Social Activism in the Autistic Community: Perceived Discrimination Predicts Disengagement



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Background

- Since the United States' civil rights movements of the 1960s, individuals have banded together for civil rights advocacy. One such movement (neurodiversity) exists for people on the autism spectrum, alongside an emergent autistic culture (Davidson, 2008).
- Neurodiversity is (1) the perspective that autism spectrum conditions represent manifestation of positive difference along a continuous spectrum, rather than negative abnormality (Baron-Cohen, 2017); and (2) a social justice movement informed by that perspective, which seeks social inclusion for autistic people (Jaarsma & Welin, 2012).

Hypotheses

The present study predicted that internalized stigma would be related to:

- 1) higher levels of perceived discrimination, and thus
- 2) more frequent social, autism, and disability activism,

Method

Participants

- N = 111 individuals either professionally diagnosed (n=81) or self-identified as being on the autism spectrum (n=30)
- 55.9% women; 25% men; 21.6% non-binary individuals;92.8% Caucasian
- Participants were recruited internationally via social media.

Materials/Procedure

Using a Qualtrics survey, participants indicated (1) tendencies for social and political activism/advocacy (Social Issues Advocacy Scale, SIAS; Nilsson et al., 2010), (2) internalized stigma (10-item Internalized Stigma of Mental Illness scale, ISMI, Boyd et al., 2014), and (3) perceived discrimination (Perceived Discrimination-Devaluation scale, PDD; Link et al. 1991).

Participants were also asked about the importance of nationalism, disability advocacy, gender identity, and autism-specific activism.

Results

- See Table 1 for correlations. As expected, we found a positive relationship between social/political activism and perceived discrimination, r(79) = .229, p=.04.
- Surprisingly, general social activism engagement was negatively correlated with both disability, r(97) = -.223, p = .046, and autism r(97) = -.319, p = .004 advocacy.
- Further, internalized stigma was positively correlated with perceived discrimination, r(80) = .555, p < .001, but negatively correlated with importance of acceptance, both by autistic, r(80) = -.408, p = < .001, and non-autistic individuals, r(80) = -.271, p = .014.
- Perceived discrimination was negatively correlated with disability, r(80) = -.280, p = .011, and autism advocacy, r(80) = -.375, p = .001 as well as with importance of gender identity, r(80) = -.272, p = .014, and desire for acceptance by other autistics, r(80) = -.396, p < .001.

Table 1. Correlations between advocacy, perceived discrimination, and internalized Stigma.

	Importance of Disability Advocacy	Importance of Autism Advocacy	Internal- ized Stigma	Perceived Discrimin- ation	Need for Uniqueness		Importance of Nationalism	Importance of Gender Identity	Importance of ASC acceptance
Importance of Disability Advocacy	1								
Importance of Autism Advocacy	.84**	1							
Internalized Stigma	11	18	1						
Perceived Discrimin- ation	28*	38**	.56**	1					
Need for Uniqueness	.23*	.25*	.21	00	1				
Importance of Social Issues Advocacy	22*	32**	.06	.23*	24*	1			
Importance of Nationalism	06	10	10	23*	23*	.17	1		
Importance of Gender Identity	.32**	.29**	10	27*	11	14	.07	1	
Importance of ASC acceptance	.42**	.40**	41**	40**	23*	04	.11	.47**	1

Note. All *Pearson r* coefficients denoted with * are significant at the p<.05 level. Coefficients denoted with ** are significant at the p<.01 level. Nonsignificant coefficients are labeled ns.

References

Baron-Cohen, S. (2017). Editorial perspective: Neurodiversity – a revolutionary concept for autism and psychiatry. Journal of Child Psychology and Psychiatry, *58*(6), 744–747. Boyd, J. E., Otilingam, P. G., & DeForge, B. R. (2014). Brief version of the Internalized Stigma of Mental Illness (ISMI) scale: Psychometric properties and relationship to depression, self esteem, recovery orientation, empowerment, and perceived devaluation and discrimination. *Psychiatric Rehabilitation Journal*, *37*(1), 17–23.

Davidson, J. (2008). Autistic culture online: Virtual communication and cultural expression on the spectrum. *Social & Cultural Geography*, *9*(7), 791–806.

Jaarsma, P., & Welin, S. (2012). Autism as a natural human variation: Reflections on the claims of the neurodiversity movement. *Health Care Analysis*, *20*(1), 20–30.

Discussion

Summary

- Contrary to our prediction, internalized stigma was unrelated to either autism- or disability-advocacy.
- Those who perceived more discrimination appeared to be less involved in self- and disability-advocacy and had less need for acceptance by others, in spite of their greater internalized stigma.
- Internalized stigma, in turn, was associated with less advocacy, less concern for others' acceptance, and less importance of gender identity.
- Those who advocate for autism are those who advocate for disabilities in general; consider their uniqueness, gender, and acceptance by others with ASC (autism spectrum condition) important to their identities; perceive less discrimination against themselves; and are less concerned with generalized social issues advocacy.

Limitations

- This study was based off an online survey, so self-report problems like understanding of questions and honesty are especially in need of consideration.
- This study is correlational we cannot assume these motives underlie or cause activism or inaction.
- Our sample size was small; we need a larger sample for reliable correlations given the number of tests.

Future Research

- Depression or learned helplessness might explain disengagement by the most aggrieved, and should be measured in further studies.
- Analysis of archival communication data (such as twitter) among individuals in the online autistic community will allow examination of hostility, interest, and attitudes about autism research and researchers.
- Further investigation is needed as to why those high in perceived discrimination place *more* importance on social issues advocacy (but not ASC or disability advocacy), and less importance on gender identity, nationalism, and acceptance of their ASC.

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Poster Presented at the 30th Annual Convention of the Association for Psychological Science, San Francisco, 2018.