

Working Together to Improve Community Mental Health Services for Adults on the Autism Spectrum

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 - Judith Miller, PhD

Learning Objectives

- Describe common co-occurring mental health conditions in autistic adults.
- Discuss barriers to autistic adults receiving quality mental healthcare.
- Identify actionable strategies to improve community mental health services for autistic adults.

Note about Language

- Identity-first (“autistic adult”) vs. person-first (“adult with autism”)

AUTISM IN ADULTHOOD
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Avoiding Ableist Language: Suggestions for Autism Researchers

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What does autism mean to you?

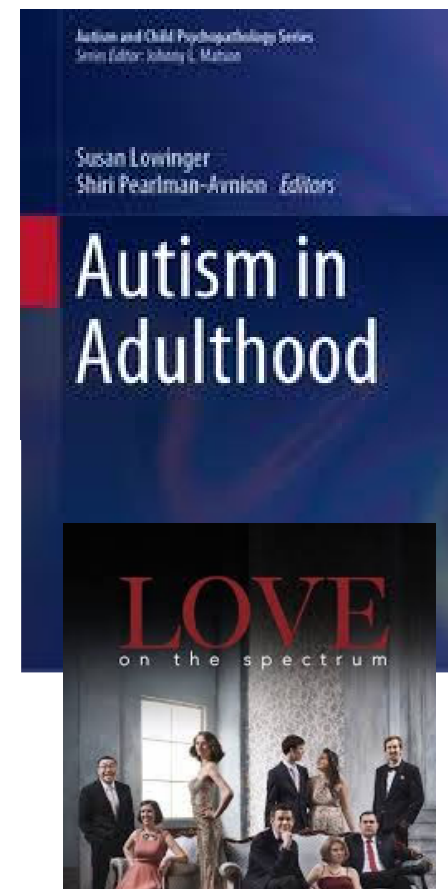
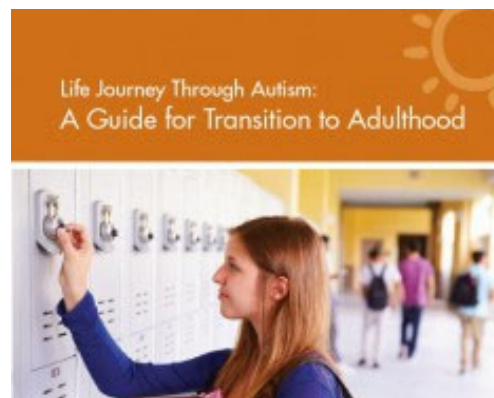


Autistic Adults

- Autism is not only a childhood condition
- In the next decade, over 700,000 autistic teens will enter adulthood
- On average, autistic individuals will spend the majority of their lives as adults



Mandell, 2013; Shattuck, 2019



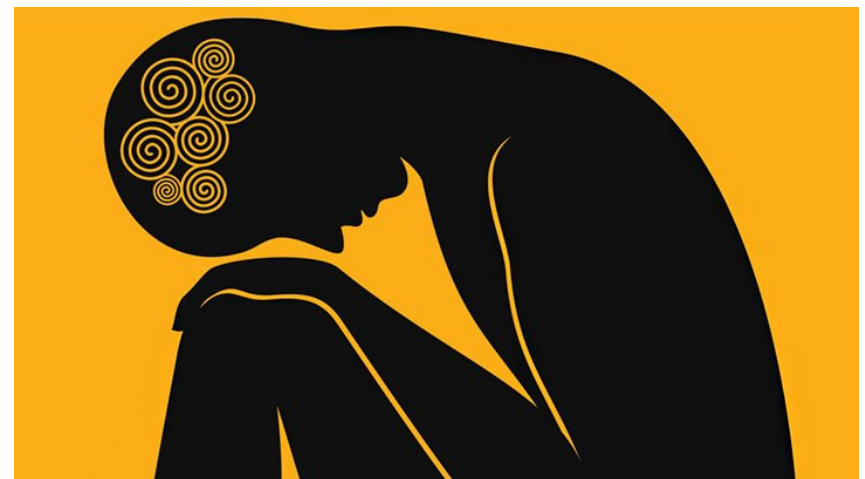
Growing old with autism

For many autistic adults, the golden years are tarnished by poor health, poverty and, in some cases, homelessness. Their plight reveals huge gaps in care.

Participating Organization(s)	National Institutes of Health (NIH)
Components of Participating Organizations	National Institute of Mental Health (NIMH)
Funding Opportunity Title	Services Research for Autism Spectrum Disorders across the Lifespan (ServASD): Pilot Studies of Services Strategies for Adults with ASD (R34)

Co-Occurring Psychiatric Conditions

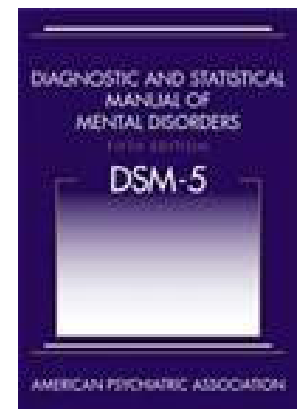
- High rates
 - Particularly anxiety, depression, suicidality
- Significant impairment
- Priority area



Benevides et al., 2020; Cassidy et al., 2014; Croen et al., 2015; Hirvikoski et al., 2016; Hollocks et al., 2019; Frazier et al., 2018; Maddox & Gaus, 2019

Co-Occurring Psychiatric Conditions

- Relatively little attention in autism research until recent years
- Be careful of ***diagnostic overshadowing***!
- Very important to identify behaviors that may respond to specific treatment



Anxiety Manifestations

- Vague statements (e.g., “bad feelings”)
- Inflexibility
- Crying
- Yelling
- Withdrawal
- Unusual phobias
- Avoidance/escape
- Hyperactivity
- Increased repetitive behaviors
- Verbal perseveration
- Irritability, aggression
- Self-injury

Depression Manifestations

- Loss of pleasure participating in or talking about a focused interest
- Refusal to engage in previously motivating activities
- Focus on negative topics
- Decline in self-care
- Regression behavior
- Exacerbated eating, sleep, and/or concentration problems
- Weight changes

Suicide: Potential Warning Signs and Risk Factors

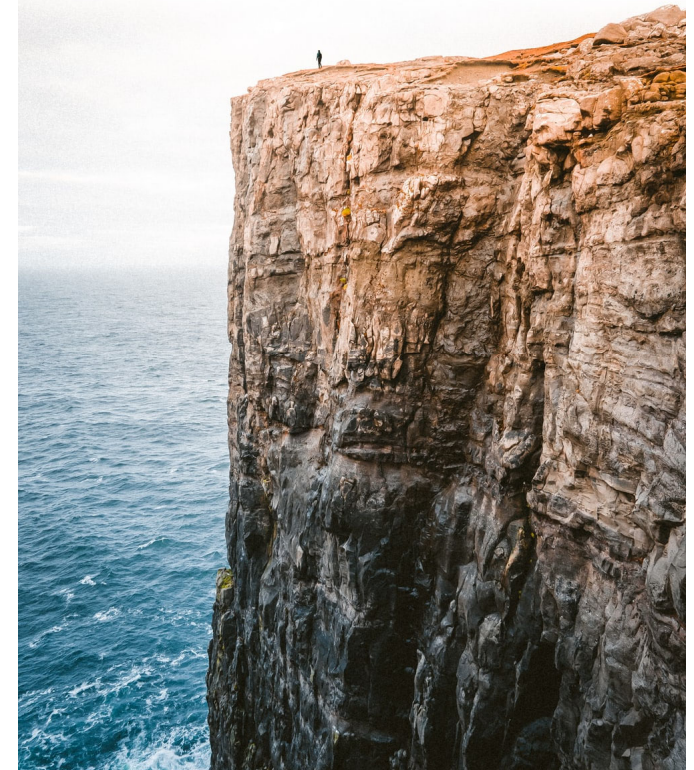
- **Change from baseline**
- Hopelessness
- Withdrawal from friends, family, society
- No reason for living; no sense of purpose in life
- Loss of interest in typical activities, especially restricted interests
- Perseveration around death
- Non-suicidal self-injury
- *Unmet support needs*
- *Camouflaging*

Mental Health and Autism



Services Cliff

- Difficulty accessing treatment after high school
- Negative outcomes of untreated psychiatric conditions



Camm-Crosbie et al., 2018; Maddox et al., 2020; Roux et al., 2015; Shattuck et al., 2011

What are the Barriers to Effective Mental Healthcare for Autistic Adults?

Many clinicians do not feel
confident about working
with autistic adults.

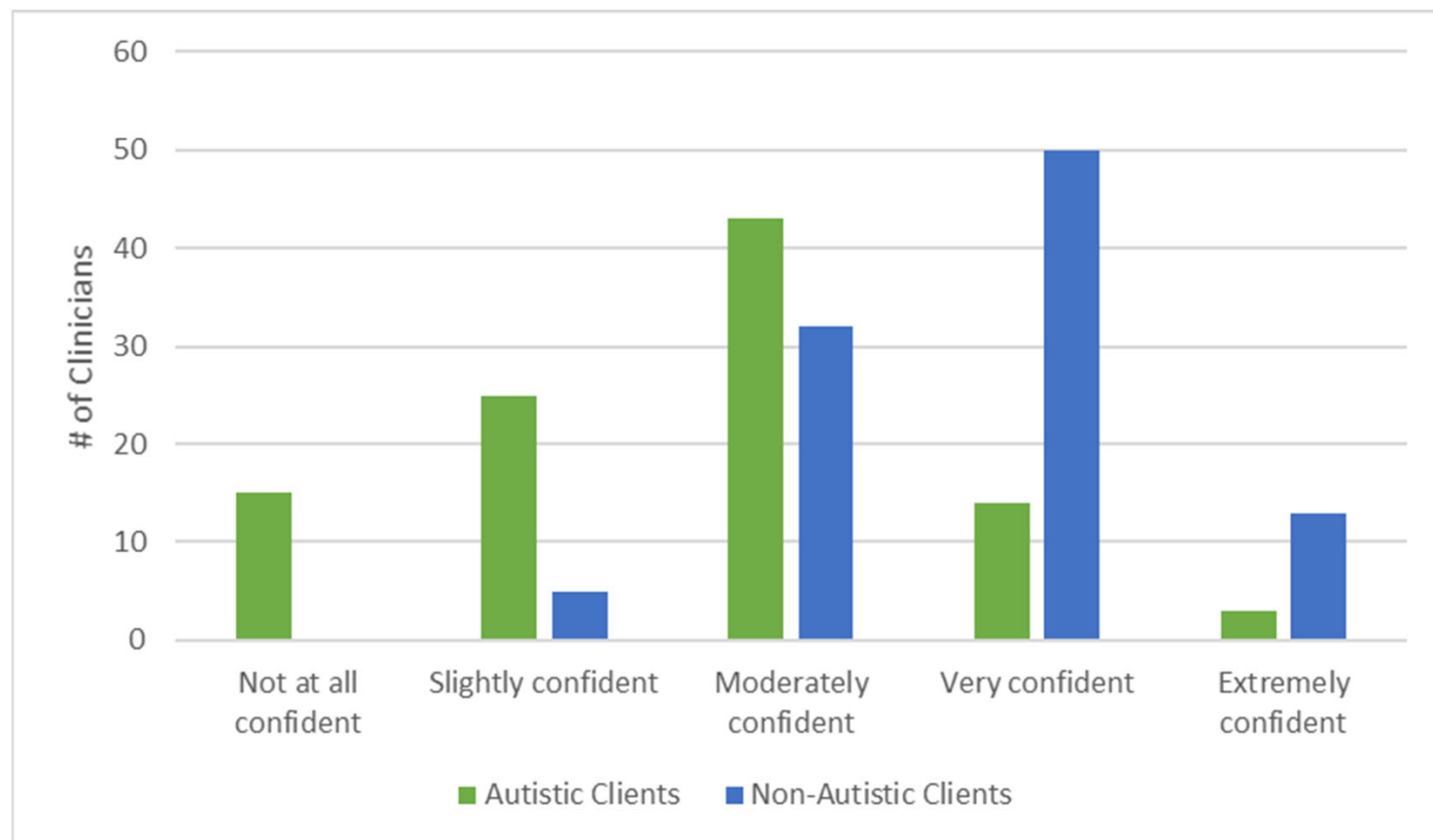
Maddox et al., 2019; Maddox et al., 2020; Zerbo et al., 2015

“I've worked with a lot of diverse populations of all ages, but this is the one area that **I would not feel competent to work with.**”

– Community mental health clinician

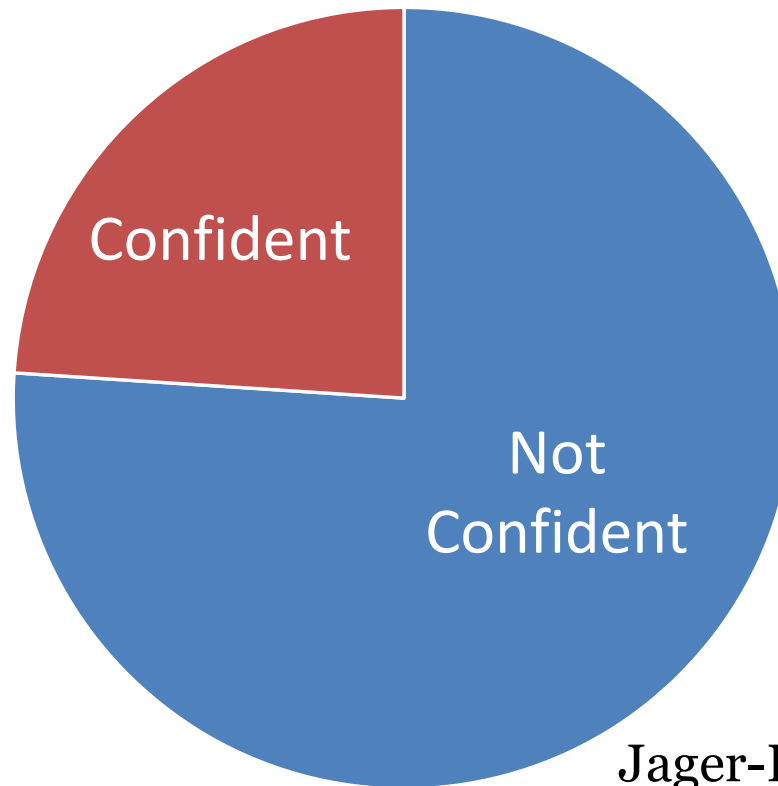
Maddox et al., 2020

Clinicians' Confidence in Treating Anxiety or Depression in Adult Clients



Maddox
et al.,
2019

Clinicians' Confidence in Intervening with an Autistic Client with Suicidality

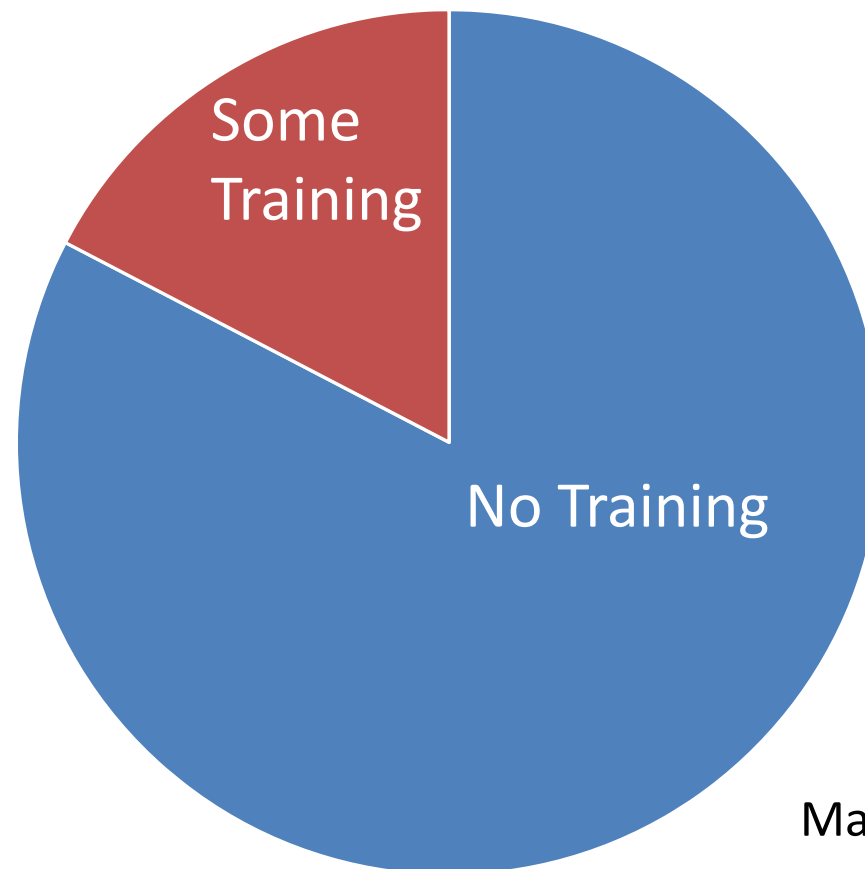


Jager-Hyman et al., 2019

Many clinicians are not
trained to work with autistic
adults.

Camm-Crosbie et al., 2018; Cooper et al., 2018; Lake et al., 2014; Maddox et al., 2019;
Maddox et al., 2020

% of Clinicians with Adult Autism Training



Maddox et al., 2019

“I don’t think I would feel that comfortable [working with autistic adults] because I don’t really have the skills. I don’t see myself helping that person because of my training. **It would be a disservice to that client.**”

– Community mental health clinician

Maddox et al., 2020

“I can't even find therapists who know very much about autism spectrum disorders. So I have to continually be trying to tell them that my needs are not the same and it is a real challenge to sometimes work with these folks [therapists].” – Autistic woman

Maddox et al., 2020

Most evidence-based
practices were not designed
for autistic people in
community mental health
settings.

Brookman-Frazee et al., 2012; Wood et al., 2015

The mental health and
developmental disabilities
systems are disconnected.

Brookman-Frazee et al., 2019; Maddox et al., 2020; Maddox & Gaus, 2019

“I think people are afraid to treat people with autism because they don’t know what to do. I think if clients have anxiety or depression or schizophrenia, then there’s a better road map and they feel better trained to do that. They’re **not trained to deal with people with autism or to manage that. So I think that people are scared to do it.** They don’t know what to do.” – Agency leader

Maddox et al., 2020



A Path Forward

- Evidence-based treatments adapted or tailored for autistic adults
- Feasible and sustainable in community settings
- Training and support for clinicians
- Coordination between mental health and developmental disabilities systems
- **Meaningful partnerships with autistic adults**



Benevides et al., 2020; Frazier et al., 2018; Maddox & Gaus, 2019; Maddox et al., 2020; Pellicano et al., 2014

Recommendations for Clinicians: What Autistic Adults Want You to Know

1. Use Clear and Direct Language

“One of my favorite sayings is **say what you mean and mean what you say**, especially with working with people on the spectrum because we're not going to get the nuances. **So if you don't say it, I didn't hear it.**”

2. Individualize Treatment

“Just know who you’re talking to. Know that a lot of people with autism are very smart and a lot of them have great skills and a lot of them have great potential, and just **figure out how can you specifically tailor to this specific person’s needs and interests.** And how can you make it relatable and memorable. And what’s relatable to him may not be relatable to her and vice versa.”

3. Use Practical, Present-Focused Approaches

“I need, as someone who is in their mid-thirties, to get my life together. So I really don’t wanna go through neurotic stuff from my childhood and things like that. If that’s important for what’s happening right now, then yes, but otherwise I don’t wanna sit around talking about that. **I want you to talk to me about how I can get a job, how to talk to people, those social skills.**”

4. Provide Structure and Predictability

“He very much likes predictability and routine, so he wouldn’t really like to go and then just not know what to expect each time. **He’d like to know that this is what the hour’s going to look like.”**

5. Consider Sensory Issues

“I wanted to take a whole bunch of therapists in the same room, have them close their eyes, and **imagine being bombarded by sensations that they cannot filter out. Just imagine the stress.** You’re trying to concentrate on something and somebody’s whistling or knocking or doing something like that.”

6. Be Comfortable with Silence and Slow Pacing

“It seems like for neurotypical people silence is really uncomfortable and space is really uncomfortable. **It’s something that people with autism need more of.** So just allowing that, whatever it’s for - because you need to process the sensory information or you need to process the messages that you’re getting. Yeah. **Take it slow.** Take it slow.”

7. Focus on Treating the Co-Occurring Conditions

“My therapist is really principally just trying to treat the depression and the anxiety. **He’s trying to treat what he can** because autism, you can’t really treat it.”

Overlap with Recommended Modifications to Cognitive-Behavioral Therapy for Autistic Adults

- Increased use of visual aids
- Simple and direct language
- Extended time period
- Incorporation of focused interests
- Increased involvement of family members
- Accommodation of sensory sensitivities

Toolkit: Crisis Supports for the Autism Community

- <https://suicidology.org/wp-content/uploads/2019/07/Autism-Crisis-Supports.pdf>
- Developed by Lisa Morgan: <https://autism-crisis-support.com/>

Conclusions

Change



Acceptance

Thank you!