

When Autism and Depression Come Together:

What We Know, How to Manage,
and Key Resources

Tuesday, October 26, 2021



About Our Sponsors

- SPARK is a landmark autism research project which aims to make important progress possible. SPARK's mission is simple: we want to speed up research and advance our understanding of autism to help improve lives. Visit sparkforautism.org to learn more.
- The Anxiety and Depression Association of America (ADAA) works to prevent, treat, and cure anxiety disorders and depression through the alignment of science, treatment, and education. Visit ADAA.org to learn more.



Today's Topics



- Recent findings from longitudinal studies

- What we know about mental health disparities in Autistic individuals

- How depression looks different across the lifespan for Autistic individuals

- Factors impacting co-occurring Autism & Depression

- Accessing better supports and increasing access to better treatment for co-occurring Autism & Depression

Housekeeping...

- Purpose is educational content and not to serve as a replacement for therapy
- While we will be speaking about depression, we will not be speaking about suicide
- If you are in a crisis, or you are ever feeling suicidal or unsafe, please go to your local emergency or call the suicide prevention hotline at **800-273-8255**
- Public forum to create a safe and supportive space during Q & A

Why are we are talking about this?

- Autistic children & adults have similar mental health problems as typical children & adults
- Autistic children & adults experience negative factors that can affect health & mental health
- Autistic children & adults experience mental health challenges including Depression at higher rates
- Autistic Individuals can benefit from psychotherapy

Recent findings from the SPARK longitudinal study on Depression and Depression Services

Shuting Zheng, PhD, BCBA
University of California, San Francisco



Motivation for the Study

- Autistic adults are **more likely to experience depression**
- Poor mental health **impedes adults' functioning** in life
- **Evidence for effective depression treatment is limited**
 - Insufficiently treated depression leads to dire consequences
 - Treatment targets need to be identified to address depression
- Little is known about:
 - **How autistic adults with depression are served in the community**
 - **How life experiences are associated with their mental health**

(Au-Yeung et al., 2019; Fombonne et al., 2020; Gotham et al., 2020; Hirvikoski et al., 2020; Hollocks et al., 2019; Hudson et al., 2019; Joshi et al., 2013; Lai et al., 2019; Lugenagaard et al., 2011)

The SPARK Longitudinal Study

- 315 autistic adults (*18-35 years old*) were recruited from **Simons Foundation Powering Autism Research for Knowledge (SPARK)** research match registry
- **Initial online surveys were completed in March 2020**
 - Depression services
 - Mental Health Symptoms: Depression, Anxiety, Stress, Loneliness
 - Life circumstances: e.g., Employment, Social Experiences, Sleep



Depression Diagnosis and Treatment Services

- 47% of adults surveyed scored above clinical cut-offs on depression
 - Majority (83%) of them had been diagnosed with depression
- **Depressed females (91%) were more likely than depressed males (74%) to have received a depression diagnosis**
 - Possible sex biases in screening and diagnosing depression in males

Depression Diagnosis and Treatment Services

- 47% of adults surveyed scored above clinical cut-offs on depression
 - Majority (83%) of them had been diagnosed with depression
- **Depressed females (91%) were more likely than depressed males (74%) to have received a depression diagnosis**
 - Possible sex biases in screening and diagnosing depression in males
- Depression diagnosis and education levels predict who receives depression treatment
 - Diagnosis is the gateway to treatment services
 - Services disparities across socioeconomic status



Depression Service Barriers

- 60 adults reported having experienced barriers to depression-related services, and 54 of them provided open-text responses

Commonly Mentioned Barriers to Depression related services among the Currently Depressed

Themes	Frequency (% out of 54)
Financial and insurance issues	32(59.26%)
Accessibility of care/a good fit	15(27.78%)
Professional's lack of understanding	10(18.52%)
Logistics (e.g., scheduling, transportation)	7(12.96%)
Difficulty describing and explaining feelings	5(9.26%)
Symptoms preventing them from seeking care	5(9.26%)
Side effects, majorly medications	3(5.56%)
Family members' lack of understanding	1(1.85%)

Note: One individual might mention multiple barriers in their responses, and each of those barriers was coded and counted in the frequency table. Thus, percentages add up to more than 100.

Depression Service Barriers

- 60 adults reported having experienced barriers to depression-related services, and 54 of them provided open-text responses

Commonly Mentioned Barriers to Depression related services among the Currently Depressed

Themes	Frequency (% out of 54)
Financial and insurance issues	32(59.26%)
Accessibility of care/a good fit	15(27.78%)
Professional's lack of understanding	10(18.52%)
Logistics (e.g., scheduling, transportation)	7(12.96%)
Difficulty describing and explaining feelings	5(9.26%)
Symptoms preventing them from seeking care	5(9.26%)
Side effects, majorly medications	3(5.56%)
Family members' lack of understanding	1(1.85%)

Note: One individual might mention multiple barriers in their responses, and each of those barriers was coded and counted in the frequency table. Thus, percentages add up to more than 100.

“I originally had a therapist, but since I am unemployed, I could not afford to continue therapy long-term. Especially with my insurance doubling this year, [...], I cannot afford to receive help anymore. I just take my anti-depressants and struggle through it, since I cannot get access to any other helpful sources.”

Depression Service Barriers

- 60 adults reported having experienced barriers to depression-related services, and 54 of them provided open-text responses

Commonly Mentioned Barriers to Depression related services among the Currently Depressed

Themes	Frequency (% out of 54)
Financial and insurance issues	32(59.26%)
Accessibility of care/a good fit	15(27.78%)
Professional's lack of understanding	10(18.52%)
Logistics (e.g., scheduling, transportation)	7(12.96%)
Difficulty describing and explaining feelings	5(9.26%)
Symptoms preventing them from seeking care	5(9.26%)
Side effects, majorly medications	3(5.56%)
Family members' lack of understanding	1(1.85%)

Note: One individual might mention multiple barriers in their responses, and each of those barriers was coded and counted in the frequency table. Thus, percentages add up to more than 100.

“The lack of providers in my area who were willing to treat me and had the time to treat me because there are so many people who need services.”

Depression Service Barriers

- 60 adults reported having experienced barriers to depression-related services, and 54 of them provided open-text responses

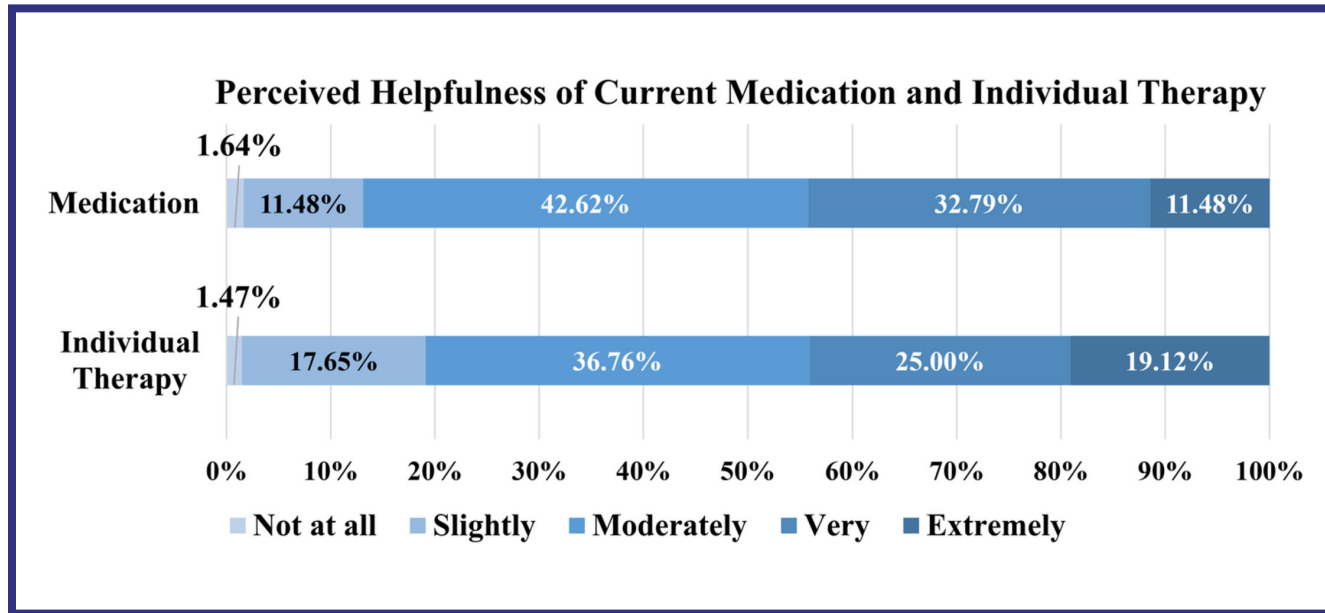
Commonly Mentioned Barriers to Depression related services among the Currently Depressed

Themes	Frequency (% out of 54)
Financial and insurance issues	32(59.26%)
Accessibility of care/a good fit	15(27.78%)
Professional's lack of understanding	10(18.52%)
Logistics (e.g., scheduling, transportation)	7(12.96%)
Difficulty describing and explaining feelings	5(9.26%)
Symptoms preventing them from seeking care	5(9.26%)
Side effects, majorly medications	3(5.56%)
Family members' lack of understanding	1(1.85%)

Note: One individual might mention multiple barriers in their responses, and each of those barriers was coded and counted in the frequency table. Thus, percentages add up to more than 100.

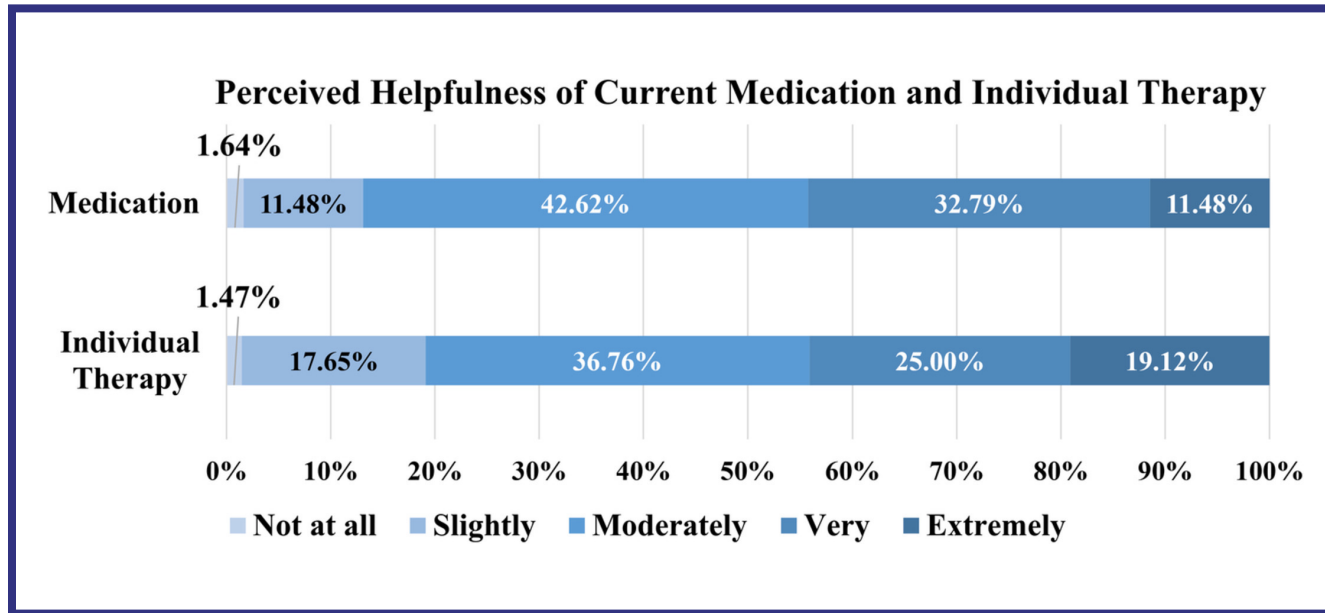
“Most therapy is geared for neuro-normative people. Therapists struggle [to] understand that I am Autistic and what being Autistic means.”

How helpful are Depression Treatments in the Community?



Zheng, S., Taylor, J. L., Adams, R. E., Pezzimenti, F., & Bishop, S. L. (2021). Perceived helpfulness of depression treatments among young adults with ASD. *Autism Research*. <https://doi.org/10.1002/aur.2515>

How helpful are Depression Treatments in the Community?



Adults reported to be in depression treatments for an average of 5-6 years

- Persistent depression & ineffective treatment
- Incompatible with insurance-based care systems and unsustainable with growing needs and limited resources

Changes in Depressive Symptoms over time

- In May 2020, this sample of adults reported **lower** depressive symptom, and anxiety, and loneliness on average
 - However, those who started out with more depression and anxiety symptoms are more likely to experience the negative impact of COVID-19 related distress and difficulties coping with changes.

Changes in Depressive Symptoms over time

- In May 2020, this sample of adults reported **lower** depressive symptom, and anxiety, and loneliness on average
 - However, those who started out with more depression and anxiety symptoms are more likely to experience the negative impact of COVID-19 related distress and difficulties coping with changes.
- In March and July 2021, autistic adults reported increases in stress, and loneliness, anxiety and depression symptom levels were back to baseline.
 - **Large between-individual variability** in patterns of changes over time
 - **Associations between loneliness and depression vary across individuals**

Changes in Depressive Symptoms over time

- In May 2020, this sample of adults reported **lower** depressive symptom, and anxiety, and loneliness on average
 - However, those who started out with more depression and anxiety symptoms are more likely to experience the negative impact of COVID-19 related distress and difficulties coping with changes.
- In March and July 2021, autistic adults reported increases in stress, and loneliness, anxiety and depression symptom levels were back to baseline.
 - **Large between-individual variability** in patterns of changes over time
 - **Associations between loneliness and depression vary across individuals**

Individual differences matter when studying mental health in autism!

What individual factors matter for depression?



- **Feelings about spending too little time with friends or socially**, but not the amount of time spent, are associated with depression;
- **Feelings of Loneliness** mediated the associations between perception of time spent socially and depressive symptoms

Personal needs and feelings matter!

What individual factors matter for depression?



- **Higher levels of mental health symptoms, including depression and anxiety, were associated with the higher likelihood of being fired;**
- **Autistic adults who experienced COVID-19 related job loss/reduction reported higher depressive symptoms in May 2020 than those without an employment change**

Employment Support matters!

Taylor, J., Adams, R., Pezzimenti, F., Zheng, S., & Bishop, S. (Accepted). Job loss predicts worsening depressive symptoms for young adults with autism: A COVID-19 natural experiment. Autism Research.

What individual factors matter for depression?



- **Autistic adults reported high rates of sleep disturbances**
- **Lower sleep efficiency and delayed sleep phase (i.e., sleep after 1am) were associated with higher depressive symptoms.**

Consistent and healthy sleep habits matter!

**Depression service
access and quality need
to be improved!**

**Individual differences
and individual
perceptions matter!**

**It is not just about
Depression; it is also the
larger life contexts!**

**Treatments could
target novel aspects
to promote positive
changes.**

**Final take-aways
from our study**

Health & Mental Health Disparities

Care Access & Impact on Health & Mental Health

High rate of co-occurring health conditions

- May be symptom of depression or exacerbated by depression
-

Lack of expedited health care with providers who know Autism. Costs are:

- Higher mortality rates, Overmedication, **Delays in treatment**, Executive Functioning & Communication Challenges
-

Increased complications upon presentation, Depression/anxiety

Croen (1507) KP study, Burke and Stoddard (Canada) Access, Malik-Soni et al. (2021)

Care Access & Delivery of Care

Siloed Services

Concurrently receiving services from different sectors for different needs (school, mental health, DD)

Lack of Provider training, knowledge & confidence

- Therapists providing outpatient psychotherapy in community indicate that they perceive children with Autism to be particularly challenging to treat
- Research on community providers' knowledge about Autism indicates providers (including mental health professionals) hold a number of inaccurate beliefs about Autism
- One in Fifty-Four = you will see an Autistic person in your office

How Depression Looks Different Across the Lifespan for Autistic Individuals

How Depression looks Different for Autistic Individuals

Autistic individuals are 4x more likely than neurotypicals to experience depression over the course of their lives Rates of depression rise with intelligence and with age

>70% of autistic youth have mental health conditions, including depression and anxiety → often persist or worsen into adulthood

Major depression can severely impair:

- Independence
- Daily living skills (ADL)
- Executive functioning
- Coping Social skills & communication
- Interoception

How Depression looks Different for Autistic Individuals

In Autistics depression may present as restlessness or insomnia

Depression is more likely to present as physical complaints

More likely to present as aggression, self-injury and irritability, weepiness
Also, may experience more paradoxical or negative side-effects from anti-depressants

Self-Injurious Behavior is Different for Autistic Individuals (Non-Suicidal)

Autistics have higher rates of risk factors for non-suicidal self-injurious behavior

- Depression
- Poor emotion regulation skills
- Lack of control
- Interactions with Interoception issues Sensory issues

Suicide talk/provocative talk may be more likely when Autistic individual struggle to be understood

50% reported a history of non-suicidal self-injury

Women with Autism were significantly more likely to endorse non-suicidal self-injury

Maddox, B. B., Trubanova, A., & White, S. W. (2016). Untended wounds: Non-suicidal self-injury in adults with autism spectrum disorder. *Autism*, 1362361316644731.

Factors Impacting Co-Occurring Autism & Depression

Impact of Misdiagnosis, Underdiagnosis & Maltreatment

Diagnostic Trauma: misdiagnoses, partial diagnoses, recommendations not given

- Symptom Severity: Heterogeneity
 - Differing expressions of Autism
-

Impact of misdiagnosis on treatment

Gender, sexual identity, racial and cultural disparities

Diagnostic overshadowing

- Comorbid health conditions that can be conflated with Autism
- Missing co-occurring trauma (single event and chronic)
- Missing other co-occurring mental health conditions
- How internalized ASD might be mislabeled
- How executive functioning difficulties/ADHD might be mislabeled as depression

Impact of Poverty & Challenges of Living Independently ----->

Poverty line for a single adults is **\$11,770**

- Those on SSI: annual income is **\$8,830.84**

U.S. Census: Overall poverty rate is **14.5%**

- Disabled is **28.8%**.

Unemployed & Underemployed *vs Job Supports*

Living Independently:

- **17%** of autistic adults 21-25 ever lived independently compared to **34%** of non-autistics with ID

Other Factors to Consider

Bullying, Isolation & Invalidation vs Radical Inclusion

- **Loneliness is a strong predictor of depression**

Family histories of Autism, Mood disorders, other mental health conditions

More Autistic people identify as gender fluid/expansive, and gender fluid/expansive persons experience higher than typical rates of Autism

Impact of Sleep and Information Processing Differences

Circadian rhythms.
Depression can be thought of as a sleep disorder

Movement & physical activity:
the role of social isolation.
Depression can be thought of as a loneliness disorder

Sensory sensitivities may impact social isolation and distress tolerance & coping

Interoceptive dysregulation may impact on emotion regulation

Emotion Regulation Differences:
Difficulty identifying & expressing experience & thus accessing help, Hyper-arousal & reactivity

Repetitive thinking may create vulnerability for rumination:
Rumination — repetitive behaviors and intensely focused interests, can be detrimental to mental health if that focus turns to sad or undesirable experiences.

Impact of Social Camouflage & Masking

When there are less community resources and safe relationships, the demand is higher

Role of social camouflage & masking: more effortful & labor intensive

Increased risk of suicidality

Accessing better supports and
increasing access to better treatment for
co-occurring Autism & Depression

Recommendations

Tailor screening tools for depression in Autism

Therapists and doctors to get trained & close the knowledge/confidence gap

Ask the autistic person about their symptoms too (vs caregivers)

Research tailored interventions and use them

Individualize treatment- heterogeneity in Autism

Understanding of thinking differences & the concept of double empathy problem

Community & Inclusion

Address other factors- new skills, accommodation, structural changes

Listen to Autistic people- what are their priorities & motivation