

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.¹⁻³ Given that co-occurring mental health conditions are significant risk markers for suicidal thoughts and behaviors in both autistic⁴⁻⁶ and non-autistic^{7,8} adult populations, it is unsurprising that suicidality (encompassing suicide-related ideations, behaviors, and communications^{9,10}) occurs at significantly elevated rates in autistic individual compared to the general population, and comparable to other clinical groups^{2,11,12}. 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.⁵ 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.¹³⁻¹⁶ 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;¹⁷ and this is consistent with findings regarding the interplay of stressors, psychopathology and suicide rates in the autistic population.¹⁴ Indeed, autistic adults consider accessing and receiving effective services for mental healthcare a priority,¹⁸ a finding echoed by a recent roundtable focused on mental health and suicidality in autism.¹⁹

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.²⁰⁻²³ These studies have examined autistic adults' service experiences via focus groups²² and online surveys,^{21,23} 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.²¹ 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).²³ Thus, there is urgent need to

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

Provision of services to the autistic population comes at considerable economic cost to both the families of autistic people and governments.²⁴⁻²⁶ 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, 2021.²⁷ Similar government costs as a percentage of gross domestic product are reported in the United Kingdom, Canada and the United States.²⁴⁻²⁶ 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),²⁸ 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.^{29,30} 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 protocol³¹ 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 approach³² 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.³³⁻³⁵ 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.³⁴ We applied a constructivist epistemology and experiential orientation to the data, in line with Braun and Clarke's approach to RTA.³⁴ J.W. performed an iterative, inductive analysis, with both latent and semantic coding of data.³⁵ RTA was chosen because this approach aims "to provide a coherent and compelling interpretation of the data, grounded in the data".³⁶ 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.^{34,36-38} 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.^{35,39,40} 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".³⁸ 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 literature⁴¹. 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 complete⁴². 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 commission⁴³⁻⁴⁵. These acts of harm may be both unintentional and un-noticed by the perpetrator,^{46,47} leading the victim of harm to feel invalidated and unseen⁴², 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,⁴⁸ 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.⁴⁹ 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.⁵⁰ Michael suggests that ‘being othered’ could be considered a co-occurring condition of autism,⁵¹ 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.⁵² Invalidation is likely to have significant and long-term impacts on one’s health and wellbeing, including internalizing invalidation,⁵³ overcompensating for the perceived problem,⁵² and rejecting or avoiding care.⁵⁴ Moreover, invalidation can lead to worsening of psychological distress and subsequent intensification of mental illness.^{52,54-56}

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.^{57,58} “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.⁵⁹ 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^{1-3,60,61}, 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.^{59,62} 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.⁶³ 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.⁶⁴ 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.⁶⁵ 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.^{66,67} “[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),⁶⁸ 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)⁶⁹ 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.^{70,71}

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.⁷² 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.^{72,73} Autistic voices have consistently suggested the need for individualized approaches;²⁰⁻²³ 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;⁷⁴ as has lack of provider knowledge of autism.⁷⁵ 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.⁷⁶

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.⁷⁷ 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.⁷⁷⁻⁷⁹ 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.⁸⁰ 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.⁸¹ 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.^{82,83} In contrast, when the caregiver consciously and deliberately shares power with the consumer, a collaborative, generative relationship of "power with" can develop.^{83,84} Cultural humility describes a personal accountability-based approach to managing this potential power imbalance.⁸⁵ 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.⁸⁵⁻⁸⁷ 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.^{81,85,88}

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.³⁸

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.^{38,40}

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,²⁰⁻²³ 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 violence⁴⁷ 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. ²³	Brede et al. ²⁰	Camm-Crosbie et al. ²¹	Tint and Weiss ²²
*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		

The Current Study	Mazurek et al. ²³	Brede et al. ²⁰	Camm-Crosbie et al. ²¹	Tint and Weiss ²²
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			

The Current Study	Mazurek et al. ²³	Brede et al. ²⁰	Camm-Crosbie et al. ²¹	Tint and Weiss ²²
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		

The Current Study	Mazurek et al. ²³	Brede et al. ²⁰	Camm-Crosbie et al. ²¹	Tint and Weiss ²²
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.

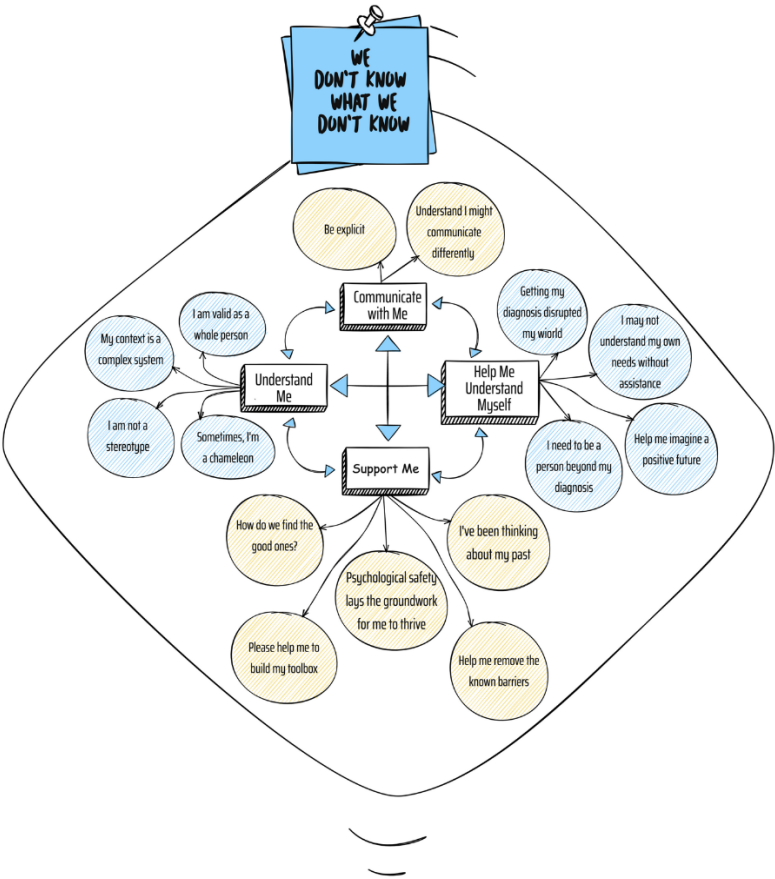


Figure 1. Thematic Map

Supplementary Materials

Appendix 1.

Interview Guide

Instructions
<ul style="list-style-type: none"> • <i>Introduce self. Let participants know that they will be asked a series of questions about their experiences in seeking and receiving support for their mental health, including specific questions about support for suicidal thoughts and behavior.</i> • <i>An example question is: “Do you have a specific support or coping strategy in place if you are feeling suicidal or experiencing suicidal thoughts?”</i> • <i>Acknowledge that we are here to learn from the participants and that they have important experiences, needs and perspectives that we hope to capture, in order to understand their experiences.</i> • <i>Thank participants for their time and participation and let them know that the information they share is valuable for the project and their identity will be kept confidential.</i> • <i>Let participants know it should take around 60 minutes to complete the interview, and that they can take a break at any time they want.</i> • <i>Let participants know that they can stop at any time they choose, and either end the interview, or resume at another time or on another day, if they want.</i> • <i>Ask participants if there is anything they would prefer not to be asked about during the interview.</i> • <i>Let them know they can also call on someone if they feel the need during the interview.</i> • <i>Ask about language preference (e.g., autistic/with autism/on the spectrum etc.)</i> • <i>Any questions prior to starting?</i> • <i>Ask participants how often they would like to take a break. If unsure, suggest taking a break after each 20 minutes and whenever else they require.</i> <p>[Optional prompts in brackets]</p>
<p>Interviewer tips:</p> <ol style="list-style-type: none"> 1. Thinking about digging deeper and probing each question to get at the depth and richness of a substantive area. 2. Use the interview guide only as a guide, not a script i.e., if the participant has already addressed an area in the course of the interview, use discretion to skip areas on the guide and go to the next (to save time and cover the breadth of the interview).

<p>A. Experiences getting help for mental health <i>The first questions ask about getting help to assist with your mental health and wellbeing</i></p>
<p>Q1. Would you reach out for or seek support for your mental health if you need it? If yes:</p> <ul style="list-style-type: none"> • Who would you reach out to for mental health support? (these people could be professional or non-professional) • Is there anything that has made it difficult for you when trying to reach out for help from these people/services? <p>If no:</p> <ul style="list-style-type: none"> • what stops you from reaching out for support for your mental health? [probe for physical/environmental/systemic/internal barriers]
<p>Q2. What have your experiences getting help, or treatment for mental health concerns in general, been like?</p> <ul style="list-style-type: none"> • Can you describe any positive elements of the process of getting help? • Can you describe any negative elements of the process of getting help? • How could the process of getting help have been improved? • Has your access to mental health care changed (i.e., improved or worsened) during the COVID-19 pandemic? If yes, how?
<p>B. Supports and coping strategies</p>
<p><i>*The next questions ask about supports you currently have for your mental health and wellbeing</i></p>
<p>Q3. If you have them, can you tell me about any supports you have for your mental health? [probe for both professional and non-professional supports]</p> <ul style="list-style-type: none"> • [for professional supports/services] Has there been a particular type of provider that has been better for you? If so, how/why? [providers examples: service, hospital, psychologist/social worker, mental health crisis center/team, telephone line] • Are there things that they said or did that were helpful or useful to you? • Is there anything they said or did that was not helpful or useful to you? • What might be things that these others could do or have done to be more helpful? • In your opinion, does the understanding a service or professional have of autism affect their effectiveness in supporting you?
<p><i>*The next questions ask specifically about supports when you feel, or have in the past, felt suicidal; for example, thinking about suicide, planning a suicide attempt.</i></p>
<p>Q4. Do you have a specific support or coping strategy in place if you are feeling suicidal or experiencing suicidal thoughts? If yes:</p> <ul style="list-style-type: none"> • Can you tell me a bit about what the support or coping strategy is?

- Has this strategy been effective for you? If yes/no, what makes it that way?
- Are there situations where this strategy has been less effective?
- Is there anything else you think might be helpful for you when you are feeling suicidal or having suicidal thoughts?

Q5. [If applicable] What are some of the most important things you would want someone to know to support you if/when you are experiencing a suicidal crisis?

Q6. [If applicable] Is there anything else you haven't already talked about that you would suggest to others to better support you if you were specifically experiencing suicidal thoughts or a suicide crisis?

C. Safety Plan

**The next questions ask about safety plans. A safety plan is a step-by-step plan to help people stay safe when they have thoughts about suicide. It is often developed with a mental health professional but can also be an informal plan developed by a person without professional help.*

Q7. Do you have a safety plan in place for when you are feeling suicidal?

If yes:

- Can you tell me a bit about what the plan involves? When might you use it? How was it developed, and with whom?
- Does your Safety Plan involve assistance from others? How helpful has this been?
- Have you actually used your safety plan before?
[If yes, would you use it again? What makes it something you would use in the future?]
[If no, is there anything about the plan that would prevent you from using it?]

If no safety plan:

- What has stopped you from developing a safety plan for if you are feeling suicidal?
- Are there ways you could make a plan useful to you?

**The next questions relate to your diagnosis of autism, and how it might affect the services you receive, either positively or negatively, and about disclosure and/or awareness of your diagnosis by the service or professional.*

D. Autism and support received from mental health sector

Q8. Have you had experiences where a mental health professional or service was aware of your autism diagnosis?

If yes:

- Do you think it helped that they knew about your diagnosis?
[If so, how was it helpful?]
[If not, what elements made this not helpful?]
- Have you ever been denied a service due to your diagnosis of autism? If so, please explain and give an example.

<p><i>Q9. Do you think it's important for health professionals to know about your autism diagnosis in order to provide effective mental health services, including for treating behavior or thoughts related to suicide?</i></p> <ul style="list-style-type: none"> • If yes, what makes it important? • If not, can you explain further your reasons for thinking that professionals' knowledge about your autism diagnosis would not be helpful in providing mental health treatment?
<p><i>Q10. Do you think your autism diagnosis has impacted your access to services/getting the help you need? If so, how?</i></p>
<p><i>Q11. What could be changed to make mental health services more accessible to autistic people?</i></p>
<p><i>Q12. 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?</i></p>
<p>E. Closing</p>
<p><i>Q13. Before we finish, is there anything you wanted to say today that you haven't yet had a chance to?</i></p>
<p>[Thank participant for their time and tell them that what they have provided has been very helpful]</p>

Appendix 2.*Guiding Research Questions*

1. What are the experiences of autistic adults seeking and receiving support for their mental health and suicidality?
2. What are the barriers to access, and to effective utilization, for autistic adults seeking and receiving support for their mental health and suicidality?
3. Are there any common factors that are associated with successful navigation of the process by autistic adults seeking and receiving support for their mental health and suicidality?
4. Are there any common factors that are associated with less than successful navigation of the process by autistic adults seeking and receiving support for their mental health and suicidality?
5. How can these insights inform service design and provision to remove obstacles and enable success for autistic adults seeking and receiving support for their mental health and suicidality?

Appendix 3.*Extract of Research Journal and Memos***Reflection on our Data Analysis Approach**

We analyzed open-ended narrative survey responses using a reflexive thematic analysis (RTA) approach^{1,2}. 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 process². We are cognizant of the need to be explicit, deliberate, and transparent, in our processes. In response to this, data memos and journaling were utilized during the RTA process and these research artefacts were available to all authors during the study. J.W. performed the RTA, with regular meetings and collaboration between all authors in order to maximize understanding and synthesis of meaning from the rich, contextual data generated during the interviews. We broke the RTA process into eight steps.

Step 1: Research Questions

During step one, we defined and refined our research questions, as presented in Appendix 2.

Step 2: Researcher Positionality

In step two, we interrogated our underlying theoretical assumptions, as well as explicitly stating our approaches and orientations, following a framework outlined by Braun and Clarke^{3,4}. In addition, we interrogated our understandings of the need for inter-rater reliability, our understanding of bias, and the differentiation of "codes" from "themes" and "themes" from "topics". The resulting understandings are summarized in Supplement Table S1.

(Insert Supplement Table S1 about here)

We examined our own positionality, and our self-identification of positionality are summarized in Supplement Table S2. Additionally, J.W., as the person performing the data analysis, further examined her own position and privilege to understand the layers of lived experience she brought to the analysis. This is J.W.'s understanding of her positioning in the world.

I am a white, cisgender, queer, autistic, ADHD, physically disabled woman. I primarily use oral speech to communicate, particularly in public. I am a native English-language speaker and reside in a country where English is the majority language used. I have experienced ableism, ageism, discrimination based on sexuality, and sexism/misogyny. I acknowledge that because I am cisgender, white, English-speaking, primarily use oral language to communicate, and can present as abled and straight, I have also experienced privilege relating to those identities, in addition to my economic and educational privilege.

(Insert Supplement Table S2 about here)

Step 3: Familiarization with Data

In step three, J.W. read and re-read the interview transcripts, initially three times, as well as listening to recordings of interviews, becoming intimately familiar with the dataset. During the second read-through, J.W. began note-taking of casual observations, and documented thoughts and feelings that arose during the reading. She also observed and noted initial trends and interesting passages as she read, generating over one hundred pages of notes. Once the third read-through was complete, all authors again met to discuss J.W.'s initial thoughts, and to finalize agreement to begin step four: generation of initial codes.

The ensuing discussion was robust, and included discussions around objectivity and subjectivity, Braun and Clarke's detailed descriptions of RTA and its potential pitfalls^{2,5}, and our expectations of the coding process. The final outcome of the discussion was to clarify that whilst we recognize that the data must drive the stories we uncover, it is likely those stories will be influenced by the researcher coding, however subtly; and that we would use Braun and Clarke's framework for assessing the quality of a thematic analysis⁵ as a guidepost to ensure that we do justice to the generosity of our research participants and truly honor their lived experiences in the stories we tell.

Step 4: Generation of Initial Codes

J.W. began coding the transcripts *in vivo*, ensuring each coding unit captured a 'bite of meaning' rather than a 'snippet of information', to ensure our participants voices were authentically

represented in our analysis, e.g., a participant's experience was coded as "being on the mental health unit does not actually constitute mental health supports though" rather than "mental health supports" (P1110). The process was iterative, with new codes often sparking a connection with a previously read transcript, necessitating a back-and-forth approach to understand the meanings beyond the units of information being coded.

Step 5: Generate Themes

Once initial coding was completed, J.W. loosely grouped codes into tentative thematic groups, using both the semantic and latent meanings derived from the data. J.W. used a narrative process to clarify her conceptualization of the data, writing in first person voice to 'explain' the meaning constructed from the data. See Supplement Table S3 for examples.

(Insert Supplement Table S3 about here)

Step 6: Review Potential Themes

Another iteration of coding was performed, to ensure all examples of each potential theme had been coded, and to discover any additional meaning not previously construed from the data. Potential themes were then reviewed, and codes collapsed into initial thematic groups. Another read through of the transcripts was performed, and thematic groups further collapsed into initial themes.

Step 7: Define and Name Themes

Further definition and naming of themes was an iterative process, moving backwards and forwards between steps 4-8 as needed. Initial themes were further collapsed into four central themes, with several sub-themes below each.

Step 8: Produce the Report

As the report was being written, new understanding gained, and new knowledge synthesized by the authors, themes and sub-themes were revisited and adjusted to ensure accurate representation of participants' experiences and acknowledgement of autistic voices in the literature generally. Report writing was part of the iterative process of analysis during this study, and as such,

discussion of results is presented as part of the results section, rather than in a separate discussion section. It is also worth noting that the literature across a wide range of disciplines was examined and referenced during report writing. Our study focused on the mental health of autistic adults, but supports accessed and used can come from a wide range of disciplines, and these supports also exist in contexts of business, organization, communication, culture, society, etc.

Once initial report writing was completed, the report was assessed against the twenty questions in Braun and Clarke's Quality Assessment Framework.⁵ As a part of this assessment, several items initially conceptualized as themes were recognized as topic summaries and removed from the thematic map. This included information about barriers to access and use. These participant-identified barriers are summarized in Supplement Table S4. While this was important and valuable information, it was not a theme, so it was not reported as part of the thematic analysis.

(Insert Supplement Table S4 about here)

Supplement Table S1.*Addressing and Understanding Our Underlying Theoretical Assumptions.*

Factor	Position
Essentialist versus constructionist epistemologies	We adopted a constructionist epistemology in our analysis, acknowledging the importance of recurrence, but also appreciating that a search for meaning and meaningfulness are central to the analysis of the dataset ⁶ .
Experiential versus critical orientation	We took an experiential orientation to the data, as we wanted to focus on meaning and meaningfulness that reflected our participants experiences ⁴ . This was appropriate in order to prioritize the lived experiences of autistic adults and authentically represent the meaning they had ascribed to those experiences. This approach allowed prioritization of “meaning made” by study participants, rather than “meaning making” by the researcher ⁶ .
Inductive versus deductive analysis	An inductive approach is, by definition, data driven, and aims to be solely reflective of the content of the dataset ⁶ . We note that it may not be possible to achieve purely inductive analysis, as divorcing oneself completely from the conceptual frameworks by which we interpret the world is unlikely ^{2,3,5} . We adopted an open-coding approach in an attempt to be primarily inductive; we also aimed to be transparent about the theories and frames that may overlay our analysis (e.g., J.W. has a background in applied positive psychology, and has been transparent about her engagement with the constructs of positive psychology during discussions of the data).
Semantic versus latent coding	Semantic coding is a descriptive analysis, engaging with explicit/surface meaning of data, while latent coding is an active attempt by the researcher to interpret the deeper layers of meaning, and discover underlying beliefs that may inform the descriptive layer of data ⁶ . We have used both semantic and latent coding: semantic coding where meaningful semantic information was recognized, and latent coding where meaningful latent information was generated.
Inter-rater reliability and bias	The ideas that qualitative studies need coding by consensus, and that avoiding researcher bias is a priority, discounts the understanding that meaning, and knowledge are informed by situation and context. Braun & Clarke go as far as labelling a concern with “demonstrating coding reliability and the avoidance of ‘bias’ (as) illogical, incoherent and ultimately

Factor	Position
	<p>meaningless in a qualitative paradigm”⁵. They further conceptualize researcher subjectivity as “a resource for knowledge production, which inevitably sculpts the knowledge produced, rather than a must-be-contained threat to credibility”⁵. As such, we have embraced the RTA paradigm, and utilized J.W.’s familiarity with the autistic context (as an autistic adult herself) as a resource to enhance understanding of our dataset. By explicitly and transparently stating J.W.’s subjective connection with the context we are investigating, we add richness to our analysis, rather than detracting from it.</p>
Codes, themes, and topics	<p>RTA conceptualizes a code as an analytic unit or tool, capturing an observation - a single facet - which when synthesized by the researcher together with other single-facet codes, can build rich, multi-faceted themes, where themes are the stories told by our data⁵.</p> <p>Topics represent the structural coding of our dataset: the answers to the questions explicitly asked during the interviews. While the data produced by structural coding is often relevant, and even useful, it rarely provides a rich understanding of a context in the same way thematic coding can.</p>

Supplement Table S2.*Researcher Positionality.*

Researcher	Self-identification of Positionality
J.W.	Adult-diagnosed lived experience researcher. Parent to adult autistic children.
C.B.	Adult-diagnosed neurodivergent researcher, focusing on autistic experiences of mental health concerns. Lived experience of significant mental health concerns & disability.
S.B.	Late-diagnosed autistic researcher with 17 years' work experience in community settings including as a clinician in forensic settings. Now, and for the past 9 years, she is a researcher in the field of autism, employment, and wellbeing.
M.S.	Non-autistic researcher with >30 years' experience as a psychological clinician and active researcher in the field of autism and developmental disability. And with autistic family members and experience of suicide.
D.N.	Non-autistic researcher with >20 years' experience as a clinician and researcher in the field of autism, developmental disability and health, and has focused on transition to adulthood, service access, employment and more recently, access to post-secondary education. He also is a family caregiver.
D.H.	Non-autistic researcher with >20 years' experience as a clinician and researcher in the field of autism and developmental disability.

Supplement Table S3.*Example Researcher Conceptualizations of Initial Thematic Groups.*

Initial Thematic Group	Conceptualization
I am autistic - it is not a label, it's who I am.	My way of being underpins my identity, and my way of being is inherently autistic. My diagnosis is not a label, it's a descriptor of who I am.
I deserve validation	Like every human being, feeling authentically seen and heard is important to me. I am the expert on my own life and self, and I need you to respect that. I understand that being autistic is integral to who I am, so when I tell you I'm autistic, and you invalidate my diagnosis, even with the best of intentions, it causes me harm. On the other hand, when you validate me, my identity, and my experiences, it helps me to feel safe.
Please don't other me	I am a human being, but when you use my diagnosis or support needs to view or treat me as intrinsically different from and alien to yourself, you "other" me. My basic needs as a human being are no different to yours (physiological needs, safety, connection, contribution, self-actualization). Please don't use my diagnosis, communication, or behaviors, as an excuse to pretend otherwise.
My context is a complex system	Complex systems are characterized by dynamic interrelatedness within their parts. You cannot understand the system by individually looking at any components, or combination of components, alone. indeed, the sum of the components is not the system. Any investigation of the system while ignoring certain components will leave a faulty understanding of the system.
I might not experience the world the same way you do	Autism is the lens through which I view, interpret, interact with, and experience the world. It colors my every thought, feeling and action.

Initial Thematic Group	Conceptualization
intersectional issues and co-occurring conditions make things more complicated	Because of my complex system, intersectional issues and co-occurring conditions may impact me in ways you don't expect or cause more or less impact than you consider "usual".
My thinking can be rigid	My rigidity of thought might interfere with recognition and management of my own needs, as well as problematic thoughts, feelings, and behaviors before they become overwhelming; this can make early intervention strategies for mental health less effective
systems thinking is essential	Considering the collective interactions of my parts is essential to understanding me - without this consideration, we cannot plan or predict outcomes, and seemingly benign actions may be harmful.
transitions are particularly difficult	Because of my complex system, it is difficult to predict how a change might impact me. This uncertainty is particularly difficult for me to cope with. Life transitions are chains of change that may disrupt me beyond what is considered usual.
life stage changes	Puberty, cusp of adulthood, parenting, menopause, etc., seem to be particularly vulnerable stages for the mental health of autistic people
physical changes	changes in physical capacity (e.g. chronic illness or acquired disability) may require changes in mental health strategies

Supplement Table S4.*Participant-Identified Barriers to Access and Utilization of Mental Health Supports.*

Top Level	Participant Identified Barrier		Sample Quote	Quote Origin
	Mid-Level	Specific		
Financial	Expense	High costs of treatment	It's hard to get a good match, and it's very expensive, trying to get that match.	P009
		Poverty	So some of my own limiting factors - poverty is the first one. To access really skilled and experienced psychologists, for instance, they're usually the ones that charge the most.	P002
	NDIS ^a	Criteria for acceptance by NDIS	Because I'm apparently functional, I don't qualify for NDIS stuff	P002
		Process of acceptance to NDIS is difficult	I haven't gone down the NDIS pathway, because from what I understand, it's a nightmare, and if you can possibly get away with not using it, it's not worth it. So, I have decided at this point not to put myself through that process.	P007
		Process of acceptance to NDIS is pathologizing	Because I applied for the NDIS, I had to go down that whole medical model road, where you're pathologized. I know that's just a means to an end, in that you have to - well, they have to speak that language, too, but as an individual, it's hard not to over-identify with that kind of thing.	P006
Travel		Transport	If their office is nowhere near any public transport, again, it comes back to the flow on effects	P005

Top Level	Participant Identified Barrier		Sample Quote	Quote Origin
	Mid-Level	Specific		
Provider	Lack of Availability	Distance	Like sometimes I feel like I need a specific psychologist who has an expertise in specific areas and they're either really hard to find or really expensive or far away.	P023
		Location	So usually, you don't have a whole lot of options, you go to the doctor and they say, here's one or two people, pick from them. Yeah, so then also trying to find, eventually after I had been diagnosed as well, then finding someone who specialized in that in my area was basically, that it was nonexistent.	P017
		Gatekeeping	Yeah, it seems to be only particular groups of certain people and being in a regional area, there's only facilities for that one group of people rather than - to be in that facility or get access you've got to be on certain - you've got to be unemployed. You've got to be - certain boxes you've got to tick and if you don't tick those boxes then you don't get anything. Which doesn't help because stereotyping. So yeah.	P010
		Lack of services for adults	However, another difficult thing is, when I go to see them, I'm quite old, so most of the clinics, they basically make an exception for me. Otherwise, they don't tend to treat lots of adult clients. Or, you can say the support services - they are not that equipped to deal with adults with the ASD, since they mostly focus on children, and adults have adult issues.	P025
		Hours of service	If you're awake at 3:00am feeling really awful and you can't speak, there is no-one you can speak to. It's very lonely. It's very scary.	P033

Top Level	Participant Identified Barrier		Sample Quote	Quote Origin
	Mid-Level	Specific		
		Too few providers	More psychiatrists, honestly, just more being available, more across different time ranges and in difficult geographical areas and more training on intersecting mental illness.	P001
		Waiting lists	Oh, definitely just delays in getting a spot for someone who has time. Who has enough appointments or enough time. Yeah. Just definitely long delay. Long, long delay. Being on a waiting list.	P009
		Too few appointments	When I haven't had that service available, trying to get a recommendation to see someone or trying to even get a doctor's appointment sometimes can be impossible, especially you need it now and not in three months when they're opening up their books again.	P012
	Approach	OSFA ^b approach	They don't seem to understand the reasons that I'm there or looking for help, and they're just sort of going through their own checklist of things that they should do or must do because rules, or whatever, that are completely pointless for my own situation [...] It felt kind of perfunctory, I don't know how to describe it. It was just I didn't want to be there, he didn't see that I needed to be there, and there was no need for a follow up.	P023
		Infantilization	I found the program really infantilizing and not that useful, and the doctor was just not interested in listening to me. It wasn't seen as a fit reaction to a situation with him, he just saw me as a diagnosis and didn't want to know anything else	P031
		Punitive approach	Sure. I felt like the - many of the practitioners took sort of a punitive approach. I felt like I wasn't really seen as a human being. I didn't - yeah it was very dehumanizing.	P013

Participant Identified Barrier			Sample Quote	Quote Origin
Top Level	Mid-Level	Specific		
		Erosion of agency	They took it off me, which meant I couldn't eat my breakfast. It was interfering with all of my schedules, you know. It makes you feel like a child. [You're going like] hello, when you let me out of here I'm going to be doing this all by myself again. So, just ridiculously - I just - I don't know, stripping you of your identity. It was just weird.	P008
		Poor PAF ^c : CBT ^d	also that CBT for me feels like gaslighting and psychology needs to move away from it as a default go-to	P027 ^e
		Poor PAF: Mindfulness	They fob you off with stupid things and like stupid advice. Mindfulness and CBT. Oh, so I don't even bother going to a service that are going to just try and flog mindfulness crap into me.	P031
		Poor PAF: Talk Therapy	whenever I saw a specialist, like the psychologist that I see, he was working as a team of psychologists that they got me to go talk to about something or other, and I just found that I was just talking it through, but I don't find there's any resolution to anything. Does that make sense? You talk about what the issue is and people turn around - well, they just sort of go either, you need to think differently about it, which is not going to happen, or there's nothing you can do about it, kind of thing.	P026
	Lack of provider understanding	Response to disclosure	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
		Misdiagnosis	So, she gave me a - she gave me a PTSD diagnosis and major depressive disorder. Then it was probably within the 12 months after that, I was finishing researching PTSD and CPTSD and then went, something is missing here. I started looking back. I went, I think we're autistic, because my dad is really weird. I went and did all the formal testing and	P008

Participant Identified Barrier			Sample Quote	Quote Origin
Top Level	Mid-Level	Specific		
			stuff through [Autism Organization] and two psychologists, and then a psychiatrist confirmed it.	
		Diagnostic overshadowing	The focus is on whatever the diagnosis is. It's kind of all they want to see. First, I was diagnosed with generalized anxiety disorder. So, everything's seen in the context of that, it doesn't fit, really. I spent time in an inpatient unit, and when the diagnosis was generalized anxiety disorder, there was no kind of acknowledgement of the things I was actually struggling with.	P032
		Loss of trust	I don't want to say incompetence, but psychologists who didn't seem to have a clue.	P012
		Understanding of autism	But there is still so many misunderstandings about autistic experience. Really unhelpful stereotypes and things.	P002
		Presumed incompetence	As soon as they find out we're autistic, they think that we're brain damaged, a lot of people, even professional.	P021
		Invalidation of lived experience	Kind of believing or acting they know my feelings and perceptions better than I do. If I say, I feel a way, they say, no, you feel this way.	P032
		Invalidation of diagnosis	It also makes me have absolutely no faith in their ability because they should know better than to say that. But ideally, they should know better than to think they know that based on – like the GP that said it, he said [<i>I don't think you're autistic</i>] within three	P007

Top Level	Participant Identified Barrier		Sample Quote	Quote Origin
	Mid-Level	Specific		
			minutes of me walking in the door for the first time to see him. So, obviously you can't tell in that time.	
Autism & co-occurring conditions	Executive function	Multistep processes	Yeah, there is - yeah if - so I remember going to my GP and I had an injury from running and I had to go and get an MRI or an x-ray or something. So going to the next bit, it's like but I don't know how to get there and trying to organize that would be easier just not to go. I had a back x-ray done here and I still haven't taken it to the GP because I have to plan and work out how to get there and it's a whole day. It takes a lot of work.	P024
		Excessive cognitive load	I guess from my perspective, emotionally, I'm often just too fatigued to reach out. I get tired of thinking about stuff. I get tired of trying and looking for new people, and I get tired of feeling that they're getting tired	P009
	Social Rules	Waiting for a call back	I think I phoned and I talked to the staff there and they said they can't make an appointment yet, but they will call back and let me know when there's an opening. I think a month or two went by with nothing and I called them again and [...] after another couple of months of delay, I emailed. <i>[It]</i> is that thing I mentioned earlier about having difficulties knowing how long to leave it and when to follow it up.	P030
		Office hours	I'm also reluctant to bother my friends or my therapist too, outside of hours.	P006
		Taking up space	I get concerned about using up appointments with things that aren't important.	P007

Participant Identified Barrier			Sample Quote	Quote Origin
Top Level	Mid-Level	Specific		
		Not severe enough to qualify for help	But because I was only a level 1 when I applied to NDIS I got rejected. So then I felt like maybe I'm just not bad enough to need any help.	P019
	Social difficulties	Starting a new relationship with a caregiver	If I don't feel comfortable and I don't understand I won't go to your room. I'd rather like stay in pain for longer until I can get in to somebody who I can.	P022
		Lack of social network/informal supports	Well, for people who already have trouble getting on with people. For a group of people like us, that already struggle to interact and to get on well with people and to actually connect with people. Because the whole thing is connection.	P005
		Informal supports are complicated	I have a partner. But there is a lot of things that are difficult to talk - for us to talk about. Because it gets tangled up in our own emotional things.	P002
	Hyper-empathy	Caring for others, disregarding cost to self	[<i>I didn't have the time or energy to seek support for myself because</i>] I didn't really have many strategies to be honest and I think that contributed to it and [<i>I</i>] felt isolated and had to take care of this other person.	P014
	Masking	Masking can lead to invalidation of diagnosis	Some of them just questioned if it was a right diagnosis, because I'm – and particularly in a first appointment, I'm generally very masked, but I can't help that	P001

Top Level	Participant Identified Barrier		Sample Quote	Quote Origin
	Mid-Level	Specific		
		Masking can lead to refusal of access to services	And, because I present pretty normally, on the surface, they don't really take me seriously or - yeah. Because I've gone through this in my head so much, and I'm controlled when I'm seeing someone, they kind of - I can tell they don't really take it seriously. They're very ready to dismiss that I have problems [laughs].	P009
	Rigidity	Sense of obligation	I've got this whole obligation thing, like if I'm, it's expected, if you're doing a consult or a meeting or an interview, whatever, you obviously are committed to spending that time with that person. I think I'm overly conscientious in that respect, because I feel like there's no opportunity for me to cut something short, where, in reality, I guess, there is.	P006
		Need for routine	I guess the other thing I would say, if you are on the ward, you're very much on the hospital's routine whether that does or doesn't suit you.	P033
		Need for predictability	I think that's the hardest because that's probably when you're dealing with people that are only able to manage their most basic functioning stuff like breathing is important at that point. I think, I mean for me, routine and change is hard. So strangers coming around, so familiarity is - I don't know how you do that - how you make something comfortable and familiar.	P024
		Need for privacy	I share a house with my daughter and her partner and kid, and it's sometimes hard to get space to have some privacy.	P006
		Avoidance	The psychiatrist at ED basically told my partner, while I was sitting next to them, that clearly, I was just attention seeking, and to just take me home, and I'd get over it [...] It	P007

Participant Identified Barrier			Sample Quote	Quote Origin
Top Level	Mid-Level	Specific		
			also makes me have absolutely no faith in their ability because they should know better than to say that.	
		Cynicism	I sort of worked for a few years and got married and had children and my relationship was horrible with the mother of my children and we sort of looked at counselling quite a few times and had horrible outcomes. Then after she tried to kill me I had a prolonged series of consultations with a psychiatrist. Although he eventually dropped me as a patient and took on my wife as a patient and talked her into leaving me, which was an interesting outcome.	P003
		Increased stress	So for years I had gone through a psychologist, and they never really understood me I don't think. So, I think that they had a very negative view of me and of, and that they felt like they needed to change a lot of things about me. That's not, I wasn't going there to change those things about me. I was going there, say, because I was depressed or anxious. But then they felt like they wanted to change more of who I was, they felt that that was a problem. So, I always got a very bad feel from psychologist, and I really didn't like going there [...] Seeking help was always very nerve-wracking because I always just had negative experiences.	P017
		Aversion	I've tried seeing many psychologists. Most of them were a bunch of idiots, to be honest [...] I'm actually very therapy resistant. Various things we've tried over the years haven't helped at all. Some of it's made it worse, some of it's just done nothing	P005
		Escalation	I had an appointment with my gp that afternoon, my worker came along. my worker and the patient rights advocate had spent the morning at the hospital trying to avoid me being discharged. after the gp my worker left, she phoned the gp, they sent an ambulance. the ambulance came and couldn't believe i would be discharged with being so suicidal. i had them call my worker to confirm. they took me back to the hospital on	P027 ^e

Top Level	Participant Identified Barrier		Sample Quote	Quote Origin
	Mid-Level	Specific		
			an EEA. i saw the mental health team in emergency and told them i fully intended to go take responsibility for myself and go home to die, they read the discharge notes and were happy that I agreed that hospital was inappropriate for me. they overrode the EEA and sent me home. I got home at 4am and then attempted suicide which by all laws of science and logic should have been fatal. i was found and taken to hospital and it took them 6 days to medically stabilize me that's one example of me initially seeking and agreeing to mental health supports and it ending traumatically	
	Emotions	Alexithymia	Sometimes it's difficult for me to actually tell that I'm having problems and so I might not know that I need some extra assistance.	P033
		Dysregulation	The emotional dysregulation part is the hardest thing to explain. It's the most significant impact. It impacts my work, it impacts relationships, impacts my ability to cope with things and my mental health a lot more, but it's not at all described anywhere and it's so universal within the neurodiverse group.	P015
		Melt down or shut down	Usually, if I'm in quite a bad mental state, I don't feel like talking to other people, and asking for help is hard.	P007
		Rejection sensitive dysphoria	I'd say immediate family members but I've learnt over the years that the support offered by them probably because they're not professionals and they don't really understand nuances of these issues, they - the support is kind of limited and oftentimes it's not especially helpful. It actually exacerbates things. So I might reach out but very tentatively and it would be a very limited kind of interaction as well.	P013

Top Level	Participant Identified Barrier		Sample Quote	Quote Origin
	Mid-Level	Specific		
	Sensory sensitivities	Noise	Like, I go to my GP and I sit in the incredibly noisy waiting room, with incredibly bright lights, and I get given various bits of information in various different ways, and I have to almost argue with the receptionist to achieve the tiniest little thing [...] I get very anxious in medical settings anyway, and then you pile on all of that sensory stuff on top. I find it so overwhelming, and so stressful, that I avoid going, despite having significant physical health issues that I should be probably there a lot more regularly.	P007
		Lights	If they don't know about the sensory issues - we have to go into hospital and there's all these bright lights and there's lots of people around.	P020
		Touch	I hate hugs, right? There's nothing worse than you're really struggling and somebody keeps trying to force hugs on you. It's like the worst thing you could do.	P005
	Communication	Situational mutism	If I'm extremely distressed, I suffer from some selective mutism, I may not be able to speak at all.	P033
		Difficulty with telephone calls	I just can't bear the thought of calling someone on the telephone	P012
		Non-verbal communication	Kind of like sometimes when I'm talking I feel like my emotional state is plain in the way that I'm like moving my body and the expressions on my face. But I've encountered a lot of people that just can't read what I'm putting out. So they make erroneous assumptions about how I'm feeling when I'm not actually feeling that way and I get frustrated. Because like I feel like I'm being very plain about how I'm feeling.	P023

^aNational Disability Insurance Scheme (NDIS)

^bOne Size Fits All (OSFA)

^cPerson-Activity Fit (PAF)

^dCognitive Behavioral Therapy (CBT)

^eP027 participated in the study via text chat, and responses have been included as typed.

Supplement References

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