

An abstract graphic on the left side of the slide. It features a vertical gradient bar transitioning from brown at the top to green at the bottom. To the left of this bar, there are several overlapping, semi-transparent shapes in various colors including orange, red, blue, and green. These shapes are mostly rounded rectangles and circles, some of which are tilted at an angle. The overall effect is a layered, colorful composition.

“Who says a meltdown is a bad thing?”

Analyzing participant feedback on a
communication tool for meltdowns &
shutdowns

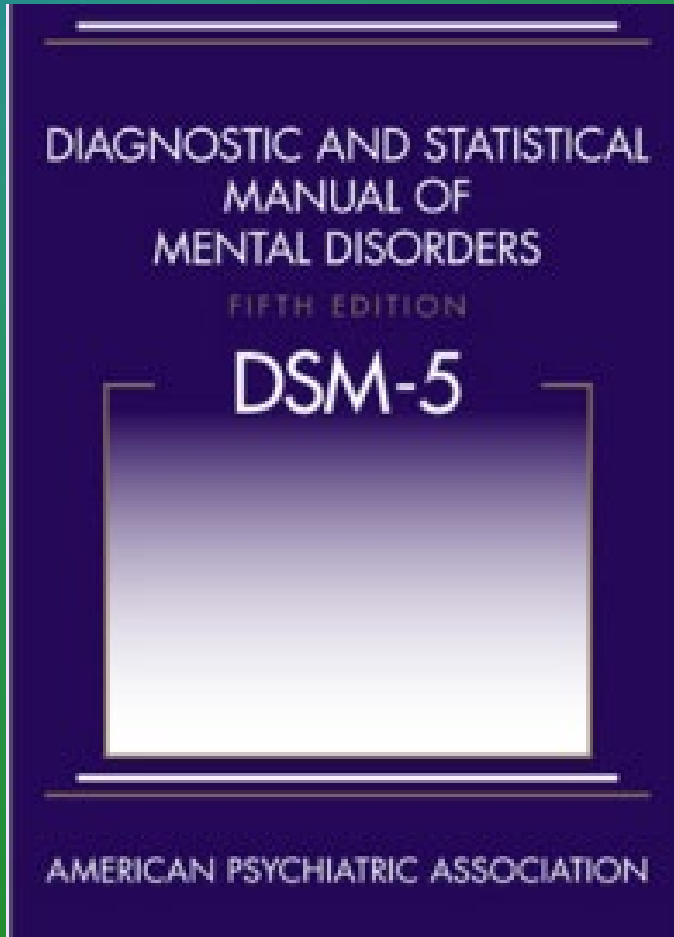
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Autism



- According to the DSM-5:
 - “Persistent deficits in social communication & social interaction”
 - “Restricted, repetitive patterns of behavior, interest, or activities”
- In 2021: 1 in 44 individuals are autistic¹
- As common in adults as in children¹
- Frequently associated with disability

Shifting Lens of Disability

Her **impairment** is the problem!
They should cure her or give her prosthetics.

The *medical model* of disability



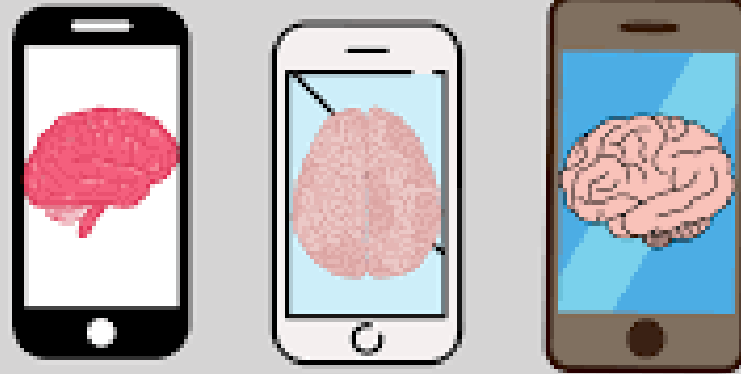
The **stairs** are the problem!
They should build a ramp.

The *social model* of disability

Image by UAA: <http://www.uaa.alaska.edu/accessibility/topic/architecture.cfm>

Neurodiversity Movement

Different brains also have names.
There is Neurotypical, Autistic and
ADHD (plus more)



All these brains have their own way of
doing things. One isn't better than the
other, they are different.

@more than one neurotype

Ableism

“a set of beliefs or practices that **devalue and discriminate** against people with physical, intellectual, or psychiatric disabilities and often **rests on the assumption that disabled people need to be ‘fixed’** in one form or the other”

Common Feature of Autism: Autistic Meltdowns & Shutdowns

- Loss of control of behavior
- Occurs in response to overwhelming stimuli & dysregulation

Meltdowns³⁻⁵

- Appear similar to “temper tantrums”
- Common characteristics:
 - Crying
 - Screaming
 - Hitting
 - Kicking
 - Self-injurious behavior

Shutdowns³⁻⁴

- Appear similar to catatonia
- Common characteristics:
 - Nonverbal
 - Immobile
 - Unable to perceive or respond to surroundings

Our Goal

To develop a communication tool that providers could use to talk to autistic patients about their meltdowns & shutdowns & assess for potential safety risks

MSSAA: Meltdown & Shutdown Scale for Autistic Adults

- Developed based on qualitative interviews with autistic adults about their experiences having meltdowns ($n = 32$) and shutdowns ($n = 26$)
- Pilot version:
 - 65 items to measure conceptual constructs across 14 dimensions, each rated on a 5-point Likert-type scale to indicate level of agreement
 - 10 additional items to capture:
 - Preferred terms for meltdowns & shutdowns
 - Frequency, typical length, & typical recovery time
 - Perceived impact on overall wellbeing

Example of Developing Items

Dimension	Conceptual Construct	Participant Quote	Pilot Item
Cognitive changes	Loss of sense of time	“Shutdowns are like if your computer crashes and you’re stuck on the blue screen of death for hours before rebooting.”	I feel stuck, like when a computer crashes and takes a long time to start up again.
Inhibited ability to respond	Lack of social energy	“I couldn’t muster the energy to make conversation anymore, didn’t want anything to drink, and didn’t want to be there anymore.”	It is difficult for me to muster the energy to make conversation.

When I am experiencing a *meltdown*, on the inside, I think...

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I am unable to calm down or remove myself from the situation.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have no control over myself or my emotions, as if I'd just tripped myself and started rolling down a hill.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Research Question

Is the MSSAA an effective tool to capture key information about stress responses among autistic adults?

Method Plan

- **Qualitative strand:**
 - Explore understandability & acceptability
- **Quantitative strand:**
 - Explore initial psychometric properties

Target sample size ~300 participants

- Recruited via online autistic spaces (e.g. Facebook, Reddit, Wrongplanet) & word of mouth
- Inclusion criteria: 18+ years, self-identified as autistic



Reached saturation early...

Unexpectedly stopped data collection
after only **54 responses**

Research Question

Is the MSSAA an effective tool to capture key information about stress responses among autistic adults?

NO.

New Research Purpose

To understand *why* the MSSAA
was problematic

Methods

- Reflexive Thematic Analysis
 - Braun & Clarke⁶
- Allowed us to explore **semantic-level themes** (e.g. what did they say) **AND latent-level themes** (e.g. why did they say that?)
- Used a relativist lens

Steps of Reflexive Thematic Analysis

1. Becoming familiar with the data
2. Generating initial codes
3. Constructing themes
4. Reviewing potential themes
5. Refining, defining, & naming themes
6. Producing the report

Sample ($n = 54$)

- Age: 18-69 years ($M = 36.4$, $SD = 13.2$)
- Gender:
 - 56.5% female
 - 23.9% male
 - 19.6% agender, gender fluid, non-binary
- Diagnosis:
 - 69.6% formally evaluated & diagnosed
 - 17.4% told by a health professional they are likely autistic
 - 13% self-diagnosed
- Race: 87% White
- Five countries represented, mostly USA



Results: Theme 1

It is the premise of the scale, not necessarily its execution, that is most problematic

Results: Theme 2

*This is an adaptive response to stress,
not a maladaptive response*

Results: Theme 3

*Using person-first language is akin
to using a racial slur*

Results: Theme 4

Differentiating between internal and external responses is arbitrary

Results: Theme 5

*It is important to offer different ways
to share information*

Results: Theme 6

Safety in discussing this is all about the context of the relationship, not the structured prompt

Implications

- Importance of participatory action approach
- Next steps:
 - Explore relationships between autistics & health care professionals to understand what makes safe space for disclosure
 - Education to health care professionals about ableist micro-aggressions
- Limitations:
 - No ability to ask follow-up questions or gather contextual information
 - Recruitment strategy targeted a group with a shared view of autism
 - Lack of diversity in race/ethnicity of sample

Selected References

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Questions?

