Title: Covid-19 and Mobility Impacts on Employment of Adult Social Security Beneficiaries with Autism Spectrum Disorder

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Abstract of the Study

Background: Autistic individuals are significantly unemployed or underemployed compared to other disability groups. A recent study showed 36% of highly skilled autistic individuals with employment potential were receiving Social Security Administration (SSA) benefits.[1] Transportation, a possible Impairment Related Work Expense (IRWEs), is often identified by autistic individuals as a barrier to employment.[2] The COVID-19 pandemic has had a significant impact on employment and transportation for millions of Americans. Autistic individuals are no exception and at times are at an increased risk for unemployment due to rapid changes to work and transportation environments and procedures. The possible differential effects of the pandemic restrictions on employment and related transportation issues in autistic adults are not known.

Objective: The purpose of this study is to better understand the employment barriers for individuals with Autism Spectrum Disorder (ASD) who are Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) beneficiaries. The study explores how the COVID-19 pandemic effected autistic adults' employment. The research identifies how transportation, a known employment barrier, affects this population.

Methods: To answer the research questions a survey was distributed to adult participants with ASD. Temple University Investigational Review Board (IRB) approval was obtained, and the quantitative data were collected. The data were analyzed using SPSS software to determine descriptive and frequencies.

Results: Five hundred seventy-two participants completed the survey. The majority of participants were males ages 21-30. The majority of individuals reported reduced hours or being laid off as an impact of COVID-19. Transportation was identified as a barrier to employment. The most significant barriers to public transportation reported by those with ASD included wait times, lack of parental support, and unpleasant odors at transportation terminals and on vehicles. In addition, most participants reported they agree or strongly agree that transportation could help them find a better job and that they would like to use public transportation to increase their participation in the community. Individuals who receive SSA benefits report a higher agreement that public transportation increases their quality of life.

Conclusion: Sustained employment is a challenge for autistic adults. Transportation has been and continues to be a barrier to employment. The COVID-19 pandemic exacerbated employment barriers making it even more difficult for sustained employment of the autistic community. Those who receive Social Security, either Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) have a greater belief that public transportation would increase employment opportunities, participation, and overall quality of life. Decreasing transportation barriers would allow SSA beneficiaries more employment opportunities and decrease their reliance on these benefits.

Background:

Autism Spectrum Disorder (ASD) is a group of brain disorders that affect communication, social interactions and adaptive behaviors.[3] Individuals with ASD qualify for the Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI) programs when they are between 18-64 years old and meet the required inclusion criteria.[1,2] SSI is designed to help disabled low income individuals meet basic needs.[4] SSDI is designed to assist disabled individuals who have previously worked and are no longer able to work in substantial gainful activity (SGA) for at least a year. [4] SSI and SSDI beneficiaries are subject to conditions to receive financial benefits. [4] Improved, reliable, and more permanent employment of those autistic individuals would enhance their quality of life and reduce their reliance on scarce social security resources. A specific health problem associated with ASD is lack of community participation because of impairments in intellectual function, language, and social interactions. [5,6] Individuals receiving Social Security Administration (SSA) benefits have opportunities for employment training and are more likely to have successful competitive employment and particpation.[7]

Community participation is associated with social determinants of health and well-being for individuals of all ages in the general populationn.[5,8] Autistic individuals face challenges with community participation. [9,10] It is reported that 50% of adults with ASD demonstrate poor community participation outcomes with regard to work, friendship and independent living. [11,12] Only 50-66% report close friendships.[13] Further, independent living for autistic individuals is rare.[14] A 2005 study reported that only 3.3% of adults with ASD lived alone.[15] Participation is associated with positive social determinants of health and wellbeing. [5,16–18]According to the World Health Organization (WHO) meaningful community participation can occur in many areas of life.[19] These include employment and school, community, social, and civic life.[19] Employment is a significant socioeconomic factor that influences health outcomes. [20] As a social determinant of health, employment is closely linked to income and subsequent access to goods, services, and environments that promote health. [20,21]

For many individuals with developmental disabilities, transportation difficulties serve as a primary barrier to accessing important needs like employment.[10,19] For the ASD population, driving is often not a viable option due to the impact of disabilities (i.e. executive function issues, perceptual motor issues) or financial resources.[10] Many individuals with developmental disabilities are dependent on others, such as parents or other family members, to drive them to life events and appointments outside of the home.[19] Transportation challenges are identified as a primary barrier to obtaining and maintaining employment. [19] Transportation interventions that remove barriers are crucial to increasing community participation for individuals with ASD. Travel training interventions have been designed to increase mobility for autistic individuals.[22] Existing travel training interventions are intended to help individuals build the skills to safely and efficiently use one or more select modes of transportation (e.g., use of a bus, walking). Research on travel training interventions has identified evidence-based techniques for improving specific transportation-related competencies in adults and young adults with intellectual and developmental disabilities (IDD),[23,24] although these are often limited to one specific skill or one type of

transportation. There is additional evidence to support travel training for one mode of transportation such as public transportation [25] or walking,[26] but limited evidence that examines more comprehensive travel training interventions that address multiple skills for a variety of transportation modes.

For autistic individuals, COVID-19 is creating new barriers to employment and transportation. Many autistic individuals, who often thrive in a structured environment, are having their lives "turned upside down" by the pandemic.[6,26] Autistic individuals often hold jobs in essential employment. Essential employment includes but is not limited to work in healthcare facilities, the food service industry, commercial retail (including grocery, pharmacy, and convenience stores), and maintenance and sanitation services. Essential employees were not able to work remotely.[4] Many autistic individuals had services and jobs interrupted as a result of COVID-19. Improved understanding of the impact of COVID-19 on the barriers to the actual use of public transportation and how best to ameliorate the impact of COVID-19 on employment of autistic individuals is needed to improve outcomes.

Method The purpose of this project is to explore the transportation barriers to employment that autistic individuals encounter, and to determine aspects that can be addressed by training programs for autistic individuals who receive SSI and/or SSDI benefits. Reduction in transportation barriers will allow those with ASD better access to employment and ultimately decrease those receiving SSI. This project intends to answer three primary questions as they relate to autistic individuals who receive SSI and/or SSDI benefits:

1. What were the impacts of COVID-19 on employment among autistic individuals particularly on employment-related transportation?
2. What are the current barriers and facilitators related to transportation and employment for autistic individuals?
3. What content and delivery format for training programs are preferred or considered of high value to autistic individuals?

Data Sample

The quantitative data was collected from the distribution of The Employment Transportation Survey conducted between October 2021 and March 2022. The survey consists of basic demographic questions including but not limited to; age, race, gender, education level, and support needed to complete the survey. It also includes questions regarding SSI and or SSDI benefits, employment status, transportation habits, ASD characteristics, ASD severity, caregiver assistance, financial means and other pertinent data that may describe challenges of these systems. The survey's transportation questions address usage pre, present, and post COVID-19. In addition, personal protective equipment (PPE) usage, and community involvement pre, present, and post COVID-19 are explored. Semi-structured interviews were completed with interested participants who completed the survey. Recruitment strategies were designed to maximize participation. Emails were sent to local agencies that support autistic individuals. The emails introduced the

study and asked to share the survey link and information. Additionally, individuals who participated in previous research studies who identified that they want to participate if other studies were available were contacted. Individuals that responded to the survey self-reported as having autism, were English speaking, and were 18 years or older. Researchers, family, or support persons could provide survey assistance as needed. This could include reading questions, explaining what the questions mean, marking answers, or providing access to a device that has Internet access. Participants reviewed and gave consent online prior to completing the survey.

A total of 572 autistic individuals completed the online survey. Participants reported COVID-19 employment impacts, transportation use, barriers to transportations, and preferred training styles. Twelve autistic adults completed brief semi structured interviews further describing COVID-19 and transportation barriers to employment.

Survey

Employment and COVID-19 Employment Impact

Participants reported their employment status based on the following response options: Employed, Student, Retired, Unable to work because of disability, Unemployed, Homemaker, Other. Social security benefits were assessed asking participants to respond to: " In the past 12 months have you had any financial support from the list of sources below".

The impact of COVID-19 on employment was assessed using the following question: "In which of the following ways has the COVID-19 pandemic impacted your work or work life?" A long list of options was available. For example, options included, laid off from job or had to close own business, increase in workload or work responsibilities, hard time making the transition to working from home.

Transportation

Participants were asked to report how much they agree or disagree with statements about how transportation impacts their participation. The questions asked about specific barriers to transportation. The following are examples of those questions- Please tell me how much you agree or disagree with the following statements about your ability to use public transportation; "I was never trained", "Scared to use on my own," "Easy for me to use," "I don't know how to use," and "Parents won't let me use" etc.

Participants were also asked about their transportation training preferences. They were asked "Who would be the best person to support you while using transportation systems?" "What is the best way for you to learn a new activity?"

Data Analysis.
All analyses were performed using SPSS 26.0. General descriptives were run for demographics, social security benefits, employment status, transportation barriers, and COVID-19 impact. Those receiving social security benefits compared to those not receiving benefits were compared across variables. Differences between groups equal or greater than 5% were reported.

Results

Sample Characteristics

Forty-five percent (258) of participants were ages 21-30 and 34% (192) were 31-40 years old. The sample consisted of 51% males of whom 59% were non-Hispanic white. Fifty-four percent had ASD, 40% had Pervasive Developmental Disorder and 5% had Asperger's. Thirty-one percent report mental health/emotional disorders e.g. (anxiety depression) and 18 % identified also having had a co-existing ID. About 36% lived in urban areas, 41% in suburban areas, and 22% in rural areas. Thirty-six percent were employed adults with ASD and 61% were considered unemployed. Forty-three percent received financial support from Social Security Benefits, 40% (218) SSI and 38% (202) SSDI. A total of 74% of individuals received some form of SSA benefits either SSI and/or SSDI.

Table 1: Demographics

Demographics	Responses
18-20	6% (36)
21-30	45% (258)
31-40	34% (192)
41-50	9% (50)
51-older	2% (13)
Female	43% (238)
Male	50.9% (291)
Transgender Male	1.2% (7)

Transgender Female	4.7% (27)
Mixed	2.4% (7)
White Caucasian	58.2% (333)
Native American	4/9% (34)
African American/Black	24% (137)
Asian	7.2% (41)
Another Race	2.4% (7)
Asperger	5% (29)
Autism Spectrum Disorder	54% (300)
Autism Pervasive Developmental Disorder PDD	40% (223)

COVID-19 Impact: SSA beneficiaries' vs Non SSA beneficiaries

Fifty-three percent of the total participants reported being laid off because of COVID-19. Forty- seven percent reported reduced hours and 52% reported increased hours. Work related social distancing and quality of work were also reported by more than 50% as an impact of COVID-19. Overall, those with SSA benefits vs those without reported more impact due to COVID-19 (Table 2). The greatest differences were seen in the following areas: "had a hard time getting to medical appointments" (64-58), "received employer training for COVID-19" (64-55), "increased work load" (56-49). Additionally, those receiving SSA benefits reported COVID-19 induced employment COVID-19 training and increases in preventative behaviors at work. A total of 76% of autistic adults reported working any time since March 2020.

Table 2: COVID-19 Impact on SSA and Non SSA beneficiaries

	Responses		SS		No SS	
			N=354 78missing	%	N=218 missing 27	%
Laid off COVID-19	246	53%	150	54%	96	51%
Reduced Hours	224	47%	130	47%	94	49%
Had to lay others off	247	54%	150	54%	97	51%
Spend time disinfecting home due to contact at work	287	60%	170	62%	117	62%
Increase in work load	249	52%	155	56%	94	49%
Increased PPE at work	295	62%	180	65%	115	61%
Social Distance at work	272	57%	169	61%	103	54%
Quarantine because of co-worker	256	54%	162	59%	94	49%
Hard time doing job because of needing to take care of people at home	271	58%	164	59%	107	56%
Greater meaning at work	255	53%	146	53%	109	57%
More efficient at work	231	49%	138	50%	93	49%
Hard time transitioning from work	234	50%	144	52%	90	47%
Received employer training for COVID-19	281	59%	177	64%	104	55%
Had hard time getting to social outings	281	58%	171	62%	110	58%
Had a hard time getting to medical appointments	259	51%	177	64%	82	43%

**Those highlighted in yellow represent a 5% or greater difference between the two groups*

Employment related Transportation

Most respondents and especially those that receive SSA report public transportation would improve their lives (Table 3 and Figure 1). Sixty-one percent of the total sample believe transportation could help them find better/different jobs, and 54% percent report lack of transportation "limits my participation in activities". Finally, 55% would like to use transportation more often. Those receiving SSA benefits shared more agreement with the above statements then those who do not receive SSA benefits. Individuals who do not receive SSA benefits disagreed the most with the notion that transportation would increase their quality of life.

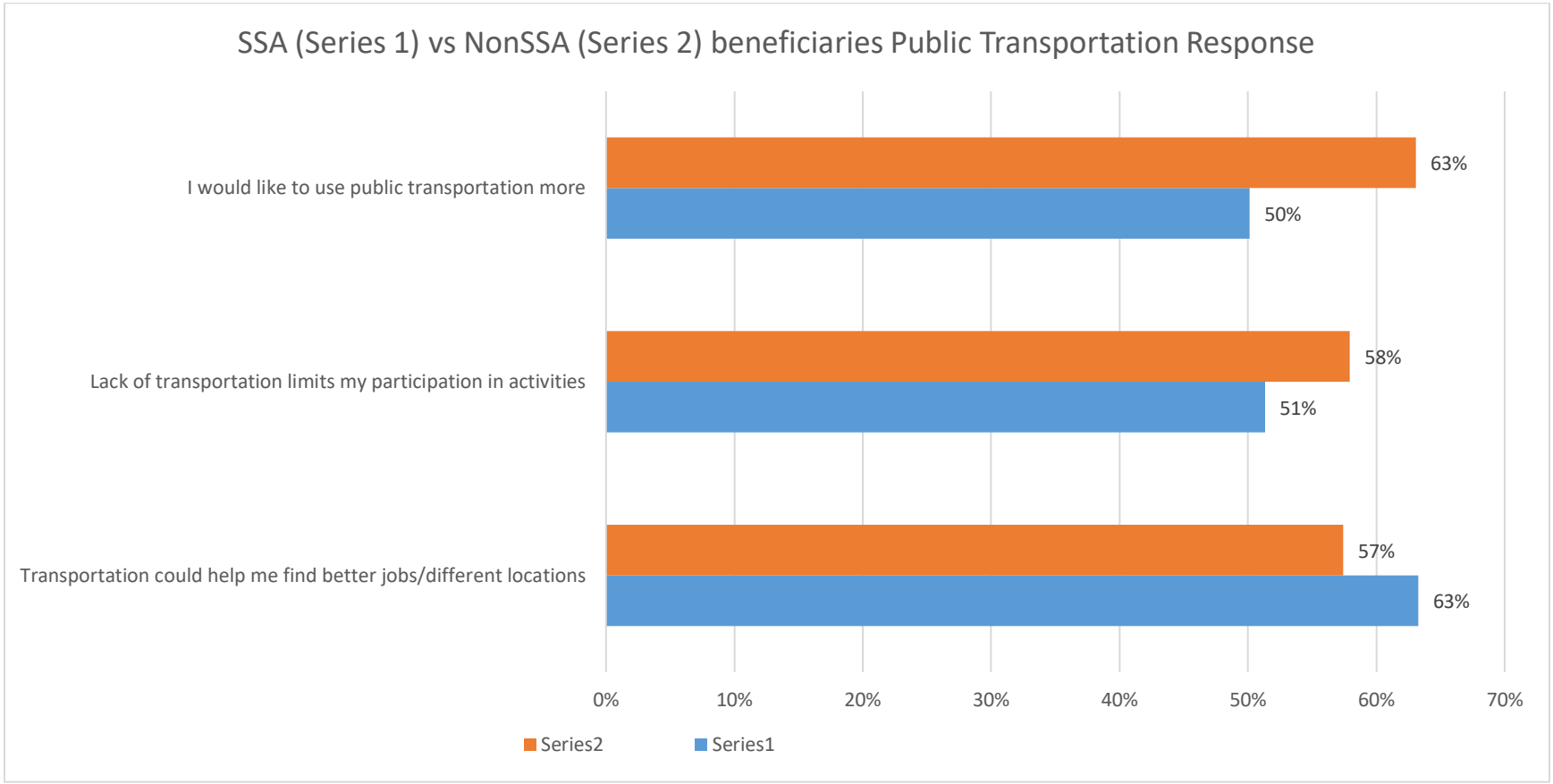
Table 3: Transportation Impact SSA and Non SSA beneficiaries

	Total Sample Agree/ Strongly Agree	Total Sample Disagree/ Strongly Disagree	SSA Agree/ Strongly Agree	SSA Disagree/Strongly Disagree	Non SSA Agree Strongly Agree	Non SSA Disagree/Strongly Disagree
Transportation could help me find better jobs/different locations	61%	5%	63%	6%	57%	5%
Lack of transportation limits my participation in activities	54%	12%	51%	14%	58%	8%
I would like to use public transportation more	55%	11%	50%	13%	63%	8%

I would like to use public transportation to increase my participation	55%	10%	55%	11%	55%	9%
Using public transportation could help me feel less isolate	51%	10%	52%	11%	51%	7%
Public transportation could improve my quality of life	51%	11%	50%	12%	49%	43%

**Those highlighted in yellow represent a 5% or greater difference between the two groups*

Figure 1: SSA vs Non SSA Beneficiaries response to Public Transportation Impact



Barriers to Public Transport

The survey looked at 14 barriers to public transportation. The survey results identified that over 30% of participants reported personal and/or environmental barriers. The most important barriers included; "Bothered by waiting for transportation (41%)", "parents won't let me use (40%)", and "bothered by smell (39%)". (Table 4)

Table 4: Public Transportation Barriers

Barriers to Public Transportation	N=354 missing 19	N		
	I was never trained	198	37%	
	Scared to use on my own	184	35%	
	Easy for me to use	171	32%	
	I don't know how to use	186	35%	
	Parents won't let me use	212	40%	
	Bothered by noises	201	38%	
	Bothered by smells	209	39%	
	Bothered by people sitting next to me	190	36%	
	Bothered by on and off bus	188	35%	
	bothered by waiting for transportation	217	41%	
	bothered by too many distractions	190	36%	
	I might get lost	191	36%	
	Worried about bad weather	204	38%	
	I feel unsafe when using transportation	188	35%	

Preferred Training Styles (Figure 2)

Autistic individuals reported using a mix of multiple learning styles as their preference to learning new material. Watching a video was the most preferred learning style followed closely by watching someone else perform the learned task. Autistic individuals preferred multiple supporters to help them with transportation, but the majority chose "Family Members" as the best support option.

Figure 2: Prefered Learning Style (Individuals could select multiple learning styles)

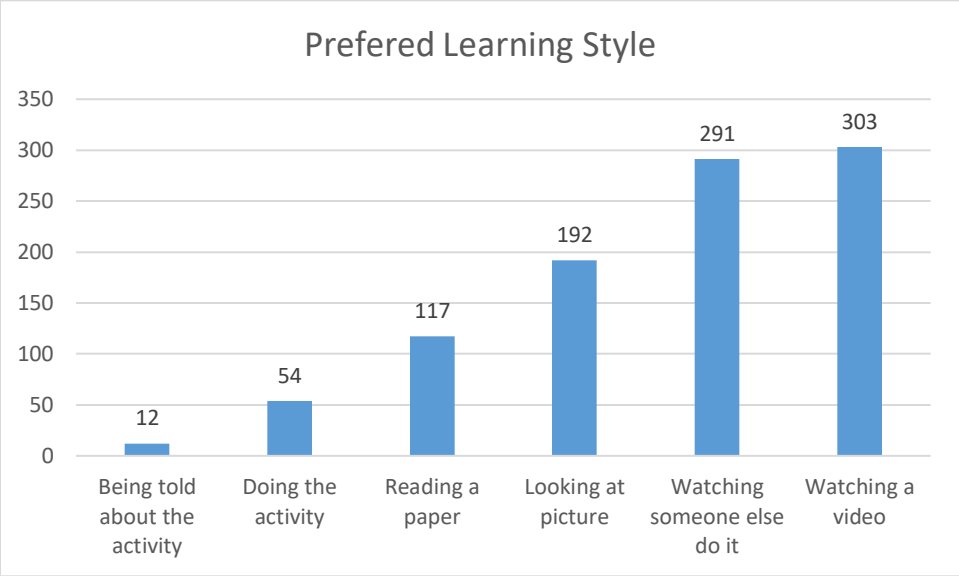
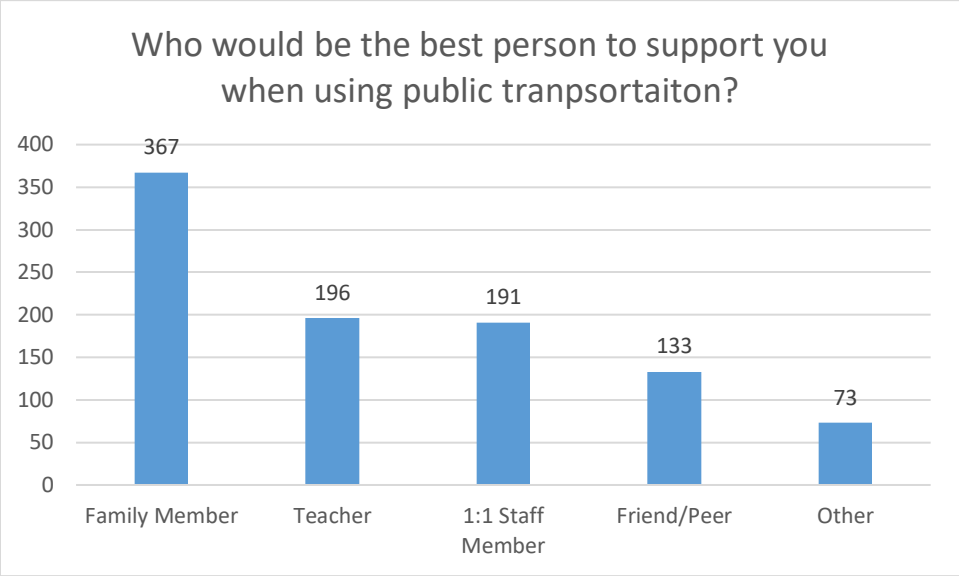


Figure 3: Best Support Person when using Transportation (Individuals could select multiple best persons)



Discussion:

The study provides information about the impact of COVID-19 on employment of autistic individuals. It also reveals the perceived impact transportation has on participation for autistic individuals. The research results emphasize some key barriers identified to transportation. Finally, preferred learning style and transportation support were identified by autistic individuals.

Autistic individuals are often unemployed or underemployed even when they exhibit the characteristics and abilities to hold a job.[27,28] These individuals are often recipients of Social Security Administration (SSA) benefits like Supplemental Security Income (SSI) and/or Social Security Disability Insurance (SSDI). Individuals within this population like those within many populations, experienced job loss, job changes and limited access to employment.[29] A 2021 study reported that those young adults with autism employed at the early stages of the pandemic reported job loss or reduced hours and pay within the first few months.[28] This study supports many researchers' findings that COVID-19 had an impact on autistic individuals' employment and particpation.[16,28,30] Sustained employment is challenging for individuals with disabilities and in particular at a higher rate for autistic individuals.[27,31] This

can often be attributed to their developmental differences in adaptably and communication.[7] The COVID-19 pandemic has further intensified competitive and sustained employment issues for many autistic individuals due to new workplace safety requirements, loss of non-essential jobs and increased risk of adverse outcomes associated with COVID-19 infections that are more prevalent in this group.[32] During the early stages of the COVID-19 pandemic autistic individuals had to respond quickly to new procedures and changed environments.[30] Autistic individuals have trouble with changes and flexibility.[33] They also reported that PPE was necessary for the employment and often times those preventative requirements created workplace challenges for all populations but even more significantly for those with autism. Those autistic individuals who received SSA benefits had slightly higher impact form COVID-19 on their employment. This increase may be related to qualifications to receive SSA benefits. Autistic individuals often require greater support and experience greater impact because of their disability. Some of these individuals might also have worked in essential roles that required more work hours or increased workload. This study showed that COVID-19 impacts employment for all populations but for those with autism it is even more complicated. Moving forward, employment training and preparedness is necessary for this population.

Employment training that addresses pandemic procedures and change is one way to decrease unemployment in this population. Research has shown that access to transportation increases participation, which includes employment, for autistic individuals.[34,35] This increase is also greatly associated with positive health outcomes. Autistic individuals were asked how public transportation may increase employment and participation. Autistic individuals shared that they agreed or strongly agreed that public transportation would have a benefit on their employment. Public transportation allows individuals a greater radius to seek employment and participation. This type of participation leads to higher quality lives.

Autistic individuals experience many barriers when trying to access public transportation.[36,37] The results reported are consistent with the research. Autistic individuals experience personal and environmental barriers related to public transportation. These can include sensory issues, neighborhood walkability, support, and confidence and efficacy. Autistic individuals are concerned they do not have the training or ability to access transportation on their own. They lack the confidence in their ability to navigate and use transportation systems. Many of the individuals that are middle to low support levels may be able to access transportation and increase their participation options. Parents and caregivers often do not believe or trust that their child can access transportation independently. This is a concern that may be addressed. Travel training may benefit autistic individuals and may decrease parents' concerns as they see their child's abilities and confidence. Travel training may also teach different strategies to minimize sensory concerns.

Travel trainings programs need to accessible. Recent literature has identified the importance of person centered approaches to goal setting. [38] This type of environment allows for the autistic individual to be a part of their plan and goals. Creating an employment goal that includes travel training in a person-centered plan should lead to successful travel training engagement.

The travel training programs need to include formats that speak to different learning styles. Teaching individuals the skills needed to plan trips, navigate, plan for unexpected events and handle stress related to sensory or environmental factors would improve the likelihood of success for autistic individuals. Improved travel skills may increase an individual's travel radius and therefore allow individuals access to more employment opportunities. Incorporating preferred learning styles into the training and using technology as shown in other research may help with the development of travel skills. [39] This training should support the preferred learning style for this population which is often a mix that includes videos and hands on learning. Autistic individuals often feel most comfortable learning from family and teachers. They often need to trust and have some relationship with those who train new skills. Peer supported or led travel trainings should be considered. This method has shown promise in other populations and often increases self-efficacy.

Limitations:

The study results shed light upon the impact of COVID-19 on the autism community and the desire for public transportation for autistic adults. The study survey was completed electronically by autistic individuals. Self-reported data for autistic individuals can be less accurate. The survey was created for this study and psychometrics were not performed on the survey.

Implications:

Autistic individuals are unemployed at higher rates compared to other disability groups. Their lack of employment and inability to engage in substantial gainful activities (SGA) makes them particularly dependent upon SSDI benefits. Disability and low-income status makes many of them qualify for SSI benefits. Many autistic individuals are able to work but because of barriers, like access to transportation, do not work and continue to rely on SSA benefits. The status of transportation as IRWEs (an expense deemed necessary to work) in both SSI and SSDI is unclear and often underutilized. However, for autistic adults, transportation clearly meets the definition of IRWEs and is reported as a significant barrier to sustained employment. Research demonstrates that removing transportation barriers can positively affect employment. Sustained employment of autistic adults who receive SSI and/or SSDI is an advantage for SSA. Autistic adults' financial dependence upon SSDI is removed if the individuals prove sustained employment during their trial work period and extended period of eligibility. Those who currently received SSI and improve or begin employment will collect adjusted rates of SS monthly income. It is financially better to work then to receive SSI. Quality of life is improved with sustained employment. Sustained employment for autistic adults can result in less dependency on funds from SSA.

Transportation access is a significant barrier to employment. Travel training is a key tool to increase sustained employment by removing transportation barriers. Results from this study suggest that travel training programs that utilize multiple learning

styles would be beneficial to autistic individuals. These training programs would help develop travel skills that increase employment opportunities. More accessible and effective travel training programs may lead to more competitive and sustained employment for autistic individuals.

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