



Five Ways Providers Can Improve Mental Healthcare for Autistic Adults: A Review of Mental Healthcare Use, Barriers to Care, and Evidence-Based Recommendations

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Accepted: 21 July 2022 / Published online: 15 August 2022

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Abstract

Purpose of Review We reviewed the literature from 2017 to 2022 on autistic adults' use of mental healthcare and barriers to care. To encourage immediate improvement in mental healthcare, we provide five strategies mental health providers can use to better care for autistic adults.

Recent Findings Most autistic adults use mental healthcare and use it more often than non-autistic adults. Autistic adults' experiences with mental healthcare are characterized by (1) lack of providers knowledgeable about autism, (2) use of treatments that may not be accommodating to individual needs, and (3) difficulty navigating the complex healthcare system. These barriers contribute to prevalent unmet needs for mental healthcare.

Summary Autistic adults use mental healthcare frequently but have unmet mental health needs. As necessary systemic changes develop, providers can begin immediately to better care for autistic adults by learning about their needs and taking personalized care approaches to meet those needs.

Keywords Autism · Autistic adult · Mental health · Review

Introduction

Autism is a “broad spectrum of neurodevelopmental differences characterized by social and communication challenges, repetitive behaviors, sensory issues, and unique strengths and differences” [1, 2]. While autism is commonly conceptualized as a condition of childhood, these

neurodevelopmental differences are lifelong. As a result, mental healthcare professionals can expect to encounter autistic adults in their practice settings frequently. Fifty thousand autistic individuals reach adulthood each year [3], 10–20% of whom have co-occurring mental health conditions like depression or anxiety [4•]. However, autistic adults often experience barriers to accessing mental healthcare [5, 6••]. These barriers can be due to [a] patient-level characteristics, like challenges with expressive and/or receptive language; [b] provider-level characteristics, like the limited availability of providers trained in autism; and [c] system-level characteristics, like environments that are not accommodating to sensory needs [7••]. Indeed, the healthcare system is unprepared to accommodate the unique needs of autistic adults, underscoring the need for targeted change throughout the system. This position has been voiced strongly by autistic adults, autism advocacy groups, and other members of the autism community [8].

It is particularly important that mental healthcare services are a target of change so that they better meet autistic adults' needs. In the wake of the global coronavirus pandemic, autistic adults' mental health has catapulted to the forefront of attention in the autism community [9]. Mental health is

This article is part of the Topical Collection on *Autism Spectrum Disorders*

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universally recognized as indispensable to overall health and wellbeing and is associated with important outcomes like quality of life among autistic people [10]. Autistic adults' access to high-quality mental healthcare is therefore of paramount importance, especially when considering they are disproportionately more likely to have co-occurring mental health conditions than the general population [4•, 11••, 12]. Consistent evidence indicates that autistic adults who use mental healthcare services do so more frequently than non-autistic adults [13], but they continue to experience unmet mental healthcare needs [14••, 15–17]. As such, the quality of these services for autistic adults may be poor [14••, 18]. In this paper, we review the literature that has been published in the last five years on autistic adults' use of and experiences with mental healthcare services. We included studies of any type of mental healthcare (e.g., counseling, psychiatry, psychology), clinical setting (e.g., inpatient, outpatient), and country of origin. An understanding of service use and experiences is necessary to inform systemic change and guide decision making for resource allocation within the mental healthcare service system so that it better meets autistic adults' needs. While we emphasize the need for systemic change in mental healthcare for autistic adults, it is our position that mental healthcare providers can begin immediately to better care for their autistic adult patients. To this end, we also draw on the included literature and our own professional experience to provide five practical recommendations for mental healthcare providers so that they can provide better care for autistic adults.

Autistic Adults' Use of Mental Healthcare Services

Most (53%) autistic adults use mental healthcare services [15]. Often, autistic adults seek mental healthcare services for management of conditions that are common among this population such as attention deficit hyperactivity disorder (ADHD) (25–38%) [4•, 19, 20], anxiety (20%) [4•], depression (11%), and obsessive compulsive disorder (OCD) (5%) [21], rather than for core features of autism itself. One study found that counseling and psychiatry are among the most commonly used services by autistic adults [22]. Overall, approximately 30–64% of autistic adults received psychiatry services in the past year [23, 24]. Among a German sample, 27.98% of autistic adults had at least one visit with an adult psychiatrist, 19.79% had at least one visit with an adult psychotherapist, 7.14% had at least one inpatient psychiatric hospitalization, and 2.5% used a psychiatric outpatient clinic in the past year [23]. A greater proportion of autistic girls and women access psychiatry services, relative to autistic

boys and men [24], and they tend to have higher healthcare costs [23].

Overall, autistic adults also tend to use mental healthcare more than the general population and other diagnostic groups [13]. In a Canadian study, autistic adults were twice as likely as adults with other developmental disabilities, and almost 12 times as likely as adults without developmental disabilities, to see a psychiatrist in the past year [25]. Similarly, US-based samples of autistic adults received talk therapy for anxiety or depression more often than non-autistic adults [26], and were more than two times as likely as adults with attention-deficit-hyperactivity disorder (ADHD), and 12 times as likely as non-autistic adults, to have an outpatient mental health visit [27•]. Autistic adults tend to use the emergency department for mental health-related conditions more than non-autistic adults [28] and are nearly five times as likely to have a psychiatric-related emergency department visit than adults without a developmental disability [25].

Further, emerging evidence suggests a significant portion of adults seeking psychiatric care may have undiagnosed autism. A recent study from Sweden found that approximately 19% of adults presenting for outpatient psychiatry services met criteria for an autism diagnosis [29]. Other studies have found that approximately 16% of adults receiving outpatient psychiatry care for depression in Japan [30] and up to 10% of adults receiving inpatient psychiatric care for eating disorders meet criteria for an autism diagnosis [31]. Additional work is needed in this area to understand the generalizability of these findings. However, these studies promote advocating for “routinely considering autism as part of [a] global, holistic assessment” of adults referred to psychiatry [32]. Ultimately, identifying undiagnosed autism among adults may lead to better management of anxiety, depression, eating disorders, and other mental health conditions among this population.

Barriers to Mental Healthcare for Autistic Adults

Lack of Trained Providers

Autistic adults often have difficulty getting adequate support and treatment for their mental health needs [14••]. In part, one reason for this difficulty is the limited availability of autism-trained providers, despite evidence that having a provider who will tailor care to meet autistic adults' needs may be even more important in mental healthcare than in other healthcare contexts [33]. As a result, autistic adults may seek care from a mental health provider not trained in working with autistic adults who may have preconceived misconceptions about autistic people. For example, some providers may inaccurately believe that autistic adults are unable to or uninterested in developing

social, romantic, or therapeutic patient-provider relationships; these inaccurate assumptions will likely be detrimental to the autistic adults' wellbeing and hinder their access to equitable, patient-centered healthcare [33–37]. This may also contribute to autistic adults' lack of comfort in discussing mental health conditions with providers [18], disagreements about the accuracy of their mental health diagnoses [38], and unmet mental healthcare needs.

Rigid Approaches to Care

Another barrier is that some providers or clinics are unwilling or unable (e.g., due to being under-resourced) to deviate from the status-quo to meet autistic adults' individualized needs. These needs might include [a] needing more time to establish rapport [14••], [b] using language literally rather than abstractly [14••], [c] having challenges with receptive and/or expressive language [35], and [d] requiring unique pharmacotherapy approaches [21, 39]. If an autistic adult needs more time to establish rapport with a new provider, having appointments that are too short or too infrequent may hinder the development of a therapeutic relationship and, consequently, hinder improvements in autistic adults' mental health [14••]. A tendency toward literal use of language may make treatment approaches like cognitive behavioral therapy (CBT), which often relies on abstract verbal reasoning, less helpful for some autistic adults [14••]. When describing how CBT didn't work for them, one autistic adult said, “[the provider] expected me to be neurotypical, so I would take things too literally and they thought it was a defense mechanism, or I'd try to explain meltdowns and they focused on my thoughts rather than how to deal with over-reactive sensory perception [14••].” Other autistic adults may have difficulty with receptive and/or expressive language; one parent of an autistic adult described how their son “gets overwhelmed with too much verbal input” and, as a result, was discharged from mental healthcare that relied heavily on group therapy and talking [40]. Traditional pharmacotherapy approaches for managing conditions such as ADHD or obsessive-compulsive disorder (OCD) may be less effective for some autistic people [21, 41]. Consideration of different medications or types of therapy in these situations is essential for success. These examples illustrate how a rigid one-size-fits all approach to mental healthcare, rather than a flexible-patient centered approach, may be detrimental to autistic adults' mental health outcomes.

System-Level Barriers

The healthcare system itself also presents barriers to autistic people accessing the care they need. One Canadian study found 40% of college-aged autistic adults needed mental healthcare but did not receive it because the steps to access care were too complex [42]. Additionally, months-long wait lists for mental healthcare have been described in both USA-based [43] and UK-based studies [18]. Autistic adults described that they felt

that they were hurried through care as quickly as possible to make room in the service system for the long list of people waiting for services [18]. This could result in premature discharge from care, which might be dangerous for some patients. High costs for mental healthcare serve as an additional barrier [23, 44, 45]. Further, as a result of the global coronavirus pandemic, some autistic adults have lost access to mental healthcare that they were receiving before the pandemic [46, 47], requiring them to re-navigate these systems-level barriers as they start over in their search for care; these barriers may be especially problematic for certain subgroups of autistic adults, such as those who are uninsured/underinsured or have highly acute needs for services.

As a result of these barriers, autistic adults experience high rates of unmet mental healthcare needs, despite high utilization of mental healthcare. Recent estimates of the prevalence of unmet mental healthcare needs among autistic adults have ranged from roughly 20–40% [16, 17, 42, 43, 48]. However, some subgroups of autistic adults, such as those who are non-binary, may be at even greater risk of unmet needs for mental healthcare [49] and poorer mental health [50]. Autistic adults' unmet needs for mental health necessitate immediate action to improve care for this population. While other studies have highlighted system-level strategies [25, 51] or necessary changes at the policy-level [52], we sought to identify five strategies that every mental healthcare provider can use to immediately improve the quality of care they can provide for autistic adults.

Five Things Every Mental Health Provider Can Do to Better Meet Autistic Adults' Needs

Be an Agent of Change in the Workplace

Mental healthcare providers can serve an important role as catalysts to build an autism-informed environment. Attending continuing education courses on autism, completing other autism-focused trainings, or self-directed study is a simple way to increase knowledge about autism and correct misconceptions and harmful stereotypes about autistic people. Trainings can help providers to understand their autistic patients' needs and provide better care, which has been recommended by autistic adults [14••, 53]. We believe practical trainings are typically more salient for enhancing mental health providers' practice than those that focus on biological or molecular mechanisms behind autism. Also, when locating a training opportunity or self-directed study materials, we suggest providers: [a] look for trainings/materials that were created by autistic people or co-created via collaboration between autistic and non-autistic people; and [b] select trainings/materials that emphasize neurodiversity-affirming care by promoting well-being in autistic people rather than

encouraging “passing” as non-autistic at the expense of the autistic person’s health and well-being [54••, 55–57]. We recommend providers look to the following sources of information to enhance their knowledge about autism: Autistic Self Advocacy Network’s resource library (<https://autisticadvocacy.org/resources/>), Academic Autistic Spectrum Partnership in Research and Education (AASPIRE)’s topics for healthcare providers (<https://autismandhealth.org/?a=pv&p=main&theme=ltlc&size=small>), Asperger/Autism Network (AANE) provider resources (<https://www.aane.org/resources/professionals/>). We encourage mental health providers to share what they learn about autism with their colleagues (e.g., via lunch-and-learns or other group-based activities), and to talk to other leaders in the workplace about how to be more accommodating of the needs of autistic adults.

Make Thoughtful Language Choices

The language that is used to talk about autism or to refer to autistic people is very important. How autism is discussed, especially by healthcare providers, has implications for how society views autistic people and how autistic people shape their own identity [58]. Some language choices perpetuate the idea that autism is something to be “fixed” or that autistic people are inherently inferior to non-autistic people [54••]. We strongly recommend that providers use thoughtful language that does not perpetuate biases against autistic people or focus solely on perceived deficits. For example, instead of using “functioning labels” (e.g., high/low functioning, high/low severity), we recommend providers instead refer to the individual’s specific strengths and needs, while recognizing that the level of support likely varies across contexts and environments [54••, 59–62]. Rather than referring broadly to “challenging behavior” or “problem behavior,” providers should use more accurate, specific terms such as meltdowns, stimming, self-injury, aggressive behavior, or other descriptors as appropriate [54••, 56, 63–65]. Additional examples of potentially problematic language choices and preferred alternatives recommended by members of the autistic community are summarized in Table 1 of [54••].

Additionally, when speaking to an autistic individual, we recommend providers mirror the language used by the autistic person (e.g., when deciding whether to say “adult with autism” or “autistic adult”) or ask the individual how they would like to be addressed. If this is not possible to do, we suggest using the language “adult on the autism spectrum” as this phrasing may be considered the least offensive [62, 66]. Providers can positively impact the way that autism is discussed in their workplace by sharing these suggestions, and the importance of language choice when speaking about autism, with colleagues.

Take an Individualized Approach for Autistic Adults’ Mental Health Treatment

Recognizing autistic adults as individuals rather than as members of a homogenous group is an important step to meeting their needs [67•]. Like with any patient, providers should aim to build a working relationship with autistic adult patients to better understand their needs. Ultimately, this may help improve mental health outcomes for autistic adults. For example, providers can take steps to accommodate an autistic adult’s sensory needs to help the individual feel as comfortable as possible and promote satisfaction with healthcare [68]. These accommodations could be as simple as dimming the lights or using only natural light from a window, shutting a door to reduce background noise, or allowing the patient to bypass the waiting room before their appointment.

Regarding treatment and planning, we recommend providers collaborate with the patient to find a treatment approach and style that works well for them. We encourage providers to adjust their patient schedules for autistic adults who may need more mental health session time [26], or increase the frequency of appointments for medication management, as autistic adults may be at increased risk for side-effects of psychotropic medications often used in mental healthcare [69]. To modify CBT to accommodate a patient’s literal use and understanding of language [14••], providers may increase the use of visual supports by using video models of relaxation exercises or reduce abstract language by using concrete terms to explain concepts [70]. Developing autism-specific crisis management plans may be beneficial as well [9]. These, and other individualized patient-centered approaches, are a solid foundation for successful mental health care for autistic adults.

Leverage Autistic Adults’ Strengths in Treatment

Another benefit of establishing a relationship with autistic adults is that providers can learn about their strengths, which can often be leveraged in treatment. For example, if an autistic adult has strengths in planning and decision-making [71], the provider can encourage them to develop a schedule for how they would like to spend the appointment time or prepare a list of talking points [72•]. If an autistic adult is experiencing high levels of stress or anxiety, the provider can inquire about and encourage the autistic adult’s intense interests, which may be effective coping strategies [73]. Importantly, leveraging strengths may improve confidence [73], and is congruent with high-quality patient-centered care [74] and a neurodiversity-affirming approach to care [32].

Provide Actionable Steps to Promote Patient Progress

Providers can facilitate autistic adults' progress in meeting their mental health goals by providing practical recommendations and guidance for how to navigate life situations that impact their mental health. Focusing heavily on autism itself, early childhood experiences [72•], or other topics (unless directed by the patient) may not be helpful for autistic adults in their day-to-day lives. Many autistic adults have jobs, relationships, community involvements, and many other facets to their lives, all of which may affect their mental health and may need to be points of emphasis during mental health treatment. For example, if an autistic adult is struggling with social anxiety about interactions with work colleagues, it may be more helpful to talk through recent situations and identify practical strategies for managing anxiety rather than to analyze early childhood experiences that could have originated the social anxiety. We encourage providers to check-in with autistic adults regularly about their experiences with treatment, listen to their feedback, and be willing to modify treatment approaches when necessary.

Conclusions

We reviewed the published literature from the past five years on autistic adults' use of mental healthcare and their experiences with those services. Most autistic adults use mental healthcare, and they tend to use mental healthcare more often than non-autistic adults or adults from other diagnostic groups. Yet, autistic adults frequently have unmet needs for mental healthcare. Contributing to unmet needs are barriers including the lack of healthcare providers with training in working with autistic adults, not tailoring care to meet individual needs, and the complex healthcare system. There is an urgent need for systemic and policy-level change in mental healthcare to better serve the needs of autistic adults [25, 51, 52]. Mental healthcare providers can begin immediately to better care for autistic adults by being an agent of change in the workplace, learning more about autism, using an individualized approach to provide care, leveraging autistic adults' strengths in treatment, and providing actionable steps to improve mental health and well-being.

Acknowledgements The authors wish to acknowledge Paige Clappier for assisting with the literature search.

Funding The author(s) received no financial support for the research, authorship, and/or publication of this article.

Declarations

Conflicts of Interests The authors declare that they have no conflicts of interest.

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