SPARK
Simons Powering Autism Research

MUSC Health
Medical University of South Carolina
Changing What's Possible

Comparative analysis of autistic women across the lifespan: Childhood vs. adulthood diagnosis



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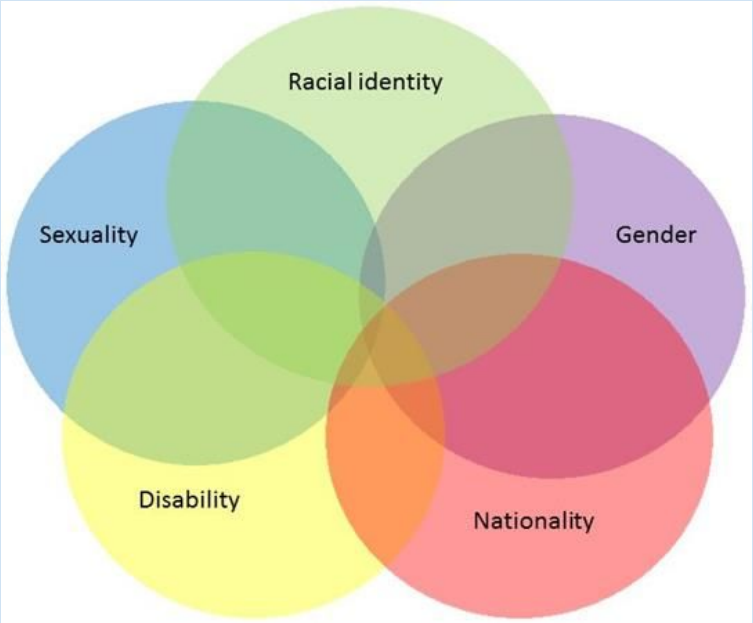
Presentation Themes



Intersectionality

a. Approaching research question from a framework which explores how overlapping identity features influence experience
b. Evaluate the way systems of discrimination and exclusion have influenced these experiences in research and clinical realms
c. What challenges do we run into, even when we, as researchers, set out with a goal of producing equitable research?

*A note on language: I aim to use identity-first throughout my presentation, in line with current research into the preferred language of the autistic community.



Crenshaw, K. (1989).
Schuck et al., 2025

Autism and the Lifespan

- *Age of diagnosis* is often used as a proxy for healthcare access in research literature

- Research and clinical focus has been on children
- Existing literature indicates increased psychiatric and medical care needs across the lifespan
- Growing interest in research in transition to adulthood
  - What challenges might people face? What strengths are they bringing?



(Baldwin and Costley 2016; Daniels and Mandell 2014;
Malow et al., 2023 Russell et al. 2025).

Autistic Women and Girls

Limited research due to patterns of exclusion

- Genetic research
- Intellectual disability
- Sample Sizes
- Delays in diagnosis

Findings currently indicate:

- Masking/connection to mental health
- Increased sensory concerns and repetitive play
- More complex interpersonal relationships
- Increased complexity of relationship with gender identity



(Baldwin & Costley, 2016; Bargiela et al., 2016; Diemer et al., 2023, Green et al., 2019, Kanfiszer et al., 2017)

Our Data



- Simons Foundation SPARK data; (n = 50,000+)
  - Autism Research Initiative with national collaboration
  - Genetics, family, and medical/behavioral measures
- Large secondary datasets can help address some challenges related to systemic inequities
  - Pros: Big sample, fewer recruitment challenges, tends to improve diversity of sample
  - Cons: Missing data, working within choices made by others
- Adult Female SPARK data
  - SPARK is trying to understand the representativeness and skew in this sample
  - SPARK is noting an increase in female participation in autism research

Current Study Aims



- Tell a **strengths-based** story about autistic adult women
  - Characterize the sample through detailing demographics, describing family and relationships, education, employment, and income; measuring mental well-being, and co-occurring psychiatric conditions and symptoms.

- Investigate differences between those **diagnosed in adulthood vs. childhood**
  - Different life experiences
    - Early intervention, Educational supports, and Identity
  - Different symptom presentation and co-occurring conditions?

(Baldwin & Costley, 2016; Bargiela et al., 2016; Green et al., 2019)

Participant Demographics

n = 1424

- 37 trans women, all other AFAB**
- 285 non-binary

Limited overlap in data between independent and under guardianship adults

- *22% of original sample of autistic women was under guardianship*

Lack of racial diversity in sample

- 91.99% identify as white, 4.84% identify as Black, 8.00% identify as Hispanic and 8.00% identify as more than 1
- Limitations (generalizability)
- SPARK is focused on recruitment of minoritized racial groups, but combined adult recruitment challenges remain

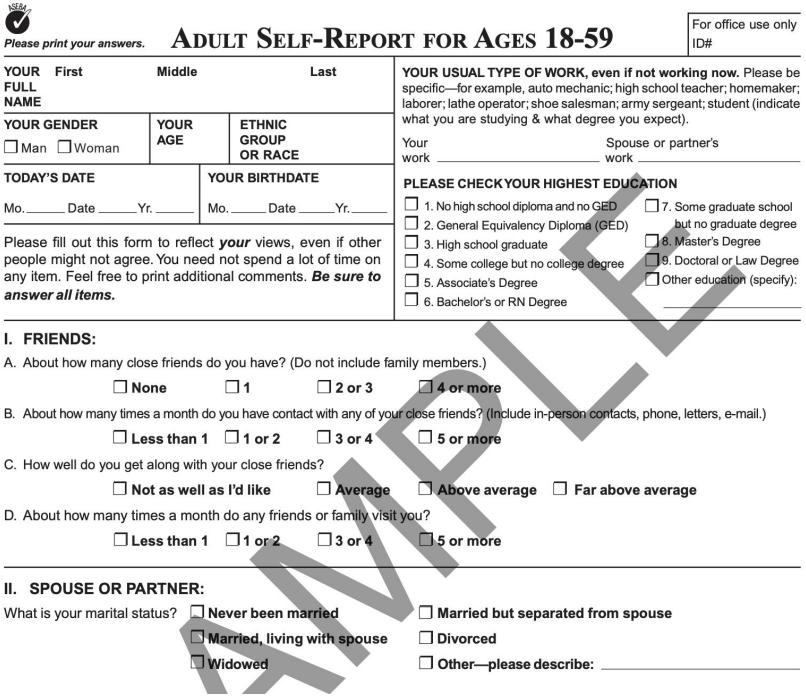


**Assigned female at birth

Measures

1. SPARK Background History and Basic Medical Screening

2. Adult Self Report
   a. Part of the CBCL Family of measures (Achenbach and Rescorla, 2003).
   b. 3 point comprehensive rating scale
   c. Reporting on psychiatric symptoms, relationship health, and employment questions



Please print your answers. **ADULT SELF-REPORT FOR AGES 18-59**

For office use only
ID#

YOUR FULL NAME First Middle Last

YOUR GENDER ☐ Man ☐ Woman

YOUR AGE

ETHNIC GROUP OR RACE

TODAY'S DATE Mo.____ Date____ Yr.____

YOUR BIRTHDATE Mo.____ Date____ Yr.____

Please fill out this form to reflect ***your*** views, even if other people might not agree. You need not spend a lot of time on any item. Feel free to print additional comments. ***Be sure to answer all items.***

YOUR USUAL TYPE OF WORK, even if not working now. Please be specific—for example, auto mechanic; high school teacher; homemaker; laborer; lathe operator; shoe salesman; army sergeant; student (indicate what you are studying & what degree you expect).

Your work _____ Spouse or partner's work _____

PLEASE CHECK YOUR HIGHEST EDUCATION

☐ 1. No high school diploma and no GED
☐ 2. General Equivalency Diploma (GED)
☐ 3. High school graduate
☐ 4. Some college but no college degree
☐ 5. Associate's Degree
☐ 6. Bachelor's or RN Degree
☐ 7. Some graduate school but no graduate degree
☐ 8. Master's Degree
☐ 9. Doctoral or Law Degree
☐ Other education (specify): _____

I. FRIENDS:

A. About how many close friends do you have? (Do not include family members.)
☐ None ☐ 1 ☐ 2 or 3 ☐ 4 or more

B. About how many times a month do you have contact with any of your close friends? (Include in-person contacts, phone, letters, e-mail.)
☐ Less than 1 ☐ 1 or 2 ☐ 3 or 4 ☐ 5 or more

C. How well do you get along with your close friends?
☐ Not as well as I'd like ☐ Average ☐ Above average ☐ Far above average

D. About how many times a month do any friends or family visit you?
☐ Less than 1 ☐ 1 or 2 ☐ 3 or 4 ☐ 5 or more

II. SPOUSE OR PARTNER:

What is your marital status? ☐ Never been married ☐ Married but separated from spouse ☐ Married, living with spouse ☐ Divorced ☐ Widowed ☐ Other—please describe: _____

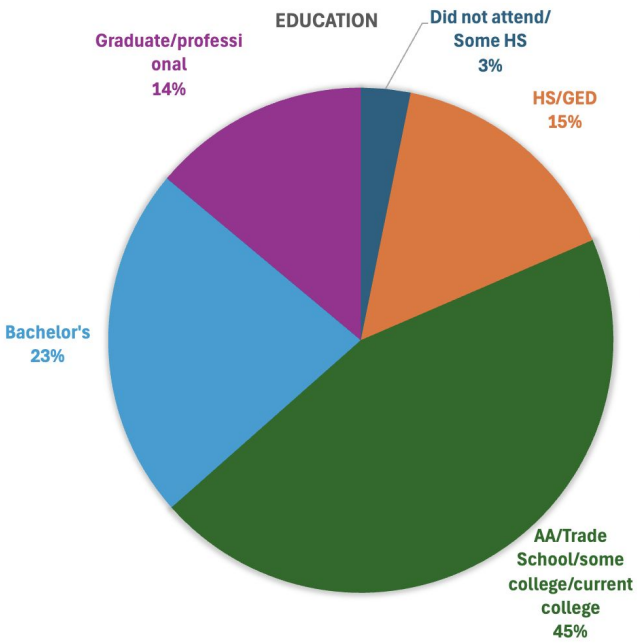
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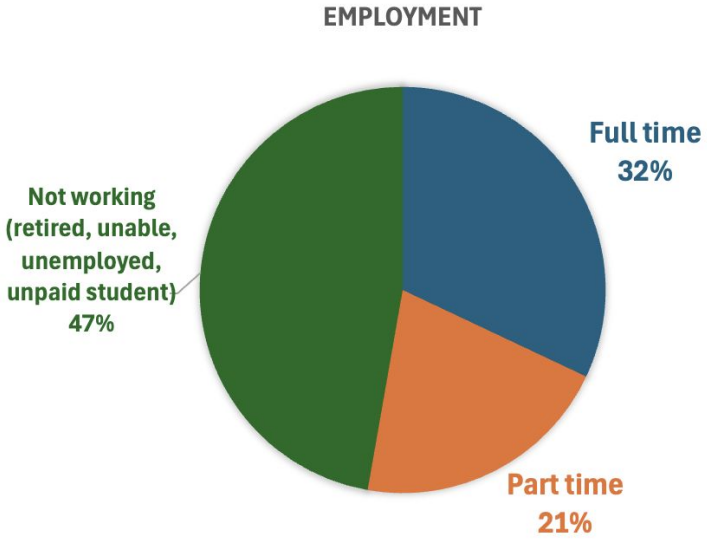
Age of diagnosis

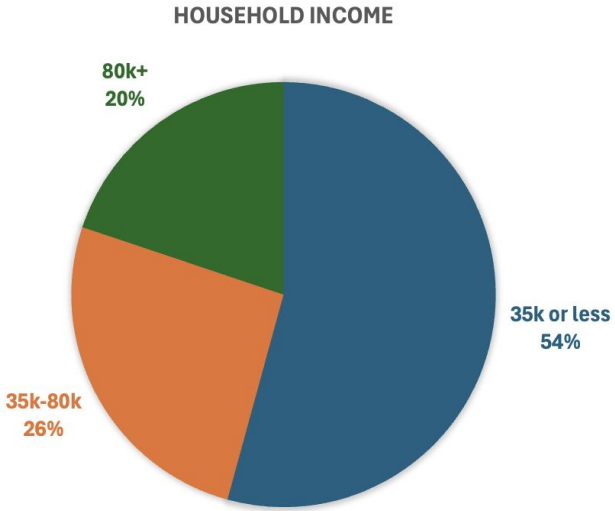
Mode = 3 years old
Range = 18 months to 58 years
34.4% diagnosed before 18 years of age
15.7% diagnosed 8 and younger

	Full Sample	Diagnosed 0-18	Diagnosed 18+	
	M	M	M	P Value
Age at diagnosis	24.20	9.67	31.83	
Age at study participation	32.74	28.29	35.70	< .001

Work & Education







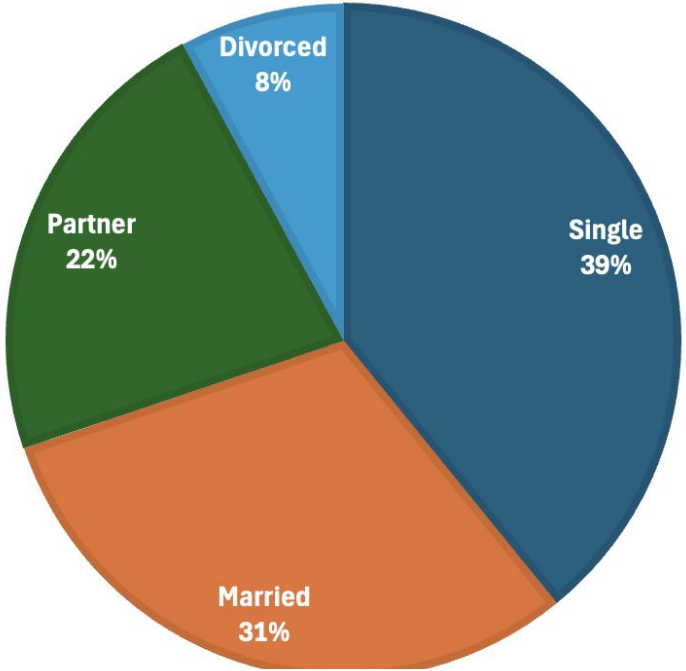
(Bureau of Labor Statistics, 2023).

US Census data indicates 23% of women finish 4-year college and 14% post-grad, median household income in 2022 was $74,580

Census data indicates 56.8% participation of women in the labor force

** Women **diagnosed as adults** were more likely to attain higher levels of education, and work full time

Relationships



- 38.06% have children
- More likely to be married if diagnosed as adult



Sexual Orientation Identification:

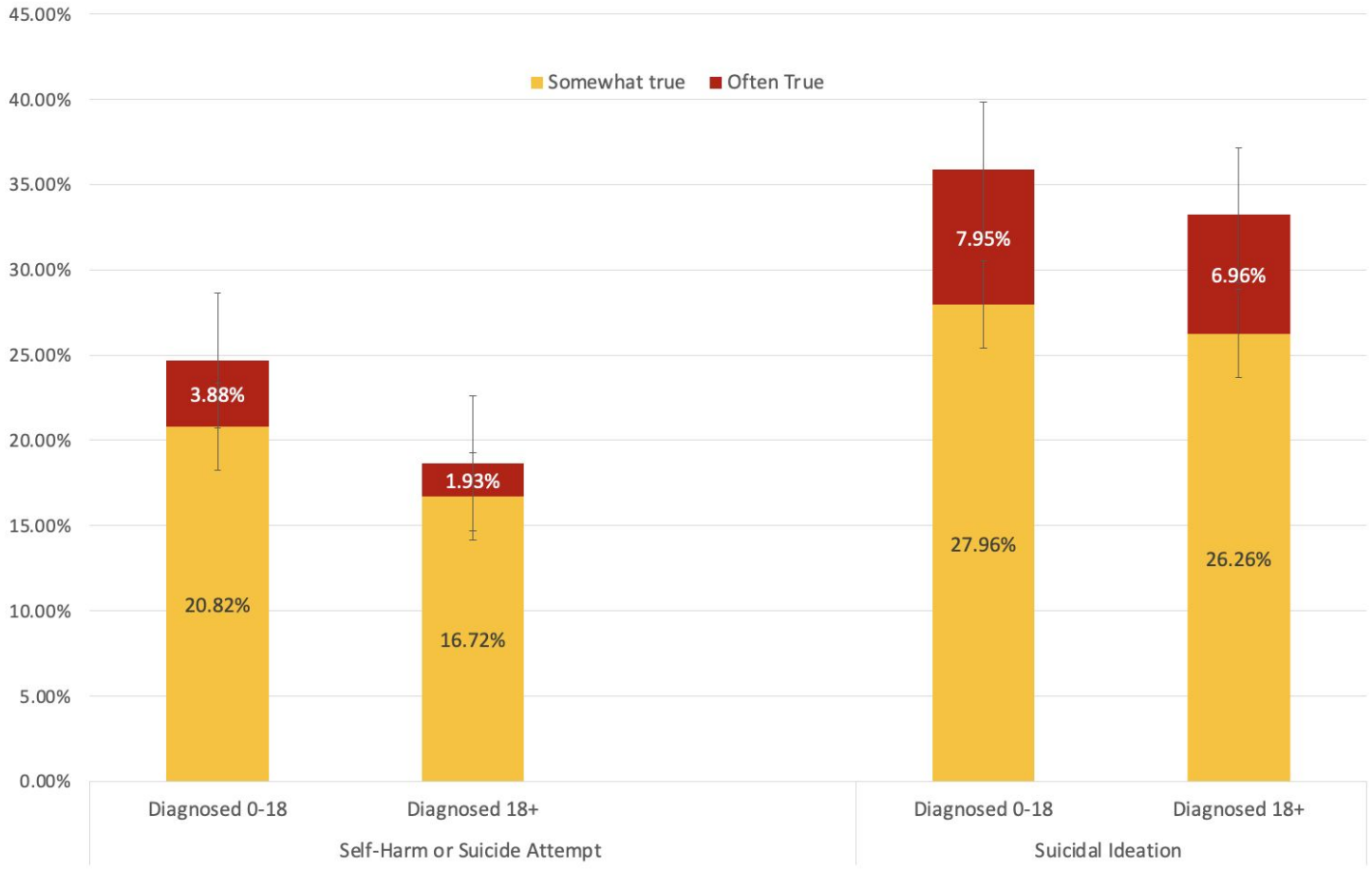
- 41.50% heterosexual
- 6.18% gay, 4.78% queer
- 27.59% pan or bisexual
- 9.69% asexual

Co-occurring Diagnoses

	Total %	Diagnosed younger than 18	Diagnosed 18+	p value
Neurodevelopmental/Childhood				
ADHD	46.07%	46.73%	45.65%	.463
ODD	**4.85%**	**8.57%**	**2.79%**	**<.001**
Conduct	**1.05%**	**2.04%**	**0.54%**	**<.001**
Mood				
Anxiety Disorder	**69.87%**	**68.16%**	**70.74%**	**0.049**
OCD	25.49%	26.12%	25.19%	.445
Bipolar Disorder	18.26%	19.59%	17.47%	.051
Depression	**61.79%**	**56.94%**	**64.42%**	**<.001**
Other				
Schizophrenia	3.79%	3.67%	3.85%	.729
Personality Disorder	12.35%	11.63%	12.65%	.266
Sleep diagnosis	31.81%	33.47%	30.87%	.052
Substance abuse	**8.85%**	**6.94%**	**9.86%**	**<.001**
Eating disorder	**17.28%**	**13.27%**	**19.39%**	**<.001**

ASR findings indicate symptom report in line with these findings on internalizing and substance use

Concern for Suicidal Behavior, Self-harm, and Ideation



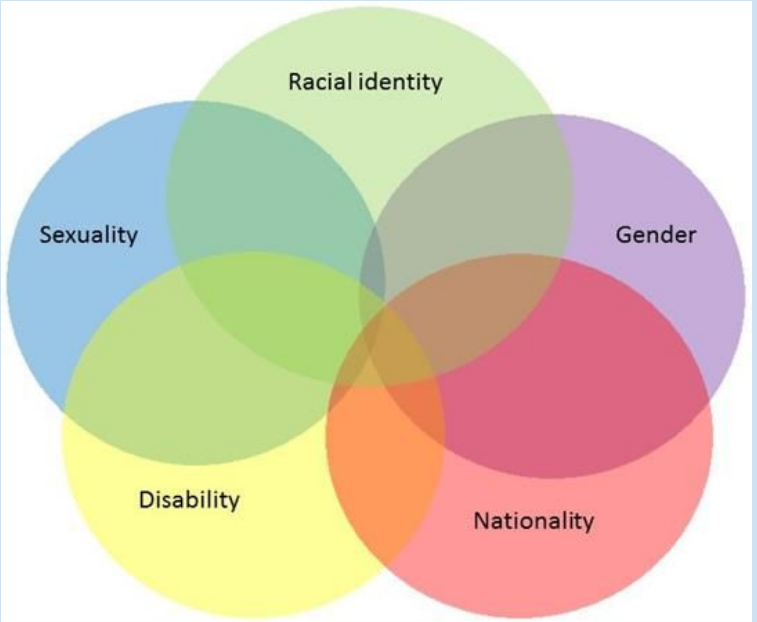
Returning to our theme… How did we do?

We aimed to take an intersectional approach to our research:

1. We've evaluated the way that systems in research have combined to contribute to autism research participants being overwhelmingly male, and caucasian
2. We've highlighted the ways that using secondary data was helpful for sample size and diversity
    - SES / Household income data
    - Sexual orientation
    - Gender Identity, with such a diverse sample, making decisions about inclusion was challenging and challenged.
    - We struggled still to establish a racially and ethnically diverse sample
    - Disability Status

As researcher, I attempted to prioritize inclusion and strengths in reporting, while taking seriously concerns and real challenges faced by this population.

- High educational attainment
- High rates of employment
- High engagement in long-term relationships



Full Sample

- Majority are identified as white
- Less than half identify as heterosexual & cisgender
- More than a third identified suicidal or self-harm thoughts and behaviors; higher rates amongst those gender/sexual orientation diverse
- Majority report household income less than 35k per year

Major findings from diagnosed 0-18



- More likely to be diagnosed with Oppositional Defiant Disorder or Conduct Disorder



Major findings from diagnosed 18+

- More likely to be employed full time, higher education, and married
- More likely diagnosed with depression, eating disorders, & substance use; higher internalizing & externalizing

Limitations

Lack of racial diversity

- Limits of generalizability

Unusual sample (?)

- Highly educated
- Higher SES
- Late diagnoses

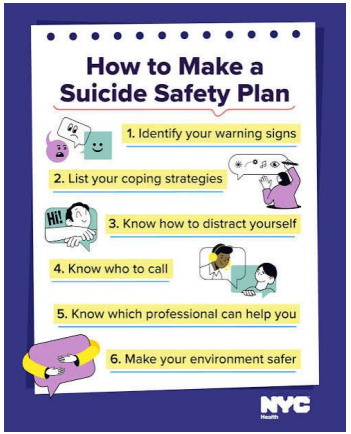
Self reported professional autism diagnosis

- Validity flag



Future directions and clinical implications

- Making suicidal prevention treatment accessible to autistic women
- Evaluating our research questions in a sample with co-occurring intellectual disabilities
- Sexual health





Questions?

Major Findings

	Full sample	Diagnosed as children	Diagnosed 18+
Demographics	Majority are white, less than half identified as heterosexual	More Black participants diagnosed as children	Older at time of participation in study
Education/ Employment/ Income	Majority have household income less than 35k per year	Similar to diagnosed as adults in satisfaction with job and school	More likely to be employed full time and complete university+
Family / Relationships	Scores on satisfaction in family and friend relationships below clinical cut off	About half report being single	More likely to be married
Wellbeing	Average score was in 69th percentile	No significant differences found	Wellbeing in the average range
Medical/ Psychiatric	A third report self-harm & suicidal ideation. High rates of ADHD, OCD, and sleep diagnosis	More likely to be diagnosed with ODD or CD	More diagnosed with anxiety, depression, eating disorders, and substance use; higher levels of internalizing