Brief Report: Exploring Some Aspects of Social Activism in the Online Autistic Community

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Abstract

The socio-political landscape surrounding autism, a set of neurological conditions existing on a spectrum and marked by difficulties in socializing, narrow interests, repetitive behaviors, and sensory sensitivities, has seen the neurodiversity social movement emerge with the perspective that neurological conditions represent normative differences rather than abnormality. Despite the movement, however, autistic people (we use both identity- and person-first language in our work, to respect the multiple language perspectives of people on the spectrum) still struggle with overt stigmatization. The present study tested the prediction that perceived discrimination—the extent to which individuals are aware of others’ negative views of their own group—would be related to higher levels of internalized stigma (the incorporation of stereotypes about one’s group into one’s identity), broad social activism, and autism/disability-related advocacy. Results partially supported hypotheses: Perceived discrimination and internalized stigma were negatively correlated, $r(80) = -.55, p < .001$; and general social-issues advocacy was negatively correlated with self-reported importance of disability, $r(80) = -.22, p < .05$ and autism-specific activism, $r(80) = -.32, p < .01$. In support, however, perceived discrimination correlated positively with the importance of autism-specific activism, $r(80) = .38, p < .01$, and with importance of general disability advocacy, $r(80) = .28, p < .05$. Hence, autistic people who valued activism reported engaging less in broad social-issues advocacy, but more in disability- and autism-related advocacy, and tended to perceive discrimination but not to internalize stigma. Implications for the activist online autistic community and future population-specific scale development are discussed.

Keywords: Autism, Social Activism, Stigma, Discrimination, Prejudice

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Since the 1960s race- and gender- related civil rights movements in the United States, disabled individuals have formed cohesive communities focused on the combatting of stigma, discrimination, and other negative attitudes fostered by society. Neurodiversity is an autism-oriented social movement that developed from the perspective that neurological conditions represent positive, normative differences rather than abnormality (Baron-Cohen, 2000, 2017; Beardon, 2007; Wing, 1997, 1988). Autism is a set of neurological conditions marked by difficulties in socializing, a tendency to exhibit interests across a narrow range of topics, repetitive behaviors, and sensory sensitivities (American Psychiatric Association, 2013). Autistic¹ people, hereafter referred to as having an autism spectrum condition (ASC) to reflect their intrinsic state of being, express and experience various levels of these characteristics depending on where they fall upon the spectrum.

An online autistic community has emerged alongside the neurodiversity movement (Biever, 2007; Davidson, 2008) with its own shared values, beliefs, and knowledge (Silverman, 2008). This community, within which members celebrate their differences and express anger at non-autistic people for stigmatizing them (Clarke & van Ameron, 2007), provides a social platform and peer network from which support may be drawn (Brownlow & O'Dell, 2006). Neurodiversity proponents are angry about the notion that autism should be cured (Davidson, 2008), and the community resists and resents the medicalization of autism and how typically-developed autism professionals and researchers seem to “own” autism (Clarke & van Ameron, 2007). One response is the “nothing about us without us” mantra directed at non-autistic autism researchers who, in the community view, should collaborate with autistic people in research.²

¹ Out of respect for people on the autism spectrum, who prefer a mix of reference terms (see Bolton & Ault, 2018, for discussion), we use both identity- and person-first language in our work.

² See the Autistic Self-advocacy Network (2019), Participatory Autism Research Collective (<https://participatoryautismresearch.wordpress.com/>), and Fletcher-Watson et al., 2018.

An area of research relevant to the present study focuses on the effects of stigma and discrimination on marginalized social groups and individuals (Bell, Salmon, Bowers, Bell, & McCullough, 2010; Johnson, 2013; Milton & Sims, 2016; Ohan, Ellefson, & Corrigan, 2015; Peters, Schwenk, Ahlstrom, & McIalwain, 2017). Perceived discrimination is the extent to which individuals are aware of others' negative attitudes of their own group (Link, Mirotznik, & Cullen, 1991), while internalized stigma is the incorporation of those stereotypes and attitudes into one's personal identity (Ritscher, Otilingam, & Grajales, 2003). Perceived discrimination could easily result from more salient overt prejudice, although the cognitive or affective process by which one internalizes perceived discrimination into his or her identity is not thoroughly understood. The heuristic nature of categorization is just one reason individuals engage in stereotyping (Fiske, & Taylor, 1984), through a perceived broader social consensus supporting these stereotypes (Whitley & Webster, 2019). Lysaker, Roe, and Yanos (2007), for example, found less hope and lower self-esteem among those with schizophrenia who internalized stigma. In our view, people who feel isolated in their condition have little exposure to views countering negativity, and thus experience more validation of felt prejudice. Provided little opportunity for identifying with a broader, shared community, they may be more likely to internalize stigma—which could either encourage activist participation, via anger, or decrease activism self-efficacy and political mobilization via learned helplessness (Seligman, 1975).

Political and social activism are not new, but interest in them is increasing (Curtin & McGarty, 2016). Prior studies suggest that predictors of collective activism include a shared group identity, shared group emotions, and efficacy beliefs (Klandermans & van Zomeren, 2011; van Zomeren & Iyer, 2009). As those on the spectrum begin to self-advocate, it is pertinent to examine who exactly is involved, especially since this mobilization seems, both empirically and in our anecdotal observation of the online community, driven by anger and perceptions of stigma and discrimination (also see Thibodeau & Finley, 2017). Autistic people attuned to overt

discrimination may respond to it *either* by recognizing and rejecting it, *or* by recognizing and acquiescing to it. Considering these two possible responses, the present study drew on prior literature on social advocacy and activism among other activism collectives (e. g., van Zomeren & Iyer, 2009) to investigate some political aspects of autistic self-advocacy in the context of discrimination and stigmatization.

Fully investigating activism/advocacy, perceived discrimination, and internalized stigma necessitated measurement of relevant individual differences not directly tied to discrimination and stigma but rather to activism: Importance of social class (van Zomeren, Leach, & Spears, 2012); of one's own culture (to measure solidarity and collectivism; Lake, 1997); and of acceptance by one's own and other groups (Bäck, Bäck, & Knapton, 2015). Nationalism, used as a proxy for strong in-group identity (Chang & Kang, 2018), and need for uniqueness (Shumpe, Philipp, Herzberg & Erb, 2016), as a way to capture the need to stand out, were also assessed.

Upon literature review, we hypothesized the following: Perceived discrimination would positively correlate with internalized stigma, social issues activism, and autism- and disability-specific activism. This would be especially true for autism and disability-focused activism, since those to whom marginalization is more salient were thought more likely to perceive and internalize stigma (Fiske & Taylor, 1984), and to desire to combat it through social issues activism (Clarke & van Amerom, 2007). Finally, from prior research (e. g., Bäck et al., 2015), we predicted positive correlations between activism and the group-focused values of nationalism, gender identity, and importance of acceptance from one's own and other groups.

Method

Participants read an implied consent form and proceeded upon agreement to the uniformly-ordered survey items and measures, all approved by the authors' institutional review board. No remuneration or incentive was offered for the completion of this approximately 15-minute-long survey. Survey materials and data are available via the OSF website

(<https://osf.io/u49v3/>). Some items in the survey, relating to perceptions of autism research, were not analyzed as part of this study but were included for possible later, archival use.

Participants

One-hundred-eleven individuals who self-reported they were either diagnosed with an ASC (81%) or self-identified as being on the autism spectrum (29%) took part in an anonymous, Qualtrics-hosted survey in the fall of 2017. The survey was distributed internationally via social media (origin data are available for 99 participants; Reddit $n = 58$, Twitter $n = 23$, Facebook $n = 18$). Participants ($M_{\text{Age}} = 30.3$; $SD = 10.18$) were largely European-American/white ($n = 103$), with the remainder consisting of Asian ($n = 2$), Latino ($n = 1$), and bi- or multi-racial individuals ($n = 5$). Participants were 62 women, 25 men, and 24 nonbinary individuals. The number of non-binary participants reflects the online autistic community's embrace of many factors existing on a spectrum, including gender (Cooper, Smith, & Russell, 2018; Jacobs, Rachlin, Erickson-Schroth, & Janssen, 2014). Geographically, nearly half were from the United States ($n = 55$), with the rest from the United Kingdom ($n = 27$), Canada ($n = 8$), or other countries ($n = 21$).³

Description of Measures

Demographic questions related to age, gender identity, race/ethnicity, country of residence, whether participants had received an autism diagnosis from a professional or self-identified as being on the spectrum, and political orientation. Participants rated their political interest on a 10-point Likert scale,⁴ and indicated whether they had a political affiliation. Those who did were asked their political leanings ("left," "right," and "middle of the road / moderate"). On 7-point Likert scales ($1 = \text{lowest}$ and $7 = \text{highest}$), participants rated the importance they place on their culture, gender identity, social class, sense of nationalism, being accepted by non-

³ Of these, Australia $n = 8$, Netherlands $n = 3$, Germany $n = 2$, Ireland $n = 2$; Austria, New Zealand, Scotland, South Africa, Sweden all $n = 1$.

⁴ Lowest-highest, following Nilsson, Marszalek, Linnemeyer, Bahner, & Misialek, 2010

autistic individuals, being accepted by fellow autistic individuals, autism self-advocacy, and disability advocacy. See Table 1 for a list of precise items.

We assessed participant tendencies for social and political activism/advocacy (Social Issues Advocacy Scale, SIAS; Nilsson et al., 2010; Cronbach's $\alpha = 0.75$), psychological need for uniqueness (Need for Uniqueness Scale, NfU; Schumpe et al., 2016; $\alpha = 0.93$) internalized stigma (10-item Internalized Stigma of Mental Illness Scale, ISMI; Boyd, Otilingam, & DeForge, 2014; $\alpha = 0.74$), and the degree to which they felt devalued by and discriminated against by non-autistic individuals (12-item Perceived Discrimination-Devaluation Scale, PDD; Link, et al., 1991; $\alpha = 0.70$).

Attrition was mitigated by reducing the SIAS from 21 to 9 items, and the NfU from 26 to 20—see the survey listed on OSF for details of specific items used—with resulting reliabilities acceptable considering the modifications and the typically-accepted “reliable” threshold of 0.70 but lower than originally reported (SAIS $\alpha = 0.75$; NfU $\alpha = 0.64$). The ISMI ($\alpha = 0.60$) and PDD ($\alpha = 0.12$)⁵ were modified to reference autism instead of general mental illness, and social context (Gernsbacher, Stevenson, & Dern, 2017). The ISMI was re-worded to reference judgement about being autistic and the PDD to reference judgements of autism by non-autistic people.

⁵ Although lower internal consistencies were anticipated and considered acceptable, the PDD items initially had an unacceptably low alpha. Principle components factor analysis revealed two highly but inversely related factors and suggested interpretation may have been affected by the items' context and how they referenced non-autistic people as judges of autistic people. This conjecture is consistent with Gernsbacher and colleagues' 2017 work and recent evidence that differential item functioning properties influence interpretation of negatively phrased items by people with and without autism (Agelink van Rentergem, Lever, & Geurts, 2019). The PDD required interpreting outgroup judges' positive and negative evaluations, which could have been confusing given weaknesses in mentalizing for people on the spectrum (Morrison, Pinkham, Kelsven, Ludwig, Penn, & Sasson, 2019). The 6 positively framed items, indicating non-autistic others viewed those on the spectrum supportively, appear to have been problematic. Removing them, we derived a reliable six-item factor (Cronbach's $\alpha = 0.83$) explaining 43.18% of the variance in perceived discrimination (see Table 2 for factor items and loadings). These items were used to test our hypotheses.

Results and Discussion

While descriptive and political analyses include the majority of the sample, correlations involving either the PDD or the ISMI only reflect responses from 82 participants. Seventeen participants were missing at least 10% of their responses to both measures, possibly due to sensitivity or difficulty. Twelve additional participants' PDD, ISMI, and importance data were missing, although demographics and political questions were answered. A power analysis revealed that a sample size of 98 participants would be sufficient to detect a correlation of $r = .28$. Therefore, some effects may not be detected with our present sample. Most participants indicated no formal political affiliation (47 affiliated; 64 unaffiliated). Political interest was high, however, for those with an affiliation ($M = 7.23/10$, which could reflect politics as an autistic special interest; see Grove, Roth, & Hoekstra, 2016). Interestingly, 81% (34) indicated a left-leaning political perspective. Another 4.5% (5) indicated having moderate views, while 1 individual (0.9%) each identified as undecided, as not supporting political parties/groups, and having a right-leaning political perspective. Table 3 shows our correlational analyses.

Counter to our hypothesis that perceived discrimination would correlate positively with internalized stigma, PDD and ISMI scores correlated negatively, $r(80) = -.55$, $p < .001$. This inverse relationship between discrimination and stigma suggests two separate patterns for those with ASC. Participants reporting a formal diagnosis ($n = 60$) were higher ($M = 2.67$) in perceived discrimination than those who self-diagnosed ($n = 22$; $M = 2.30$). They were, concurrently, lower in internalized stigma ($M = 23.70$) than the self-diagnosed participants ($M = 24.09$; both p -values > 0.05 in a one-way ANOVA). These results begin to explain the observed correlations. While there are some vocal self-advocates online, autistic people who carry stigma appear to show less interest in the notion of an ASC community and autism advocacy. Future research should explore why autistic people reporting internalized stigma advocate less about autism. Internalized stigma is correlated with low morale (defined by low self-esteem and depression;

Dohrenwend, 1990). Feelings of isolation and subsequent decisions to socially disengage might, therefore, give way to learned helplessness (Seligman, 1975).

Further contrary to predictions, general social-issues advocacy (SAIS) was negatively correlated with self-reported importance of disability, $r(80) = -.22, p < .05$ and autism-specific activism, $r(80) = -.32, p < .01$. The discovery that broader social issues advocacy is less likely when individuals are engaged in disability and autism advocacy (and vice-versa) is important, but negates need for further discussion of broad social-issues activism.

In support of our prediction, however, PDD scores were correlated positively with the importance of autism-specific activism, $r(80) = .38, p < .01$, and with importance of general disability advocacy, $r(80) = .28, p < .05$. Thus, those who perceive more discrimination tend to become involved in activism for autism and disability-specific issues. Perceived discrimination scores also positively correlated with importance of ASC acceptance, and with importance of gender identity. Given the negative relationship between perceived discrimination and internalized stigma, and subsequently the negative relationship between internalized stigma and activism, examining correlates of both variables might explain these two alternate “paths” in response to prejudice or ostracism. Our data provide a theoretical foundation for some of these questions to be asked in the future, and support prior research that feelings of efficacy promote activism (van Zomeren, & Iyer, 2009).

Based on our correlations, those who perceive discrimination internalize less stigma and value activism and a broader social network within the scope of, but also outside of, those with ASCs. Further, those highly perceiving discrimination are more likely to value shared identities, become involved in ASC and disability advocacy, and avoid internalizing stigma. In turn, they value their gender identity and acceptance by others on the spectrum. Those internalizing stigma, conversely, show less concern with activism and reject acceptance by others—possibly because they perceive social consensus regarding their status (Whitley & Webster, 2019) and thus lack

activism efficacy. They are more likely to value their own culture. Own-culture importance may suggest perceived isolation from outside groups rather than feeling a part of a united collective, although future research should explore this possibility.

Limitations

The present study had multiple methodological limitations. First, since it was survey-based, problems including question comprehension and honesty are in need of consideration. Our scale reliability problems might have been related to this; hence, researchers in this area should seek to balance such concerns as how item interpretation might be affected by context change. Psychometric issues are generally difficult to quantify when working with autistic people, as little research has focused on this topic, and people on the spectrum often interpret and respond differently to items and measures than do neurotypical individuals (e.g., Pellicano, Dinsmore, & Charman, 2014). Given participant geographic distribution, results might also have been affected by cultural differences in social norms or understanding. Another important consideration is the perceptions of autistic people towards science, reflected in the ways people in the online autistic community respond to and participate in research (e.g., Bolton, 2018; Guest, 2019; Musikar, 2018; Pellicano et al., 2014).

People on the spectrum have reported discomfort and uncertainty about how researchers view them, and this can influence their response rates as well as their anger and reactivity to surveys (Fletcher-Watson et al., 2019). Such reactivity—which can, according to Milton (2014) result from “a negative feedback spiral” (p. 794) and “a breakdown in trust and communication leading to increased tension...” (p. 794) among researchers and people on the autism spectrum—may explain at least part of our high attrition rate (82/111 usable responses for the correlations) and inconsistent scale reliabilities. These results must therefore be replicated in light of our scale alterations and abbreviations, and with an eye towards increasing comfort and reducing respondent reactivity.

Second, the relationships reported here are correlational. We therefore cannot, of course, assume possible causes for activism or inaction. Third, the sample size was small. While the sample size was sufficient to detect most relationships, replication with more participants is needed to test the robustness of the reported correlations as well as the reliability of the measures used. In future work, in addition to an exact replication, a mixed-methods approach incorporating qualitative comments from participants, could prove useful in further illuminating the pattern of findings, particularly if such work also uses population-specific activism, stigma, and discrimination scales. Fourth, and finally, we did not account for the accessibility of physical political events and gatherings to autistic people or others with disabilities, and how these factors might affect subsequent involvement and engagement in activism by these individuals. Thus, these findings' generalizability is constrained to online advocacy and activism at present.

Conclusions and Future Work

This study was an investigation into the politics and self-perceptions of individuals on the autism spectrum, with participants exhibiting an interesting pattern of correlational results. Autistic self-advocates reported engaging in less broad social-issues advocacy, but more disability-related advocacy and autism-specific advocacy, suggesting their interests focus on their in-group, in line with prior work (e. g., Bäck et al., 2015). Those for whom advocacy is important tended to perceive *more* discrimination but to internalize *less* stigma. While there is too little evidence in the present study to draw conclusions, internalized stigma could point to an avenue of isolation some on the spectrum might follow to deal with discrimination, reporting less interest in identifying with ASC or other groups and failing to seek external validation of a positive identity. Perhaps those who perceive discrimination, and tend not to internalize the associated stigma, draw meaning from identities outside of autism (e. g., gender and disability advocacy), while still feeling a sense of belonging to the autistic group. This may be supported

by the finding that those perceiving discrimination are more likely to endorse the importance of autism activism, while less importance is placed on activism among those internalizing stigma.

Given the different tendencies among people on the spectrum to perceive discrimination and internalize stigma, future research should examine the interplay of ASCs and these two constructs more closely. Psychometric concerns with the measures used here point to the consideration of ASC population-specific assessments of advocacy, perceived discrimination, and internalized stigma for future work in this area.

Additionally, future research should seek to identify other variables, such as personality characteristics or social networks, that might explain why people on the autism spectrum respond to prejudice with internalized stigma. Would decreasing the tendency to internalize stigma potentially influence willingness to, or interest in, autism advocacy? What factors predict, and what other outcomes are related to, internalized stigma? Internalizing stigma as a coping mechanism, at this point, appears to be ineffective and possibly damaging (Boyd et al., 2014), and studies should examine the circumstances under which some people with autism use this mechanism, as well as related coping strategies.

Investigation should also focus on why some people self-diagnose/identify as being on the spectrum, and examine whether this decision relates to internalized stigma. Perhaps lack of access to healthcare is confounded with whether one is professionally or self-diagnosed. If so, a plethora of other variables, including economic status or access to resources, or rural/urban locations and physical or psychological isolation, may assist in explaining some of these differences in activism involvement.

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Table 1. List of Individual Items Asking Level of Variable Importance

<u>How Important are These Things to You? (1 = most important, 7 = least important)</u>
The culture you are part of.
Your social class (whether you are in the lower, middle, or upper part of society).
Nationalism / pride in your country.
Your gender identity.
Being accepted by autistic individuals.
Being accepted by non-autistic individuals.
Being an advocate for general disability issues/topics.
Being a self-advocate for autistic civil rights.

Table 2. Principle Components Analysis of the Perceived Discrimination-Devaluation Scale (PDD).

Item	Loading
(Item 6) Most non-autistic people would not hire an individual who is on the spectrum to take care of their children	.76
(Item 11) Most non-autistic people would be reluctant to date someone who is on the autism spectrum.	.73
(Item 9) Most non-autistic employers will pass over the application of a person on the spectrum in favor of another applicant.	.71
(Item 7) Most non-autistic people think less of people who are on the spectrum.	.66
(item 12) Once they know a person is on the spectrum, most non-autistic people will take that person's opinions less seriously.	.64
(Item 5) Most non-autistic people believe that being on the autism spectrum is a sign of personal failure.	.59

Note. Cronbach's $\alpha = 0.83$; $M = 15.43$, $SD = 5.55$

Table 3. *Correlations Among Importance of Advocacy and Acceptance, Internalized Stigma, Perceived Discrimination, and Importance variables.*

Variables	1	2	3	4	5	6	7	8	9	10	11	12
1. Perceived Discrimination	-											
2. Need for Uniqueness	ns	-										
3. Social Advocacy	-.23*	-.24*	-									
4. Internalized Stigma	-.55**	ns	ns	-								
5. Importance of Autism Advocacy	.38**	.25*	-.32**	ns	-							
6. Importance of Disability Advocacy	.28*	.23*	-.22*	ns	.84**	-						
7. Importance of NT Acceptance	ns	-.54**	ns	-.27*	ns	ns	-					
8. Importance of ASC acceptance	.42**	-.23*	ns	-.41**	.40**	.42**	.43**	-				
9. Degree of Nationalism	ns	-.23*	ns	ns	ns	ns	.22*	ns	-			
10. Importance of Social Class	ns	-.23*	ns	ns	ns	ns	.28*	.23*	.27*	-		
11. Importance of Culture	ns	-.23	.40**	.39**	ns	ns	.31**	.40**	.39**	ns	-	
12. Importance of Gender Identity	.26*	ns	ns	ns	.29*	.32**	ns	.47**	ns	ns	.31**	-

Note. Correlations denoted with * are significant at the $p < .05$ significant at the $p < .01$ level level; those denoted with ** are. NT stands for “neurotypical.” ASC stands for Autism Spectrum Condition.