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# "A Week in the Life:" Exploring community participation of autistic adults through GPS mapping<sup>★</sup>

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#### ABSTRACT

Participation is connected to health-related quality of life for autistic adults. However, autistic adults engage in less community participation compared to their non-autistic peers and individuals of other disability groups. More data are needed to understand community participation from autistic adults' perspective. This study aims to address how autistic adults are engaging in their communities, what are predictors of community participation, and what types of community locations are important. This study used a mixed methods approach. Forty autistic adults (ages 24 - 62 years) completed survey data, 1 week of Global Positioning System (GPS) tracking, and interviews to assess the importance of community locations and feelings of belonging. GPS data showed participants engaged in a variety of community activities; most frequently grocery shopping, eating fast food, working, and walking in the community. Least frequent activities observed included dating; going to a park, festival, or sporting event; and getting a haircut. Participants who lived with parents/guardians were more likely to have community activities closer to home and therefore smaller activity spaces than those who lived more independently, while currently employed participants spent more time away from home and visited more unique locations than those who were unemployed. Age was also positively associated with time spent away from home. While many autistic adults were involved in activities in the community, less than half (38 %) endorsed feeling a part of the community. Results of this study indicate that adults who live less independently may require additional support to participate broadly in the community, but supporting autistic adults in securing employment in any capacity may provide additional benefits to community participation.

One in 36 children are now diagnosed with autism spectrum disorder (ASD) (Maenner et al., 2023). While much of the research to date has focused on early diagnosis and intervention for autistic children, life for autistic adults is "woefully under researched" (Howlin & Taylor, 2015, p. 771). Systematic reviews consistently demonstrate autistic adults are less likely to live independently, have poorer

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outcomes maintaining employment and completing post-secondary education, and have fewer social connections than both non-autistic peers and those with intellectual disabilities, learning disabilities, and speech-language disorders (Gotham et al., 2015; Kirby et al., 2016; Levy & Perry, 2011; Orsmond et al., 2013; Roux et al., 2013). Each of these outcomes contributes to the individual's overall participation in the community, which has been measured with similar discrepant findings (Brown et al., 2022; Song et al., 2021).

These findings of adult outcomes are important, as systematic reviews of social participation identified presence of meaningful daytime activity as one of the most important factors contributing to quality of life (QoL) for autistic adults (Cameron et al., 2022; Tobin et al., 2014). Flores and Delariarte (2021) similarly found participation, especially participation in social and leisure activities, is connected to health-related QoL for autistic adults without intellectual disabilities.

Notably, there is a sharp decline in community participation following high school for individuals with autism. A review of the National Longitudinal Transition Study-2 (NLTS-2) data reported a significant decrease in participation from adolescence to adulthood for autistic individuals, even when considering participation in one community activity per year as a positive outcome (Myers et al., 2015). In a separate study, approximately 50 % of autistic adults had poor social participation outcomes related to occupation, friendships, and independent living (Steinhausen et al., 2016). Rates of paid employment are low across all autistic individuals, and most community outings and social activities are organized by others, even in adulthood (Gray et al., 2014; Levy & Perry, 2011). There is often a loss of community connections and supports after high school that are not replaced by the adult service system (Myers et al., 2015).

At the same time, current participation measures for autistic individuals and the definition of "success" for adult outcomes are also being debated. Much of the available research relies on objective measures of counts of frequency of activities without consideration of satisfaction with activities or amount of participation from the individual's perspective, which may be a better predictor of QoL (Orsmond et al., 2013; Tint et al., 2017). Defining participation as frequency alone is not a reliable measure, as it only weakly and inconsistently correlates with satisfaction (Tint et al., 2017). There is a need to examine the duration of participation in activities and assess the desired level of participation for more meaningful data and a more complete picture of community participation (Gray et al., 2014; Tint et al., 2017). As one research group poignantly noted, "What we cannot know from these close-ended surveys is what autistic adults do with their time if they are not employed and do not have access to services and programming" (Gotham et al., 2015, p. 800). Lord et al. (2020) highlighted further challenges of adult outcome research including reliance on small samples, caregiver responses, and survey data.

Current survey measures of participation have limited ability to capture the individual's physical presence in the community, how time is spent, and use of community resources. Through passively and consistently collecting geographic information, Global Positioning System (GPS) tracking devices provide objective data on the frequency and duration of actual participation in community activities, distance traveled, and locations visited. Further, Geographic Information Systems (GIS) mapping of GPS collected data extends the ability to synthesize and analyze geospatial data. Combining GIS and GPS data is a method emerging in rehabilitation research to enhance understanding of mobility, participation, and social interactions (Doherty et al., 2014; McCluskey et al., 2012; Jayaraman et al., 2014).

Although there is emerging literature using GIS and GPS to examine community participation in disability populations, there are few published studies using GIS or GPS to examine community participation in autistic adults. One study used GPS tracking to measure community participation before and after the COVID-19 pandemic with six autistic young adults and found all measures of community participation and mobility decreased after COVID-19 (Pfeiffer et al., 2022). A separate study with six adults aged 29 - 51 years combined GPS data with sensory processing profiles to understand how sensory sensitivities and preferences impacted participation (Bagatell et al., 2022). Here, individuals who were sensory avoidant or sensitive spent less time and visited fewer locations in the community.

While GPS and GIS data can provide a comprehensive picture of daily activities and access to resources, it does not entirely capture the meaningfulness of these activities and services. Individual perceptions of satisfaction with current level of activity, desired amount of participation, and what promotes meaningful participation from the perspective of autistic adults as the experts are needed (Brown et al., 2022; McCollum et al., 2016; Tint et al., 2017; Tobin et al., 2014). Measures of sufficiency in the Temple University Community Participation survey revealed that even with less participation, autistic adults are doing enough activities that are important to them (Brown et al., 2022). Further understanding of what is meaningful to the individual and factors that facilitate participation is needed to develop client-centered services (McCollum et al., 2016), and to assess the utility of "normative" measures of adult outcomes when examining subjective well-being in autistic adults (Clarke et al., 2021). Research on the individual subjective experience of autistic adults and their desired outcomes will meet this gap (Tint et al., 2017). Therefore, it is important to use multiple methods to capture the community participation of autistic adults, both subjectively and objectively. The purpose of this mixed-methods study was to use GPS and GIS measures of participation to examine the community activities of autistic adults and predictors of community participation, combined with survey and interview data to understand the meaning and importance of these activities from the person's perspective. Specifically, we hypothesized that:

- 1. GPS measures of time spent away from home and number of unique locations will be more important predictors of community participation and feeling part of the community than activity space size.
- 2. Adults who are employed will have more time away from home and more unique locations than those who are unemployed, and feel more connected to the community.
- Adults with greater daily living, communication, and transportation skills will have greater participation than those with lower skills.

4. Compared to vocational and instrumental activities of daily living-related activity locations, autistic adults will most frequently report social locations as "most important."

#### Methods

This research followed a mixed methods design. Surveys, interviews, and 1 week of GPS tracking gathered information about community participation among autistic adults and specifically, what they perceive as meaningful community locations and participation. All aspects of the study were approved by the university's institutional review board.

#### **Participants**

Recruitment was completed through a university-based autism research registry that keeps a list of autistic individuals who are interested in participating in research. Inclusion criteria required participants to be between the ages of 25 and 64 years, have a documented diagnosis of autism spectrum disorder, and an IQ of 70 or above or a previous diagnosis of Asperger's disorder. ASD diagnosis and IQ scores were verified through psychological reports submitted to the registry. This IQ requirement was necessary because our study included participation in two 60-minute interviews, and past research has revealed that IQ is associated with language development in autistic individuals (Howlin et al., 2004). However, participants' IQ scores were not available to researchers to protect participants' private information.

The principal investigator or graduate research assistant conducted 30-minute screening calls with interested individuals to inquire about their ability to participate in two 1-hour interviews and confirm the study period would represent a typical week. All participants who were their own legal guardian consented to study participation. If the participant had a legal guardian, in the first interview the guardian provided written consent and the participant verbally assented to participate.

Forty autistic adults participated in the study; demographic information is summarized in Table 1. Most (n = 22) were employed either full-time or part-time, Approximately half (45%; n = 18) lived independently or with a spouse, partner or roommate, and 67.5% (n = 27) drove independently. One participant had minimal spoken language, and five participants had legal guardians.

Data were collected February 2019 through February 2020 (n = 29) and resumed October 2020 to April 2021 (n = 11) due to the COVID-19 pandemic. While pre-COVID participants were significantly younger than those collected after the break (x = 34.69 vs. 46.09, p = .003), there were no significant differences in community participation measures or other demographic variables between these groups.

**Table 1**Sample Demographics, SRS and WADL scores.

Demographics	n	%
Age		
M (SD)	37.80 (10.77)	-
Range	24 - 62 years	-
Gender		
Female	13	32.5%
Male	27	67.5%
Race		
White	33	82.5%
Black	4	10%
Multiracial	3	7.5%
Relationship Status		
Single, never married	28	70%
Married	8	20%
Divorced or separated	4	10%
Comorbid Diagnoses		
Mild intellectual disability	3	7.5%
ADHD	16	40%
Anxiety	18	45%
Depression	20	50%
Population Density of Residence		
Urban	36	90%
Rural	4	10%
Waisman Activities of Daily Living		
M (SD)	30.75 (4.99)	-
Range	10 – 34	-
Social Responsiveness Scale-2		
M (SD)	64.92 (9.85)	-
Range	47 – 88	-

 $Note.\ Population\ density\ was\ classified\ by\ the\ Rural-Urban\ Commuting\ Area\ Codes\ (https://www.ers.usda.gov/data-products/rural-urban-commuting-area-codes.aspx$ 

#### Procedure and Measures

#### Surveys

Participants or their legal guardians completed web-based versions of the Waisman Activities of Daily Living (W-ADL; Maenner et al., 2013), the Social Responsiveness Scale-2 adult form (SRS-2; Constantino & Gruber, 2012), and the TEACCH Autism Survey in Adulthood. The W-ADL was designed for individuals with developmental disabilities and contains 17 items that assess the individual's ability to complete daily living activities. Each activity is rated as 0 ("does not do at all"), 1 ("does with help"), or 2 ("independent"), with a total possible score of 34. A higher total score reflects greater independence in ADL performance. Internal consistency and test-retest reliability of the W-ADL ranges from good to excellent (Cronbach's alpha = 0.88–0.94; weighted kappas = 0.92–0.93), and scores were correlated with the Vineland screener, supporting its validity (Maenner et al., 2013).

The SRS-2 has four subscales (Social Awareness, Social Cognition, Social Communication, Social Motivation and Restricted Interests and Repetitive Behavior) and scores are reported as *T*-scores. Scores that fall between 60–65, 66–75, and above 75 are in the mild, moderate, and severe range of ASD symptomology, respectively. Inter-rater reliability coefficients ranged between 0.61 and 0.92. Content validity was supported through expert review and questions were aligned with diagnostic criteria in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text-Revision*. Construct validity of the SRS-2 was demonstrated through confirmatory factor analysis, where a two-factor structure was demonstrated (Bruni, 2014).

The TEACCH Autism Survey in Adulthood is a demographic questionnaire that inquires about age, race, living status, gender, driving skills, marital status, employment status, and comorbid conditions. This survey also includes questions about conversation ability through four questions rated on a 4-point Likert scale where higher scores reflect more communication impairment (i.e., 3 =doesn't communicate at all; 0 =has no trouble communicating).

# GPS tracking and travel diaries

All participants carried a GPS device with them whenever they left home for 1 week. GPS tracking data were downloaded to create a daily activity map. GPS data provided information about locations where participants spent time in the community, and this information was confirmed during the second interview. Each location extracted from the daily travel maps was entered into ArcGIS to create the individual's composite activity space map. Activity space is the spatial measure of all locations that an individual has direct daily contact with such as for work, shopping, and socializing (Zenk et al., 2011), and was computed in ArcGIS using the 1 Standard Deviation Ellipse method. The 1 Standard Deviation Ellipse method is used to capture the size and direction of approximately 66.7 % of the community locations visited, with the understanding that individuals do not typically visit every location each day. Three measures of community participation were calculated from the GPS data: average distance traveled (activity space size), the number of unique locations visited across the entire study week, and the average amount of time spent away from home on a daily basis across the study week.

Participants also completed daily travel diaries each day, filled out on paper or online to provide more information about the places visited and as a safeguard if the participant forgot the GPS device when they left home. Participants filled out the name of each location visited, time of the activity, purpose of the outing, the main type of activity, if they participated alone or with others, and mode of transportation.

# Interviews

After the GPS tracking period, participants completed online or in-person interviews. Interview questions centered around community and social participation, and important community locations. Additional information and qualitative analysis of interview data are published elsewhere (Chan et al., 2022). For the purposes of the current study, relevant interview questions included where participants felt they belonged the most, which community locations were most important to them, where they wished they spent more time, and if they felt part of the community.

#### Analysis

All analyses were performed in R Core Team (2022) at an alpha level of .05. Descriptive statistics were calculated for participant demographic information, SRS-2, WADL and GPS data. Backward selection stepwise regression analyses examined the association between individuals' characteristics and community participation, using three main outcomes (i.e., unique locations, time away from home, and activity space size). Predictors for each analysis included age, gender, race, current employment status, relationship status, independent living status, driving ability, having children, W-ADL score, TEACCH conversation ability score, and the four different subscale scores of the SRS-2 (communication, awareness, cognition, and motivation). For each of the outcomes, all predictors listed above were entered into the initial models. Final models were established through the minimization of the Akaike information criterion (AIC), where lower values of the AIC reflect better overall model fit compared to higher values of the AIC. Correlations between outcome variables were calculated. One participant's data was removed from the activity space analysis because he frequently traveled far distances for work, thus making his activity space much larger than the other participants (x = 1793.70, M = 80.79). In a logistic regression, we examined predictors of feeling a part of the community including average time away from home, unique locations, activity space, and current employment living status. One participant was missing data on the SRS-2 scales. Thus, this participant was removed from the analysis.

# Results

# Community participation

To examine the community participation patterns, we conducted descriptive analysis focusing on the type of activities, number of unique locations visited, time away from home, activity space size, and sense of belonging to the community. Participants averaged 13.73 (SD = 6.62) unique locations visited during their study week, but this ranged from 2-29 total locations during the week. Fig. 1

Ac	tivity type	% (N = 40)
-	Went grocery shopping	72.5% (N = 29)
-	Ate fast food (total)	60% (N = 24)
	<ul> <li>Ate fast food, including take out</li> </ul>	55% (N = 22)
	<ul> <li>Ate fast food (mainly pick up or drive thru)</li> </ul>	50% (N = 20)
	- Ate fast food as a social outing	10% (N = 4)
+	Went to work, including regular work, plasma donation (N = 2), freelance	
	work, pet sitting, and deliveries	55% (N = 22)
-	Went shopping for other products (hardware, beauty supplies, home goods)	52.5% (N = 21)
	<ul> <li>Went clothes or shoe shopping</li> </ul>	17.5% (N = 7)
•	Went to a restaurant with family or friends	52.5% (N = 21)
•	Went for a walk or participated in some form of exercise	45% (N = 18)
-	Got gas at a gas station	45% (N = 18)
•	Visited family or friends	37.5% (N = 15)
-	Picked up a prescription	32.5% (N = 13)
-	Ran errands for themselves, family members or friends, or with family	
	members but stayed in the car	30% (N = 12)
-	Went to the doctor for a health care visit	25% (N = 10)
•	Attended church or other religious activity	22.5% (N = 9)
-	Engaged in pet care (shopping for pets, grooming)	22.5% (N = 9)
	(• also social/recreational component: dog park, dog training)	7.5% (N = 3)
-	Went to the bank	22.5% (N = 9)
-	Picked up snacks or drinks from a gas station	17.5% (N = 7)
•	Went out for a social event (game night, out for drinks, a party, meet up, or	
	work social)	17.5% (N = 7)
•	Went out for coffee	15% (N = 6)
-	Got their car repaired	15% (N = 6)
•	Walked their dog	12.5% (N = 5)
+	Applied for a job, had a job interview, or met with their job coach $(N = 2)$	12.5% (N = 5)
•	Went to the movies	12.5% (N = 5)
•	Picked up family members	12.5% (N = 5)
+	Volunteered in the community	10% (N = 4)
-	Dropped off their trash or recycling	10% (N = 4)
-	Went to a restaurant alone	10% (N = 4)
-	Attended counseling or a support group	7.5% (N = 3)
•	Went to the library	7.5% (N = 3)
-	Picked up mail or went to the post office	7.5% (N = 3)
-	Went to a day program	5% (N = 2)
	(• also social/recreational component)	2.5% (N = 1)
-	Rode the bus (bus stop)	5% (N = 2)
-	Stopped to fill a water bottle	5% (N = 2)
-	Did laundry at a laundromat	5% (N = 2)
•	Went on a date	5% (N = 2)
•	Went to a festival/event	5% (N = 2)
•	Went to a park or playground	5% (N = 2)
•	Went to a sporting event	5% (N = 2)
•	Went to a lesson (Improv, horse riding)	5% (N = 2)
-	Got a haircut	2.5% (N = 1)

Legend Activity type color and symbol:	- = Daily Living • = Social/Recreational + = Vocational
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Fig. 1. Frequency of engagement in different types of community activities based on 1 week of GPS tracking data, categorized by location type.

summarizes the GPS data of frequency of activities completed in "A Week in the Life" of the autistic adults in the sample. Individuals were primarily visiting locations related to activities of daily living (M = 7.13, SD = 4.09, range 0 - 20), with 75 % of participants going grocery shopping, 60 % picking up fast food, 58 % shopping for other goods, and 45 % getting gas during the study week. These transactional community activities, where individuals are procuring goods or services in the community, typically involve an exchange of money through a mutually beneficial, but routine interaction. Also in this category, notably 30 % of participants picked up prescriptions and 25 % went to the doctor but only 7.5 % attended counseling or a support group during the study week. Participants visited an average of 4.63 social/recreation locations (as identified by the participants) (SD = 3.33, range 0 - 12) during the study week, most frequently going to a restaurant with family or friends (58 %), going for a walk or other form of exercise (45 %), or visiting family or friends (37.5 %). Participants averaged 2.04 vocational locations (SD = 2.91, range = 0.11) during the study week including work, volunteer, educational, and work-related locations, such as applying for jobs.

Participants spent an average of approximately 4.5 h away from home per day (range = < 1 h - 11.5 h per day). However, 47.5 % of the sample (n = 19) had at least one day they did not leave home, and an additional 11 participants (n = 30 total) left their home for less than 1 h on at least one day. Most of these individuals (56.7 %) were part of the study prior to the onset of COVID-19. Activity space ranged from 0.13 to 616.23 square miles (M = 80.79 square miles, SD = 112.40 square miles) based on the spatial dispersion of the locations visited in the community during the study week. Participant activity space size was significantly associated with average time away from home per day (r = .43, p = .005). Number of unique locations during the study week were not significantly associated with activity space (r = .26, p = .112) or average time away from home during the week (r = .23, p = .149).

To more comprehensively represent participants' sense of belonging to the community and the importance of community locations, we integrated descriptive findings with illustrative interview quotations. The descriptive results convey the broader picture of how participants rated their sense of belonging, while the interviews provide deeper insight into personal experiences and perceptions. Overall, 37.5 % of participants felt a part of the community, 32.5 % indicated they did not feel a part of the community and 30 % were unsure or ambivalent. When asked if one participant felt a part of the community, he commented, "I just feel like I exist in it rather than take part in it." Alternatively, in response to the same question, another participant stated, "I do feel I'm a part of the community. I have a lot of connections. I mean, if having friends is a requirement, then I guess the answer would be no. But I have good, friendly, they pass for friendships, with a lot of my clients."

Home was most frequently identified as the location most important to participants (45 %) and where they felt they belonged the most (60 %), often tied to home being a place of safety, comfort, and where one's personal belongings, family, and pets resided. For example, a participant stated, "Home is definitely most important. There's no contest. That's where I spend most of my time, and it's where I usually feel most comfortable." Social/recreational locations, including places for religious activities or locations connected with visiting with family members were the next most frequent type of location identified as most important (35 %), and the next most frequent location where participants felt they belonged the most (20 %). One participant noted that church was the most important location to him, stating, "My faith is always important, and I guess I [have] just always gone to church all my life."

# Inferential Results

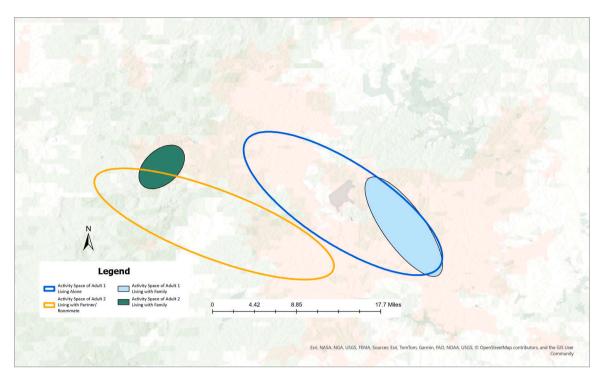
Backward stepwise regression analysis was used to establish a model predicting activity space. Table 2 includes slopes, standard errors and p-values of the final model of predictors of activity space (AIC = 350.44; beginning model AIC = 367.25). In the final model, independent living status and SRS-2 Social Cognition scores predicted activity space,  $R^2 = 0.32$ , F(2, 35) = 8.09, p = .001, 90 % CI [0.10, 0.50]. Those who lived less independently (lived with parents/guardians) had significantly smaller activity spaces during the study week than those who lived more independently (see Fig. 2 for example). Additionally, for every 1-point increase in SRS-2 Social Cognition score (i.e., more impairment), activity space increased by 8.27 square miles.

Another backward stepwise regression analysis was used to determine a model of predictors of average time away from home per day across the study week. Table 3 includes slopes, standard errors and p-values of the final model of predictors of average time away from home per day during the study week (AIC = 50.84; beginning model AIC = 65.95). Age, current employment status, having a partner, conversation ability (TEACCH survey), and SRS-2 Social Awareness and Motivation scores predicted time away from home per day during the study week,  $R^2 = 0.64$ , F(6, 32) = 9.31, p < .001, 90 % CI [0.36, 0.73]. Increased age was associated with increased time away from home per day. Additionally, participants who were currently employed spent an average of 3.27 additional hours away from home per day during the study week compared to those who were unemployed. Regarding conversation impairment on the TEACCH survey, a 1-point increase in conversation impairment was associated with an average of 1.42 additional hours away from home per day during the study week. Having a partner and SR-2 Social Awareness and Motivation scores were not significant predictors in the final model.

A final backward stepwise regression analysis was used to establish a model of predictors of the number of unique locations visited during the study week. Table 4 includes slopes, standard errors and *p*-values of the final model of predictors of the number of unique

**Table 2** Final model predicting activity space size.

Predictor	b	se	p
Living less independently	-114.74	32.66	.001
SRS-2 Social Cognition Subscale Score	8.27	3.07	.011



**Fig. 2.** Example comparison of the activity spaces of two autistic adults who were living more independently (hollow ellipse) and two autistic adults who were living with their family of origin (shaded ellipse) in the same geographic area. *Note: Map lines delineate study areas and do not necessarily depict accepted national boundaries.* 

locations visited during the entire study week (AIC = 142.55; beginning model AIC =150.20). Age, gender, race/ethnicity, employment status, having children, and SRS-2 Social Communication, Awareness and Cognition subscale scores predicted the number of unique locations visited,  $R^2$  = 0.44, F(8, 30) = 2.97, P = .014, F(8, 30) = 0.14, F(8, 30)

The logistic regression revealed no significant predictors of feeling a part of the community, including living status, employment status, activity space, time away from home and unique locations.

**Table 3** Final model predicting average time away from home.

Predictor	b	se	p
Age	0.08	0.03	.006
Current Employment	3.27	0.67	< .001
Current Partner	1.33	0.83	.120
Conversation Ability	1.42	0.62	.028
SRS-2 Social Awareness Subscale Score	0.16	0.09	.097
SRS-2 Social Motivation Subscale Score	-0.09	0.06	.120

**Table 4**Final model predicting unique locations visited during the study week.

Predictor	ь	se	p
Age	0.21	0.10	.049
Gender (women)	3.91	2.35	.107
Minoritized Race/Ethnicity	3.57	2.64	.187
Current Employment	7.46	2.32	.003
Had at least one child	4.34	3.32	.201
SRS-2 Social Communication Subscale Score	-0.49	0.15	.004
SRS-2 Social Awareness Subscale Score	1.13	0.42	.011
SRS-2 Social Cognition Subscale Score	0.57	0.29	.057

#### Discussion

The current study provides a descriptive picture of where autistic adults are going in the community, how they spend their time, and what types of locations and activities they feel are important. Most, but not all, adults in the current study visited several locations throughout the community, most frequently related to grocery shopping, eating fast food, and working. Yet, less than half felt connected to the community. This is perhaps due to the transactional nature of most daily living activities, the most frequent type of locations visited, not being offset by engagement in more valued activities. Many individuals participated in social/recreational activities such as going out to eat with family or friends, visiting others, and walking/exercising, and rated these locations with high importance, but participated less frequently. Moreover, using GPS data to capture community participation in the current study provided objective information on how autistic adults spent their time, and highlighted gaps in desired activities, such as social events and mental health services (Chan & Doran, 2023).

In comparison with past participation survey data completed by autistic adults, shopping was similarly the main type of community activity completed, followed by working and going to a restaurant/coffee shop (Shea et al., 2021; Song et al., 2021). This lends some support for using self-report participation measures. However, the current data fills in details, such as grocery shopping being the most frequent type of shopping activity. More importantly, the data distinguishes whether going out to eat included a social aspect with family and friends, or whether one was picking up fast food and/or eating alone, which can possibly be an important distinction in overall health-related QoL. Additionally, GPS data distinguished the types of errands/activities autistic adults spent time in the community completing, which may denote responsibilities assumed in adulthood such as picking up their prescriptions, banking, and getting gas. Another important finding captured by GPS was the high rate of autistic adults going for a walk in the community, which may not be captured if measures only ask about going to a gym or exercise facility. While a small sample, findings from the current GPS data may assist in how we conceptualize and refine future participation measures for autistic adults.

In attempting to understand what predicted greater community participation, current employment emerged as a significant predictor of more unique locations and time spent away from home, consistent with our hypothesis. As expected, those who were employed spent more time away from home compared to those who were unemployed. However, they also visited more unique locations during the study week, suggesting that those who were employed, even in a part-time capacity, had greater opportunities for participation in a variety of locations. Yet employment did not emerge as a significant predictor of activity space or feeling part of the community. These findings support the complexity in attempts to understand and measure the multiple aspects of participation, which includes not just whether one engages in community activities, but also the presence of social connections and the meaningfulness of engagement (Kim et al., 2024).

Living more independently (alone or with a partner or roommate) was also a significant predictor of community participation related to larger spatial presence in the community compared to those who lived with parents/guardians, who were more likely to visit locations close to home. This finding was supported in the interviews, as participants noted spouses or partners who provided motivation to engage in activities, or involvement in attending their children's activities. As one participant noted, "My wife is the one that pushes me more than anybody else to get out and do stuff and meet people." However, there was no difference in living situation related to the other outcomes of time spent in the community or number of unique locations visited. Previous research has suggested that parents/caregivers often plan and organize most community outings even in adulthood (Levy & Perry, 2011; Gray et al., 2014). This is significant as, similar to the current sample, research continues to support that at least 50 % of autistic adults live with parents/relatives (Marsack-Topolewski et al., 2021; Dudley et al., 2019). With a lack of adult services, caregivers often fill the role of assisting individuals with daily living skills, but often have limited ability to address social needs (Cheak-Zamora et al., 2015). This notion was also supported through the travel diary data, which indicated some individuals traveled with family members around the community area to complete daily living routines and get out of the house, but did not always find these activities meaningful and sometimes simply stayed in the car.

Older age was associated with visiting more unique locations and more time spent away from home. Our sample inclusion criteria for age (i.e., > 25 years) was specifically chosen to examine the community participation of autistic adults beyond transition age. While some interventions and supports are targeted toward transition age youth (e.g., Stepped Transition in Education Program for Students with ASD; White et al., 2021), our findings may suggest that those just beyond transition age (e.g., 25–35 years) may need more support related to community participation than older autistic adults. Although we did not examine underlying mechanisms, one possibility is that younger autistic adults may still be developing routines, building confidence in navigating community settings, or identifying personally meaningful opportunities for participation. These potential mechanisms should be examined in future research to better understand age-related differences in participation and to inform the design of targeted supports.

Regarding autism symptoms, we had some unexpected findings related to participant scores on the SRS-2 subscales, TEACCH conversation ability scores, and community participation outcomes. In the regression models, more impairment in social cognition was associated with larger activity spaces, and more impairment in social awareness was associated with more unique locations visited. Additionally, more impairment in conversation ability (per TEACCH survey) corresponded with more time spent away from home. Therefore, self-report (or guardian-report) of increased autism symptomology related to communication and sociability predicted greater objective community participation in our sample. However, while about one-third of participants said they felt part of the community, the majority were ambivalent or reported that they did not. Taken together, these findings may indicate that although autism symptomology may increase objective community participation, this does not necessarily correlate with autistic adults feeling part of their communities.

Assessing community participation and feelings of connectedness in the community for autistic adults is a complex topic best studied using multiple methods. One type of data (survey, geospatial, or interviews) was insufficient to answer questions of how

autistic adults were participating in the community and what types of locations were most important to them. Feeling part of the community was more complicated, and not well answered from quantitative, spatial, or dichotomous yes/no survey data. Our qualitative findings suggest the home and social/recreational locations are important to autistic adults, which diverges from prior participation survey results showing grocery shopping as most important (Shea et al., 2021; Song et al., 2021). However, missing from the current study is an understanding of important social connections and activities occurring in the home that may contribute to one feeling part of the community, such as connecting with others through phone or text exchanges, online social networks and gaming, or participation in internet-based groups and social media. The lack of significant findings between feelings of belonging connected to any quantitative measures of community participation may provide additional support for the important role of online connections for autistic adults (Chan et al., 2022; Mazurek, 2013), and reflects a need for future research.

#### Limitations

Aside from the limitations of a small sample in one geographic region, most of the sample had an IQ of 70 or above, which does not represent individuals across the autism spectrum. While the rate of comorbid mental health conditions is high in the sample, and matches previously reported prevalence rates in adulthood (Vogan et al., 2017), participants self-reported whether they had ever been diagnosed with comorbid conditions. Therefore, comorbid conditions may have been under- or over-reported, and comorbid conditions may have impacted community participation during the study. Finally, our study did not include measures of online social participation or QoL, which may have further informed findings related to feelings of belonging.

# Implications for practice

In our sample, participants who lived with parents/guardians had smaller activity spaces compared to those who lived more independently. Therefore, it may be important for service providers who work with autistic adults living with parents/guardians to focus on methods to increase their community participation. Additionally, our data provide more support for the importance of connecting autistic youth and adults to employment services. Not only did participants who were currently employed spend more time away from home, they also visited more unique locations indicating that employment may encourage community participation beyond simply being outside of the home. Providers working with autistic adults may wish to connect autistic adults to employment services to increase objective community participation outcomes.

Because older age was associated with more community participation, services may be warranted for young autistic adults beyond transition age. Young autistic adults may benefit from existing transition-age services and programs extending the age limit for service provision. With a drop-off in services after high school, our findings may reflect that young autistic adults beyond the transition age are less connected to the community. Further services, perhaps focused on helping them develop new routines in adulthood outside of the home, or building confidence in navigating community settings with or without support, may be warranted for this group (Carey et al., 2024; Lindsay, 2016).

# Future directions

While our study included an analysis of predictors of objective community participation outcomes, future research may wish to focus on factors associated with feeling part of the community, as our analyses did not reveal any significant predictors of feelings of belonging in the community. Few participants in our study felt integrated into the community, and future research could focus on identifying actionable targets of intervention to help increase autistic adults' feelings of community integration, which may include feelings of belonging in less traditional communities (e.g., online communities) (Chan et al., 2022). Our findings also revealed unexpected associations between autism symptoms and community participation, which could be investigated further to understand why impairment in social cognition and awareness predicted increased community participation. Currently, we are uncertain of mediators of this association. Community-based participatory studies where autistic individuals assist researchers in identifying important components of community integration and meaningful lines of inquiry for autistic individuals are also warranted.

# Conclusion

While many autistic adults in the study were present and participating in the community, less than half reported feeling connected to the community. It is possible that the transactional nature of the daily living locations, which were most frequently visited, was not sufficiently counterbalanced with socially based locations that were rated as important. However, living more independently, age, and current employment emerged as significant predictors of increased participation. Adults who live with parents/guardians and who are younger may need additional support to meaningfully participate in the community, but supporting autistic adults in securing employment in any capacity may provide additional benefits to community participation.

#### CRediT authorship contribution statement

**Dara V. Chan:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Julie D. Doran:** Writing – review & editing, Writing – original draft, Project administration, Investigation, Formal analysis. **Zhaoying Li:** Writing – review & editing,

Formal analysis.

# **Declaration of Competing Interest**

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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#### Data availability

Data will be made available on request.

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