Autism Spectrum Identity and the "Lost Generation": Comparison between Diagnosed and Self-Diagnosed Adults on Identity and Other Characteristics

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Introduction

Definition of ASD has changed (i.e., DSM-III, DSM IV, DSM 5)

- Narrow definition until 1994

"Lost Generation" (e.g., Lai & Baron-Cohen, 2015))

- Unidentified individuals born before (and during) 1990's

- Women continue to be "at risk" for being under-identified (Loomes, Hull, & Mandy, 2017).

- Barriers exist for receiving DX:
  - Low access to diagnostic services
  - No autism diagnosis measure validated for adult population

Some Adults "Self-Diagnose"

- Little known about this population

Autism Spectrum Identity Scale (ASIS; McDonald, 2017)

- Previously validated in diagnosed population

- For Factors: Positive Difference, Changeability, Context Dependent, and Spectrum Abilities

- Relate to better psychological health, self-concept, employment/student status, quality of life

- Need to examine those who "self-diagnose"

Research Question

How do adult participants who "self-diagnose" with an ASD compare with adult participants with an ASD diagnosis in:

- Age
- Gender
- Employment
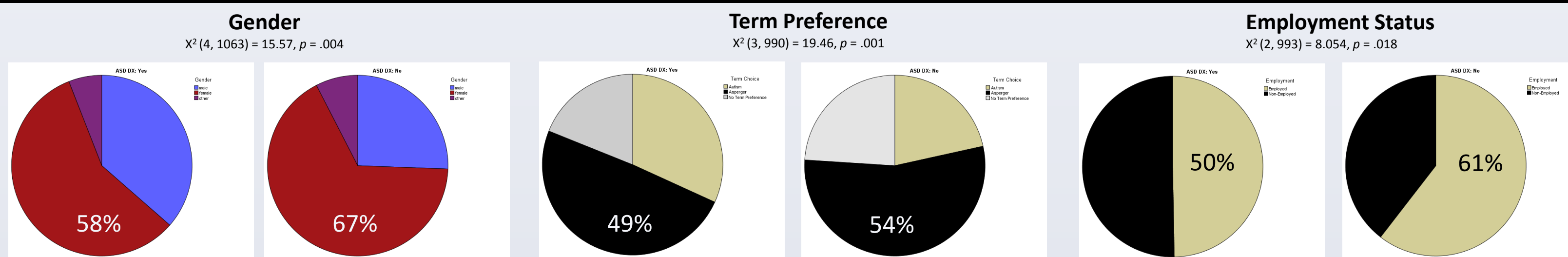- ASD DX Term Preference
- Autism Identity

Methods

Participants
- 1139 Participants (Dx: 893, SI: 246)
- Age 18 and over
- No legal guardian
- Have diagnosis of, or identify with, the Autism Spectrum
- 75% of individuals reported having an ASD diagnoses
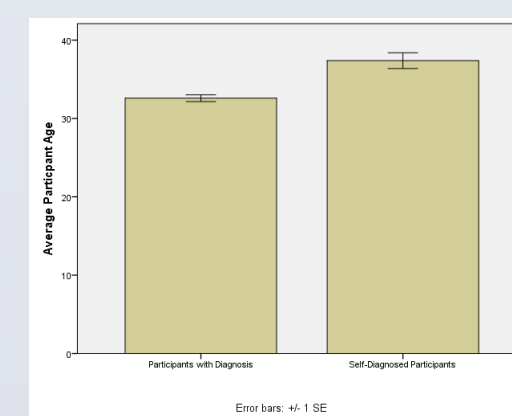- 43% Not in employment, education, or training (NEET)

Outcome Measures
- **Employment**
- Education
- Rosenberg Self-Esteem Scale (RSE)
- The Stigma Scale (SS)
- Adult ADHD Quality of Life Scale (AAQOL)
- Future Quality of Life (FQOL)

Results

Gender $X^2 (4, 1063) = 15.57, p = .004$

Term Preference $X^2 (3, 990) = 19.46, p = .001$

Employment Status $X^2 (2, 993) = 8.054, p = .018$

Age $t(1048,) = -4.47, p < .001$
Dx: M = 32.59, SD = 12.65
SI: M = 37.38, SD 12.02

No Differences in Treatment for:
- Anxiety
- Depression
- Bipolar
- ADHD
- OCD

Cross-Validation

Cross validation of Non-ASD-Diagnosis group: Predicting factor structure of second data set from first data set

Second half data	First half data			
	Factor 1	Factor 2	Factor 3	Factor 4
Factor 1	**1.00**	0.01	-0.15	0.47
Factor 2	0.01	**0.99**	0.47	0.09
Factor 3	-0.15	0.45	**0.99**	0.04
Factor 4	0.49	0.13	0.01	**0.98**

ASIS Factor Structure

Factor Solution for ASIS with Factor Loadings for the Self-Identified and Diagnosed Participants

		Factor 1		Factor 2		Factor 3		Factor 4	
		SI	DX	SI	DX	SI	DX	SI	DX
Positive Difference (α = .84; proportion of var = .14)									
17	I like having Aspergers/autism or being autistic.	**0.94**	**0.94**	-0.04	-0.01	-0.09	0.10	-0.00	-0.07
*9	I would be better off if I didn't have Aspergers/autism.	**-0.69**	**0.79**	0.14	0.14	0.07	-0.04	0.02	-0.07
10	I am better off because I have Aspergers/autism.	**0.70**	**0.83**	0.10	0.08	-0.08	0.02	0.07	0.01
15	I like the way I am different from everyone else.	**0.66**	**0.66**	0.17	0.08	-0.04	0.00	-0.02	-0.01
21	I feel Aspergers/autism has more benefits in abilities than challenges.	**0.45**	**0.56**	0.17	0.08	0.17	-0.07	0.14	0.06
*12	Aspergers/autism only makes things harder for me.	**-0.39**	**-0.46**	-0.14	-0.05	-0.22	0.12	-0.02	-0.16
5	If I were cured of Aspergers/autism, I wouldn't be me anymore.	**0.43**	**0.40**	-0.07	-0.05	0.25	-0.24	-0.06	-0.06
Context Dependent (α = .84; proportion of var = .16)									
38	I feel like I only have Aspergers/autism in certain places, like school, home, work or somewhere new.	0.05	0.05	**0.88**	**0.87**	-0.03	0.02	-0.03	-0.04
34	I feel like I only have Aspergers/autism around certain people, like classmates, teachers, parents, or co-workers.	0.08	0.04	**0.79**	**0.86**	-0.05	-0.03	-0.03	-0.10
37	There are some people with whom I don't feel I have Aspergers/autism.	-0.00	-0.03	**0.76**	**0.69**	0.00	-0.02	-0.02	0.09
35	I feel like I only have Aspergers/autism in certain activities, like completing work, organizing, getting ready to go somewhere, or new activities.	-0.13	0.08	**0.74**	**0.72**	0.01	0.01	0.13	0.06
32	There are some places where I don't have Aspergers/autism.	-0.10	-0.09	**0.55**	**0.58**	0.03	0.02	0.21	0.14
36	I only "have Aspergers/autism" when people treat me like I do.	0.08	0.12	**0.42**	**0.53**	-0.05	0.07	0.04	0.03
33	When I'm alone, I don't feel like I have Aspergers/autism.	-0.04	-0.05	**0.54**	**0.51**	0.11	-0.06	-0.20	-0.06
Spectrum Abilities (α = .77; proportion of var = .11)									
*20	I don't feel I have additional abilities from my Aspergers/autism.	0.12	0.07	-0.03	0.10	**-0.75**	**-0.80**	0.06	-0.06
*25	My strengths have little to do with Aspergers/autism.	0.02	0.06	0.15	0.06	**-0.72**	**-0.77**	0.07	0.11
*23	My good qualities have little to do with Aspergers/autism.	-0.13	0.06	0.21	0.09	**-0.47**	**-0.63**	0.22	0.12
22	I am good at some things because I have Aspergers/autism.	0.13	0.09	0.10	0.06	**0.57**	**0.71**	0.13	0.06
18	Aspergers/autism means having unique abilities.	0.12	0.20	0.11	0.10	**0.61**	**0.62**	0.18	0.05
Changeability (α = .55; proportion of var = .07)									
27	If I work hard enough, I can minimize the challenges associated with Aspergers/autism.	0.14	0.02	0.02	0.04	-0.05	0.05	**0.76**	**0.76**
28	If I work hard enough, I can minimize my Aspergers/autism.	-0.13	0.02	0.00	-0.04	-0.09	0.02	**0.69**	**0.65**
*31	There is little I can do about my Aspergers/autism.	0.08	0.09	0.14	0.12	-0.24	0.14	**-0.30**	**-0.52**

* Reversed items

Conclusions

"Self-Diagnosed" were more likely to:
- Be Older
- Be Female
- Be Employed
- Prefer term "Asperger" over "Autism"
- Have same co-morbid conditions

Autism Identity:

Same ASIS factor structure for both groups
Same strength of factor cross-validation

Implications:

Individuals who "Self-Diagnose" may represent "Lost Generation" of undiagnosed adults with ASD.

Future research:

ASIS factors relate to employment, quality of life, psychological health in diagnosed population.

These relationships should be examined with the "Self-Diagnosed" population.

Need "Gold-Standard" assessments for first time ASD diagnosis in adulthood