

# Autism & Suicide: From Epidemiology to Personal Accounts

ANNE V. KIRBY, PHD, OTR/L  
ACT WORKSHOP-APRIL 2024



# Disclosures

- Research funding from:
  - National Institutes of Health (KL2 TR001065)
  - National Institute of Mental Health (K23 MH123934)
  - *The content is solely the responsibility of the author and does not necessarily represent the official views of the NIH.*
- I have no personal financial relationships to disclose

# Terminology

- **Suicide (Suicide Death)**

“death caused by self-directed injurious behavior with intent to die as a result of the behavior”

- **Suicide Attempt**

“non-fatal, self-directed, potentially injurious behavior with intent to die as a result of the behavior”

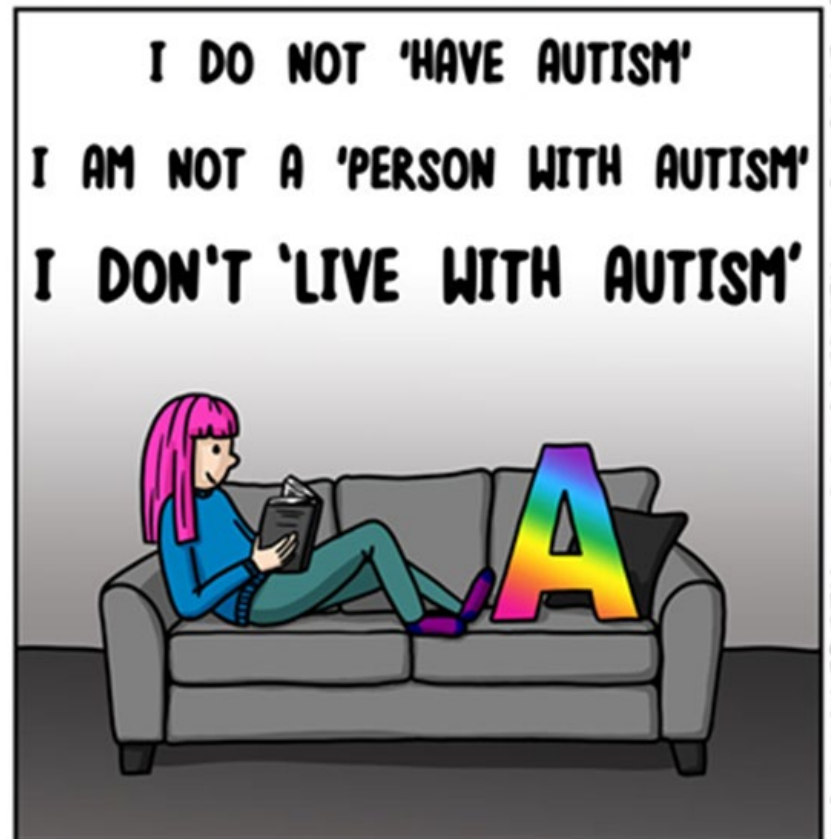
- **Suicidal Ideation**

“thinking about, considering, or planning suicide”

# Language Use

<b>Person-first</b> Child with autism Adult with ASD	<i>This is typically taught to <u>professionals</u></i>
<b>Identity-first</b> Autistic people Autist	<i>This is preferred by many <u>self-advocates</u></i>
<b>Other</b> Youth on the autism spectrum	<i>This is sometimes seen as a <u>neutral in-between</u></i>

(Kenny et al., 2016)



©BETH WILSON 2017 ☆

# Background

- Suicide is a leading cause of death in the autistic population
- Suicidal thoughts, actions, & attempts are highly common
  - Suicide risk affects autistic people of all genders, all racial & ethnic backgrounds, and across the lifespan
- Research on suicide risks and prevention is a top priority of autistic community members

(Hirvikoski et al., 2016; Benevides et al., 2020; Blanchard et al., 2021)

# STUDY ONE: Epidemiological Approach

- Using administrative data from the Utah Registry of Autism and Developmental Disabilities, Utah Office of the Medical Examiner, Utah Population Database, and Utah Department of Health, we conducted a **20-year study**
- **49 individuals** in Utah who died from suicide between 1998 - 2017 had autism diagnosis in records
- Compared to whole Utah population

# Suicide Incidence

- Increases in incidence over time
- Significantly higher in autism group in 2013-2017

Years	ASD	Non-ASD	Relative Risk
1998 – 2002	0.04%	0.08%	0.46
2003 – 2007	0.06%	0.09%	0.66
2008 – 2012	0.10%	0.11%	0.95
<b>2013 – 2017</b>	<b>0.17%</b>	<b>0.11%</b>	<b>1.56*</b>
Male	0.16%	0.16%	1.01
<b>Female</b>	<b>0.17%</b>	<b>0.05%</b>	<b>3.42*</b>

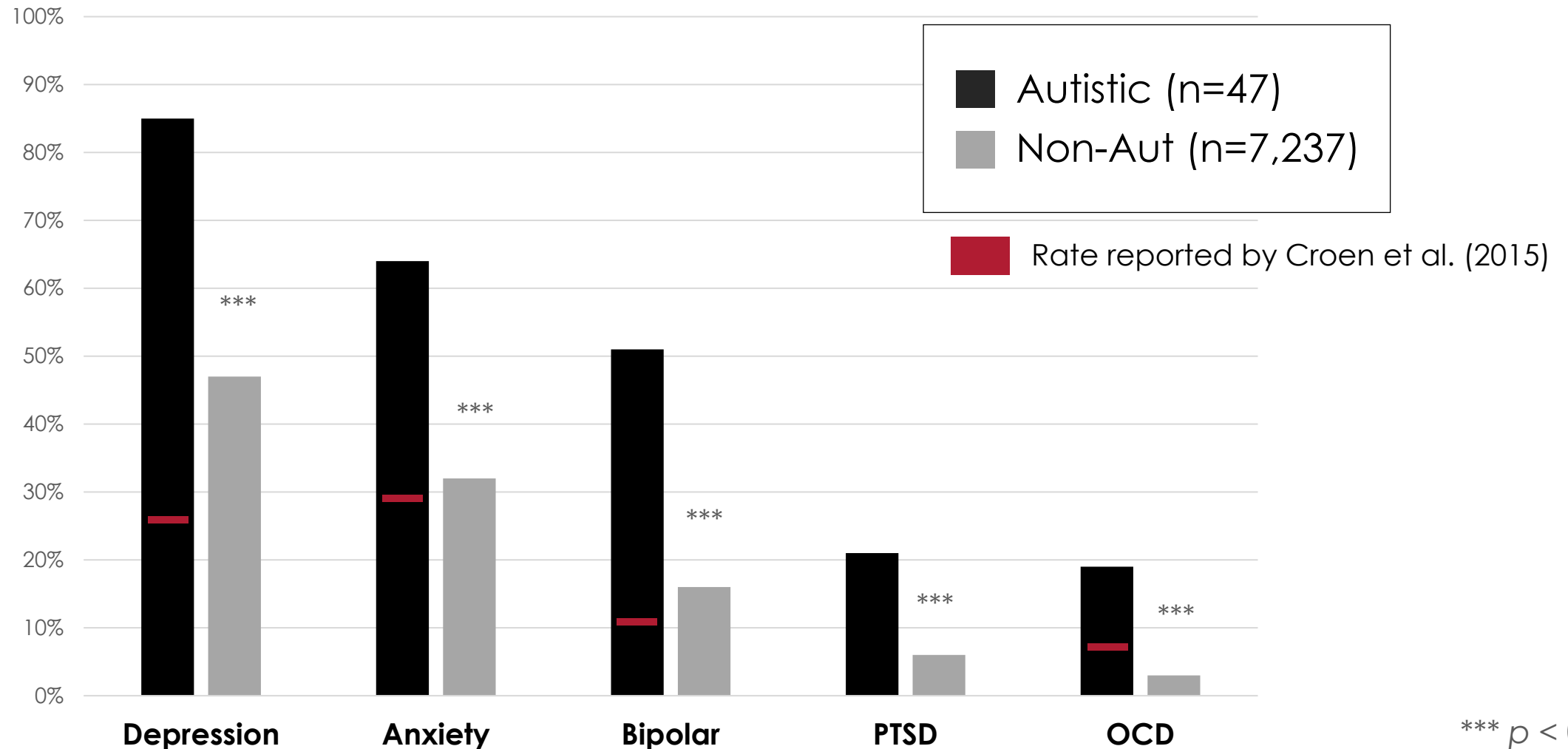
**Table 3. ASD + Suicide Case Characteristics, Total and by Sex**

	Total N = 49	Male N = 42	Female N = 7
Age at Death (years)			
Range	14–70	14–70	16–43
Mean (SD)	32.41 (15.98)	32.85 (16.75)	29.72 (11.64)
Median	27	26.40	29.96
Marital Status			
Married	6 (12%)	5 (12%)	1 (14%)
Never married	24 (49%)	23 (55%)	1 (14%)
Other	5 (10%)	3 (7%)	2 (29%)
Missing	14 (29%)	11 (26%)	3 (43%)
Occupation			
Student	12 (24.5%)	11 (26.2%)	1 (14.3%)
Employed	12 (24.5%)	11 (26.2%)	1 (14.3%)
Did not work	5 (10.2%)	3 (7.1%)	2 (28.6%)
Missing	20 (40.8%)	17 (40.5%)	3 (42.9%)
Method of Suicide <sup>b</sup>			
Violent	36 (73%)	30 (71%)	6 (85.7%)
Nonviolent	13 (26%)	12 (29%)	1 (14.3%)



# Co-occurring conditions were common

*\*preliminary data*



# Epidemiological Conclusions

- Our Utah research found growth in autistic suicide risk over time. Updated study needed with more recent years.
- Other epidemiological studies have found even more substantial elevations in risk compared to non-autistic pop.
- Autistic males and females have similar risk of suicide
  - Mixed findings related to reporting suicidal thoughts & actions
- Significant elevations in co-occurring conditions are important to pay attention to, but do not explain the risk.

(Chen et al., 2017; Hirvikoski et al., 2016; Kirby et al., 2024)

# STUDY TWO: Personal Accounts

- In-depth interviews to gather the perspectives of:
  - autistic adults with a history of suicidality + mental health providers + family members **(N=38)**
- Using community based participatory research (CBPR) in partnership with autistic adults (through AASPIRE)


# AASPIRE Organization



- Conducts Community-Based Participatory Research (CBPR) to work on topics important to the community since 2006
- Suicide Prevention Project (SPP) team formed in 2022
- 7 autistic team members from multiple U.S. states
  - Community partners are paid for their time and expertise
- Meet over Zoom 1-2x/month

Recording...

# SUICIDE PREVENTION PROJECT TEAM



Rachel Kripke-Ludwig



ANNE V. KIRBY (she/her)




Kristina Feldman (she/her)



Zack Siddeek (He/Him)



Kayla Rodriguez (she/her)



Whitney Lee



Bobbi Duncan-Ishcomer (they/the...)



Frank Vales



ALISSA M ATISME



Andee Joyce

**Ai-Media Capti...**

Ai-Media Captioner April

# Preliminary Results *(Currently finalizing the qualitative results!)*

## **What experiences influence suicidality for autistic people?**

- Societal Pressure to Conform to Neurotypical Expectations
- Daily Life Challenges
- Social Exclusion and Marginalization
- Traumatic and Disruptive Life Events
- Lack of Accessible or Helpful Supports
- Difficulty with Emotions & Thought Patterns

*“I'd say probably the number one thing that researchers should know about autism and suicide is that **it's the rule rather than the exception.**”*

*If an Autistic adult isn't suicidal then they probably are doing things to push it out of their mind because it's pretty much always there **because we are constantly rejected.**”*

*And I'd say that's true especially of queer and trans Autistic folks and Autistic folks of color. That's no exception for me.”*

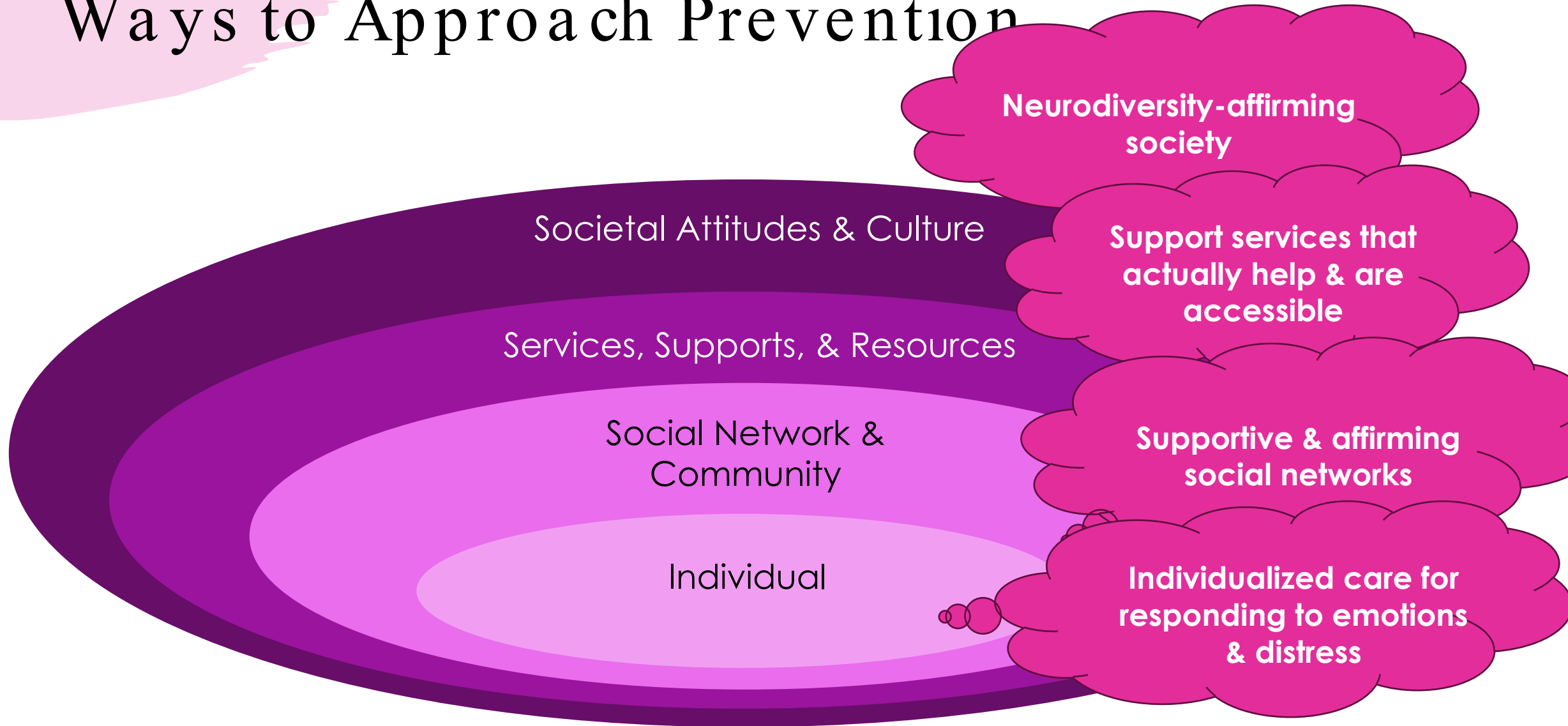
# Preliminary Results *(Thematic qualitative analysis is ongoing)*

## What are important implications for practice?

- Suicidality can onset in childhood and persist in older adulthood
  - Often, recurrent suicidal thinking, actions, and attempts
- Unmet needs require support, including:
  - practical (e.g., concrete support for managing life challenges)
  - social (e.g., people who can listen, understand, & validate their experiences)
- Need to address related issues, e.g., co-occurring mental health Dx's, trauma, unaccommodating environments, and burnout

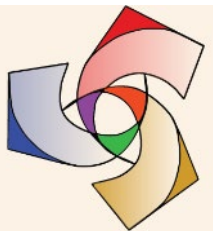


# Ways to Approach Prevention



# Thank you

anne.kirby@hsc.utah.edu  
X: @avkirbyPhD



Academic Autism  
Spectrum Partnership  
in Research and  
Education

Google scholar:

