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## Promoting Quality of Life: Suggestions for Mental Health Care Providers Working with Young Autistic Adults

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### Abstract

There is a growing population of autistic adults in need of supports from a service delivery system that, at present, fails to accommodate their needs adequately and equitably. Unfortunately, there is a shortage of trained behavioral health service providers to meet the needs of young autistic adults. Quality of life (QoL), or one's perception of, and satisfaction with, life in relation to held goals and expectations, has been identified as a key outcome of interest by autistic self-advocates. By supporting autistic clients to hone their strengths and interests, integrate various aspects of their identity, identify goals, and connect to appropriate resources, providers can promote clients' self-knowledge and self-determination, in the service of improving QoL. In this Perspectives article, we offer concrete recommendations to mental health providers, including those who do not specialize in autism, with the goal of supporting implementation of evidence-based strategies that improve QoL and promote self-determination among young autistic clients.

**Keywords:** autism, adult, transition, implementation, quality of life

### Community Brief

#### *Why is this topic important?*

Mental health care providers who are not autism specialists often feel unable to help autistic adult clients. However, relying on specialists to provide treatment for autistic adults can delay access to needed care. There is a need for well-trained clinicians and other service providers who can effectively work with autistic adults.

#### *What is the purpose of this article?*

Young autistic adults face many challenges related to transition into adulthood, including greater independence desires and external expectations. The early adult years are also a period of heightened risk for emerging mental health problems. The goal of this article is to offer guidance to mental health service providers on how to effectively support autistic adults, while respecting autonomy, identity, and diversity. The guidance we offer is drawn from research, clinical practice, and lived experience.

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*What personal or professional perspectives do the authors bring to this topic?*

In addition to an autistic adult and self-advocate, the authors are clinical researchers and clinicians with expertise in working with adolescents and adults as service providers.

*What is already known about this topic?*

Although a wider range of effective intervention practices is needed, there are a growing number of scientifically based and respectful treatments now available to address mental health concerns and promote quality of life (QoL). Unfortunately, it is widely recognized that there is a shortage of providers who work with autistic clients. One reason for the shortage is that some highly capable and well-trained providers do not treat autistic clients.

*What do the authors recommend?*

We recommend that providers focus on strengths, abilities, and potential rather than focus on perceived deficits when working with autistic clients, so that we as a society can better meet the service needs of the autistic community. Specifically, we encourage a focus on improving QoL, structuring services to focus on self-determination and empowerment, emphasizing intersectionality or existence of multiple identities with personal meaning, and helping clients and their families navigate service systems and supports that are available.

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

By increasing the number of providers who can work effectively work with adult autistic clients, we can hopefully minimize delays in service delivery and increase availability of high-quality services.

## Introduction

**F**OR THE PAST FEW DECADES, the prevalence of autism has increased and is now reported to be ~2% of the adult population.<sup>1</sup> While more than 70,000 autistic teens enter adulthood every year,<sup>2</sup> supports available for autistic adults are limited.<sup>3</sup> The Interagency Autism Coordinating Committee, a United States Federal advisory committee whose membership includes autistic advocates, public stakeholders, federal agency officials, and researchers, identified the need for services to support the transition to adulthood as its first objective within the domain of lifespan research.<sup>4</sup> This is echoed in the recommendations of the Lancet Commission on the future of care and clinical research in autism where panel 4 noted the need for personalized health interventions in a stepped care model for autistic children and adults.<sup>5</sup>

Our understanding of the significantly higher risk of co-occurring mental health diagnoses associated with autism has also increased in recent years.<sup>6</sup> Many psychiatric disorders, notably mood disturbance, certain anxiety disorders, and substance use disorders, tend to have first onset between late adolescence and early adulthood.<sup>7,8</sup> The provision of services has, however, not kept pace with the increasing population of autistic adults who have a critical need for quality mental health services.<sup>9</sup> The swelling population and the knowledge we have of their high mental health needs, combined with the lack of service providers, has created a bottleneck where demand significantly outstrips supply. This leaves the population of autistic adults at high risk.

Thus, our aim in this perspectives article is to offer research-based recommendations for mental health care providers (e.g., psychologists, counselors, social workers, and psychiatrists) who are working with autistic adults, with the goal of improving access to quality services that meet the

transition-related and mental health needs of emerging autistic adults. The recommendations provided are rooted in good clinical practice (i.e., general considerations for any client), with considerations targeting specific needs seen in the autistic young adult population. The developmental period termed “emerging adulthood” is thought to span the ages of 18–25 years roughly.<sup>10</sup> This developmental phase involves moving from (1) school to work, (2) home to community, and (3) child- to adult-oriented systems of care and is characterized by several milestones, including forming sustained intimate relationships, engaging in self-directed learning, and gaining employment.<sup>11</sup>

Although much of the content herein is relevant for autistic adults who are older, the target population is young adults given heightened risk for onset of mental health concerns and the separation of child and adult services in our mental health care systems. In addition, most of the recommendations we offer are appropriate for speaking autistic adults without intellectual disability; different types of supports are likely needed for adults with higher needs.<sup>8</sup> Transitioning to adulthood encompasses navigating many service delivery systems and foci of clinical care. The recommendations below are meant to be most relevant to what can be feasibly accomplished by a mental health care provider within the therapeutic setting.

The recommendations offered herein stem from the authors’ experience and from good clinical practice, and a growing although incomplete research base.<sup>5</sup> The recommendations are meant to assist mental health providers, regardless of whether one specializes in autism. We acknowledge debate as to how effective nonspecialist providers are in treating autistic clients.<sup>12–14</sup> However, given the crisis in access to services, which is in large part due to a shortage of qualified providers,<sup>9</sup> we assert that well-trained providers who engage in good clinical practice, including

those who do not usually treat autistic clients, can be effective in helping autistic emerging adults improve their quality of life (QoL).

Our recommendations also reflect three core beliefs, or tenets, about mental health services: (1) QoL is the main goal of intervention; (2) clinicians should take a personalized strengths-based approach; and (3) all adults have the right to self-determination. These tenets are anti-ableist functionally; in other words, a provider who adopts the tenets values the client as a person who is whole and does not need to be cured or fixed, but instead supports the client in working toward their own life goals.

Acknowledging the influence of positionality on the perspectives offered, the authors of this article are researchers and clinicians whose work focuses on increasing access to employment and education, and implementation of evidence-based services within the community. One author is an autistic adult and self-advocate. We acknowledge that, as the authors are based in the United States, the recommendations reflect both the associated privilege and complexity of U.S. service system integration. Pulling from the extant literature, the authors' applied work, advocacy by autistic adults, and lived experience, we suggest first and foremost that QoL should be a primary focus for supporting emerging autistic adults, and that self-determination is the principal tool, or mechanism, for attaining positive outcomes.

#### Client QoL as Benchmark for Treatment Success

QoL, a broad construct including both objective and subjective factors of well-being, has long been suggested as one of the most important indicators of success in adulthood and has been highlighted among the autistic community as a crucial lens through which to understand and evaluate their lived experience.<sup>10,11,15</sup> QoL is correlated with happiness, life satisfaction, and positive affect.<sup>16</sup> As it is both multifaceted and subjective by definition (and both perception and experience changes over the life course), QoL is not static, or trait-like, and it can be difficult to define.<sup>17</sup> Research on QoL and its measurement in autism is quite underdeveloped, including how autistic individuals define QoL themselves and how well this aligns to current measures of QoL.<sup>15,18</sup>

However, some measures have been validated for the autism population such as the World Health Organization Quality of Life Instrument, Short Form.<sup>18,19</sup> From childhood through adulthood, autistic people report lower QoL than do nonautistic people.<sup>20,21</sup> Although the research base is still developing, studies have identified factors that influence autistic people's QoL. For instance, anxiety worsens QoL,<sup>15</sup> whereas competitive integrated employment<sup>22,23</sup> and structured programming<sup>24-26</sup> improve QoL. Given the centrality of QoL, we view this as the primary goal from which two broad sets of inter-related recommendations follow. Set one pertains to developing self-knowledge and set two to self-determination (Fig. 1). The actions in the bottom half of the triangle refer to strategies that the provider might use to support QoL specifically related to psychological or mental health, the focus of this article, although we acknowledge that QoL is a larger construct that involves much more than just self-knowledge and self-determination.<sup>15,16,18,20,27</sup>

Self-knowledge is thought of as the ability to identify strengths, achieve selected goals, and know enough about



**FIG. 1.** Self-knowledge and self-determination in the service of quality of life.

oneself to make informed decisions.<sup>28</sup> Self-knowledge is linked to adult outcomes, including QoL, among autistic people.<sup>29,30</sup> Knowledge of self, including strengths and limitations, is linked closely to self-determination.<sup>31,32</sup> Self-determination refers to a person's sense of agency and empowerment, including ability to determine one's own behaviors and life course.<sup>33,34</sup>

Often likened to internal motivation, self-determination is essential to independent functioning and personal thriving as it involves knowing one's goals and behaving in ways that are consistent with the goals.<sup>28</sup> Moreover, self-determination is associated with postschool outcomes and positive treatment response among nonautistic clients<sup>29,35</sup> as well as greater community access, employment attainment, and overall life satisfaction among people with intellectual and developmental disabilities.<sup>36,37</sup> Self-determination is inversely correlated with autistic traits among autistic young adults<sup>38</sup>

#### Support Development of Self-Knowledge

##### *Develop a strengths-based mindset*

The first recommendation is to use a strengths-based approach to support goal development and attainment. A strengths-based approach involves focusing on the individual's current skills and abilities, and leveraging those to develop new skills relevant to the client's needs and goals. The provider assists the autistic adult to recognize and use their strengths as well as their interests when defining themselves and identifying their goals.<sup>39</sup> Many autistic adults are well aware of their challenges but have difficulty identifying their strengths and utilizing those strengths to facilitate goal attainment.<sup>40,41</sup> Connecting one's strengths, and sometimes interests, to personally relevant goals and behaviors (e.g., hobbies, employment, and further education) can improve community engagement and sense of fulfillment.

A strong sense of identity has been linked to community cohesion.<sup>42</sup> When people have jobs and hobbies that align with their strengths and interests, they more readily engage in their communities, hone their skills, build self-efficacy, and sustain QoL.<sup>22,23</sup> One must be cautious, however, when attempting to align a person's focused interests with employment. Interests that are highly narrow or esoteric often cannot be "fit" with an employment setting, and some interests,

when held exclusively, can interfere with flexibility and other behaviors that are needed for job success.<sup>43</sup> From an implementation stance, providers have many options. For example, the provider might introduce interest surveys to promote self-discovery or support the client in gaining a range of experiences and processing their reactions (e.g., what they liked and did not like) afterward.

#### *Acknowledge intersectionality*

Autistic adults frequently view autism as one of their identities, considering their neurodiversity another aspect of diversity such as race or gender. A strengths-based approach advocates supporting clients to embrace their diversity and the unique perspectives that it provides. However, intersectionality suggests that individuals who have more than one underrepresented status experience exponential effects from discrimination and disenfranchisement that is unique to the intersection of those statuses.<sup>44</sup> Applying intersectionality to the lived experiences of autistic adults requires clinicians to consider specific ways that factors such as race, ethnicity, religion, socioeconomic status, living and work community, disability, sexual orientation, and gender identity or expression at the macrolevel impacts both the client's sense of identity and mental and physical health problems.<sup>6,45</sup>

Although intersectionality is perhaps relevant to all autistic individuals, it is especially germane when working with young adult autistic clients as identity formation, or sense of self, is a critical milestone of emerging adulthood, along with psychological experiences such as self-exploration and instability.<sup>10,11</sup> Autistic individuals are often stereotyped as White cisgender males with savant abilities who come from highly educated middle- and upper-class families—similar to the composition of the samples upon whom diagnostic measures were normed. As a result, women, minorities, and other marginalized populations are diagnosed later or not at all, limiting access to services and supports.<sup>46–50</sup>

A growing body of research indicates greater gender and sexual orientation variance among autistic people relative to those without autism.<sup>51–54</sup> Familial, cultural, and structural barriers can add even more complexity to attaining much-needed services.<sup>55–57</sup> There is substantial evidence that systemic disparities experienced by autistic individuals from underrepresented groups or marginalized identities contribute to disconnection from services.<sup>45</sup> Finally, stigma experienced by members of cultural and racial minorities results in reluctance to seek services.<sup>58</sup>

Although the ultimate solution to these systemic issues is beyond the scope of any individual provider, acknowledging marginalization and identity can promote alliance building in treatment, and foster growth. Providers are encouraged to directly ask the client about held identities and assess personal and cultural values, including perceptions and beliefs related to disability, ideally during intake. Working within an intersectionality framework can result in a slower pace of work, as the provider gives space and follows the client's lead.

Oftentimes, when exploring intersectionality and identity, it can help to acknowledge and label any use of masking, as well as past pain, adverse childhood experiences, and trauma related to identity-hiding. Masking, also referred to as camouflaging, is a behavior engaged in by the autistic person

to maneuver within the neurotypical social world.<sup>59,60</sup> Masking is energy depleting, harmful, and related to risk for secondary mood disorders in autism.<sup>61</sup> Autistic adults have a higher rate of trauma, including post-traumatic stress disorder, than do nonautistic adults.<sup>62</sup> The client can benefit from leading the provider through their lived experience, and providers must routinely screen new autistic clients for trauma.

Autistic adults who experience intersectionality or inequity in health care due to identity factors such as race, sexual orientation, gender identity, ethnicity, and socioeconomic status are frequently isolated from other members of those groups. This isolation seems to increase the risk of mental and physical health challenges.<sup>63</sup> There is evidence that belonging to an affinity or advocacy group mitigates the mental health challenges faced by underrepresented groups, including LGBTQ+, ethnic, and racial minorities.<sup>64–66</sup> This requires the provider to be aware of, or try to learn about, healthy and helpful affinity and advocacy groups that will assist the individual in connecting to their community. Ultimately the provider can be invaluable in helping the adult client connect with others and find suitable mentorship from people who understand intersectionality and its impacts through their own lived experience.

#### *Identifying and overcoming person-environment mismatches*

In an interdependent community, people rely upon and work with each other's strengths so that everyone can get needs met. However, in many developed societies, young adults are expected to (and often expect themselves to) be nearly completely independent. For autistic emerging adults, who must manage both loss of services and increased demands, such unmet expectations can create a crisis situation. Mental health providers can help autistic clients understand that *all* people have strengths and weaknesses and needing help is a universally human experience. Because our society is built largely for neurotypical individuals, however, neurodivergent people who experience the world in different ways are likely to experience a greater mismatch between their skillset and environmental demands or tasks.

This is particularly important for emerging adults who may be transitioning to new environments with fewer (or no) services to support their needs. Difficulty recognizing a mismatch, not knowing which supports are needed to manage the mismatch, and trouble advocating for help can lead to autistic burnout.<sup>67</sup> Providers can play a key role in shifting away from a focus on treatment goals that attempt to “normalize” an autistic client and instead focus on identifying strengths and targeting self-advocacy skills to obtain and retain needed environmental supports and accommodations. For example, a therapist can help the client identify and describe differences in sensory needs (e.g., need to work in an environment with less noise and fewer sensory demands) or learning styles (e.g., need to use an organizational system to support executive function), so they can more successfully advocate for accommodations or support in reaching their goals.

A recognition of the unique learning styles often associated with autism (e.g., attention and executive function challenges) would help a therapist support autistic clients in

identifying their specific needs.<sup>68</sup> Providers can recognize and embrace neurodiversity by supporting clients with different thinking styles. For instance, a person might find a job that capitalizes on high attention to detail, or routinized behaviors. Providers can be instrumental in helping clients learn to reframe “failure” as a poor fit between person and setting, and in identifying ways that clients can both highlight and even enhance their skills.

### Promote Self-Determination

#### *Support individualized and autonomous goal setting*

There is a long history of relying on sources other than the autistic client to set goals, identify needs, and create a treatment plan. Professionals and/or parents may believe the autistic adult has limited insight or ability to introspect, when in fact the autistic client can communicate about their needs—sometimes verbally and sometimes through other means. Providers should ask their autistic clients to share their perspectives and experiences and honor the client’s preferences while encouraging the person to expand past their “growth edge.” A mental health care provider can sometimes offer a different unique perspective on what the client is facing, and help the autistic adult consider previously unseen alternatives.

Providers should treat the autistic client as an autonomous agent regardless of communication method or intellectual ability (e.g., greet the client first, speak and direct questions to the client even if a parent/caregiver provides responses). The client’s interests can be embedded into all aspects of their goal setting and learning. Providers should assess decision-making status (e.g., consent to share personal health information), but start from an assumption that the client is competent to make decisions and direct their own life choices by asking questions to the individual and encouraging them to define their vision of their life.

#### *Conduct a gap analysis*

When designing supports and interventions, providers must rethink traditional deficit-based paradigms regarding therapeutic interventions in favor of those that support self-determination.<sup>26,69</sup> Deficit-based intervention plans often include goals focused on compliance or other neurotypical standards of progress.<sup>70</sup> Compliance-based learning limits independence, self-reliance, creativity, and problem-solving.<sup>71</sup> Autistic adults often enter emerging adulthood lacking self-determination skills required for independence such as the ability to make choices, set goals, and solve problems.<sup>23,72–74</sup> This is probably due to several factors, including lack of sufficient consideration to long-term goals and reliance on programming that takes a deficit focus. Focusing on the client’s goals and optimization of QoL, from the client’s perspective, is likely to promote sustained motivation to both achieve independence and address ongoing challenges.

In a gap analysis, the discrepancy (gap) between the client’s goals and their current status (e.g., performance, ability, and situation) directly informs therapy. Instead of taking a deficit approach to “fix” a problem, we create action steps toward goal attainment (i.e., close the gap). For example, many autistic adults have received intensive social skills

training. Although such skills can be important in securing a job, the focus on remediating skill deficits (e.g., making small talk) may also unintentionally increase anxiety through heightened self-monitoring and awareness of differences.

It can be useful to teach specific self-advocacy skills that are usable in the client’s natural, or targeted, environment (e.g., at work). Instead of a goal to reduce “arguing” with others, the gap analysis would suggest that a goal for increasing self-advocacy in context-appropriate ways to get one’s needs met should be prioritized.<sup>75</sup> To be effective, the provider adopting a gap analysis approach must also ensure that the client has ample opportunities to build skills and gain experiences. This might mean, for example, trying to create interpersonal situations at work that will call upon the skill the client is targeting.

#### *Help connect the client to services and supports*

For the autistic emerging adult, navigating adult service systems can take significant future-oriented planning. In the United States, for example, it can take up to a decade to get well-matched adult supports.<sup>76</sup> An autistic person seeking assistance with employment, trying to secure independent living, and accessing federal financial benefits such as housing assistance or health care will have to interact with multiple agencies with varying eligibility criteria and policies governing services.<sup>69</sup> Although these services are helpful, most community services are delivered through systems designed for neurotypical adults or adults with intellectual disability and not autistic adults. Most autistic adults must rely upon informal systems of support, including family and friends, and must self-advocate or have a dedicated advocate. Providers can be instrumental in connecting their clients to services and facilitating effective communication.

There is a service shortage for autistic adults due to many factors, including a lack of available autism-specific adult programs, and a confusing and rather disjointed service system that often separates mental health and developmental disability supports.<sup>12,13,77</sup> As a result, autistic emerging adults often see a significant decline in services just when additional supports are most needed.<sup>78</sup> Clinicians can be a vital source of support by providing appropriate and accessible information aimed at connecting autistic adults and their families to adult-relevant service agencies and systems of support.

Clinicians can discuss concerns, make appropriate referrals, and, most importantly, encourage individuals to access and engage in these services as early as possible. It is critical that clinicians who provide services to autistic emerging adults become familiar with local agencies to address these service areas critical to the emerging adult: employment, community inclusion, intimate relationship development and exploration, independent living, financial literacy and stability, transportation, and health care access.

To that end, we recommend referral for adult services (e.g., Vocational Rehabilitation Services) that support two major tasks often associated with emerging adulthood: gaining employment and going to college or getting advanced training. Employment is an essential component of adulthood, enabling access to a multitude of benefits associated with a higher QoL, including financial independence, a sense of autonomy, personal growth and well-being, and access to

socialization within the community.<sup>22,23,79</sup> Research on effective pathways to competitive employment for autistic emerging adults shows clearly that the supported and customized employment models are the most effective approaches.<sup>80,81</sup> Another avenue to competitive employment is postsecondary education. Autistic young adults who receive postsecondary education or training are more likely to obtain employment and earn higher hourly wages.<sup>82–85</sup>

Many autistic young adults seem to fare better when they experience a more gradual entry into higher education, starting perhaps as a commuter, with smaller and/or fewer classes, such as at a community college.<sup>68,86</sup> Because the autistic young person must self-advocate for academic accommodations, it is critical for them to work on self-knowledge and self-determination.<sup>83,84,87</sup> Providers are encouraged to use explicit instruction on, and practice in, self-determination.<sup>88</sup> One area in which the need for self-determination arises is disclosure of the diagnosis; providers can help their clients determine when, to whom, and how to disclose the autism diagnosis. Providers can also help autistic college students learn self-advocacy and self-determination skills, including identifying and accessing the service networks often available on college campuses (e.g., academic advising and tutoring, faculty and peer mentors, counseling or support groups, and career centers).<sup>89</sup>

## Conclusion

We have observed that the shortage of providers who work with autistic clients can be alleviated, at least partially, by increasing clinician confidence as well as efficacy when working with autistic clients. This requires better preservice preparation to meet the needs of the large and growing population of autistic adults, as well as ongoing opportunities for practicing clinicians to embrace this work and receive support (e.g., peer consultation) to increase skill and confidence. As we continue to learn how to embrace diverse viewpoints and re-evaluate the very concept of disability as a society, so too should clinicians evolve. In this commentary, we have identified two broad recommendations: supporting the development of self-knowledge and promoting self-determination for autistic emerging adults. Much of the content comprising these recommendations stems from work initiated by, or done in collaboration with, the autistic community.

Given the prevalence of autism, it is highly likely that practicing clinicians who do not specialize in autism have *already* provided services to undiagnosed autistic adults.<sup>1,90</sup> Clinicians should address their own practice needs by engaging in self-directed learning, seeking consultation from others with more experience, and incorporating good clinical practice when serving autistic adults. These recommendations are intended to help mental health service providers effectively support the autistic people with whom they work. The recommended focus on QoL, through self-knowledge and self-determination, is relevant to mental health care services for all autistic young adults. However, in practice, when working with clients who are nonspeaking or have intellectual disability, the provider may need to adapt specific recommendations and provide more directive supports.

In addition, it was not our intent to provide a treatise on therapeutic process when working with autistic clients, which

is beyond the scope of this commentary. There are several strategies that are variably effective in this regard such as arranging the office and seating, so direct eye contact is not an expectation, minimizing unnecessary sensory input, allowing sufficient time for the client to respond, and addressing any internalized ableism in the client.<sup>91–93</sup> We contend that well-trained clinicians without prior autism training or expertise can develop the skills necessary to effectively support autistic adult clients when they confront their own ableism, view their clients as equal partners in the therapeutic relationship, and respect their clients' goals with a focus on guiding the autistic adult to greater self-knowledge and teaching self-determination skills, including goal setting and self-advocacy to enhance QoL.

## Authorship Contribution Statement

All authors conceived of this article, discussed its focus and breadth, and identified the recommendations. S.W.W. led development and writing of the article. All authors provided substantive input on multiple drafts, approved the final article, and agree to be accountable for all aspects of this study.

## Author Disclosure Statement

No competing financial interests exist.

## Funding Information

National Institute of Mental Health (White: R34MH131599), Department of Defense (Klinger: W81XWH-19-1-0825), National Institute of Mental Health (Pugliese: R01MH124772).

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