

# Inclusion

## Examining differences in community participation in adults with autism spectrum disorder --Manuscript Draft--

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<b>Abstract:</b>	Adults with autism spectrum disorder (ASD) demonstrate low levels of community participation, though no studies have examined the perceived value and satisfaction when assessing community participation among young adults with ASD. Using the Temple University Community Participation measure, young adults with and without ASD were compared on the frequency, perceived importance, and satisfaction of community participation. Adults with ASD participated less frequently in participation areas and identified fewer important participation areas. Importantly, no differences were reported in satisfaction with participation between the two groups despite adults with ASD participating less frequently in the community. Results suggest a need for further exploration of predictors of poor community participation in adults with ASD, as well as effective interventions targeting community participation in this population.

**Abstract**

Adults with autism spectrum disorder (ASD) demonstrate low levels of community participation, though no studies have examined the perceived value and satisfaction when assessing community participation among young adults with ASD. Using the Temple University Community Participation measure, young adults with and without ASD were compared on the frequency, perceived importance, and satisfaction of community participation. Adults with ASD participated less frequently in participation areas and identified fewer important participation areas. Importantly, no differences were reported in satisfaction with participation between the two groups despite adults with ASD participating less frequently in the community. Results suggest a need for further exploration of predictors of poor community participation in adults with ASD, as well as effective interventions targeting community participation in this population.

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### **Examining Differences in Community Participation in Adults with Autism Spectrum Disorder**

In the 1990s, prevalence rates for autism spectrum disorder (ASD) began to show a steep increase in the number of children diagnosed with ASD (Fombonne, 2018). The first published prevalence rates by the Centers for Disease Control and Prevention (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network documented this trend, which found one in 150 children were diagnosed with ASD (CDC, 2007). Now, estimates from the CDC find that one in 54 children meet criteria for ASD (Maenner et al., 2020). A large population of individuals with ASD enter adulthood with a significant lack of support and resources, which has led to less than optimal outcomes. Despite improvements in early diagnosis and improvement in ASD symptoms (Clark et al., 2018; Shulman et al., 2020 Woodman et al., 2015), outcomes for adults with ASD remain poor (Howlin & Magiati, 2017; Robison, 2019). As a result, there has been a growing interest in improving the quality of life of adults with ASD, including increasing participation within the community.

Community participation is defined as the engagement in interpersonal activities, domestic life, education and vocational activities, and community, civic, and social activities (Whiteneck & Dijkers, 2009; World Health Organization, 2007). Hammel and colleagues (2008) argue that in addition to the physical presence, community participation should also include the subjective experience of individuals when they are engaged in the community. Meaningful community participation is essential to improved quality of life, and it is essential that the individual determine which aspects of community participation is valued or important to them (Hammel et al., 2008). Following this definition, investigators have extensively researched the patterns of community participation for specific populations, particularly in relation to

individuals diagnosed with serious mental illness (Burns-Lunch et al., 2016; Salzer et al., 2014). However, Scheeren and Geurts (2015) noted significant gaps in community participation research for individuals with ASD compared to the literature for serious mental illness.

Adults with ASD demonstrate low participation in social, vocational, and postsecondary education domains. A pioneering study conducted on a large nationally representative sample of adults with ASD by Myers and colleagues (2015) found that participation in community or educational activities decreased by 17% over a five-year period following graduation from high school. Approximately 54% of young adults with ASD in the sample reported that they did not participate in any community activities (Myers et al., 2015). This suggests a pattern of decreased community participation that begins in childhood and persists into adulthood. Additionally, adults with ASD present with unique challenges that may hinder independent choice and participation in their communities. Hallmark characteristics of ASD, including poor social communication, social interaction, and deficits in adaptive functioning, contribute to challenges in developing and maintaining relationships in adulthood (Howlin et al., 2013; Orsmond et al., 2013), decreased social engagement (Stacey et al., 2019), increased social isolation (et al., 2019), and overall low rates of community participation (Liptak et al., 2011; Orsmond et al., 2004; Tint et al., 2016). Educational attainment of adults with ASD suggest that many individuals have little participation in postsecondary activities (Ohl et al., 2017; Taylor & Selzer, 2011). Individuals with ASD also have significant difficulty gaining and maintaining employment. Rates of paid employment for adults with ASD are low, with most studies showing high un-employment or under-employment as in part-time or low-skilled positions (Chan et al., 2018; Roux et al., 2013; Shattuck et al., 2012). Social, leisure, or vocational participation are important aspects of functioning in adulthood, individually they do not address the wide variety of activities

individuals participate in within their communities and neglect to examine valued participation for the individual with ASD.

While several studies have examined community participation in individuals diagnosed with ASD, there is a significant gap in information related to the perceived importance and value of the various activities and life experiences for the individual. Given the extensive research that points to poor outcomes for adults with ASD, community participation has become a specific area of interest in the adult population of individuals with ASD (Interagency Autism Coordinating Committee, 2017). Taken together, extant research suggests that there is a need for the examination of community participation and related barriers, as well as the impact of community participation on the quality of life for adults with ASD. Increased community participation is favorable for the service and treatment of adults with ASD as community participation is one indicator of a successful outcome for individuals with disabilities as well as an indicator for quality of life (Chang et al., 2013). In addition, community participation reduces stigma and fosters the development of important life skills.

### **The Present Study**

The present study seeks to expand the literature by examining the frequency of participation of adults with ASD in the community across domains and capturing a subjective evaluation of meaningful participation. The present study aims to evaluate patterns of community participation in a sample of adults diagnosed with ASD who primarily live in less urban settings compared to the general population using the Temple University Community Participation (TUCP) measure. The TUCP is a self-report measure that assesses the frequency of community participation across multiple domains, but also the individuals' subjective rating of importance and sufficiency of engagement in the activity (i.e., are they doing it as much as they

would like, too much or too little). This measure includes the individual's perceived value of participation in the activity, reflecting a more person-centered perspective of community participation. Given the lack of community participation measures for individuals with autism (Lami et al., 2018); the TUCP may provide insight into community participation patterns of young adults with ASD as well as subjective ratings of preference and satisfaction.

The current study will test three hypotheses. First, consistent with previous literature (McCollum et al., 2016; Stacy et al., 2019), results from a self-reported measure of community participation will indicate that young adults with ASD will report fewer days engaged in community activities and fewer participation areas in the community compared to adults without ASD. Second, young adults with ASD will identify fewer important participation areas and more unimportant participation areas in comparison to individuals without ASD. Finally, young adults with ASD will report less perceived sufficiency with their frequency of participation in important participation areas (i.e., fewer days in important activities regarded as “done enough”) in comparison to young adults without ASD.

## **Methods**

### **Sample**

#### ***Adults with ASD***

Data from young adults with ASD were included in this study from two ongoing research studies: 1) either a social skills intervention for adults with ASD or, 2) a measurement-based care system for adults with ASD enrolled in state-based waiver services. Informed consent was collected from all participants and all data for the current study was collected from the baseline time point prior to the implementation of either intervention. All participants completed a community participation self-report measure. Adults with ASD included 32 participants living in

rural communities who were between the ages of 18- and 35-years-old at the time of assessment. The mean age of participants was 25.9 (SD = 6.56) years old; 87.5% of participants were male, and 68.8% identified as Caucasian. Inclusion criteria for both studies included the ability to self-report. Additional participant demographic characteristics are presented in Table 1.

### *Adults without ASD*

The comparison group is a subsample of young adults without ASD selected from a sample of 300 adults recruited through the Truven Health Analytics' PULSE survey. Truven Health Analytics 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. The Truven surveys approximately 7,000 respondents each month regarding questions about various health-related topics. Truven provided data from 40,831 individuals between the ages of 18 and 65 over a nine-month period between September 2014 and December 2015 and responded in English. Researchers are able to include additional items in the survey for a fee. To obtain a sample of adults without serious mental illness, Truven respondents were asked, "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?" The researchers randomized individuals who responded "No" to this question for each of the nine months and agreed to provide their contact information for future studies. Research staff then called individuals in blocks of 40 up to four times (two daytime call attempts and two evening or weekend call attempts) before moving on to the next block. These calls were made until 33 to 34 individuals were recruited each month totaling 300 participants. Data from these individuals were also previously published (Nagata et al., 2020; Song et al., 2021) Researchers collected various information from this sample about

their community participation including the TUCP, as well as assessments of psychosocial well-being, and perceptions of their neighborhood (Kriegel et al., 2020).

To obtain a sample of young adults without ASD, the current study included a subset of 36 participants under the age of 35 from the original sample of 300 participants. The comparison group was matched based on age and gender. These participants, on average, were 28.71 (SD = 3.78) years old, 20 (55.56%) were female, and 24 (66.67%) identified as Caucasian.

## **Measures**

### ***Demographics***

Data were collected regarding participant's age, ethnicity, education, marital status, and employment status. Table 1 depicts demographic information of participants in both groups.

### ***Autism Symptom Severity***

Adults with ASD completed the Social Responsiveness Scale- Second Edition to measure severity of ASD symptoms (SRS-2; Constantino & Gruber 2012). The SRS-2 is a 65-item measure completed by adult informant measuring social interaction, social communication, and repetitive behavior and restricted interests. In the current study, an adult informant completed a SRS-2 for participants diagnosed with ASD to assess functioning level. Respondents rate each item on a scale from 'never true' to 'almost always true' within five domains: Social Awareness, Social Cognition, Social Communication, Social Motivation, and Repetitive Behavior and Restricted Interest (RRB). The SRS-2 provides an overall Total T-Score indicating the severity of global social functioning deficits. Participants' functioning levels classified as 'within normal limits', 'mild', 'moderate', or 'severe' as suggested by the SRS-2 total score descriptive categories. The comparison group did not complete the SRS-2.

### ***Community participation***

The TUCP Measure (Salzer et al., 2014, Salzer et al., 2015) assesses the frequency of independent participation in 26 different participation areas within the past 30 days without support staff, the perceived importance of each area (i.e., important, unimportant), and if participation was more than desired, less than desired, or as much as desired in the past 30 days. The participation areas span a variety of activities in domestic, interpersonal, employment, community, leisure and recreation domains. This measure was selected as an objective report of the frequency of participation across multiple domains, as the subjective measure of importance and sufficiency of each activity.

Several TUCP constructs were calculated for this study including: (a) the total number of participation days across all 26 areas, (b) total number of participation areas, (c) total number of participation areas considered important, (d) total number of participation areas considered unimportant, (e) number of areas with sufficient participation (important areas reported as done “enough”), and (f) the percent of important areas with sufficient participation. Sufficient participation was calculated as the total number of important participation areas done enough divided by the total number of important participation areas. Additionally, based on Thomas and colleagues (2017), a “sufficiency threshold” was calculated as the number of days in a specific participation area that a participant endorsed as important and done as much as desired.

### **Statistical Analyses**

Independent samples t-tests were conducted to compare responses between participants with and without ASD on key variables of the TUCP. Table 2 presents the means and standard deviations of community participation for both groups. Table 3 presents the chi-square analyses to compare the percentage of individuals who believe participation in each area is important.

### **Results**

Table 2 shows the results from the independent samples t-test of the TUCP constructs (e.g., number of participation days, number of participation areas) as well as comparing groups on specific items on the TUCP. The number of community participation days for adults with ASD was significantly lower than individuals without ASD,  $t(66)=-4.75$ ,  $p<.0001$ . Significant differences were also observed in the number of participation areas that adults with ASD engaged in compared to individuals without ASD,  $t(63.59)=-4.74$ ,  $p<.0001$ . Table 2 also presents comparison of the two groups at the item level. Adults with ASD reported fewer days participating in the following areas: working for pay ( $p < .001$ ), running for errands ( $p < .001$ ), going shopping ( $p = .002$ ), going to a zoo, botanical garden or museum ( $p = .010$ ), going to a restaurant or coffee shop ( $p = .014$ ), getting together in the community with family/friends ( $p = .014$ ), going to the gym or sporting event ( $p = .020$ ), going to a park or recreation center ( $p = .039$ ), and attending civic/political activities ( $p = .047$ ).

Hypothesis 2 was also supported, as individuals with ASD rated fewer participation areas as important than the adults without ASD ( $t(63.60)=-2.54$ ,  $p=.014$ ), and more participation areas as unimportant ( $t(63.12)=2.46$ ,  $p=.017$ ). Table 3 shows significantly more individuals in the comparison group endorsed the following activities to be important compared to the ASD sample: going to a park or recreation center, going to a zoo, botanical garden or museum, running errands, participating in volunteer activities, getting together in the community or attending a celebration with family or friends, or entertaining family or friends at home or visiting them in their homes.

Hypotheses 3 however, was not supported, as individuals with ASD did not report less sufficiency with their frequency of participation in important activities. Table 2 shows that adults with and without ASD reported similar frequencies and percentages of sufficient participation in

important participation areas ( $t(64.70) = .61, p = .545$ ). Among individuals who endorsed any given participation area as both important and done enough, individuals in the comparison group had significantly more participation days in that area compared to adults with autism (Table 4). The participation areas considered important and done enough included running errands, going to the gym or participating in a sports event, working for pay, entertaining family or friends at home or visiting them in their homes, and participating in civic or political activities or organizations (Table 4). The group differences in sufficiency threshold for many other participation areas, such as participating in volunteer activities, going to a restaurant or coffee shop, or using public transportation, were not statistically significant (Table 4).

### **Discussion**

The current study is an important first examination in understanding patterns of participation and the perceived importance of community participation for adults with ASD. Overall, adults with ASD differed in frequency of participation (number of days), in the evaluation of activities (importance), and in variety (number of activities) of activities compared to adults without ASD. This is consistent with previous literature that has shown that adults with ASD participate in the community far less frequently than neurotypical adults (Tint et al., 2016). Interestingly, though adults with ASD are not participating in the community as frequently as adults without ASD, the sufficiency threshold suggested that adults with ASD perceived their participation levels as equally satisfactory even while participating in statistically significant lesser number of days in those activities. Individuals with ASD recognize the value in many community activities and most participants within this sample endorsed these areas as important. However, adults with ASD appeared to report satisfaction with fewer participation days even in areas identified as important by both groups. To illustrate this point, adults with ASD rated the

activity “working for pay” as “important” at the same rate as the comparison group. However, the ASD group also reported fewer days of working for pay as sufficient compared to the comparison group.

The current findings are in contradiction to previous literature examining community participation in adults with serious mental illness. Salzer and colleagues (2014) found patterns of low community participation in individuals with serious mental illness compared to adults without serious mental illness similar to that seen with participation levels of individuals with ASD in this study. Contrary to the current study, however, the Salzer study (2014) showed that individuals diagnosed with serious mental illness expressed dissatisfaction with their current levels of engagement in important community activities. The adult ASD sample in the current study did not seem to be dissatisfied with their level of community participation.

These results raise important questions regarding the conceptualization of community participation that may be unique for adults with ASD. Many adults with ASD continue to struggle with adaptive functioning regardless of symptom severity, and may have difficulty navigating and participating in the community. Individuals with ASD recognize the value in many community activities and most participants within this sample indicated similar areas as important. One conclusion that can be drawn from the results of the current study is that adults with ASD are more likely to feel as if they are doing enough in the community, despite low participation in their communities. However, several factors may contribute to the discrepancy in subjective experience of participation not specifically addressed in the current study, including issues of stigma and expectations. Results of the current study warrants further investigation into the use of the TUCP with the adult ASD population. Factors including stigma, expectations for independence, and limited opportunities for community inclusion have a significant impact on a

person's perceived and actual ability to participate meaningfully in the community. Family expectations, for example, is an important factor in increasing community participation in a multitude of areas as well as predicting outcomes in adulthood (Doren et al., 2012; Kirby, 2016). Young adults with ASD may have internalized limited expectations regarding their ability to engage in community participation. Another interpretation inferred from the data is that although individuals with ASD participate infrequently in the community, it is more often in activities that are not important to them. The data in this sample show that individuals with ASD report higher engagement in subjectively unimportant activities than adults without ASD. Future studies examining the use of the TUCP as a measure of community participation for adults with ASD will be needed to determine the impact of additional potential factors on the perceived satisfaction with community participation.

There are likely moderating situations unidentified in the current study that could influence adults' reports of sufficiency with low community participation and low identification of important participation areas. Contributing factors such as social isolation, social anxiety, or a pattern of stigma while interacting in the community may also influence the perceived satisfaction with community participation reported in this study. As identified in the literature, adults with ASD report a high level of loneliness and social isolation (Schiltz et al., 2021). However, adults with ASD have also reported a high level of motivation for social engagement when they were comfortable and could predict the social environment (Chen et al., 2015).

Certainly, adults with ASD experience these challenges at a higher rate than the comparison group. Adults with ASD face many additional barriers to community participation that were not explored in the current sample such as access to resources and opportunities (e.g., transportation, physical or sensory limitations, income, time, availability). These factors may

pose significant barriers for independent functioning and community participation (Tint et al., 2016) and a large number of adults with ASD benefit from formal supports to continue developing independent living skills well into adulthood (Kraeper et al., 2017; Matthews et al., 2015). With respect to the current study, these limitations can also make it challenging for adults with ASD to subjectively self-evaluate their participation in the community, when their choices or perceived opportunities are limited to a much greater degree than adults without ASD.

Though the TUCP measure (Salzer et al., 2014) has not yet established reliability and validity for adults with ASD, it was selected for the current study for several reasons. The TUCP is a comprehensive measure of community participation areas and assesses perceived importance and sufficiency of participation. The TUCP is unique in that it not only assesses a broad range of participation domains but also incorporates notions of self-determination in the subjective experience of the importance and sufficiency of participation for the individual. Additionally, there are no validated measures for adults with ASD that assess both community participation patterns and the subjective importance of these activities (Lami et. al, 2018). While the conclusions cannot be generalized to describe the community participation patterns of a broader population of adults with ASD, they do provide both a novel framework for future studies. The TUCP does require the participant to be able to self-report and recall independent participation in the past 30 days to complete this measure, which may be a limitation within the adult ASD population. The TUCP measure's applicability may be limited to adults with ASD with greater communication and adaptive behavior skills. This is an important limitation when considering the generalizability of these results to the broader autism spectrum. It is also conceivable that, while the TUCP assesses a wide variety of community areas, the measure might not have captured the specific type of community participation that is most valuable to adults with ASD.

Despite these limitations, the use of the TUCP in this study allowed for the unique examination of participation in a wide variety of community activities, as well as the perceived value and subjective sufficiency of these activities in a sample of young adults with ASD. The combination of assessing both objective frequency of community participation along with more qualitative measures of preference and satisfaction with community participation among young adults with ASD may lead to a more person-centered approach to interventions with the population related to participation in community. Future studies of community participation that incorporate the TUCP will be needed to determine the validity, reliability, and functional use of this measure for adults with ASD.

### **Implications for Actions**

The current results have important implications for assessment and treatment of adults with ASD, particularly when addressing community participation. The types of community activities most valued by individuals with ASD, the role of moderating variables (e.g., co-morbid anxiety, skills limitations, environmental and societal barriers), and how this information can be used to foster self-determination skills to increase community participation are all currently unknown.

While it is important to implement interventions to improve activities of daily living or instrumental activities of daily living, these skills may not naturally progress into meaningful community participation. This study suggests a benefit to rethinking how to measure community participation in adults with ASD and consequently, how clinicians intervene to increase community participation in this population. The subjective assessment of one's community participation is important and may prove to be more relevant than objective measures of participation alone. Community activities that are of known value to an individual would be

more likely to maintain a high level of participation independent of external support providers.

Including both objective and subjective measures in future work with adults with ASD, potentially through use of the TUCP, will maintain focus on both potential opportunities for increased community participation and self-determination.

### References

- Burns-Lynch, W., Brusilovskiy, E., & Salzer, M.S. (2016). An empirical study of the relationship between community participation, recovery, and quality of life of individuals with serious mental illnesses. *Israel Journal of Psychiatry, 53*, 46-55. <https://pubmed.ncbi.nlm.nih.gov/28856880/>
- Centers for Disease Control and Prevention. (2007). Prevalence of autism spectrum disorders—Autism and Developmental Disabilities Monitoring Network, Six Sites, United States, 2000. *MMWR, 56*(SS-1), 1–10. <https://www.cdc.gov/mmwr/preview/mmwrhtml/ss5601a1.htm>
- Chan, W., Smith, L. E., Hong, J., Greenberg, J. S., Lounds Taylor, J., & Mailick, M. R. (2018). Factors associated with sustained community employment among adults with autism and co-occurring intellectual disability. *Autism, 22*(7), 794-803. <https://doi.org/10.1177/1362361317703760>
- Chang, F. H., Coster, W. J., & Helfrich, C. A. (2013). Community participation measures for people with disabilities: A systematic review of content from an international classification of functioning, disability and health perspective. *Archives of Physical Medicine and Rehabilitation, 94*(4), 771-781. <https://doi.org/10.1016/j.apmr.2012.10.031>
- Chen, Y. W., Bundy, A. C., Cordier, R., Chien, Y. L., & Einfeld, S. L. (2015). Motivation for everyday social participation in cognitively able individuals with autism spectrum disorder. *Neuropsychiatric Disease and Treatment, 11*, 2699 - 2709. <https://doi.org/10.2147/NDT.S87844>

- Clark, M. L. E., Vinen, Z., Barbaro, J., & Dissanayake, C. (2018). School age outcomes of children diagnosed early and later with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(1), 92-102. <https://doi.org/10.1007/s10803-017-3279-x>
- Constantino, J.N., & Gruber, C.P. (2012). *Social Responsiveness Scale Manual, Second Edition*. Los Angeles: Western Psychological Services.
- Doren, B., Gau, J. M., Lindstrom, L. E. (2012). The relationship between parent expectations and postschool outcomes of adolescents with disabilities. *Exceptional Children, 79*, 7–23. <https://doi.org/10.1177/001440291207900101>
- Fombonne, E. (2018). Editorial: The rising prevalence of autism. *Journal of Child Psychology and Psychiatry, 59*(7), 717 – 720. <https://doi.org/10.1111/jcpp.12941>
- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation, 30*(19), 1445-1460. <https://doi.org/10.1080/09638280701625534>
- Han, G. T., Tomarken, A. J., & Gotham, K. O. (2019). Social and nonsocial reward moderate the relation between autism symptoms and loneliness in adults with ASD, depression, and controls. *Autism Research, 12*(6), 884-896. <https://doi.org/10.1002/aur.2088>
- Howlin, P., Moss, P., Savage, S., & Rutter, M. (2013). Social outcomes in mid-to later adulthood among individuals diagnosed with autism and average nonverbal IQ as children. *Journal of the American Academy of Child and Adolescent Psychiatry, 52*(6), 572-581. <https://doi.org/10.1016/j.jaac.2013.02.017>
- Howlin, P., & Magiati, I. (2017). Autism Spectrum Disorder: Outcomes in adulthood. *Current Opinion in Psychiatry, 30*(2), 69-76. <https://doi.org/10.1097/YCO.0000000000000308>

- Interagency Autism Coordinating Committee. (2017). 2016-2017 Interagency Autism Coordinating Committee strategic plan for autism spectrum disorder. Retrieved December 14, 2020 from <https://iacc.hhs.gov/publications/strategic-plan/2017/>
- Kirby, A. V. (2016). Parent expectations mediate outcomes for young adults with autism spectrum disorder. *Journal of autism and developmental disorders*, 46(5), 1643-1655. <https://doi.org/10.1007/s10803-015-2691-3>
- Kraper, C. K., Kenworthy, L., Popal, H., Martin, A., & Wallace, G. L. (2017). The gap between adaptive behavior and intelligence in autism persists into young adulthood and is linked to psychiatric co-morbidities. *Journal of Autism and Developmental Disorders*, 47(10), 3007-3017. <https://doi.org/10.1007/s10803-017-3213-2>
- Kriegel, L. S., Townley, G., Brusilovskiy, E., & Salzer, M. S. (2020). Neighbors as distal support for individuals with serious mental illnesses. *American Journal of Orthopsychiatry*, 90(1), 98 – 105. <https://doi.org/10.1037/ort0000403>
- Lami, F., Egberts, K., Ure, A., Conroy, R., & Williams, K. (2018). Measurement properties of instruments that assess participation in young people with autism spectrum disorder: a systematic review. *Developmental Medicine & Child Neurology*, 60(3), 230-243. <https://doi.org/10.1111/dmcn.13631>
- Liptak, G. S., Kennedy, J. A., & Dosa, N. P. (2011). Social participation in a nationally representative sample of older youth and young adults with autism. *Journal of Developmental & Behavioral Pediatrics*, 32(4), 277-283. <https://doi.org/10.1097/DBP.0b013e31820b49fc>
- Maenner M.J., Shaw K.A., Baio J., Washington, A., Patrick, M., DiRienzo, M., Christensen, D. L., Wiggins, L.D., Pettygrove, S., Andrews, J. G., Lopez, M., Hudson, A., Baroud, T.,

- Schwenk, Y., White, T., Robinson Rosenberg, C., Lee, L., Harrington, R. A., Huston, M. ... Dietz, P. M. (2020). Prevalence of Autism Spectrum Disorder among children aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2016. *Morbidity and mortality weekly report. Surveillance summaries (Washington, D.C.:2002)*, 69(4), 1–12. <http://dx.doi.org/10.15585/mmwr.ss6904a1>
- Matthews, N.L., Smith, C.J., Pollard, E., Ober-Reynolds, S., Kirwan, J., & Malligo, A. (2015). Adaptive functioning in autism spectrum disorder during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 45(8), 2349 - 2360. <https://doi.org/10.1007/s10803-015-2400-2>
- McCollum, M., LaVesser, P., & Berg, C. (2016). Participation in daily activities of young adults with high functioning autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(3), 987-997. <https://doi.org/10.1007/s10803-015-2642-z>
- Myers, E., Davis, B. E., Stobbe, G., & Bjornson, K. (2015). Community and social participation among individuals with autism spectrum disorder transitioning to adulthood. *Journal of Autism and Developmental Disorders*, 45(8), 2373-2381. <https://doi.org/10.1007/s10803-015-2403-z>
- Nagata, S., Townley, G., Brusilovskiy, E., & Salzer, M. S. (2021). Community participation differences between adults with or without serious mental illness. *Psychiatric Services*, 71(11), 1191-1194. <https://doi.org/10.1176/appi.ps.201900608>
- Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with Autism Spectrum Disorder. *Work*, 56(2), 345-355. <https://doi.org/10.3233/WOR-172492>

- Orsmond, G. I., Krauss, M. W., & Seltzer, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 34*(3), 245-256.  
<https://doi.org/10.1023/B:JADD.0000029547.96610.df>
- Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders, 43*(11), 2710-2719. <https://doi.org/10.1007/s10803-015-2403-z>
- Robison, J. E. (2019). Autism prevalence and outcomes in older adults. *Autism Research, 12*(3), 370-374. <https://doi.org/10.1002/aur.2080>
- Roux, A. M., Shattuck, P. T., Cooper, B. P., Anderson, K. A., Wagner, M., & Narendorf, S. C. (2013). Postsecondary employment experiences among young adults with an autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 52*(9), 931-939. <https://doi.org/10.1016/j.jaac.2013.05.019>
- Salzer, M.S., Brusilovskiy, E., Prvu-Bettger, J., & Kottsieper, P. (2014). Measuring community participation of adults with psychiatric disabilities: Reliability of two modes of data collection. *Rehabilitation Psychology, 59*(2), 211 - 219. <https://doi.org/10.1037/a0036002>
- Salzer, M.S., Kottsieper, P., & Brusilovskiy, E. (2015). Intermethod Reliability and Factors Affecting Recall with the Temple University Community Participation Measure. *Journal of Mental Health, 24*(4), 189-195. <https://doi.org/10.3109/09638237.2015.1036976>
- Scheeren, A. M., & Geurts, H. M. (2015). Research on community integration in autism spectrum disorder: Recommendations from research on psychosis. *Research in Autism Spectrum Disorders, 17*, 1-12. <https://doi.org/10.1016/j.rasd.2015.05.001>

- Schiltz, H. K., McVey, A. J., Dolan Wozniak, B., Haendel, A. D., Stanley, R., Arias, A., Gordon, N., & Van Hecke, A. V. (2021). The role of loneliness as a mediator between autism features and mental health among autistic young adults. *Autism*, *25*(2), 545 – 555.  
<https://doi.org/10.1177/1362361320967789>
- Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, *129*(6), 1042 - 1049. <https://doi.org/10.1542/peds.2011-2864>
- Shulman, C., Rice, C. E., Morrier, M. J., & Esler, A. (2020). The role of diagnostic instruments in dual and differential diagnosis in Autism Spectrum Disorder across the lifespan. *Psychiatric Clinics*, *43*(4), 605-628. <https://doi.org/10.1016/j.psc.2020.08.002>
- Song, W., Shea, L., Nonnemacher, S. L., Brusilovskiy, E., Townley, G., & Salzer, M. S. (2021). Community participation comparison between adults on the autism spectrum and adults in the general population. *Journal of autism and developmental disorders*, 1-12.  
<https://doi.org/10.1007/s10803-021-05059-9>
- Stacey, T. L., Froude, E. H., Trollor, J., & Foley, K. R. (2019). Leisure participation and satisfaction in autistic adults and neurotypical adults. *Autism*, *23*(4), 993-1004.  
<https://doi.org/10.1177/1362361318791275>
- Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of autism and developmental disorders*, *41*(5), 566–574. <https://doi.org/10.1007/s10803-010-1070-3>
- Thomas, E. C., Snethen, G., & Salzer, M. S. (2017). A developmental study of community participation of individuals with serious mental illnesses: Implications for policy and

practice. *American Journal of Orthopsychiatry*, 87(5), 597-605.

<https://doi.org/10.1037/ort0000269>

Tint, A., Maughan, A.L., & Weiss, J.A. (2016). Community participation of youth with intellectual disability and autism spectrum disorder. *Journal of Intellectual Disability Research*, 61(2), 168 - 180. <https://doi.org/10.1111/jir.12311>.

Whiteneck, G., & Dijkers, M. P. (2009). Difficult to measure constructs: Conceptual and methodological issues concerning participation and environmental factors. *Archives of Physical Medicine and Rehabilitation*, 90(11), S22-S35.

<https://doi.org/10.1016/j.apmr.2009.06.009>

Woodman, A. C., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2015). Change in autism symptoms and maladaptive behaviors in adolescence and adulthood: The role of positive family processes. *Journal of Autism and Developmental Disorders*, 45(1), 111-126.

<https://doi.org/10.1007/s10803-014-2199-2>

World Health Organization. (2007). International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY. World Health Organization.

<https://apps.who.int/iris/handle/10665/43737>

Table 1  
*Sample demographic characteristics*

Characteristic	Participant (n = 32)	General Population Sample (n=36)
	n (%)	n (%)
Age (years)	25.34 (4.71)	28.71 (3.78)
Gender		
Male	28 (87.5)	16 (44.4)
Female	4 (12.5)	20 (55.6)
Race		
Caucasian	22 (68.8)	24 (66.7)
Minority	10 (31.2)	12 (33.3)
Education		
Some High School	3 (9.4)	3 (8.3)
High School/GED	13 (40.6)	3 (8.3)
Some College	13 (40.6)	10 (27.8)
College Degree	2 (6.3)	10 (27.8)
Graduate Coursework or Degree	1 (3.1)	10 (27.8)
Marital Status		
Single/Never Married	32 (100)	17 (47.2)
Married	0 (0)	19 (52.8)
Divorced/Separated	0 (0)	0 (0)
Widowed	0 (0)	0 (0)
Employment Status		
Unemployed/Unable to Work	16 (50)	12 (33.3)
Student	5 (15.6)	--
Employed for Wages	11 (34.4)	24 (66.7)
ASD Impairment Level		
WNL	7 (21.9)	--
Mild	9 (28.1)	--
Moderate	12 (37.5)	--
Severe	4 (12.5)	--

*Notes.* WNL= within normal limit. Volunteers did not complete measure of ASD impairment and were not asked to indicate whether they are currently students.

Table 2  
*Independent samples t-tests comparing groups on TUCP constructs and items*

	Autism Sample		General Population Sample		<i>p</i> -value
	(n=32)		(n=36)		
	M	SD	M	SD	
<i>TUCP Constructs</i>					
Total number of participation days	34.38	30.47	71.92	34.64	<.001
Total number of important areas with 1+ days of participation	5.19	3.67	9.86	4.34	<.001
Total number of important participation areas	11.16	5.00	14.14	4.64	.014
% of important participation areas done enough	0.61	0.26	0.57	0.25	.545
<i>TUCP Items (Participation Areas)</i>					
Go shopping	4.50	5.76	8.72	4.68	.002
Go to a restaurant or coffee shop	2.88	4.57	6.11	5.92	.014
Go to a place of worship	2.41	5.01	3.42	3.96	.364
Go to a movie	0.38	0.79	0.58	1.11	.372
Go to a park or recreation center	1.03	2.28	3.28	5.86	.039
Go to a theater or cultural event	0.59	1.16	0.61	1.18	.951
Go to a zoo, botanical garden or museum	0.09	0.39	0.47	0.74	.010
Go to run errands	1.84	2.74	8.53	8.64	<.001
Go to a library	1.09	3.01	2.22	4.90	.252
Go to watch a sports event	0.72	1.61	0.64	1.33	.826
Go to a gym/participate in sports event	1.03	1.79	4.03	7.19	.020
Go to a barber shop, beauty salon, etc.	0.50	0.92	0.83	0.94	.144
Use public transportation	2.22	6.04	2.44	5.71	.875
Go to a social group in the community	1.19	3.29	1.94	2.29	.281
Work for pay	3.56	6.65	14.14	11.08	<.001
Go to school for degree/certificate	2.50	6.10	1.00	4.21	.249
Take class for leisure/life skills	0.34	1.04	0.08	0.28	.177
Participate in volunteer activities	2.81	7.06	3.39	4.16	.688
Get together in the community/attend celebration with family/friends	0.69	2.13	2.53	3.69	.014
Entertain family or friends at home/visit them in their homes	3.31	6.37	5.94	6.36	.094
Go to a community fair, block party or other community event/activity	0.63	1.58	0.56	1.11	.837
Go to or participate in civic/political activities/organizations	0.06	0.35	0.44	1.05	.047

Table 3  
*Comparing % of individuals who believe participation in each area is important*

	Autism Sample		General Population Sample		<i>p</i> -value
	N	%	N	%	
Go shopping	25	78.13	32	88.89	.229
Go to a restaurant or coffee shop	15	46.88	18	50.00	.797
Go to a place of worship	18	56.25	25	69.44	.260
Go to a movie	12	38.71	16	44.44	.635
Go to a park or recreation center	16	51.61	29	80.56	.012
Go to a theater or cultural event	15	46.88	21	58.33	.345
Go to a zoo, botanical garden or museum	9	28.13	23	63.89	.003
Go to run errands	18	56.25	29	80.56	.030
Go to a library	15	46.88	19	52.78	.627
Go to watch a sports event	10	31.25	12	33.33	.855
Go to a gym/participate in sports event	21	65.63	26	72.22	.557
Go to a barber shop, beauty salon, etc.	13	40.63	21	58.33	.145
Use public transportation	9	28.13	11	30.56	.826
Go to a social group in the community	13	40.63	20	55.56	.219
Work for pay	28	87.5	31	86.11	.866
Go to school for degree/certificate	20	62.5	24	66.67	.720
Take class for leisure/life skills	15	46.88	17	47.22	.977
Participate in volunteer activities	20	62.5	31	86.11	.025
Get together in the community/attend celebration with family/friends	20	62.5	33	91.67	.004
Entertain family or friends at home/visit them in their homes	23	71.88	35	97.22	.003
Go to a community fair, block party or other community event/activity	14	43.75	20	55.56	.331
Go to or participate in civic/political activities/organizations	8	25.00	16	44.44	.094

*Note.*  $\chi^2$  tests (df = 1) used for group comparisons.

Table 4

*Sufficiency thresholds for each participation area (number of participation days in each area marked as important and done enough)*

	Autism Sample			General Population Sample			<i>p</i> -value
	N	M	SD	N	M	SD	
Go shopping at grocery store	21	5.24	5.97	24	8.54	4.88	.051
Go to a restaurant or coffee shop	8	5.63	7.58	12	8.92	6.04	.322
Go to a church, synagogue, or place of worship	11	5.36	6.83	17	4.82	3.36	.811
Go to a movie	7	0.86	1.07	8	1.63	1.69	.307
Go to a park or recreation center	7	2.00	2.38	12	7.58	8.70	.056
Go to a theater or cultural event	4	1.50	1.00	11	1.73	1.62	.752
Go to a zoo, botanical garden, or museum	3	0.67	1.15	8	1.50	0.53	.337
Go to run errands	15	2.47	3.16	18	5.89	2.95	.003
Go to a library	9	2.44	4.90	15	4.87	6.74	.322
Go to watch a sports event	5	1.20	2.68	3	3.67	2.08	.203
Go to a gym/participate in sports event	10	2.00	2.67	9	11.89	10.20	.020
Go to a barber shop, beauty salon, nail salon, spa	10	1.30	1.25	15	1.40	0.99	.834
Use public transportation	6	4.83	4.54	9	8.22	8.90	.351
Go to a social group in the community	5	4.20	6.22	13	4.08	1.19	.967
Work for pay	12	6.92	7.88	17	18.53	8.35	.001
Go to school to earn a degree or certificate	17	4.71	7.82	15	2.40	6.38	.366
Take a class for leisure or life skills	4	1.50	1.91	5	0.40	0.55	.338
Participate in volunteer activities	11	7.55	10.71	14	5.43	4.31	.548
Get together in the community/attend an event with family/friends	14	1.57	3.06	24	3.04	4.28	.227
Entertain family or friends at home/visit them in their homes	17	3.24	4.44	19	7.89	7.33	.027
Go to a community fair, block party or other community event/activity	9	2.00	2.55	9	2.00	1.41	1.000
Go to or participate in civic or political activities or organizations	2	0.00	0.00	9	1.33	1.58	.035