



# Community Participation Comparison Between Adults on the Autism Spectrum and Adults in the General Population

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Accepted: 29 April 2021 / Published online: 9 May 2021

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## Abstract

Little research has examined the full-range of participation among adults on the autism spectrum. The current study addresses this knowledge gap by comparing the frequency, importance, breadth, and sufficiency of participation between autistic adults and adults in the general population. Autistic adults participated less, had fewer areas that were important to them, participated in fewer areas that were important to them, and were less satisfied with their participation even after controlling for demographic characteristics. Moreover, this study raises questions about what influences their perceptions about the breadth of activities that are important to them and the degree to which they desire to participate in those areas. Suggestions for future interventions and research are offered.

**Keywords** Autism spectrum disorder · Adult · Community activities · Participation · Group comparison

The World Health Organization (WHO, 2005) has identified meaningful community participation in major life areas, including work and school, community, social, and civic life, and strong interpersonal interactions and relationships, as being associated with social determinants of health and well-being for individuals of all ages in the general population (Kuykendall et al., 2015). Community participation is

an area of particular difficulty for many individuals on the autism spectrum (Askari et al., 2015) given the social and communication components of an autism spectrum disorder (ASD) diagnosis. Reduced rates of participation among autistic adults contribute to poor health outcomes, including quality of life (Billstedt et al., 2011; Bishop-Fitzpatrick et al., 2017), which has led some to refer to the promotion of community participation as a medical necessity (Salzer, 2021).

Comparisons between autistic individuals and typically developing cohorts can shed light on potential disparities that require the attention of policymakers and practitioners. A number of such studies have focused on participation among children and adolescents on the autism spectrum. Youth on the autism spectrum participate less frequently and in fewer activities compared to their typically developing peers in the areas of social activities, recreational and leisure activities (e.g., Potvin et al., 2013; Shattuck et al., 2011; Solish et al., 2010), out-of-school activities (Hilton et al., 2008), as well as community activities (Egilson et al., 2017). For instance, two studies of community participation compared the participation of ASD children and adolescents under 18 years old with non-autistic peers and found that the ASD sample had relatively lower frequency and involvement in seven out of ten community activities (e.g., community events, getting together with other children, overnight visits or trips) compared with their typically developing peers

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(Egilson et al., 2017; Lamash et al., 2020). However, for recreational activities that are skill-focused, solitary, and passive in nature, such as reading books, playing computer and video games, doing craft, several studies have found no differences between children with and without ASD in participation diversity and intensity (Hilton et al., 2008; Potvin et al., 2013; Ratcliff et al., 2018; Solish et al., 2010). The latter findings may reflect different participation preferences between autistic individuals and those without a diagnosis of ASD, such as placing more importance on activities performed in solitude.

Little research has been conducted to understand the full-range of community participation among autistic adults beyond research examining employment and social relationships. There is growing evidence that unemployment or underemployment and social isolation are common experiences among autistic adults (Billstedt et al., 2011; Farley et al., 2018; Howlin et al., 2013; Marriage et al., 2009; Orsmond et al., 2013; Tobin et al., 2014). Similar to autistic children, research has found that autistic adults participate more in solitary activities (e.g., walking, exercising by oneself) than those having social components (e.g., socializing with friends, social events) (Bishop-Fitzpatrick et al., 2017; Chen et al., 2016). Orsmond et al. (2013) compared a group of young autistic adults (21–25 years old) to other disability groups (i.e., intellectual disability, emotional disturbance, and learning disability) and found that young autistic adults had a much higher likelihood of being socially isolated, with no contact with friends, no phone calls, and no invitations to activities.

This study addresses important gaps in the literature by comparing participation among autistic adults with a general adult population in a broad range of areas that are identified in the Temple University Community Participation (TUCP) measure (see more details in the Measures section below). Findings from studies that include autistic adults are needed to identify intervention targets, especially if major differences in overall participation are discovered. Moreover, it could provide future intervention directions if gaps are particularly evident in specific areas, such as leisure, faith, or political and civic participation. Finally, it is important to determine whether there are differences between autistic adults and the general population in terms of what types of participation are important to them and how satisfied they are with their participation. It is essential to consider why disparities in participation exist as they raise questions about the participation interests and choices of autistic adults and whether less participation should necessarily be viewed negatively, especially from a self-determination perspective (Wehmeyer & Shogren, 2016). Specifically, this study examines whether autistic adults are satisfied with their level of community participation even if they have lower actual participation in community activities, and fewer areas that

are important to them. The results could provide a direction for future research, such as examining the impact of discrimination on participation, whether autistic individuals have adapted their preferences, or how sensory preferences influence participation preferences.

This study involves a large sample of autistic adults from urban and non-urban areas and compares them to a national, general population sample. Participation is assessed in a broad-range of areas and includes an assessment of the amount of participation in each area, how important each area is, and how satisfied respondents are with their participation in each area. The aims of this study are to answer the following research questions:

- (1) Are there differences in the amount, breadth, perceived importance, and sufficiency of participation between autistic adults and adults in the general population?
- (2) How is the participation and importance of participation of autistic adults and the general population similar or different in specific areas?

## Methods

### Data and Samples

#### ASD Sample

Data for this study were collected from the Pennsylvania Autism Needs Assessment (PANA) being conducted between May 2017 and June 2018 in a large, Mid-Atlantic State of the U.S. Pennsylvania. The survey aimed to inform state policy about autism services. The survey included questions about clinical characteristics, health, service assess, activities of daily living, education and employment, and community participation (measured by TUCP). Two methods were used to recruit participants. First, Pennsylvania residents who were enrolled in Medicaid and had a claim or encounter with an ASD diagnosis (ICD-9 299.XX or ICD 10 F84.X) were mailed a letter informing them about the survey. Second, information about the survey was also distributed through ASD-specific advocacy and policy organizations in the state, which maximized outreach, but also prevents an accurate assessment of a response rate. The survey was translated into 14 languages and respondents were offered multiple administration methods, including web-based, paper, and phone-based completion of the survey. The letter provided a website link where participants could go to complete the survey online and gave a contact phone number and email if individuals preferred to request a paper copy. Respondents over the age of 18 could complete the survey by themselves or with a caregiver or support

person to assist them in order to maximize accessibility and response rates. Study procedures were approved by the Drexel University Institutional Review Board.

A total of 1527 individuals on the autism spectrum completed the statewide survey. Three hundred and twenty-four respondents indicated they were under 18 years-old or did not respond to the age question and were excluded from the study, leaving 1203 adult respondents. The survey included multiple areas of participation. Respondents who had at least 75% of the responses on the TUCP measure ( $N=816$ ) were retained for analysis. An additional 15 respondents were excluded because they reported more than 250 participation days of activity over the last 30 days, which was more than two standard deviations greater than the mean participation for the sample and viewed as highly unlikely by the study team. The final ASD sample includes 801 autistic adults.

### General Population Sample

A sample of 300 community dwelling adults (18–65) who spoke English were recruited from among individuals who took part in the Truven Health Analytics' PULSE survey between September 2014 and December 2015. The PULSE survey is the largest privately funded health survey in the United States that uses landline, mobile phone and internet sampling methods to obtain a geographically stratified random sample of the continental US population. Truven provided data from 40,831 individuals who were surveyed over the nine months as part of another study aimed at identifying national samples of adults with and without serious mental illnesses. A total of 32,993 individuals answered "No" to the following question—"Have you ever been told by a psychiatrist or other mental health professional that you have major depression, bipolar disorder, manic depression, schizophrenia, or schizoaffective disorder?" A total of 15,324 of these individuals were willing to provide their contact information for a future study. Individuals who agreed to be contacted were then randomly selected in blocks of 40 to attempt to reach by phone in order to participate in a study about their community participation, well-being, and other related areas. Research staff attempted to contact 1481 individuals until the study goal of 300 enrolled participants who completed the measures through a telephone-based interview was achieved. All participants provided informed consent and received \$20 for completing the survey. The research protocol was approved by the Institutional Review Boards of the partnering universities for that study.

## Measures

### Community Participation

Community participation was measured with the 22-item version of the Temple University Community Participation (TUCP). The scale measures independent participation (e.g., without a program staff person going out with individuals) in the past 30 days capturing 22 areas such as working for pay, going to school for a degree, volunteering, going to place of worship, going to a library, going to a park, going to a social group, and hosting or visiting family or friends. For each item, the participant was also asked (a) number of days (0–30), (b) if the activity was important to them ("yes" or "no"), and (c) if they felt that they had done the activity enough ("enough," "not enough," or "too much"). The TUCP has been used previously to measure community participation in a number of published studies (e.g., Salzer et al., 2015; Terry et al., 2019). It has demonstrated good test–retest reliability (Salzer et al., 2014) and inter-method reliability (Salzer et al., 2015).

As mentioned earlier, the TUCP was administered to the general population sample by a telephone-based interview. That sample had no missing data on the TUCP. The ASD sample completed the TUCP primarily online and had a pattern of missing responses that was addressed in data cleaning. Specifically, some ASD respondents did not enter a response on amount of participation when they reported the participation area was not important. Examination of more complete responses from the ASD sample indicated that respondents rarely reported any participation in areas that were indicated as not important to them. Therefore, "0" days of participation was entered when responses were missing, and the individual reported the area as "not important" to them. Some ASD respondents also did not answer the question about doing the activity "enough," "not enough," or "too much," when they reported the activity as not important to them. Examination of more complete responses from the ASD sample indicated that they almost always reported "enough" if the activity was also viewed as "not important" to them. Therefore, "enough" was entered when responses were missing, and the individual reported the area as "not important" to them.

The following community participation constructs were created to assess overall participation and participation by area:

- (1) Frequency: total number of days of participation across the 22 items and number of participation days in each participation area, with higher number indicating greater frequency of participation.
- (2) Important areas: the total number of areas that are considered important, with higher scores reflecting a

greater number of important activities, and the proportion of individuals who considered each participation area important.

- (3) Breadth of participation: (a) the total number of important areas with at least one day of participation in the past 30 days, with higher scores reflecting greater breadth of participation; and (b) the ratio of the number of important activities with at least one day of participation (numerator) to the number of important activities (denominator), with higher scores reflecting greater breadth of participation in activities that are important to the individual (i.e., breadth ratio).
- (4) Sufficiency of participation: (a) the ratio of the number of important activities engaged in “enough” (numerator) to the number of important activities (denominator), with higher scores reflecting increased sufficiency in activities that are important to the individual (i.e., sufficiency ratio); (b) the proportion of individuals who engaged in “enough” participation in each area that is important to the individuals; and (c) sufficiency thresholds are the average number of participation days for each area among individuals who reported the area as important to them and where they had done enough.

### Covariates

Demographic variables included age (years), sex (Male or Female), race/ethnicity (non-Hispanic White and others), urbanicity (i.e., living in an urban area), and more than a high school education.

### Data Analyses

Data analyses compare autistic adults to adults in general population on the various participation constructs and at the individual item level. First, community participation amount, importance, breadth, and sufficiency over 22 items were examined with t-tests for the summary scores. We compared participation frequency, importance, and sufficiency in each activity by groups using t-tests (for continuous outcomes) or chi-square tests (for categorical outcomes). Effect sizes were calculated and evaluated by Cohen’s *d* for t-tests, with 0.2 considered as a small effect, 0.5 as moderate effect, and  $\geq .08$  as large effect (Cohen 1988). Cramer’s *Phi* ( $\phi$ ) coefficients were calculated for chi-squared tests. A  $\phi$  of .1 was considered a small effect, .3 a medium effect and .5 or higher a large effect. Second, we further compared community participation summary scores using analyses of covariance (ANCOVAs) to examine whether any differences remained significant after controlling for demographics that were identified as being associated with the outcomes for both samples. Those covariates included biological sex (male, female), race/ethnicity (non-Hispanic white and

other), age, education level (more than a high school education), and urbanicity (urban and nonurban). Effect size was estimated via partial eta-squared ( $\eta^2$ ). Covariates were also controlled for the outcomes that were different between groups in specific items using ANCOVAs or logistic regression. All analyses were conducted using SPSS version 26.

## Results

### Sample Characteristics

The final sample includes 801 autistic adults and 300 adults in the general population. Table 1 presents demographic characteristics between the two groups. Compared with the general population sample, the ASD sample had a higher proportion of men (72.0% vs. 45.3%) and was significantly younger (Mean of 27.81 vs 51.48 years). They were also less likely to live in urban areas (20.5% vs. 80.4%), be married (3.5% vs. 51.0%), and have children (5.8% vs 71.2%). The ASD group also had a lower education level, with only 52.7% receiving some sort of postsecondary education versus 84.9% for the general population group. Regarding annual income, the ASD participants had a lower level of annual income than the adults in the general population. Specifically, the majority of the ASD group earned \$10,000 or less (71.9%), whereas only 23.0% of the general population group fell into that category. The distributions of racial and ethnic groups were similar in the two samples with dominantly non-Hispanic White.

Among autistic adults, about 20% ( $n=166$ ) of the sample had intellectual disability. The majority of the sample had mental health problems (75%,  $n=609$ ). Most of the autistic adults were prescribed medication at the time of survey (74%,  $n=600$ ). About 11% ( $n=91$ ) went to the emergency room or were hospitalized due to psychiatric or behavioral reasons.

### Comparison of Community Participation Outcomes

Significant differences between autistic adults and adults in the general population were observed for all participation outcomes based on the unadjusted bivariate two-group comparison (Table 2). Given a number of demographic differences between the groups, ANCOVAs were conducted that controlled for age, sex, race/ethnicity, urbanicity, and education level. The comparisons of the covariate-adjusted means are presented in Table 2 and the groups differences remained significant: total number of participation days (31.76 vs. 61.65;  $F(1,962)=66.08$ ,  $p<.001$ ,  $\eta^2=.064$ ), total important areas (10.13 vs. 13.84;  $F(1, 962)=43.52$ ,  $p<.001$ ,  $\eta^2=.043$ ), breadth (4.54 vs. 8.39;  $F(1, 962)=79.52$ ,  $p<.001$ ,  $\eta^2=.076$ ), breadth ratio (0.47 vs. 0.62;  $F(1, 930)=17.88$ ,  $p<.001$ ,  $\eta^2=0.019$ ), and the sufficiency ratio (0.51 vs. 0.58;  $F(1, 962)=3.94$ ,  $p=.047$ ,  $\eta^2=.004$ ).

**Table 1** Summary of the characteristics of ASD (n = 801) and general population samples (n = 300)

	ASD		General population		T test or Chi-square test
	N	%	N	%	
Gender (male)	558	72.0	136	45.3	$p < .001$
Race and ethnicity					
Non-Hispanic White	637	80.0	230	76.7	$p = .223$
Non-Hispanic Black	58	7.3	29	9.7	$p = .194$
Hispanic/Latino	31	3.9	15	5.0	$p = .374$
Others	70	8.8	26	8.7	$p = .947$
Education (> a high school degree)	401	52.7	254	84.9	$p < .001$
Current employed	332	42.0	180	60.2	$p < .001$
Living in urban areas	154	20.5	230	80.4	
Married	27	3.5	150	51.0	$p < .001$
Has children	42	5.8	213	71.2	$p < .001$
Annual personal income					$p < .001$
≤ \$10,000	576	71.9	67	23.0	
\$10,001–\$20,000	108	13.5	57	19.6	
\$20,001–\$30,000	45	5.6	42	14.4	
\$30,001–\$40,000	12	1.5	30	10.3	
≥ \$40,001	60	7.5	95	32.6	
	Mean	SD	Mean	SD	
Age	27.81	10.17	51.48	11.33	$p < .001$

**Table 2** Unadjusted and covariate-adjusted descriptive statistics for community participation outcomes

	Unadjusted				t value	Covariate-adjusted				F value
	ASD		General popula- tion			ASD		General popula- tion		
	M	SD	M	SD		M	SE	M	SE	
Total number of participation days	30.10	33.02	62.67	32.63	− 14.62**	31.76	1.49	61.65	2.79	66.08**
Total number of important areas	9.96	5.29	14.03	4.16	− 11.99**	10.13	0.23	13.84	0.43	43.52**
Breadth	4.27	4.02	8.67	3.45	− 16.80**	4.54	0.17	8.39	0.33	79.52**
Breadth ratio	0.45	0.35	0.63	0.19	− 8.62**	0.47	0.01	0.62	0.03	17.88**
Sufficiency ratio	0.50	0.33	0.59	0.24	− 4.18**	0.51	0.02	0.58	0.03	3.94*

Covariates for adjusted analysis included age, sex, race/ethnicity, urbanicity, and education level

SE standard error, SD standard deviation

\* $p < 0.05$ ; \*\* $p < 0.001$

## Comparisons in Individual Community Participation Areas

### Participation Days

Table 3 provides the unadjusted means of total participation days in the last 30 days at the item level for autistic adults and adults in general population, showing significant differences between the groups in 15 out of 22 areas. Results of t-tests showed that autistic adults had a lower frequency of participation in 13 areas than the general

population sample, and a higher frequency of participating in 2 areas (i.e., going to school for degree and using public transit). The effect sizes (Cohen's  $d$ ) for going shopping, going to a restaurant or coffee shop, going to a place of worship, running errands, going to a gym, working for pay, getting together or attending events with family or friends, and entertaining or visiting friends or family were moderate to large ( $> .5$ ). After controlling for covariates, the group differences remained significant for 11 out of 15 activities, except for the following four areas: going to theater or cultural events; going to a zoo, botanical garden,

**Table 3** Group comparison of participation days by ASD status by activities

	ASD			General population			T-Test		<i>d</i>
	N	Mean	SD	N	Mean	SD	t	p	
1. Shopping	753	5.19	7.28	300	9.80	6.54	− 9.52	<0.001	− 0.94
2. Restaurant/coffee shop	760	3.42	6.07	300	6.21	5.90	− 6.81	<0.001	− 0.66
3. Place of worship	782	1.01	2.73	300	2.55	3.89	− 7.29	<0.001	− 0.65
4. Movie	782	0.53	1.30	300	0.49	0.89	0.48	0.629	0.05
5. Park/Recreation Center	777	1.25	3.70	300	2.99	5.83	− 5.82	<0.001	− 0.50
6. Theater/cultural event	790	0.33	1.32	300	0.73	1.83	− 3.97	<0.001 <sup>a</sup>	− 0.36
7. Zoo/Botanical Garden/Museum	789	0.15	0.63	300	0.28	0.81	− 2.84	0.005 <sup>a</sup>	− 0.25
8. Run errands	755	3.44	5.93	300	9.25	8.30	− 12.72	<0.001	− 1.14
9. Library	783	1.09	3.82	300	1.35	3.52	− 1.03	0.305	− 0.10
10. Watch a sports event	788	0.45	2.09	300	0.65	1.52	− 1.48	0.139	− 0.16
11. Gym	786	1.32	4.08	300	3.36	6.41	− 6.22	<0.001	− 0.54
12. Barber shop	763	0.51	1.52	300	0.78	0.99	− 2.86	0.004 <sup>a</sup>	− 0.30
13. Use public transit	773	2.16	6.00	300	1.05	3.88	2.97	0.003	0.31
14. Social group in the community	767	1.08	4.01	300	1.47	2.93	− 1.54	0.124	− 0.16
15. Work for pay	775	3.71	7.63	300	11.37	10.63	− 13.15	<0.001	− 1.17
16. School for degree	768	1.48	5.12	300	0.58	3.32	2.83	0.005 <sup>a</sup>	0.29
17. Class for leisure/life skills	786	0.45	2.24	300	0.25	1.89	1.36	0.174	0.14
18. Volunteer	779	1.24	3.88	300	2.57	5.29	− 4.53	<0.001	− 0.41
19. Get together/attend event with family & friends	771	0.65	2.13	300	1.66	2.59	− 6.50	<0.001	− 0.60
20. Entertain family or friends or visit them	760	1.63	4.05	300	4.67	5.27	− 10.05	<0.001	− 0.91
21. Community fair, event or activity	590	0.24	1.43	300	0.36	1.16	− 1.22	0.224	− 0.13
22. Civic/political activities	578	0.17	1.45	300	0.27	1.10	− 1.02	0.309	− 0.11

<sup>a</sup>No longer significant after controlling covariates based on ANVOCA

or museum; going to a barber shop; and going to school for a degree.

### Perceived Importance

Regarding perceived importance (see Table 4), results of chi-square tests showed that compared with the general population, lower percentages of ASD participants said the participation area was important on 17 out of the 22 areas. Going to a movie theater was the only area on which a higher percentage of autistic adults considered the area important, compared with the general population. Effect sizes ranged from small to medium, with the largest effects for entertaining or visiting family or friends ( $\phi = -.38$ ). The percentages for going shopping and going to a restaurant or a coffee shop, using public transit, going to school for degree, and taking a class for leisure or life skills were not different between the groups. After controlling for covariates, logistic regression revealed that group difference in 13 activities (e.g., running errands, watching a sports event, gym) remained significant, except for going to a movie, a theater or cultural event, a zoo, botanical garden, or museum, going to a library, and a barber shop.

### Participation Sufficiency

Some significant differences occurred at the item-level for participation sufficiency (i.e., # who indicated the area was important and done enough divided by # indicating it was important). Unadjusted binary group comparisons showed that significantly lower percentages of autistic adults reported participation to be sufficient in 11 out of 22 activities. After controlling for covariates, results of logistic regression with breadth of each area as dependent areas showed that autistic adults were significantly less likely to report sufficient participation in important activities compared with the general population in five areas: going to a theater or cultural event (32% vs. 44%;  $OR = .396$ ,  $p = .013$ ), going to a library (45% vs. 66%;  $OR = .314$ ,  $p = .001$ ), going to school for degree or certificate (42% vs. 65%;  $OR = .271$ ,  $p = .001$ ), getting together or attending event with friends and family (43% vs. 62%;  $OR = .416$ ,  $p = .004$ ), and entertaining or visiting family or friends (51% vs. 65%;  $OR = .561$ ,  $p = .050$ ).

When comparing sufficiency thresholds (i.e., average participation days for each area from among those participants who indicated the area was important and done enough) of each area, results of unadjusted binary t tests

**Table 4** Group comparison of percentage of important areas by ASD status by activities

	ASD			General population			Chi-Square Test		$\phi$
	N <sup>a</sup>	n <sup>b</sup>	%	N <sup>a</sup>	n <sup>b</sup>	%	$\chi^2$	p	
1. Shopping	784	627	80.0	300	259	86.3	5.88	0.015	– 0.07
2. Restaurant/coffee shop	778	511	65.7	300	210	70.0	1.82	0.177	– 0.04
3. Place of worship	777	299	38.5	300	216	72.0	97.45	<0.001	– 0.30
4. Movie	783	426	54.4	300	135	45.0	7.67	0.006 <sup>c</sup>	0.08
5. Park/Recreation Center	776	388	50.0	300	210	70.0	43.36	<0.001	– 0.20
6. Theater/cultural event	789	301	38.2	300	181	60.3	30.83	<0.001 <sup>c</sup>	– 0.18
7. Zoo/Botanical Garden/Museum	778	345	44.3	300	190	63.3	31.23	<0.001 <sup>c</sup>	– 0.17
8. Run errands	768	460	59.9	300	256	85.3	63.18	<0.001	– 0.24
9. Library	787	323	41.0	300	173	57.7	24.20	<0.001 <sup>c</sup>	– 0.15
10. Watch a sports event	782	220	28.1	300	131	43.7	23.87	<0.001	– 0.15
11. Gym	781	368	47.1	300	193	64.3	25.73	<0.001	– 0.15
12. Barber shop	777	403	51.9	300	194	64.7	14.36	<0.001 <sup>c</sup>	– 0.12
13. Use public transit	776	241	31.1	299	83	27.8	1.12	0.291	0.03
14. Social group in the community	761	318	41.8	299	172	57.5	21.39	<0.001	– 0.14
15. Work for pay	784	478	61.0	299	244	81.6	41.48	<0.001	– 0.20
16. School for degree	774	343	44.3	300	121	40.3	1.40	0.237	0.04
17. Class for leisure/life skills	785	337	42.9	300	140	46.7	1.23	0.267	– 0.03
18. Volunteer	785	395	50.3	300	235	78.3	69.96	<0.001	– 0.25
19. Get together/attend event with family & friends	782	412	52.7	300	254	84.7	93.71	<0.001	– 0.29
20. Entertain family or friends or visit them	775	450	58.1	300	291	97.0	153.09	<0.001	– 0.38
21. Community fair, event or activity	591	232	39.3	300	177	59.0	31.24	<0.001	– 0.19
22. Civic/political activities	570	103	18.1	299	143	47.8	85.56	<0.001	– 0.31

<sup>a</sup>Total number of the sample<sup>b</sup>The number of participants who said the participation area is important<sup>c</sup>No longer significant after controlling covariates based on logistic regression

revealed that autistic adults had a lower threshold for eight activities, which reduced to two activities after controlling covariates, including running errands (5.59 vs. 9.07 days;  $F(1,431)=9.13$ ,  $p=.003$ ,  $\eta^2=.021$ ) and entertaining or visiting family or friends (3.88 vs. 5.52 days;  $F(1,339)=9.89$ ,  $p=.002$ ,  $\eta^2=.028$ ). Autistic adults reported higher sufficiency thresholds for using public transit after controlling for covariates (8.91 vs. 4.15 days;  $F(1,158)=6.59$ ,  $p=.011$ ,  $\eta^2=.040$ ).

## Discussion

This study compares the frequency, importance, breadth, and sufficiency of independent community participation between autistic adults and adults in the general population across a wide range of activities. As expected, autistic adults demonstrated lower frequency, perceived importance, breadth, and sufficiency of community participation compared to a general population sample, even after controlling for possible covariates. These results echo previous studies that have found limited participation in recreational and social

activities among preschoolers (LaVesser & Berg, 2011), children (Potvin et al., 2013; Reynolds et al., 2011), adolescents (Lamash et al., 2020), and both children and adolescents (Egilson et al., 2017; Solish et al., 2010) on the autism spectrum, compared with same-age peers. Our findings verify that preferences for lower participation in community activities continues into adulthood among individuals on the autism spectrum. This study is particularly novel in understanding participation of autistic adults because it also assesses the degree to which autistic adults view various areas as important to them, whether they participate in those important areas (i.e., breadth), and whether they feel they do enough in those important areas (i.e., sufficiency), regardless of how frequently they engage in that activity. All these constructs provide valuable additional context for services and supports that may be needed for this group.

## Participation Days

Our study found group differences in overall frequency of community participation. At the item level, autistic adults participated less frequently than the adults in the general

population in 11 out of 22 activities on the TUCP measure after adjusting for covariates. The significant differences in many item-level comparisons and the large effect size in the overall participation frequency reflect great disparities between the two groups of adults. It is worth noting that autistic adults reported that they went to school to earn a degree or certificate more days than the adults in general population. However, group difference in the number of days of going to school was no longer significant after controlling for age. Autistic adults were also more likely than adults in general to use public transportation, even after controlling for covariates. This is not surprising given the limited access to private vehicles among autistic adults, such as low rates of obtaining a driver's license and reluctance of driving their own car due to anxiety (Chee, 2015). They may heavily rely on public transportation to get around in their communities.

### Areas of Importance

Our results revealed that autistic adults had fewer community activities that were important to them compared to the adults in the general population. Previous studies have suggested that autistic individuals place more value on activities performed in solitude or with people they are familiar with, such as parents (Egilson et al., 2017). Similarly, our results revealed that autistic adults were less likely to consider social activities (e.g., spending time with friends, civic participation, community affair) as important than adults in the general population. Some leisure activities (e.g., going to a park or recreation center, watching a sports event, going to a gym), working for pay, and volunteering, can also involve some degree of socialization that might not be desirable. Individuals on the autism spectrum are often intrinsically motivated to engage in either solitary or social activities as they feel more competent and experience less difficulty in these conditions (Chen et al., 2015). Previous negative experiences and fear of being excluded may result in fewer attempts at initiating social interactions and participating in social activities (Chen et al., 2015; Maddox & White, 2015). Our findings are not surprising given that autistic people nuanced social strategies, and fewer positive experiences navigating social situations, which may lead to the avoidance of social activities. It is possible that community participation, especially when it may involve social interactions, may be a low priority due to the challenges that autistic adults encounter in such activities.

### Breadth and Sufficiency of Participation

Our findings suggest that even when autistic adults indicated that an area is important to them, they are less likely to be participating in those areas or satisfied with the degree to which they are participating compared to other adults. First,

the lower breadth ratio reveals that autistic adults have lower rates of participating in the activities that fit their interests and preferences compared to the general population. Second, a lower sufficiency ratio indicates that they are not participating to the extent they desire in areas they view as important compared to the general population. For instance, our results suggest that autistic adults are significantly less likely to be satisfied with their levels of participation in going to a theater or cultural event, going to school for degree or certificate, getting together or attending event with friends and family, and entertaining or visiting family or friends. Additionally, the general lack of differences regarding sufficiency thresholds (all areas except for running errands, using public transit, and entertaining or visiting family or friends) indicates that in areas that are important to autistic adults they generally seek about the same amount of participation to be satisfied as adults in the general population.

Overall, the totality of these findings suggests that autistic adults do have fewer areas that are important to them, but the disparities in their participation reflect barriers to participation instead of individual preferences for less participation. It is highly plausible that autistic adults face more barriers, personal experiences, environmental, and related to needed services and supports, that interfere with or prevent them from participating in the areas of interests or to the degree they desire. It has been consistently documented that behavioral and social problems may also limit the opportunities of participation among autistic people (e.g., Ghanouni et al., 2019; Kirby et al., 2016), as well as a lack of support and services from their families and communities (Egilson et al., 2017; Hammel et al., 2015).

### Implications

Limited participation frequency and diversity among autistic adults inform the needs of supports and services across lifespan. Although social and communication differences are a common feature of autistic adults (Magiati et al., 2014), general access to adult service and social supports are limited by program availability after exiting the school system (Laxman et al., 2019; Myers et al., 2015). Reduced participation in certain areas may be a unique feature of autistic adults based on different interests, sensory preferences/needs, mental health issues, or because of environmental factors, such as being treated poorly by others in the course of their participation, including overt discrimination. Individuals with autism often consider the environment less supportive and encounter more environmental barriers than individuals without autism (Askari et al., 2015). For instance, lack of social or friendship relations may affect individuals' opportunities to get together with other people and participate in various events in the community (Orsmond et al., 2013). Also, inaccessible built environments as

well as services, systems, and policies that do not accommodate their needs (e.g., sensory needs) reportedly limit individuals with autism's opportunities to participate in their communities (Askari et al., 2015). Those external factors increase the difficulties with social interactions, interpersonal relationships, and community skills among autistic individuals, impacting their abilities to fully participate in community settings (Hochhauser & Engel-Yeger, 2010; Poon, 2011; Reynolds et al., 2011; Shattuck et al., 2011).

It is plausible that some autistic people may have altered their desires for participation as a result of external barriers, such as lack of money, safety of the community, or the fear of negative attitudes and behaviors toward them (Krieger et al., 2018; Lamash et al., 2020), and research has shown that autistic adults report less interest in certain areas of participation or feel less satisfied with participation experiences compared to others (Stacey et al., 2019). This phenomenon of adjusting interests to the realities one experiences in attempting to participate has been referred to as “adaptive preferences” and is discussed in many contexts, including the understanding of participation of women (Khader, 2011). Some have argued, however, that autistic adults are less susceptible to these external influences and simply have more realistic expectations for themselves (Späth & Jongsma, 2020), including less social desirability in studies about their participation amounts and interests. As our finding demonstrated, autistic adults do not share common interests or view similar activities as important or as important as people in the general population. Qualitative methods could be applied to inquire about how autistic adults explain the differences in the interests of activities and how they would identify what areas of participation are important and they are not participating in their lives. Additionally, future research is warranted to clarify if autistic adults need facilitating supports to engage in a larger spectrum of activities by overcoming environmental and personal barriers, which may further change their perceptions of importance and sufficiency of the available activities.

Participation outcomes are considered one of the most relevant goals of support services for people with disabilities (CMS, 2014). However, little is known about the opportunities that adults with disabilities have to participate in community activities. Researchers conclude that studies should be conducted with autistic adults (van Heijst & Geurts, 2014) and that interventions be provided throughout their lives (Kamio et al., 2012). Most of the published research that focused on recreational and social participation among autistic individuals addressed children under 18 years or mixed-age in and out of school settings. Our study contributes to the advancement of the understanding of community participation in autistic adults. Engagement in meaningful leisure and social activities has contributed to improving quality of life and executive functioning as well as reducing

social isolation (Taylor et al., 2017; Wallace et al., 2016), anxiety and stress for autistic individuals (Bishop-Fitzpatrick et al., 2017; Garcia-Villamizar et al., 2017; Stacey et al., 2019). Thus, information on valued and desired activities is essential for person-centered services and goal setting in the community living.

However, this study did not analyze the internal (e.g., ASD severity, language impairment) or external factors (e.g., transportation, community features, and natural supports) that hinder or facilitate participation in community activities. Factors related to physical, social, and attitudinal environment probably contribute to the constraints faced by autistic adults to participate in activities in the community. Studies have shown many factors (e.g., living arrangements, service access, family involvement, etc.) that could influence social participation patterns among autistic youth (Myers et al., 2015; Shattuck et al., 2011). Future research should determine barriers and facilitators to guarantee the fundamental rights of autistic adults to participate in community activities. It could also help implement effective programs and develop intervention strategies to promote community inclusion and the quality of life of autistic adults.

## Strengths and Limitations

This study used a large sample and a comprehensive measure (Temple University Community Participation (TUCP); Salzer et al., 2014) to better understand the patterns of community participation among autistic adults comparing to adults in the general population. The measures of community participation and the categories of activities encompassed in the different types of participation are poorly defined in the ASD literature. Many studies either used national surveys (e.g., Orsmond et al., 2013) or author-constructed measures (e.g., Solish et al., 2010). The TUCP captures a full range of participation in multiple areas, including employment, education, leisure, faith, and interactions with friends and family. It also goes beyond measuring the quantitative scales of participation (i.e., frequency and diversity) and provides information about individual preferences and sufficiency of participation. Subjective evaluation of activity importance and desire for change (not doing an important activity enough) provides key insights into priorities and valued activities for the autistic individuals that can help interpret the significance of reported activity frequency. Participants self-reported their participation in community activities in our study. Characteristics of participation, such as perceived importance and sufficiency, may best be evaluated through direct response from the participants. Additionally, the inclusion of a comparison group added significant value in understanding community participation in the larger society.

However, there were several limitations of this study. First, we acknowledged that the types of participation (as

well as importance of participation) are limited to the areas that have been identified in the TUCP measure and therefore not all inclusive. Second, the methods of data collection of ASD sample and general population sample may account for some differences found in the community participation. Specifically, the data collection of autistic adults used multiple options including web-based, paper, and phone-based methods, while the adults in the general population were only provided with phone-based option. However, the responses of adults in the general population were facilitated with an interviewer over the phone, while autistic adults self-reported community participation, potentially with assistance from caregivers or staff. Adults in the ASD sample resided in Pennsylvania, where they might experience common cultural and systems issue that impact participation, whereas the general population sample was national. Third, our ASD sample consisted primarily of young adults (18 to 30 years old), and the general population sample consisted primarily of middle-aged and older adults (40 years and older). Bias resulting from unmeasured and therefore omitted variables such as comorbidity, mental health conditions, mobility, may result in biased parameter estimates. Future studies should consider these factors. Last, although self-report is a strength of this study, we also limited our participants to those who had cognitive and language abilities, which could lead to bias in sample selection and responses. There were differences between autistic and general population groups, including the autistic group comprising a more significant proportion of young adults, males, and living in the non-urban areas, who are not married or do not have children. Qualitative studies could complement our findings by exploring individual meanings and preferences of community participation for autistic adults and offer a deeper understanding of this complex construct.

## Conclusion

This study presents objective and subjective evidence on the patterns of participation of a wide range of activities across the entire spectrum of autistic adults. The findings highlight that autistic adults had demonstrated lower frequency, diversity, and perceived importance of participation in productive, social, and recreational activities than the general population reported by participants; however, both groups demonstrated similar sufficiency in community participation. We found a striking lack of interest which might be addressed to support autistic adults to be more involved in their communities. This calls for potential avenues for intervention to improve their participation opportunities and experiences in alignment with their interests or to grow areas of interest. Engaging autistic adults in meaningful and satisfying community

activities is paramount and may positively influence depression, anxiety, stress, and overall quality of life.

**Acknowledgments** This work was supported by grant from Eagles Autism Foundation in support of the proposal *Getting Out There: Identifying Individual, Environmental, and Service Use Factors Associated with Community Participation among Adults with Autism Spectrum Disorder*.

**Author Contributions** Data collection of autistic participants were performed under the supervision of LS. EB and GT guided the collection of adults of general population. WS performed the statistical analyses. WS wrote the first draft of the manuscript. All authors provided critical feedback on the previous versions of the manuscript and approved the final version for submission and publication.

**Funding** This work was supported by grant from Eagles Autism Foundation in support of the proposal *Getting Out There: Identifying Individual, Environmental, and Service Use Factors Associated with Community Participation among Adults with Autism Spectrum Disorder*.

## Declarations

**Conflict of interest** The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Ethical Approval** All procedures performed were in line with the principles of the Declaration of Helsinki. The study protocol was approved by the Institutional Review Board of Drexel University.

**Consent to Participate** Informed consent was obtained from all individual participants included in the study.

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