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Curr Psychiatry Rep. Author manuscript; available in PMC 2022 March 29.

Published in final edited form as:

Curr Psychiatry Rep. ; 23(10): 66. doi:10.1007/s11920-021-01278-0.

Mental Health Services for Autistic Individuals Across the Lifespan: Recent Advances and Current Gaps

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Abstract

Purpose of Review—This synthesis of recent mental health services research with autistic individuals presents significant advances, current gaps, and recommendations for improving mental healthcare for this population.

Recent Findings—Recent advances include improved understanding of co-occurring mental health conditions among autistic individuals, a growing evidence base for interventions to address them, the development and implementation of new service models to support mental health for this population, and a substantial increase in mental health services and implementation research focused on autism. Ongoing challenges include a lack of mental health interventions designed for community implementation with autistic individuals, limited workforce capacity, complex and disconnected service systems, and racial, ethnic, and socioeconomic disparities in accessibility and quality of mental health services.

Summary—Despite the advances in our understanding of mental health needs and mental health services for autistic individuals, several critical gaps remain. We encourage future efforts to develop and test interventions that can be used in community settings, train and incentivize the

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Human and Animal Rights and Informed Consent All reported studies/experiments with human or animal subjects performed by the authors have been previously published and complied with all applicable ethical standards (including the Helsinki declaration and its amendments, institutional/national research committee standards, and international/national/institutional guidelines).

workforce to provide them, realign policies and funding with best practice, and embrace an equity-focused approach to autism research and care.

Keywords

Autism; Co-occurring psychiatric conditions; Mental health services; Lifespan; Disparities

Introduction

Autism spectrum disorder (ASD) comprises a constellation of social communication difficulties and restricted, repetitive patterns of behaviors or interests that have strong genetic underpinnings and appear early in life [1]. ASD prevalence continues to rise; the current youth estimate in the USA is 1 in 54 [2]. At the start of this review, we acknowledge the rich and important discussions in the autism research, practice, and self-advocacy communities about preferences for identify-first versus person-first language [3, 4]. To this end, we elected to use identity-first language (e.g., "autistic person") throughout this review to honor the preferences, autonomy, and rights of the autistic community [5–8].

Autistic individuals across the lifespan commonly experience co-occurring mental health problems that require transdisciplinary care [9, 10•]. Attention-deficit hyperactivity disorder, anxiety disorders, sleep-wake disorders, disruptive behavior disorders, and depressive disorders are the most common disorders among autistic individuals [11]. Prevalence is higher in clinically referred samples than in population-based or registry studies; both sets of estimates are significantly greater than what is found in the general population [11]. Co-occurring mental health conditions can be more impairing, distressing, and negatively impactful on quality of life than core autistic characteristics [12]. Although most research in this area to date has focused on autistic youth, mental health problems continue and often increase in adulthood [13–17].

Examining and addressing co-occurring mental health conditions, mental health service needs, evidence-based mental health treatments, and capacity building of mental health services for autistic individuals is an important priority of stakeholders, including autistic individuals, family members, providers, organization and system leaders, and researchers [18, 19]. In this review, we summarize recent advances and continued gaps in quality mental healthcare for autistic individuals across the lifespan. Because publicly funded systems, including Medicaid-reimbursed healthcare and public education services, are the primary payers for autism care in the USA, we focus on findings from research in these systems.

Overview of Mental Health Services

Mental health services comprise a wide range of interventions (both pharmacological and non-pharmacological approaches) and supports (which address challenges to mental health, but may not be directly therapeutic). Examples of mental health services include psychiatric diagnostic evaluation, individual/group/family psychotherapy, case management, psychological testing evaluation, crisis intervention, and consultation. Mental health service providers include psychologists, masters-level therapists, social workers, psychiatrists, psychiatric nurses, primary care physicians, and other allied health professionals. Based on

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funding, acuity of mental health needs, client age, and other factors, mental health services can be provided to autistic individuals in a variety of settings (see Table 1).

Recent Research and Practice Advances

Improved Understanding of Co-occurring Mental Health Conditions Among Autistic Individuals Across the Lifespan

While many studies have demonstrated high rates of co-occurring mental health conditions, there has been increased recognition of the *range* of these conditions commonly present in autistic individuals, including the sequelae of trauma and gender dysphoria [11]. There is also growing attention to the increased rates of suicidal thoughts and behaviors in autistic individuals compared with the general population [20], with co-occurring psychiatric conditions documented as a risk factor for suicide attempts and deaths in autistic individuals [21].

As we learn more about the broad range of co-occurring mental health conditions in autistic individuals, there has been an increased focus on the mental health needs among autistic adults and autistic females, two historically understudied and underserved groups. Autistic adults are at disproportionate risk for mental health problems compared with the general population, with more than half meeting criteria for a co-occurring psychiatric condition [14]. A lifespan approach is important because primary co-occurring mental health concerns change across development. For example, challenging behaviors are more common in younger children, while depression and suicidality are more common in adolescents and adults [15, 22]. Emerging research on sex differences suggests that autistic females have higher rates of internalizing disorders than autistic males [23] and experience particularly elevated rates of suicidal thoughts and behaviors [21, 24]. Despite these high rates and associated impairment of co-occurring mental health conditions, autistic adults and autistic females face significant barriers in accessing quality mental health services [16, 25•, 26, 27].

Growing Evidence Base for Mental Health Interventions for Autistic Individuals

There have been considerable efforts to develop and test interventions targeting co-occurring mental health conditions in ASD [28, 29, 30•]. For youth, this work has taken two general approaches: (1) developing interventions specifically for use with autistic individuals and (2) adapting existing evidence-based interventions (EBIs) targeting mental health conditions in other groups for use with autistic youth [31••]. The most common EBI adaptations apply to the intervention techniques, specifically tailoring or adding EBI elements to align with the unique characteristics and needs of the autistic individual (e.g., increasing parent involvement, adding visual supports, incorporating focused interests, using more concrete language) [31••]. These modifications are important to improve intervention fit, increase engagement, and promote generalization of skills at home. In addition, the inclusion of EBI adaptations can enhance the efficacy of these interventions, with recent work demonstrating improved efficacy of an EBI (cognitive behavioral therapy) adapted for autistic youth with co-occurring anxiety compared to the standard EBI and treatment as usual [32].

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Developing and Implementing New Service Models to Address the Documented Disparities in Access to Services for Autistic Individuals

Navigating mental health services for autistic individuals is extremely complicated, and many families need assistance accessing and engaging in services. Family navigation is an evidence-based case management practice that involves motivational interviewing, service navigation, and collaborative problem solving to increase access to diagnostic and intervention services within a time-limited period. Family navigation has been adapted for ASD [33, 34] and is currently being adapted for ASD and co-occurring mental health needs. Other service delivery models with goals of identifying co-occurring mental health needs and managing or linking to mental healthcare have been adopted in primary care settings. Primary care is well positioned to reach those who may be at most risk of facing health disparities. In addition, primary care may be a less stigmatizing and more holistic place to provide mental healthcare to autistic individuals, similar to collaborative care models for individuals with psychiatric conditions [35]. Recent examples include the Extension for Community Healthcare Outcomes (ECHO) Autism program [36, 37] and the Access to Tailored Autism Integrated Care model [38••, 39], which are both accumulating evidence for feasibility, acceptability, and adoption.

Substantial Increase in Mental Health Services and Implementation Research

Another recent advance is the growing application of implementation science methods, models, and measures to reduce the gap between research and practice in community mental health services. Implementation science has emerged and evolved as a transdisciplinary field to accelerate uptake of evidence-based policies, practices, and programs into routine healthcare systems. It has been applied to autism to address similar quality and access gaps [40, 41]. This has resulted in the field starting to move beyond a "train and hope" model of translating EBIs into community practice. Attention to both the characteristics of EBIs and the use of systematic strategies to implement EBIs is essential for adoption and sustainment in service contexts. A central component of this work is the inclusion of community-partnered and stakeholder-engaged approaches. The close collaboration with relevant community stakeholders helps to ensure that EBIs are not only feasible and acceptable for community settings, but that they address community-identified needs or implementation gaps, for organizations, providers, and autistic individuals. There has also been notable progress in developing and testing implementation strategies at both the provider and organizational level for EBIs with autistic youth in community-based children's mental health settings [42, 43••, 44]. An additional important methodological feature of these efforts has been the examination of the impact of these EBIs and implementation strategies using hybrid effectiveness-implementation designs that include a simultaneous focus on examining the effects of the clinical EBI as well as key implementation factors, processes, or strategies [45]. This combination of effectiveness and implementation trial designs serves to both speed and improve the translation of research into routine practice and improve the quality of mental health services for autistic individuals. Overall, the application of implementation science methods and frameworks represents a critical advance in the science of translating research to community practice and assuring the significant efforts developing and adapting EBIs to date yield a positive public health impact.

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Current Gaps

Limited Representation in EBI Efficacy Studies

Despite the advances in our understanding of mental health needs and mental health services for autistic individuals, several critical gaps remain. Chief among these is the fact that few autistic individuals receive EBIs as part of their mental healthcare [46]. Several factors contribute to the limited implementation of these practices in community settings. A recent review indicates that most mental health interventions for autistic youth were primarily tested with white individuals, those with higher cognitive functioning, and/or those with a single co-occurring mental health condition, with little emphasis on older and/or transition age youth [47]. This narrow target limits the ability to meet the mental health needs of autistic individuals, who typically present with multiple co-occurring conditions [11]. The review also found limited representation of providers typical of the clinical workforce providing community mental health services. Another recent review, specific to cognitive behavior therapy research with autistic youth, found significant overrepresentation of white youth, significant underrepresentation of Black and Latino youth, and significant underrepresentation of families from low socioeconomic status backgrounds in the intervention efficacy trials [48]. Overall, these findings illuminate the critical gap in our understanding of the treatment effects and relevance of these interventions for the clinically and socio-demographically diverse range of individuals typically served in community mental health settings.

In addition, most mental health EBIs were developed and tested in tightly controlled efficacy trials conducted in academic or medical research settings with extensive expertise and resources [31••], versus developed for community implementation by providers with limited autism training and supports. This limits the feasibility and resulting uptake of these interventions in community settings. For example, an EBI may have been designed without consideration of whether the structure (e.g., length of treatment sessions) or the delivery format (e.g., group-based) fits most community service provision models, making them difficult to implement in these settings.

Limited Community Workforce Capacity

Another major barrier to quality mental health services for autistic individuals is the shortage of mental health clinicians trained to work with this population [25•, 49••, 50, 51, 52••, 53]. Mental health clinicians who regularly treat psychiatric conditions such as anxiety and depression are not confident treating these same conditions in autistic clients, given their limited training and experience in this area [25•, 50, 53]. A small subset of mental health clinicians also specializes in autism, but these specialists are often private pay only and/or based in university or urban settings, making them less accessible [52••, 54]. A lack of autism-specific training is most pronounced in adult-focused providers [53], which is partially explained by the historical view of ASD as a childhood condition.

Complex and Disconnected Service Systems

A major challenge in improving mental healthcare for autistic individuals is that no one system has responsibility for providing this care (Table 1). Because mental health

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services are delivered in multiple systems, there are complexities with understanding eligibility, accessing care, and aligning this with funding appropriateness [55], particularly as autistic individuals transition from youth-serving systems to adult-serving systems. These complexities are further amplified for autistic individuals who may be additionally eligible for autism-specific services that are typically funded differently than both general healthcare and mental healthcare [56]. For example, autism-specific services such as applied behavior analysis are often coordinated and funded by the Developmental Disability service system in states. From our collective experiences in autism research and practice, we have observed confusion by providers, caregivers, and autistic individuals about the purpose, appropriateness, and logistics of accessing different services, particularly differentiating between applied behavior analysis and mental health services. This confusion may be partially explained by service reimbursement policies that have differentiated eligibility for developmental disability and mental health services [56, 57]. A related challenge for autistic youth with co-occurring mental health needs and their families is the ongoing tension between the education system (where developmental disabilities are often supported) and the healthcare system (where mental health conditions are often managed), making it challenging to connect care [58] and raising questions about how mental health services should be financed and delivered in schools [59].

Racial, Ethnic, and Socioeconomic Disparities

Finally, the gaps and barriers described in this section are exacerbated in racial and ethnic minority and low-income communities [52••, 60–63]. A recent systematic review found racial, ethnic, and socioeconomic disparities in accessibility and quality of services for autistic children [64••]. Specifically, families of color and lower income reported reduced service access and quality and greater unmet service needs than white, higher-resourced families. In a study of Medicaid-enrolled autistic children, Black, Asian, and Native American/Pacific Islander children received fewer outpatient services relative to white children [65••]. In addition, a large statewide survey of autistic adults and their caregivers on a waiting list for home- and community-based Medicaid services found that Black autistic adults had significantly greater unmet needs for mental health services, relative to white autistic adults [66••]. These documented disparities for autistic individuals are not exclusive to mental health services (e.g., allied health services [67], healthcare transition services [68]). More research is needed to identify and test structural changes to increase equity in autistic individuals' access to evidence-based mental healthcare.

Moving Forward

Designing EBIs for Community Delivery From the Outset

To address the problem that EBIs were not designed for community implementation, we need a different approach for mental health intervention development and testing (e.g., "designing for dissemination" [69, 70]). We recommend leveraging implementation science methods, starting early in the pipeline of research-to-practice translation, in order to promote the uptake and sustainment of EBIs in community care [56, 71]. Community-academic partnerships and stakeholder engagement with end users are key aspects of this process [72]. Recent work has further highlighted the importance of listening to the voices of

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autistic individuals [73] and their caregivers [74] to improve accessibility and quality of services. In addition, investigators conducting intervention research need to explicitly recruit clinically and socio-demographically diverse samples [64••], which will require overcoming barriers to minority families participating in research (e.g., distrust of the research process [75]). More work on cultural adaptations to EBIs for autistic individuals is also needed [76, 77]. These collective efforts are critical to ensure that the mental health intervention evidence base is applicable for autistic individuals and families from diverse and minoritized backgrounds.

Strengthening Mental Health Workforce Capacity

Second, to address the limited workforce capacity, we need more mental health clinicians and other professionals willing and able to work effectively with autistic individuals. We recommend adding autism-focused curricula and training opportunities for professionals across primary, specialty, and mental healthcare, at both the preservice level (e.g., in graduate programs through coursework and practicum placements) and in continuing education [25•]. Training content should cover both the assessment and treatment of co-occurring psychiatric conditions in autistic individuals, as well as the assessment and management of suicide risk [78]. Strategies at the system/policy and organizational levels are also needed to address providers' willingness and capacity to accept autistic individuals as clients or patients (e.g., broadening or clarifying service eligibility to include autism in both youth and adult service systems, increasing dissemination of mental health EBIs for autistic individuals [79]). We note that the challenge of limited workforce capacity extends far beyond autism, and improvements will likely require significant changes to preservice training, continuing education, supervision, and reimbursement models.

Restructuring Policies and Coordination Across Service Systems

Third, to address the disconnected service systems, we need to integrate autism mental healthcare into existing systems and improve communication between systems. This process will involve developing and testing policy and fiscal innovations to address the currently disjointed organization of public services [56]. Effective communication between systems is critical because autism care necessitates a multiple service system approach — there is no single autism service system [80]. The National Association for Dual Diagnosis [81] offers helpful tools and resources to improve interagency collaboration, particularly between the mental health and developmental disabilities systems.

Structural Change for Promoting Equity

Fourth, to increase equitable access to quality mental health services for autistic individuals, we must continue to recognize and address the impact of systemic racism on autism research and clinical practice. Several recent articles offer practical recommendations to enact meaningful changes in policy, research, clinical practice, and implementation science [82–86]. We need to think both about *place* (e.g., school mental health funding tied to property taxes disenfranchises low-income communities) and *race* (e.g., underrepresentation of Black researchers and clinicians in the autism field) to promote equity in autism research, service access, and care quality. By applying a social justice lens to autism research and

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clinical practice, we can advocate for systemic change and reduce disparities in mental health services.

Conclusions

The recent advances in mental health services and implementation research for autistic individuals are encouraging. However, significant gaps remain, and much work is still needed to improve the accessibility and quality of mental health services for autistic individuals, particularly those from racial/ethnic minority and lower-income families. This change requires explicit attention to the organization and financing of mental health services. This review summarizes recent research and provides recommendations for addressing key problems, with a primary focus on publicly funded mental health services in the USA. Future work could focus on other service types and international efforts, particularly those in low- and middle-income countries. While there has been considerable progress in recognizing and treating co-occurring psychiatric conditions in autistic individuals, we still need work in developing interventions that can be used in community settings, training and incentivizing the workforce to provide them, and modifying policies and funding so that they align with best practice. Closing these gaps requires a systems- and equity-focused approach to autism research.

Funding

This work was supported by grants from the NIMH (K23 MH115100, PI: Dickson; K23 MH110602, R34 MH120190, PI: Stadnick).

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Table 1

Service settings where mental health services may be provided to autistic individuals across the lifespan (based on [55] and [80]. Bolded settings have been the focus of recent research; italicized settings have been understudied

Mental health service settings	Childhood (5–15 years)	Young adulthood (16–24 years)	Adulthood (25 years+)
Schools (elementary, secondary)	X	X	
Schools (postsecondary)		X	X
Outpatient	X	X	X
Intensive Outpatient/Partial Hospitalization	X	X	X
Community Emergency Response	X	X	X
Emergency Departments/Crisis Stabilization Units	X	X	X
Inpatient	X	X	X
Primary Care	X	X	X
Alcohol and Drug Services	X	X	X
Juvenile Justice System	X	X	
Criminal Justice System		X	X