers to access and utilization of supports. Many participants in the current study identified that they need assistance to overcome these barriers.

***Please Help Me to Build My Toolbox.*** Study participants described a range of complex mental health support needs that often changed over time, related to both autism and co-occurring conditions. Establishing a range of supports to meet these needs was a priority for many participants. One of the difficulties experienced by participants as they attempted to build their toolbox, was the need to find and co-ordinate supports themselves, as well as communicate between different caregivers to ensure important information is shared appropriately: "There's not

really much coordination between the different people involved in your [care], my GP writes the new referral letters every six months, but apart from that, no.” (P001)

Participants who had managed to develop and maintain successful and healthy formal support relationships discussed the effectiveness of having a main formal support who acted as ‘an anchor’ for their care:

I switched doctors and this new doctor for the last six months or so, she's had that capacity to ask good questions. Even when I haven't needed the appointment as such. ...She's been there as a check-in, as an anchor. We've maintained that once a month. (P002)

Participants also described difficulties with various therapies, interventions and strategies that were not adapted to accommodate their individual needs. Poor person-activity fit (whether a particular intervention is beneficial to a specific individual)<sup>69</sup> was reported by several participants when discussing their use of talk therapy, cognitive behavioral therapy (CBT), and mindfulness. This is consistent with emerging evidence that the efficacy of these interventions may have been previously overestimated, particularly for autistic adults.<sup>70,71</sup>

In terms of recommendations for clinical practice, the literature does give some guidance to improve person-activity fit of interventions. Spain and Happé found that adapting CBT interventions to accommodate autistic people’s needs significantly increased the effectiveness of the intervention.<sup>72</sup> In addition, precision medicine (tailored, individualized approaches considering not just autism; rather adapting therapy to suit every individual’s unique needs) has been shown to improve outcomes.<sup>72,73</sup> Autistic voices have consistently suggested the need for individualized approaches;<sup>20-23</sup> a sentiment echoed by participants in the current study. In addition, failure to tailor treatment has been consistently recognized as a barrier to access and use of supports;<sup>74</sup> as has lack of provider knowledge of autism.<sup>75</sup> Curnow et al. examined the literature around psychotherapy interventions for autistic adults and found that many interventions weren’t adapted to the needs of

autistic adults, nor were they evidence-based, and that they may represent interventions aimed at training neurotypical behaviors rather than supporting the mental health of autistic people.<sup>76</sup>

Implementing these recommendations may initially impose an increased burden on clinicians and training providers; such an outcome would, however, align with current clinical practice standards promoting person-centered care.

***Psychological Safety Lays the Groundwork for Me to Thrive.*** Psychological safety is a term coined by organizational psychology to describe one's assessment of the consequences of taking interpersonal risks in each situation.<sup>77</sup> High levels of psychological safety occur when an individual is confident that they won't be embarrassed, rejected or punished for speaking up or for being their whole, authentic selves.<sup>77-79</sup> Seager explored the construct of psychological safety in terms of mental healthcare, and concluded that the approach taken by many healthcare services may actively erode psychological safety.<sup>80</sup> This reflects the experiences described by many study participants when recounting their negative experiences with mental healthcare service providers.

The World Health Organization suggests there is an inherent, and often unchallenged, power imbalance between mental healthcare services staff and the people utilizing that service.<sup>81</sup> Unless explicitly addressed, this power imbalance may manifest in terms of a dynamic where the service provider, however well-intentioned, has (coercive) "power over" the consumer.<sup>82,83</sup> In contrast, when the caregiver consciously and deliberately shares power with the consumer, a collaborative, generative relationship of "power with" can develop.<sup>83,84</sup> Cultural humility describes a personal accountability-based approach to managing this potential power imbalance.<sup>85</sup> It requires the caregiver (in this case the mental healthcare service clinician) to recognize their own (often internalized and unconscious) biases, and to actively work to recognize and respect each individual patient's identity, experiences, beliefs, preferences, and the context they inhabit as an essential part of the consideration when interacting with, treating, and discussing patients.<sup>85-87</sup> Cultural humility fosters a culture of trust and safety, and is an approach that warrants further consideration by mental

healthcare service providers as a means of establishing a psychologically safe environment for autistic adults accessing services.<sup>81,85,88</sup>

An individual's experience of mental healthcare, as discussed by study participants, can range from an experience that generates safety and trust to one that is actively harmful. One participant discussed their experience of being hospitalized following a second suicide attempt immediately after discharge from hospital for an initial attempt:

I saw a psychiatrist [...] after attempting while I was still in a medical ward [...] he was doing a lot of gaslighting. I think it was an attempt to absolve the hospital of responsibility for my [suicide] attempt. (P027)

And then their later experience during the same admission of connecting with a caregiver who established a relationship grounded in cultural humility, a power-with dynamic, and ultimately, psychological safety:

She responded with understanding when I would do things. Like if I identified I was heading towards a meltdown she understood the significance of that and understood what ways best to help me. She never, ever, ever touched me without permission. She understood that if I said I needed 15 mins of leave to be able to go around the block to decompress, she would overrule the nurse who said "no" because they thought I was too big of a risk. Things like that. She understood how to communicate with me. [*That was the*] difference between knowing the world and everything in it is hopeless and there's no point in trying because it's actively hostile to your existence; and knowing that in spite of the world being hostile, there are parts of it that are safe. (P027)

***I've Been Thinking About My Past.*** Many study participants discussed that they have been able to adjust their thinking to reframe their reaction to mental ill-health and suicidal ideation, having learned to adopt an attitude of 'this too shall pass'. This was a common and consistent theme amongst study participants who continued to experience chronic suicidal ideation, and who expressed that reframing these feelings as transitory had improved their outlook.

***How Do We Find the Good Ones?*** Most participants were in consensus when it came to answering the question, "Can you suggest any changes to a mental health professional or service to assist them to provide better care to autistic people experiencing a mental health or suicide crisis?" Their answers centered around the necessity of building on-going relationships with mental healthcare supports that have a true understanding of, and willingness to engage with, autistic adults and their lived experience. "I think the key issue I find in general is the fact that, unless you really understand being on the spectrum, it's difficult to get any effective support." (P026)

Filtering potential supports to find those professionals who would be a good fit is seen as a stumbling block: "I think in practice finding professionals who do have that needed understanding, that's where the hard part is." (P028); there were several suggestions indicating that a way to filter supports would be welcomed and useful: "[We need a way of] making it easy to locate [and] identify professionals who are autism friendly and are experienced with autism." (P030)

### **Quality Assessment**

We applied Braun and Clarke's Quality Assessment Framework for Thematic Analysis Papers to ensure that our report conformed to the data analysis plan and reflected our planned RTA approach.<sup>38</sup>

This study has several strengths. Key was our co-design process, ensuring that the study topic, research questions, and interview questions were relevant and important to our identified community members. As this study was conducted within a larger study which examined suicidality of autistic people, we were able to target recruitment for autistic adults who had experienced

suicidal thoughts and behaviors, and our sample size was sufficient to generate meaningful data via RTA.<sup>38,40</sup>

Our research is novel in terms of our in-depth, qualitative analysis of a relatively large sample of autistic adults with lived experience of suicidality. Several of the themes aligned with previous findings from research conducted in the United States, United Kingdom and Canada,<sup>20-23</sup> suggesting our findings may be generalizable to other similar Western countries. However, we also note some unique findings from our research, specifically: (1) the overarching theme, ‘We Don’t Know What We Don’t Know’; and (2) the framework provided by our four central themes.

‘We Don’t Know What We Don’t Know’ synthesizes the lived experiences of research participants in engaging with supports and integrates the commonalities of experience described by study participants. This theme may be operationalized to bridge the gap between the positive intent of support services and the unmet needs of autistic individuals seeking support. The framework provided by our four central themes may be immediately operationalizable by both autistic individuals to clarify and articulate needs when seeking support, and by service providers to improve both access to and provision of support to autistic individuals. To highlight the similarities and unique findings from our research, we summarize, compare, and contrast results with several recent studies in Table 1. In addition, utilizing our data we were able to generate a list of commonly experienced barriers to access and utilization of supports, including traits of autism and co-occurring conditions, that can immediately inform service design and service provision. We do note that research participants were restricted to autistic adults who were able to independently participate in zoom interviews, and thus our results may not be generalizable to autistic adults with profound communication challenges, or those with co-occurring intellectual disability.

[Insert Table 1 about here]

### **Conclusion**

Our findings have important implications for services providing mental healthcare support for autistic adults, particularly those with a history of significant and complex mental health



concerns and suicidality. Participants described areas of significant challenge in accessing and utilizing supports. It is both poignant and concerning that more than one participant experienced an interaction where they perceived a service provider as being angry with them. Is this another example of “we don’t know what we don’t know” leading to misunderstanding, or is the participant’s perception of communication-based violence<sup>47</sup> an accurate representation of the interaction? Either way, it raises concerns for the impact of such interactions on the wellbeing of autistic adults engaging with healthcare services. Based on our findings, we suggest that accommodations need to be made to the way services communicate with autistic people, requiring better training of clinicians and staff to understand the diverse presentations and support needs of autistic adults, as well as additional support and education for autistic adults to better understand themselves and their individual support needs. Targeted improvements in removal of known barriers to access, as well as availability of services for autistic people, including a way for autistic adults to find the services they need should be prioritized. Perhaps most urgently, mental health service support providers must take action to ensure that their services are psychologically safe for the autistic adults they serve. We are not suggesting that operationalizing the knowledge gained from the lived experiences of autistic adults, such as the stories generously shared during our study, is simple. Indeed, it will require significant further iterative consultation with the people most impacted by the changes needed, and further interrogation of the underlying problems inherent in a system that is not meeting the needs of the people it aims to serve. It will require a major effort to address ‘what we don’t know we don’t know’ by all community members. While many of the experiences shared by study participants were negative, participants also provided examples of positive interactions when they felt listened to, and their experiences were validated. The resilience and optimism shared by many study participants, as well as specific recommendations to improve services described within this study, provides hope for positive change.

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## Tables

**Table 1.***Comparison of Key Papers*

The Current Study	Mazurek et al. <sup>23</sup>	Brede et al. <sup>20</sup>	Camm-Crosbie et al. <sup>21</sup>	Tint and Weiss <sup>22</sup>
*We don't know what we don't know				
Communicate with Me				(Mis)Communication with service providers
*Be explicit in your communications with me				
Understand I might communicate differently	Talking in session can be difficult	Complexity needs flexibility		Not speaking the same service language
	Verbal communication expectations	Impact of being autistic on treatment		
	Trouble talking about feelings	Communication		
	Session format can help or hinder progress			
	Session structure affects the therapy experience			
	Alternative activities can enhance therapy			
Understand me	Therapist acceptance and understanding is crucial		Lack of understanding and knowledge	(In)Experienced experts
I am valid as a whole person	Feeling heard, accepted and validated	Collaboration and empowerment	Not believed or listened to	Feeling heard
		Listening to autistic voices		

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My context is a complex system		<p>Enabling independence self-advocacy and self-care</p> <p>Complexity needs flexibility</p> <p>Impact of being autistic on treatment</p> <p>Interaction between autism and mental health difficulties</p> <p>Lonely, difficult service experience</p> <p>Negative consequences</p> <p>Tension in personal relationships</p>		
Sometimes, I'm a chameleon				Masking service needs
I am not a stereotype	<p>Therapist acceptance and understanding is crucial</p> <p>Therapist understanding of autism</p>	<p>Lonely, difficult service experience</p> <p>Barriers at every step</p> <p>Clinicians' lack of awareness and stereotyped attitudes</p>	<p>'People like me don't get support'</p> <p>Dismissed for treatment or support because seen as 'coping'</p>	<p>Hidden hurt of maintaining the mask</p> <p>Not looking the part</p> <p>Seeing is believing</p>
<p>Help me to understand myself</p> <p>*Getting my diagnosis disrupted my world</p>	Therapy offers tools for personal growth			



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I may not understand my own needs without assistance	Developing self-understanding	Complexity needs flexibility		Unworthy of services
		Impact of being autistic on treatment		
		Working with emotions		
	Importance of talking through and processing issues	Need for a comprehensive and flexible approach		
		Adjusting timings and expectations for outcomes		
Help me imagine a positive future *I need to be a person beyond my diagnosis	Gaining new perspectives			
Support me			Tailored support is beneficial and desirable	
Help me to remove the known barriers		Barriers at every step	'People like me don't get support'	Accessing appropriate services: "a constant struggle"
		Difficulties accessing support	Support geared towards children	Not fitting the bill
		System/organizational barriers	Long waiting lists and lack of funding	"A broken system"
		Services being based around neurotypical norms	Lack of understanding and knowledge	Getting there is half the battle
		Impact of being autistic on treatment		

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Please help me to build my toolbox		Sensory sensitivities Need for predictability Thinking styles Need for a comprehensive and flexible approach Being bespoke and evidence-based Bridging formal and informal support	Lack of understanding and knowledge  Not suited to my needs	Square peg in a round hole Looking outside the box for social support
*Psychological safety lays the groundwork for me to thrive *I have been thinking about my past How do we find the good ones?		Lonely, difficult service experience Negative consequences Iatrogenic harm and distrust in the service system Inappropriate use of medication	Well-being  Negative impacts  Positive and enabling	

Note: Items marked with an asterisk (\*) represent thematic conceptualizations unique to the current study.

## Figures

Figure 1.

*Thematic Map*