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Community Mental Health Services for Autistic Adults: Good News and Bad News

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Abstract

Many autistic adults experience psychiatric conditions such as anxiety and depression. However, autistic adults often do not receive effective and affordable mental health (MH) treatment. Untreated psychiatric conditions in autistic adults are associated with a host of negative outcomes, including adaptive functioning impairments, difficulties with employment and independent living, and poor quality of life. The purpose of this Perspectives piece is to shed light on the current state of community MH services in the United States for autistic adults with co-occurring psychiatric conditions. Drawing on the available research and clinical experiences, we aim to (1) highlight positive developments in community mental healthcare for autistic adults; (2) summarize the barriers that continue to exist for autistic adults in need of MH services; and (3) provide recommendations for autistic adults and their families, community MH clinicians, and MH systems administrators to consider. Significant work is needed to provide autistic adults with affordable quality MH services. This Perspectives piece presents a summary of the needed changes and specific methods to continue to improve community MH services for autistic adults.

Lay Summary

Many autistic adults experience mental health problems, such as anxiety and depression. However, autistic adults and their families often do not know where to turn for effective and affordable mental health treatment. The purpose of this Perspectives piece is to (1) highlight positive developments in community mental healthcare for autistic adults; (2) summarize the barriers that continue to exist for autistic adults in need of mental health services; and (3) provide recommendations for autistic adults and their families, community mental health clinicians, and mental health systems administrators to consider. Recommendations for autistic adults and their families include joining autism-related support and advocacy networks, looking for word-of-

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Authorship Confirmation Statement

Both authors (B.B.M. and V.L.G.) made substantial contributions to the conception of this article. After a conference call together to discuss the article, B.B.M. drafted an initial outline. B.B.M. drafted the first half of the article, and V.L.G. drafted the second half. Both authors reviewed and revised the full draft. Both authors have approved this article and agree to be accountable for all aspects of the work. This article has been submitted solely to *Autism in Adulthood* and is not published, in press, or submitted elsewhere.

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mouth referrals from peers who have had success with local mental health providers, and searching for therapists who have the core skills needed to treat the presenting problem at hand, even if they are not experts in autism per se. Recommendations for clinicians focus on the importance of adopting the same individualized approach they would use for any of their clients without autism. Recommendations for systems administrators include improving communication between the developmental disabilities and mental health systems, adding more courses and practicum experiences related to autistic adults in the required general training for physicians, psychologists, and social workers, and offering trainings to clinicians that focus on the treatment of mental health problems in autistic adults.

Keywords

adults; anxiety; autism; community mental health services; depression

Introduction

Many autistic adults experience psychiatric conditions, particularly anxiety and depression.[1–6] Psychiatric conditions refer to mental health (MH) concerns that cause significant distress and/or impairment. For some autistic people and their families, these co-occurring conditions are a primary source of impairment.[7,8] Despite their high prevalence and associated impairment, psychiatric conditions often are untreated in autistic adults.[9,10] Untreated psychiatric conditions in autistic adults are associated with a host of negative outcomes, including adaptive functioning impairments, difficulties with employment and independent living, and poor quality of life.[3,7] What stands in the way of autistic adults receiving appropriate mental healthcare in their communities? Our goal with this Perspectives piece is to draw on the available research and our own clinical experiences to shed light on the current state of community MH services in the United States for autistic adults and co-occurring psychiatric conditions. We aim to share helpful information with autistic adults and their families, community MH clinicians, and MH systems administrators, with a primary focus on psychotherapy services (not psychopharmacological treatment). We focus on adults who could benefit from psychotherapy for co-occurring psychiatric conditions, not on adults who primarily need supports related to severe cognitive or functional impairments, given our interest in how the mental healthcare system could better serve autistic adults. In addition, given that our perspectives on this topic are largely informed by research and clinical experiences completed in the United States, the focus of this article is the United States mental healthcare system.

The authors bring different perspectives to writing this piece. Dr. Maddox is a clinical researcher at an academic medical center, and Dr. Gaus is a private practice clinical psychologist. Despite our distinctive professional roles, we have had remarkably similar experiences related to community MH services for autistic adults. We have both repeatedly seen, through research and clinical work, a lack of quality community MH services for autistic adults with co-occurring psychiatric conditions. However, we have also noticed some recent trends that reflect potential improvements for autistic adults seeking MH services. Thus, the purpose of this article is threefold: we (1) highlight positive

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developments in community mental healthcare for autistic adults; (2) summarize the barriers that continue to exist for autistic adults in need of MH services; and (3) provide recommendations for autistic adults and their families, community MH clinicians, and MH systems administrators to consider.

Positive Developments in Community Mental Healthcare for Autistic Adults

Let us begin with the good news. In recent years, it appears that community MH clinicians are increasingly recognizing autism in their undiagnosed adult clients. This increased recognition is likely due to many factors, including efforts to educate clinicians about autism across the lifespan and accounts of autistic adults in the media. In our experience, clinicians frequently begin investigating the possibility of autism in their clients when they are not making progress with traditional treatment. Recognizing autism in undiagnosed clients is important for case conceptualization and treatment planning, particularly when autistic clients could benefit from modifications to traditional psychotherapy approaches.[11] Related to this increased recognition, many clinicians are also more accepting of having autistic adults on their caseload; instead of referring elsewhere for services, clinicians are showing a willingness to learn more about autism and modify their treatment strategies as needed to support autistic adults.

Another positive development is the growing number of requests from clinicians and community MH agencies for training and consultation about treating autistic adults with co-occurring psychiatric conditions. We have encountered many clinicians who are clearly eager and motivated to learn more about how to effectively work with autistic adults in a mental healthcare setting. An example of this comes from Dr. Maddox's recent partnership with two large urban community MH centers to identify autistic adults in outpatient programs (R34MH100356; PI: Mandell). Several community MH program leaders asked our research team for in-service trainings on how to treat autistic adults with co-occurring psychiatric conditions, emphasizing that this is a high-priority training need for clinicians. Of 47 clinical staff who completed a brief survey, 100% expressed interest in attending a clinician training about working with autistic adults. Importantly, these requests for training and consultation come from a wide variety of locations; for example, Dr. Gaus has been invited to train therapists and physicians working in the most remote rural of settings to the most densely populated cities across the United States, United Kingdom, Sweden, and the Netherlands. Clinicians and community MH agency leaders are aware of their gaps in knowledge and skills related to autism, and they are committed to learning more.

A third positive development involves building empirical support for using cognitive-behavioral therapy (CBT) and mindfulness-based strategies to effectively treat co-occurring psychiatric conditions in autistic adults.[11,12] Although more rigorous research in this area is needed, multiple studies demonstrate that autistic adults can benefit from these popular therapeutic approaches. Underlying this work is an important recognition that conditions such as anxiety and depression are separable or distinct from autism, and treating them can lead to significant improvements in the individual's quality of life. With more research and public awareness about co-occurring psychiatric conditions in autistic adults, the risk of diagnostic overshadowing (e.g., incorrectly attributing symptoms of anxiety or depression to

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the diagnosis of autism) decreases, which is good news for helping autistic adults find the most appropriate treatment.

Barriers Facing Autistic Adults in Need of Community MH Services

Now for the bad news. Despite the improvements already outlined, the way services are delivered to autistic adults with co-occurring psychiatric conditions is still fragmented. In many states, there are separate service delivery systems for autistic adults and adults with psychiatric conditions. Autism is categorized as a developmental disability (DD), along with intellectual disability and neurodevelopmental differences that have an early onset, and DD-related services for adults are geared toward building independent living skills. DD systems have a teaching/rehabilitation approach to addressing lifelong disabilities. Psychiatric conditions, in contrast, are addressed in most states through MH care systems that are geared toward symptom reduction and recovery. These two systems have very little integration or communication, and when systems operate in a parallel but disconnected way, or as “silos” of care,[13] clients who need both kinds of services fall through the cracks and receive no treatment or inadequate care in each system.

A common phenomenon is a “punting” that can happen at the point of first contact for an intake appointment. When an adult calls a community MH center for MH services for anxiety or depression and mentions an autism spectrum disorder (ASD) diagnosis, he or she often gets punted to the DD system. This may happen because the MH providers do not view ASD as a condition they can treat, even though the help-seeking adult is asking for help for anxiety or depression, and not the ASD. In contrast, if a serious psychiatric condition is mentioned to the DD system providers, they often punt to the MH system because they may not have training in the treatment of psychiatric conditions. The autistic adult who experiences this may feel like a “hot potato” being bounced back and forth, all the while losing precious time to treat the cooccurring psychiatric condition.

Many MH providers (e.g., experienced cognitive-behavioral therapists) have the skill set needed to treat the anxiety or depression that so often co-occurs with autism, but are reluctant to treat those conditions if the client happens to have ASD. Therapists often report limited confidence and training related to working effectively with autistic clients,[14] which is consistent with findings from medical providers serving autistic adults[15] and community MH clinicians serving autistic youth with ASD.[16] Clinicians’ lack of confidence about applying their clinical skills with autistic adults may be based on limited knowledge about ASD in adulthood. Without some exposure to recent information about ASD, providers may have outdated ideas (e.g., most autistic people have intellectual disability) or may believe myths (e.g., all autistic people have problems with aggression and other challenging behavior; autistic people cannot engage in CBT). This barrier diminishes the number of skilled therapists who are available to work with this population.

Another obstacle is a financial one. Autistic adults are more likely to be unemployed or underemployed.[17,18] Lower income adults or those relying on Medicaid (i.e., a state and federal program that provides health coverage to people with low income) may have fewer choices about where they can access MH services. Owing to the “silo” effect already

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mentioned, Medicaid clinics that are overseen by the DD system may not have staff with a strong background in treating psychiatric conditions. Likewise, Medicaid clinics operating under the MH system may have staff members who are uncomfortable treating an autistic adult, even if the primary complaint is about anxiety or depression. In either system, there can be limits on the number of sessions allowed, causing treatment to end before the problems have been adequately addressed. Finally, lower income can contribute to transportation problems, making regular attendance in therapy more challenging.

Recommendations for Continued Improvement in the Accessibility and Quality of Mental Healthcare for Autistic Adults

Fortunately, we have observed a trend of improvement across the United States mental healthcare system for autistic adults. Hereunder are recommended strategies that each group of key players can implement to reinforce existing efforts and widen the arenas in which a more integrated model of care can grow. We start with recommendations for autistic adults and their families, followed by clinicians, and finally systems administrators.

Autistic adults and their family members can utilize various self-advocacy practices to increase the likelihood that they will receive appropriate MH treatment:

- Join ASD-related support and advocacy networks and look for word-of-mouth referrals from peers who have had success with local MH providers. Information about the Autistic Self Advocacy Network chapters, which engage in self-advocacy work and support a community of autistic adults, can be found here: http://autisticadvocacy.org/chapters The Asperger/Autism Network (www.aane.org/about-us/programs-and-services/adult-programs-and-services) and Autism Society Affiliate Network (www.autism-society.org/ about-the-autism-society/affiliate-network) offer help with locating treatment referrals and support groups. The Global and Regional Asperger Syndrome Partnership also offers referral services (https://grasp.org/ resources), support groups (https://grasp.org/member shipsupportgroups), and online community spaces (https://grasp.org/resources).
- Look for therapists who have the core skills needed to treat the presenting problem at hand, even if they are not experts in ASD *per se*. For example, CBT is an evidence-based approach for adult depression, so if depression is the problem that is most interfering with your functioning, use *CBT, adult depression* as keywords in your search and pick a therapist with corresponding credentials. The Association for Behavioral and Cognitive Therapies provides information about CBT and resources for finding a cognitive-behavioral therapist here: www.abct.org/information
- During the initial meeting/intake with a new therapist, disclose the ASD diagnosis as you would any other historical factor (e.g., cultural/ethnic background and chronic medical conditions), but emphasize that it is not the reason for seeking treatment. Come with reading materials or resources that are current about adult ASD and be prepared to provide them. One example of a

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relevant book is *Aspies on Mental Health: Speaking for Ourselves*, edited by Luke Beardon and Dean Worton. If the therapist does not have any experience with ASD but is open to learning more about it and how it manifests in you, that is a sign that he/she will use the individualized approach you need for the treatment of your co-occurring psychiatric condition.

Clinicians can foster a more integrated system of mental healthcare by adopting the same individualized approach they may use for any of their clients without ASD. When autistic adults seek MH treatment for a co-occurring psychiatric condition, they are usually in need of help managing the symptoms of the latter, and less help with the ASD *per se*. Of course, the ASD characteristics may affect the way the client has developed and expressed the psychiatric condition symptoms, so clinicians must be tuned into those factors, but may not need to intervene directly on the ASD to be most helpful. Here are some strategies to consider when you have a client with an MH problem who also has a history of ASD:

- Consider ASD to be a variable that plays a similar role as a client's cultural or ethnic background; you do not have to be an expert in a person's cultural origins to be helpful, but you do need to be familiar enough with how it has influenced learning, beliefs, values, and behavior patterns so you can tailor your treatment strategies to respect this "culture" and be maximally effective. For example, if you started with a new client who came from a culture with which you have had no experience, you would not turn the client away for that reason. You would take the time to familiarize yourself enough with the culture to conceptualize your client's unique manifestation of the psychiatric condition you are treating, and to design the treatment plan in a culturally sensitive manner. Then you would practice your therapy skills in the same manner you would for anyone else.

- For some clients you may consider the ASD as you might any other disability a client may have when presenting for help with an MH problem. As with the cultural issues already mentioned, living with a lifelong disability is a background factor that needs to be considered when conceptualizing the case, but is not the issue for which the client is seeking immediate help. For example, if you had a client present for help with depression, and that person happened to have a visual impairment, you would not turn away the client and say, "Well, I have never worked with a client with a visual impairment before, so I can't help you with your depression." Rather, you would familiarize yourself with the ways living with that disability could have affected the development and expression of depressive symptoms, enough to be able to individualize your treatment plan to that client's unique needs. After that, you would treat the depression following the principles you have used to treat every other client with depression.

- In terms of individualizing your treatment plan to an autistic client's unique needs, you can draw from some of the common modifications to traditional CBT approaches used with autistic individuals.[11,19] Common adaptations for autistic adult clients include increasing the number of sessions from the number outlined in traditional treatment manuals for psychiatric conditions, including additional

information about emotion recognition and expression, directly addressing social skills in session, and increasing the use of visual cues and written materials.

- Read some autobiographical accounts of autistic adults to learn more about how various autistic adults learn and think. Examples include:

  Finch D. *The Journal of Best Practices: A Memoir of Marriage, Asperger Syndrome, and One Man's Quest to Be a Better Husband*. New York: Scribner; 2010.

  Grandin T. *Thinking in Pictures and Other Reports from My Life with Autism: Expanded Edition*. New York: Vintage; 2006.

  Paridiz V. *Elijah's Cup: A Family's Journey into the Community and Culture of High-Functioning Autism and Asperger Syndrome*. London: Kingsley; 2002.

  Shore SM. *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*. Shawnee Mission, KS: Autism Asperger; 2001.

  Wiley LH. *Pretending to Be Normal: Living with Asperger's Syndrome* (*Autism Spectrum Disorder*). London: Kingsley; 2015.

- Foster working relationships with autism experts in your region. During the course of your treatment, you may wish to collaborate with someone to get an assessment or opinions about the differential diagnosis issues that can come up when a person has both ASD and a cooccurring condition. The resources listed in the previous section for autistic adults and their families are networks that can lead you to connections in your region.

Systems administrators can improve both intra- and interdisciplinary collaboration that is essential for dually diagnosed populations to receive quality MH treatment. Systems administrators include the leadership in government agencies (DD and MH departments), university training programs (physicians, psychologists, and social workers), community MH facilities (outpatient clinics and hospitals), and professional practice associations (international, national, state, and regional medical, psychological, and social work associations). Suggestions for them include:

- Link the DD and MH systems to increase communication and mutual support to reduce the "punting" that occurs when someone on the autism spectrum calls for an intake with either system. The National Association for Dual Diagnosis (NADD) has many tools and resources to foster this kind of work; see www.thenadd.org for more information.

- Include more courses and practicum experiences related to autistic adults in the required general training for physicians, psychologists, and social workers.

- Offer trainings to MH staff in community-based facilities that focus on the treatment of MH problems in autistic adults.

- Hold trainings through professional practice organizations about autism in adults so that updated information is available to mainstream MH professionals.

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Conclusions

The positive developments in community mental healthcare for autistic adults with co-occurring psychiatric conditions are encouraging. At the same time, significant work is still needed to provide autistic adults with affordable, quality MH services. This Perspectives piece presents a summary of the needed changes and specific methods to continue to improve community MH services for autistic adults. Future efforts could focus specifically on increasing coordination between the DD and MH systems and training service providers to work more effectively with autistic clients. Autistic adults, their families, clinicians, and systems administrators all play an important role in the mission to break down the silos in community mental healthcare and build bridges instead.[13]

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