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Gender Differences in Self-Reported Social Participation in Autistic Adults

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Gender Differences in Self-Reported Social Participation in Autistic Adults

Abstract

There is a lack of research on gender differences in autistic adults' participation in social activities (i.e., activities that provide interactions with others in the community). Using a large statewide sample (N=775, 217 females and 558 males), we examined gender differences in social participation of autistic adults while considering the presence of an intellectual disability (ID). Three participation outcomes were evaluated: overall participation days, participation in activities perceived as important, and sufficient participation in activities perceived as important. No gender differences were found in the overall participation days. However, women without ID reported participating in lower percentages of social activities that were important to them and perceiving sufficient participation in lower percentages of these important social activities than their male counterparts. Autistic women without ID also reported lower satisfaction with participation level (i.e., perceived sufficiency in participation in important social activities) in social activities that were important to them than autistic women with ID. Implications of findings for understanding gender differences in autism across the life course are discussed.

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Participation in social activities in the community, such as getting together with friends and family or attending social events, is a critical contributor to the well-being and quality of life of autistic adults (e.g., Tobin et al., 2014). Gender is associated with participation, as women in the general population have been found to participate more in social activities and social interactions than men (Gilmour, 2012). However, research on how gender might affect social participation among autistic adults has been inconsistent and limited. Previous research using nationally representative data sets found gender was not a significant correlate of social activities (e.g., seeing friends) among young autistic adults

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(Myers et al., 2015; Orsmond et al., 2013). However, a study using an experience sampling method found that females were more likely to engage in social situations (e.g., talking/texting/phone) than males (Chen et al., 2016).

Notably, these studies did not examine the social participation in the larger community beyond interactions with friends and family. Entering adulthood marks the period to seek autonomy and actively choose social roles (e.g., profession, faith) in the community beyond family and school settings (Cronin et al., 2015). Furthermore, as in the general population, autistic women experience greater pressure to fit in socially and behave in more acceptable ways than autistic men, which potentially leads them to be more socially active and camouflage social difficulties to fit in better (Hull et al., 2020). A study has found that autistic adolescent girls displayed greater motivation for social contacts than boys (Sedgewick et al., 2016). This may drive autistic women to have different participation interests and choices, including what activity is important, from men and engage in social activities that fulfill their needs.

The gendered patterns in social behaviors may be influenced by cognitive functioning. In general, people with intellectual disability (ID) often experience social exclusion (Bigby, 2012) and tend to have restricted social networks (Amado et al., 2013). Additionally, women with ID experience greater gender discrimination than women without ID, leading to fewer opportunities to meet traditional gender expectation and engage in expected social roles (e.g., spouse, caregivers, friends) (Cytowska & Zierkiewicz, 2020). This reinforces that the presence of ID has different influence on gender-based experiences and opportunities for social participation.

This study is exploratory in nature. We use a large, statewide sample to examine potential gender differences in social participation among autistic adults and the role that the presence of a co-occurring ID may have on participation. We focus on the views of autistic individuals to understand how autism, gender, and ID impact social participation and satisfaction with their participation level. This paper refers to gender identity (e.g., men, women, or other) as a psychological and social concept rather than assigned sex at birth. This research also extends current knowledge by examining both amount of participation and the extent to which they are engaged in activities that are important to autistic individuals (i.e., sufficient

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participation in important activities). Given trends in the general population, we expect that autistic women to participate in more social activities but report lower sufficiency levels than autistic men. Additionally, we expect that ID will negatively associated with social participation among autistic women compared to men.

Method

Data and sample

Data came from a statewide survey conducted between 2017 and 2018 in a Mid-Atlantic state (details here: <https://needs.paautism.org/>). Two methods were used to recruit participants: (1) letters were sent to state residents enrolled in Medicaid with a claim or encounter with an ASD diagnosis (ICD-9 299.XX or ICD 10 F84.X); (2) information about the survey was distributed through ASD-specific advocacy and policy organizations in the state. Participants over 18 years old could choose to complete the survey online, on paper, or over the phone with a research staff. They completed the survey by themselves or with assistance from a caregiver or support person. The survey also asked participants to report whether they had a diagnosis of ID, which was used to separate ID and no-ID groups for the purpose of this study. All participants provided consent to participate. A detailed description of the study procedure and survey can be found in another article using the same sample (BLINDED FOR REVIEW). Study procedures were approved by the (BLINDED FOR REVIEW) Institutional Review Board.

A total of 1,203 autistic adults responded to the survey. This study includes those who completed 75% of a community participation measure after data cleaning (N=816). Furthermore, an additional 15 participants who reported more than 250 total participation days across 22 activities in the last 30 days measured using Temple University Community Participation measure (see more details in the Measure below) were considered as unrealistic outliers, whose responses were excluded from analysis. There were no differences between those who were excluded versus included based on demographic characteristics. This study also only included participants who identified as female or male. While research on nonbinary gender identity is of great interest, our sample size (n=26) was deemed insufficient for credible conclusions. The final sample was 775 participants, 217 females and 558 males.

Measure

The Temple University Community Participation measure assesses independent participation (without the support of staff) in areas such as going to a library, going to a park, working for pay, going to school for a degree, volunteering, going to a social group, and hosting or visiting family or friends. For each activity, the participant was asked (1) the number of days in the last 30 days that they engaged in the activity without the support staff (0-30), (2) if the activity was important to them (1=Yes or 0= No), and (3) the degree to which they felt that they had done enough in this activity (-1=Not enough, 0=Enough, or 1=Too much). The measure has robust evidence of test-retest reliability (BLINDED FOR REVIEW) and evidence of validity (BLINDED FOR REVIEW) with autistic adults. Five activities were used to capture social participation: go to a social group, get together with family or friends, entertain family or friends in your home or visit family or friends, go to a community event, go to a place of worship, and participate in civic or political activities. Three outcomes were examined: 1) *total participation days*; 2) *participation in activities perceived important*, calculated as the ratio of important activities where they had participated at least one day divided by total number of important activities; and 3) *sufficient participation in activities perceived important*, calculated as the ratio of important activities where the participants felt they had done enough divided by total number of important activities.

Results

Sample characteristics and community participation outcomes are shown in Table 1. Self-reported diagnosis of ID was used to categorize participants into two groups: ASD-No ID and ASD-ID. Chi-square test showed that the gender distribution was not significant different between the two groups ($p=0.132$). Two-way ANCOVAs were conducted with gender (male vs. female) and diagnostic group (ASD-ID vs. ASD-No ID) as fixed factors and age as a covariate.

Neither main effect of gender or interaction between gender and ID were significant for the total social participation days (see Figure 1a). A significant interaction for participation in activities perceived important was found ($p=0.010$; see Figure 1b). Follow-up tests were conducted to examine gender

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differences within diagnosis groups and then diagnosis group differences within gender groups. Results showed that, among adults without ID, autistic men participated in a higher ratio of activities perceived important than women ($p < 0.001$), while no gender difference was found among those with ID. Among men, autistic men without ID also participated in a higher ratio of activities perceived important than autistic men with ID ($p = 0.012$). No ID group difference was found among women.

A significant interaction effect ($p = 0.011$; see Figure 1c) was also found for the sufficient participation in activities perceived important. Among autistic adults without ID, men reported sufficient participation in a higher ratio of activities perceived important than women ($p = 0.006$), while no gender differences were found among those with ID. Among females, autistic women without ID reported sufficient participation in a lower ratio of activities perceived important than autistic women with ID ($p = 0.001$), while no difference was found for men.

Discussion

We found comparable total amounts of social participation between autistic men and women regardless of ID. However, there were notable gender differences among adults without ID in the participation in activities that were important to them and the degree to which they felt they did enough in these activities.

First, autistic women without ID participated in a lower ratio of activities perceived important and did not engaging in those important activities as much as they would like compared to autistic men without ID (i.e., sufficient participation in perceived important). These gender discrepancies may be partially attributed to expectations of and related greater interest in social activities with others among autistic females than males without cognitive impairment (Sedgewick et al. 2016). Meanwhile, autistic women may encounter specific or exacerbated challenges, including strong awareness of social expectations and the anxiety related to the pressures of concealing their social difficulties (Hull et al. 2020). This could further inhibit them from participating in meaningful activities to the extent they desire.

Similar overall participation amounts between autistic men and women were consistent with previous studies on autistic individuals where no gender differences were found in social activities (Myers

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et al., 2015; Orsmond et al., 2013). Lack of gender differences in frequency may be meaningful when considering gender differences in the general population. For instance, women in the general population tend to participate more in social activities than men (Gilmour, 2012). A lack of differences in the amount of social participation suggests autistic women might be participating in them less than nonautistic women. Autistic women may be remarkably different from women in the general population as compared to men, and they may face added barriers to social participation and feelings of sufficiency. However, this study did not include a non-autistic comparison group. Future studies are warranted to compare autistic women and men with their same-gender counterparts in the general population.

Finally, differences among autistic women and men are important to note to understand the social processes around gendered patterns of participation. We found that autistic women without ID reported less satisfaction with their participation level in important social activities (i.e., sufficient participation in lower ratios of activities perceived important) than autistic women with ID. This is likely because autistic women without ID have stronger awareness of the social demands for socializing and higher motivation for social interaction than autistic females with ID (Hull et al., 2020) and autistic males (Sedgewick et al., 2016), while their needs are not met. It is also possible that women with ID had both lower external and internal expectations of their participation levels and were more likely to be satisfied with their social participation. This finding indicates autistic women without ID may have increased, or different, service and support needs to reach their social participation goals. Additionally, differences amongst autistic men indicate that these patterns are salient for gender in general. Autistic men without ID reported higher ratio of participation in activities perceived important of social participation than those with ID. Similarly, it is possible that autistic men without ID may have different opportunities and experiences that support engaging in more diverse activities, although not more often.

Several factors limit generalizability of the results: (1) its exclusion of nonbinary participants; (2) a relatively small sample size of the ASD-ID group, especially autistic women with ID; (3) most participants being non-Hispanic white; (4) the ability to self-report that might prevent some people (e.g., those with high support needs) from participating in this study; (5) self-reported data, including the

diagnosis of ID; (6) little information collected about autistic adults with ID (e.g., cognitive ability, level of independent living). Thus, future research should seek to replicate and clarify these findings with a more diverse sample, especially those sufficient to conduct alternative tests of the hypothesis, such as types of activities (e.g., organized and structured activities) or initiation of activities. However, utilizing self-reports rather than clinical diagnoses has become more common as community methods have gained traction, especially to reach populations often in the peripherals of autism research (Garfield & Yudell, 2019). Despite limitations, our results suggest autistic adults, especially women without ID, face barriers to social and community participation in the ways they prefer. Our findings reflect the inadequacy of individuals' support network, services, and environments to accommodate distinct needs and preferences of autistic women without ID to engage in social and leisure activities. Additionally, women have not been adequately represented in autism research. Substantial inclusion of autistic women in the future research is necessary to lead robust evidence fully describing their participation motivation and experiences, which will generate knowledge on how to best support autistic women across the life course.

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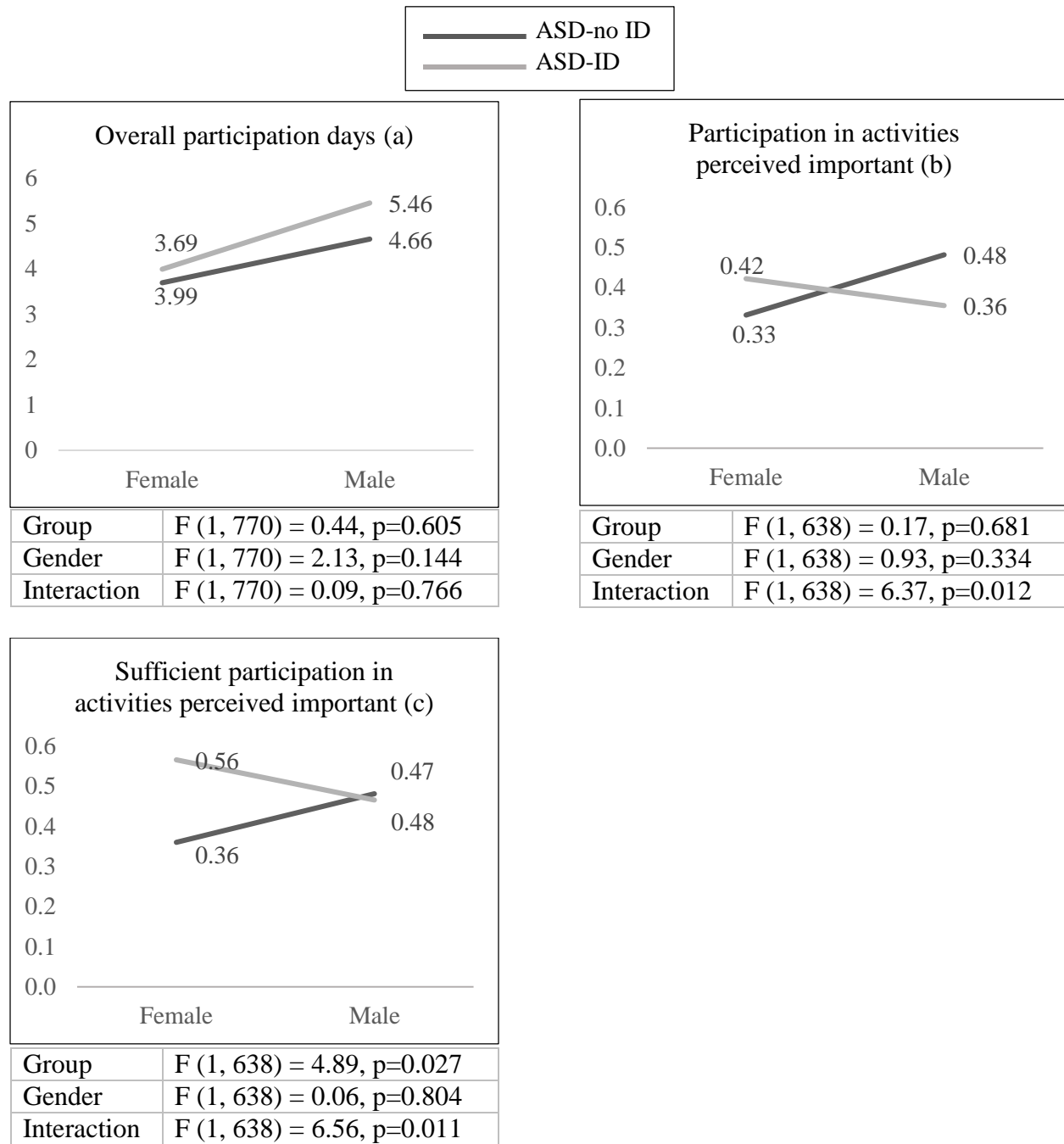


Figure 1. Participation days (a), participation in activities perceived important (b), and sufficient participation in activities perceived important (c) of social participation by gender and diagnosis group, controlling for age. The table below each figure displays the ANCOVA results of main effects of interaction effects.

Table 1. Sample characteristics and participation outcomes by groups (N=775)

	ASD-No ID			ASD-ID			<i>p</i> values ^d
	Female (n=164)	Male (n=449)	Group Total (n=613)	Female (n=53)	Male (n=109)	Group total (n=162)	
Age (SD)	29.1 (10.4)	27.0 (10.2)	27.6 (10.3)	27.2 (9.1)	29.2 (10.6)	28.5 (10.1)	0.296
<i>Race and ethnicity (%)</i>							
Non-Hispanic White	135 (83)	362 (81)	497 (81)	42 (84)	77 (71)	119 (75)	0.068
Non-Hispanic Black	11 (7)	28 (6)	39 (6)	4 (8)	14 (13)	18 (11)	0.034
Hispanic	6 (4)	18 (4)	24 (4)	0 (0)	7 (6)	7 (4)	0.815
Others	10 (6)	41 (9)	51 (8)	4 (8)	11 (10)	15 (9)	0.663
More than a high school education (%) ^{a,c}	85 (55)	266 (61)	351 (60)	5 (11)	26 (26)	31 (21)	<0.001
Currently employed (%)	65 (40)	200 (45)	265 (44)	19 (37)	43 (41)	62 (40)	0.355
<i>Living arrangement (%)</i>							
Living alone ^{a,b}	42 (26)	56 (13)	101 (17)	3 (6)	7 (7)	10 (6)	0.004
Living with family or roommate ^{a,b}	113 (69)	373 (83)	486 (80)	41 (77)	82 (76)	123 (76)	0.952
Other living situations	8(5)	15 (3)	33 (4)	9 (17)	19 (18)	28 (17)	0.001
Living in urban areas (%)	22 (15)	87 (21)	109 (19)	17 (34)	21 (20)	38 (25)	0.116
Married (%)	8 (5)	16 (4)	24 (4)	1 (2)	1 (1)	2 (1)	0.082
Has children (%) ^b	15 (10)	21 (5)	36 (7)	2 (4)	3 (3)	5 (4)	0.171
<i>Annual personal income (%)</i>							
≤ \$20,000	137 (84)	377 (84)	514 (84)	49 (93)	97 (89)	146 (90)	0.102
≥ \$20,001	27 (16)	73 (16)	99 (16)	4 (7)	12 (11)	16 (10)	/
<i>Mental health diagnosis</i>							
Any mental health diagnosis (%) ^{a,b,c}	133 (81)	327 (73)	460 (75)	43 (81)	71 (65)	114 (70)	0.148
Number of mental health diagnoses (SD) ^a	2.25 (1.23)	2.01 (1.23)	2.08 (1.24)	2.47 (1.32)	2.03 (1.03)	2.19 (1.16)	0.452

Insurance status (%)								
Public insurance (Medicaid)	122 (76)	302 (70)	424 (72)	50 (94)	98 (91)	148 (92)	<0.001	
Other	38 (23)	127 (30)	165 (28)	3 (6)	10 (9)	13 (8)	/	
Social participation								
Days (SD)	3.63 (6.26)	4.69 (7.36)	4.41 (7.09)	4.02 (5.70)	5.39 (15.55)	4.94 (13.16)	0.484	
Number of activities perceived important ^{a,b}	2.44 (1.79)	2.12 (1.58)	2.21 (1.64)	2.75 (1.74)	2.41 (1.68)	2.52 (1.70)	0.015	
Participation in activities perceived important (SD) ^{a,b}	0.33 (0.37)	0.48 (0.43)	0.44 (0.42)	0.42 (0.41)	0.35 (0.40)	0.38 (0.41)	0.056	
Sufficient participation in activities perceived important (SD) ^{a,b}	0.36 (0.38)	0.48 (0.43)	0.45 (0.42)	0.56 (0.41)	0.47 (0.41)	0.50 (0.41)	0.103	

Note. ^a A significant gender difference regardless of ID status ($p < 0.05$).

^b A significant gender difference within ASD-No ID group ($p < 0.05$).

^c A significant gender difference within ASD-ID group ($p < 0.05$).

^d p values were calculated using Chi-square test (for categorical variables) or t-test (for continuous variables) to compare ASD-No ID and ASD-ID groups.