Suicide and self-injury in autism: What we know and still need to learn about risk and management

STAR Conference 2023

Caitlin M. Conner, PhD LCP & Ligia Antezana, PhD

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I work with so many amazing people…

That they do not fit on one slide!

Pitt REAACT
Regulation of Emotion in Autistic Adults, Children & Teens
www.reaact.pitt.edu

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- THANK YOU:
  - **All individuals and families who participate in our studies**
  - Local autism groups
  - All staff and colleagues

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outline

I. Autism and…
- mental health
- suicidality
  - Prevalence
  - Differences
  - Risk factors
- self-harm
  - Defining terms
  - Prevalence
  - NSSI as a risk marker
  - Ties to other constructs

II. Assessment and management
- Do's and don'ts
- Warning signs
- Function of behavior
- Safety planning tips

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A note about content

National Suicide Prevention Lifeline:
988 (call or text)

Crisis text line:
text PA to 741741

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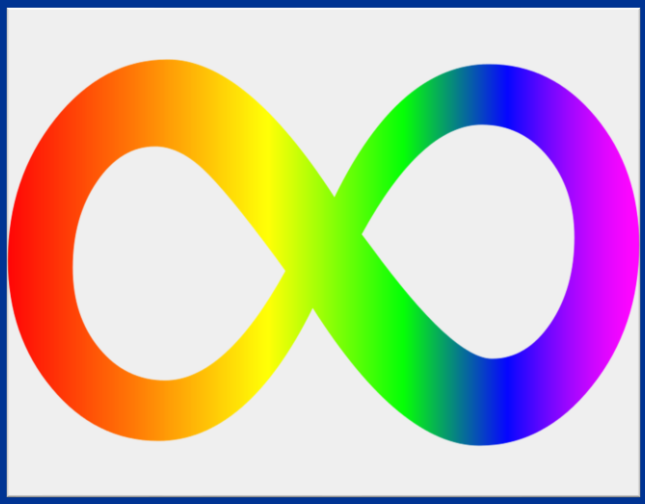
A note on language



Person with autism
vs.
Autistic
vs.
On the spectrum

- Just ask!

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Bottema-Boettal et al 2021; Keating et al., 2022

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Neurodiversity

- Natural variation in our neurology
- Difference is not deficit, not a disease to be cured

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Autism Spectrum & Developmental Disabilities
ABCT Special Interest Group
abctautism.com

Affirming Language Guidelines

The ASDD SIG aims to be a safe space for all members to communicate and collaborate, inclusive of neurotype. The guidelines below center autistic perspectives regarding strengths-based language that is accepting of differences.

Instead of This…	Try This!
Autism Spectrum Disorder, ASD[3]	Autism, autistic (the term "disorder" is unnecessarily medicalized and reinforces negative discourses that autism is wrong or needs to be cured)
Person-first language (e.g., "person with autism" or "person with ASD")[2,4]	Identity-first language (e.g., "autistic person"), on the autism spectrum, formally identified as autistic
High/low functioning; high/low severity or support needs[2]	Describe specific strengths and needs, acknowledge support needs likely vary across domains (e.g., requires substantial support to participate in unstructured recreation activities, but minimal support to complete academic work)
"At risk" for autism or ASD[2]	Increased likelihood/chance of autism/being autistic
Autism symptoms[2] and impairments[3]	Specific autistic characteristics, features, traits, or experiences
Treatment[2]	Support, services, educational strategies (when applicable)
Cure/recovery/optimal outcome[2]	Focus on quality-of-life outcomes that prioritize what autistic people want for themselves
Mild/moderate/severe language difficulties[1]; social communication difficulties[4]	Specify the language difficulties or differences; describe characteristics of autistic communication
Poor reciprocity, monologies, goes off on tangents[4]	Uses longer conversational turns and info-dumps, characteristic of autistic communication style for sharing information and connecting with others
Blunt, abrupt, rude[4]	A direct communicator, uses language efficiently
High-/low-functioning autism, severe autism or severity of autism[1], Level 1/2/3	Descriptions of individual characteristics (e.g., with/without intellectual disability or language impairment) or specific support needs (see above)
Deficit/Weakness[1]	Area of challenge, difficulty, difference
Flat affect[1,4]	Uses neutral facial expressions
Poor/unusual eye-contact[1,4]	Prefers to use reduced levels of eye-contact; eyes move around the room when speaking
Restricted/Special interests[1,2]	Focused, intense, or passionate interests; Areas of interest/expertise
Meaningless/aimless/purposeless play[4]	Preference for parallel play and interaction
Rigid, Inflexible[1]	Preference for sameness and routine; Consider whether is it the autistic individual, the environment around them, or both that is or are inflexible
Stereotyped behaviors[4]	Repetitive body movements or stimming as a form of self-regulation and communication
Aloof and disinterested, on their own agenda, in their own world[4]	Demonstrates a monotropic thinking style characteristic of neurodivergent children; hyperfocused on interests and difficulties shifting attention to less interesting activities; differences in preference for body language and proximity
Challenging behavior/disruptive behavior/problem behavior[1,2]	Meltdown (when uncontrollable behavior), stimming (when relevant), more specific description of the behavior (e.g., self-injurious or aggressive behavior)

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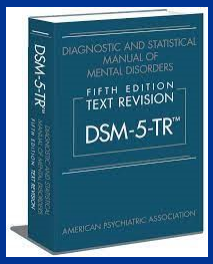
Autism characteristics



Differences in social communication and social interaction across multiple contexts, such as difficulties with:
(need all 3)

1. social-emotional reciprocity (info-dumps)
2. nonverbal communication for social interaction (facial expressions, reduced eye contact)
3. developing, maintaining, and understanding relationships

Restricted, repetitive patterns of behavior, interests, or activities, such as:
(need at least 2 of 4)

1. stereotyped or repetitive motor movements, use of objects, or speech
2. insistence on sameness, preference for routines
3. very focused, passionate interests
4. hyper- or hypo-reactivity to sensory input

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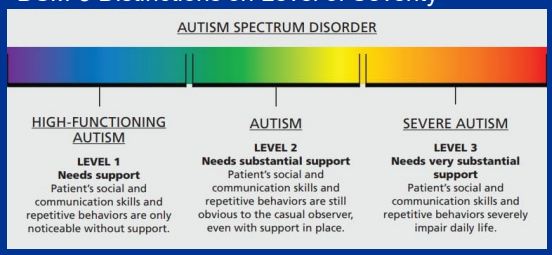
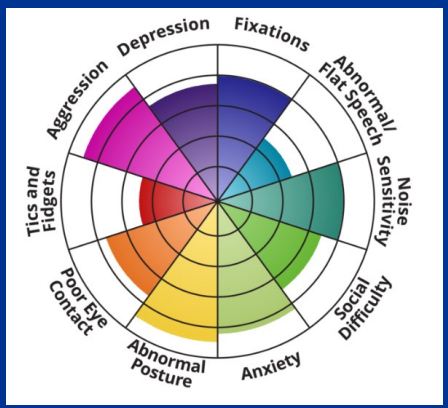
DSM-5 Distinctions on Level of Severity



A more realistic depiction:



The autism spectrum is not linear

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Slide from: Kelly Beck, Jessie Northrup, Elizabeth Rutenberg

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Autistic strengths

- Honest
- Detail-oriented
- Rule-based
- Fair
- Creative
- Adheres to routine
- Subject experts

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Autistic Challenges

- Social situations
- Sensory
- Change/Rigidity
- Perseveration/rumination
- Executive functioning
- Slow processing speed
- Alexithymia
- Sleep difficulties

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Co-occurring mental health in autism

- Child/adolescent
  - 26% ADHD
  - 22% ID
  - 11%/40% anxiety disorders
  - 7%/4-37% disruptive disorders
  - 2% bipolar disorder
  - 2.7%/14-28% depression
  - 1.8%/11% OCD
  - 0.6% psychosis

Mutluer 2022- population-based meta/
White, Maddox, Mazefsky, 2019

- Adult
  - 28% ADHD
  - 20-30% ID
  - 20% anxiety disorders
  - 12% disruptive, impulse control, or conduct disorders
  - 5% bipolar
  - 11%/50%- depression
  - 9%/24%- OCD
  - 4% schizophrenia spectrum

Lai et al 2019- pooled prevalence meta

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A lack of confidence

- Interviews about therapy
  - **20/22** autistic adults reported negative psychotherapy experiences
  - **43/44** community clinicians reported learning nothing about autism in their training
- Community clinicians + safety planning
  - Only **39**% had safety planning experience; **21**% had ever used in ASD

"They'd ask me questions, how you feel about this, how you feel about that, and the harder I thought about it, the more I couldn't figure out what I was feeling like . . That was kind of useless."

-autistic adult on therapy experiences

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Maddox et al., 2019; Jager-Hyman et al., 2020

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Autism and Suicidality

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Prevalence

- Child/adolescents
  - Ideation: **10.9%- 72%** Mayes et al., 2013; Ghaziuddin et al., 1995
- Adults
  - Ideation:
    - **20%** online sample
    - **60%** of newly diagnosed adults (vs. 17% general population)
  - Plan/attempt: **35**% (vs. 2.5% gen pop)
  - Deaths: **0.17%** (vs. 0.11% in gen pop)

Hedley et al., 2017; Cassidy et al., 2014; Kirby et al., 2019

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Risk factors: What's the same

- Co-occurring psychiatric conditions
- Lack of social support
- Social isolation
- Unmet support needs
- Victimization/ trauma
- Impulsivity
- Difficulty with decision making, finding adaptive coping
- Difficulties with executive functioning
- Self-injury

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Cassidy et al., 2018; Hedley et al., 2017, 2018; Kirby et al., 2019; Kõlves et al., 2021; Raymaker et al., 2020

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Risk factors: What's different

Autistic burnout	Camouflaging/ masking	Female	Late diagnosis
• Intense sense of exhaustion • Loss of skills • Tied to emotional outbursts	• Acting 'not autistic' • Trying to act like everyone else • Links to loneliness, depression, and anxiety	• Mixed findings; but autistic females were at particular risk in Utah study	• May be tied to female, masking

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Cassidy et al., 2014; Cassidy et al., 2018; Kirby et al., 2019; Raymaker et al., 2020

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Assessment issues

- Screening questionnaire in adults: 2/4 of items interpreted differently
  - Telling others about SI – less frequently
  - Attempt one day—more frequently
- Our own experience: 1 in 5 of 12-22 year olds
  - Sick and not eating
  - Not eating healthily
  - Repetitive behaviors
  - ideation comments when upset

"have you ever harmed yourself"

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Cassidy et al., 2020; Conner et al., 2020

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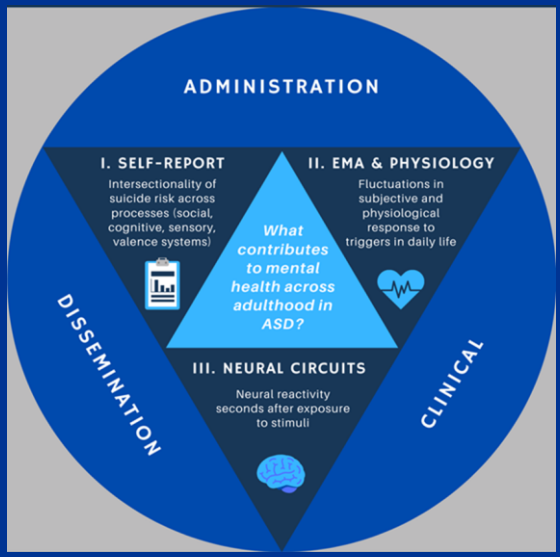
What we're doing: Autism Center of Excellence

300 people, age 18-65, through all of study (200 autistic; up to 50% with suicidality)

700 adults in online-only sample



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Project 1: Self-Report

- Objective:
  To develop and validate a self-report questionnaire (the "Autism Suicidality Inventory;" ASI) that captures a continuum of suicide risk in autistic adults

- Neurotypical suicide measures do not work the same way with autistic individuals

- We need to be able to do more than just determine if safety precautions are needed –
  - *Continuum of risk – "Propensity for Suicide"*
  - Better support research
  - Prevention and support
  - Monitor change in treatment

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Conceptual Model for ASI Items

Domain	Subdomain	Facet
Propensity for Suicidality	Negative Valence	Irritability Low tolerance for negative emotion Perseverative negative thoughts Hopelessness Intolerance of uncertainty and change Perceived victimization Loss of motivationally significant activities
	Positive Valence	Low motivation Anhedonia Emotional numbing Diminished future orientation Low fear of death Agitation/mania
	Cognitive Systems	Negative urgency; Impulsivity/risky behavior Poor emotion regulation; poor problem-solving under stress Black/white thinking Poor information processing, integration, and generalization Low emotional self-awareness Difficulty identifying and communicating the need for help
	Social Processes	Unmet desire for social connection Limited social support Sensitivity to social circumstances (e.g., rejection sensitivity, becoming overwhelmed by social interactions) Lack of group identification (thwarted belonginess) Experience of stigma Widening gap between self and peer group Low self-compassion/acceptance; Masking of own personality Burdensomeness
	Arousal and Regulatory Systems	Reactions to over-stimulation/sensory aversion (intolerable, need to escape) Pain tolerance Chronic pain Low interoceptive accuracy (out of touch with one's own body) Dissociation Poor or atypical sleep

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Self-Harm in Autistic Individuals

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Self-harm, self-injurious behavior, and Nonsuicidal self-injury

- Self-harm
  - "Self-poisoning or self-injury, irrespective of the intent" (Ourgin et al., 2012)
    - Self-harm with suicidal intent
    - Nonsuicidal self-harm
    - Self-harm with unclear intent
- Self-injurious behavior
  - "A class of behaviors, often highly repetitive and rhythmic, that result in physical harm to the individual displaying the behavior" (Fee & Matson, 1992; Weiss, 2009)
- Nonsuicidal self-injury (NSSI)
  - "Deliberate, self-directed damage of body tissue without suicidal intent and for purposes not socially or culturally sanctioned." (Klonsky et al., 2014)

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SIB vs. NSSI

- NSSI in the general population
  - Common topographies include cutting, carving and burning
- Considered distinct from the repetitive and rhythmic self-injurious behaviors typically seen in those with developmental disorders
  - Common topographies include head banging and self-hitting
- The purpose of NSSI has commonly been linked to emotion regulation
- Interpersonal/Social Functions of NSSI
  - Peer Bonding, Revenge, Interpersonal Influence
- Intrapersonal Functions of NSSI
  - Affect regulation, anti-suicide, anti-disassociation

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Prevalence of SIB and NSSI

- There is a breadth of work examining self-injurious behaviors with a strong focus on autistic people with intellectual disability
  - Prevalence ~42% (estimate includes NSSI)
  - Strong link with IQ
  - Most common topographies: hand hitting, skin picking, and hitting self against objects
  - Least common topography: self-cutting
- More recent work has examined NSSI in autistic people without intellectual disability
  - Lifetime NSSI has been reported to be
    - 50%-63.6% in autistic adults, substantially higher than the general population (~15-20%)
    - Autistic women may be more at risk
    - Most common: Severe scratching, cutting, self-biting
    - Least common: Tried to break bones

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NSSI as a risk marker for suicide attempts

- In nonautistic samples, NSSI has commonly been found to be a risk marker for suicide attempts (Nock et al., 2006; Victor & Klonsky, 2014)
  - Greater NSSI frequency
  - Number of NSSI methods
  - Cutting topography
- Emerging area for autism research
  - In mainly late-diagnosed autistic samples, risk markers included
    - Greater NSSI frequency
    - Cutting topogrpahy

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Potential risk markers of NSSI in autistic individuals

- Risk markers for NSSI in autistic adults (Moseley et al., 2019)
  - Greater alexithymia (e.g., difficulty understanding and identifying one's own emotions)
  - Greater depressive symptoms
  - Greater anxiety symptoms
  - Greater sensory sensitivities (e.g., a high response to sensation due to a low neurological threshold, which manifests in distractibility and discomfort)
- Within autistic adults with a history of NSSI (Maddox et al., 2017)
  - Greater difficulty with emotion regulation was significantly related to sensation seeking functions of NSSI

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Assessment and Management

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What you may see

- Sensory difficulties
- Opposite emotions (seems fine, joking)
- Difficulty identifying/verbalizing emotions
- Literal thinking/understanding
- Many misunderstandings/miscommunication with others
- Difficulties with making/keeping friendships/relationships
- Feels isolated from society, disconnected
- Slower processing speed
- Perseveration- getting stuck on negative
- Echolalia (echoed speech), odd tone, pace of speech

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https://suicidology.org/wp-content/uploads/2019/07/Autism-Crisis-Supports.pdf

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Do's and Don'ts

- Be direct, use few words
- No metaphors or idioms--- e.g., "I'm with you"
- More direct questions than emotion words- "what happened next," not "how do you feel?"
- Allow extra time to respond

- Ask about interests that they want to talk about
- Explain the purpose of distraction strategies
- More support in making a safety plan

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Things to consider

- Presence of a risk factor vs. Change for that person's normal
  - Anxiety
  - Sleep issues
  - Self-harm
  - Presence of interest in death-related topics
  - Distress from sensory or social situations
  - Withdrawing from people
  - Big shifts in mood
  - Explosive outbursts/meltdowns/anger

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https://suicidology.org/wp-content/uploads/2020/12/Autism-Warning-Signs-3.pdf

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Warnings signs

These warning signs are contingent upon a **marked increase or change** of specific experiences or behaviors that are different than usual for that individual. Often more than one warning sign would be present in an autistic individual at imminent risk of suicidal behavior.

1. Sudden or increased withdrawal
2. No words to communicate acute distress
3. Current traumatic event, reported by self or others
4. Marked increase in rate and/or severity of self harm
5. Worsening in levels of symptoms of anxiety and/or depression
6. A new focus on suicidal talk, ideation, or death-related topics that are not a special interest
7. Perseverative suicidal thoughts and ruminations
8. Seeking means or making plans for suicide or suicide rehearsal
9. Statements about no reason for living or no sense of purpose in life
10. Hopelessness

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https://suicidology.org/wp-content/uploads/2022/11/Warning-Signs-Resource-Sept-2021-1.pdf

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Self-harm/NSSI vs. SIB

- Can be tricky to figure out
- What's the function?
  - When/where does it happen
  - History of behavior?
- Chain analysis (DBT)

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Safety planning considerations

- May need more direction
- Short, specific instructions
- Visual aids
- Be mindful of emotion recognition to id crisis
- Coping strategies that are mindful of sensory needs

  Schwartzman et al 2020

- **Watch this space**: 2 current grants

pcori PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Research In progress; Not yet recruiting

Comparing Two Ways to Prevent Suicide among Autistic Youth

STUDY PROTOCOL Open Access

Adapted suicide safety plans to address self-harm, suicidal ideation, and suicide behaviours in autistic adults: protocol for a pilot randomised controlled trial

Jacqui Rodgers[1*], Jane Goodwin[1], Emma Nielsen[2], Nawaraj Bhattarai[3], Phil Heslop[4], Ehsan Kharatikoopaei[5], Rory C. O'Connor[6], Emmanuel Ogundimu[7], Sheena E. Ramsay[1], Katie Steele[8], Ellen Townsend[9], Luke Vale[3], Emily Walton[8], Colin Wilson[1] and Sarah Cassidy[9]

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Thank you!

Any Questions?

Email me: connercm2@upmc.edu

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